

# Appendix A: Detailed Business Plan

9/27/2013

Income	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19
Tuition revenue	0	817,277	1,530,545	2,321,310	2,411,841	2,505,902
Ext. income, incl. fellowships and tuition support	0	0	0	0	0	0
<b>Total income</b>	<b>0</b>	<b>817,277</b>	<b>1,530,545</b>	<b>2,321,310</b>	<b>2,411,841</b>	<b>2,505,902</b>
<b>Expenses</b>						
<b>Student-Related</b>						
Graduate School Per Student Appropriation	0	3,870	5,934	7,740	7,740	7,740
Scholarships for Masters students (or comparable work/study)	0	286,047	535,691	812,458	844,144	877,066
<b>Total student-related expenses</b>	<b>0</b>	<b>289,917</b>	<b>541,625</b>	<b>820,198</b>	<b>851,884</b>	<b>884,806</b>
<b>Personnel (details on Admin Staff-Faculty worksheet)</b>						
Teaching	0	364,000	390,000	465,000	490,000	505,000
Teaching assistants and course support	4,800	7,500	7,500	5,100	5,202	5,306
Faculty Mentors	0	22,500	34,500	45,000	45,000	45,000
Administrative staff	233,245	226,776	233,671	238,344	243,111	247,973
<b>Total Personnel</b>	<b>238,045</b>	<b>620,776</b>	<b>665,671</b>	<b>753,444</b>	<b>783,313</b>	<b>803,279</b>
<b>Other Expenses</b>						
Facilities and equipment (computers, furnishings, printers, etc)	20,000	10,000	8,000	8,000	8,000	8,000
Office/operational expenses (office supplies, software, telephones)	8,000	8,000	8,000	9,000	9,000	9,000
Development/Maintenance of Website	22,000	8,000	22,000	8,000	8,000	22,000
Marketing Materials (printing and mailing)	10,000	10,000	12,000	12,000	13,000	13,000
Advertising Expenses	20,000	15,000	15,000	16,000	16,000	16,000
Travel (speakers for colloquium, recruitment, alumni, employer relation	8,000	42,000	42,000	42,000	42,000	42,000
Workshops and Honoraria	0	30,000	30,000	30,000	30,000	30,000
Faculty Research Funds	15,000	35,000	35,000	35,000	35,000	35,000
Practicum Fees and other Professional Development for Students	0	4,000	7,500	11,000	11,000	11,000
Continuing Education/Professional Development	5,000	5,000	5,000	6,000	6,000	6,000
Food for business meetings/seminars	4,000	4,000	4,000	5,000	5,000	5,000
Career Services (monthly lunch w/speaker, career fair, trip to DC)	0	47,750	61,100	71,600	75,180	78,939
Social events/retreats (welcome dinner, open house, graduation)	4,000	25,000	28,000	28,000	30,000	30,000
Misc	10,000	10,000	10,000	10,000	10,000	10,000
Library and subscriptions	10,000	4,000	3,000	3,000	3,000	3,000
<b>Total other expenses</b>	<b>136,000</b>	<b>257,750</b>	<b>290,600</b>	<b>294,600</b>	<b>301,180</b>	<b>318,939</b>
<b>Total expenses</b>	<b>374,045</b>	<b>1,168,443</b>	<b>1,497,895</b>	<b>1,868,242</b>	<b>1,936,377</b>	<b>2,007,024</b>
<b>Income minus expenses</b>	<b>(374,045)</b>	<b>(351,165)</b>	<b>32,649</b>	<b>453,067</b>	<b>475,463</b>	<b>498,878</b>
Capital Investment Used	374,045	351,165				
Loan Repayment				(400,000)	(325,210)	0
Program Reserves	0	0	32,649	53,067	203,320	702,199
<b>Total Capital investment needed</b>		<b>(725,210)</b>				

## Appendix B: Graduate Level Courses Currently Offered at Duke That Can Serve as Electives

- AAAS 580S/PHIL 539S. Race Theory: Biological Classification and Moral Implications, fall and/or spring. Topics to include: Biological classification theory and its applications to humans; the fit, or lack thereof, of biological categories and folk classifications of race; the historical/political motivations behind human racial classifications; The role of race in moral interactions; and The role of race in the construction of personal identity. Instructor: Brandon
- BA (Business Admin) 925, fall. Examines the development of research in individual and group decision behavior. Major emphasis is given to theoretical developments and empirical research, with a range of articles assigned for each topic. The basic topic areas include: (1) decision problem structuring, (2) thinking about uncertainties, (3) risk taking, (4) dealing with conflicting values, and (5) combining individual judgments into a group decision. Instructor: Payne
- Bio 554. Genomic Perspectives on Human Evolution, occasionally. Human evolutionary history as studied from the perspective of the genome. Nature of contemporary genomic data and how they are interpreted in the context of the fossil record, comparative anatomy, psychology, and cultural studies. Examination of both the origin of modern humans as a distinct species and subsequent migration across the world. Emphasis on language, behavior, and disease susceptibility as traits of particular evolutionary interest. Prerequisite: Biology 201L and 202L or equivalent course. Instructor: Wray
- Bio 555S/Phil 634S. Course description under Phil.
- Bio 723. Statistical Computing for Biologists. Statistical computing for the biological sciences with an emphasis on common multivariate statistical methods and techniques for exploratory data analysis. Goal of the course is to help graduate students in the biological sciences develop practical insights into methods they are likely to encounter in their research. Provides introductions to "R" statistical computing environment and Python programming language. Instructor: Magwene
- Biostat 210. Statistical Genetics and Genetics Epidemiology. Topics from current and classical methods for assessing familiarity and heritability, linkage analysis of Mendelian and complex traits, family-based and population-based association studies, genetic heterogeneity, epistasis, and gene-environmental interactions. Computational methods and applications in current research areas. The course will include a simple overview of genetic data, terminology, and essential population genetic results. Topics will include sampling designs in human genetics, gene frequency estimation, segregation analysis, linkage analysis, tests of association, and detection of errors in genetic data. Prerequisites: Biostat 201, Biostat 204, or permission of the Director of Graduate Studies
- CRP (Clinical Research Training Program) 253. Responsible Conduct of Research. A variety of ethical and related issues that arise in the conduct of medical research are explored. Topics include human subjects and medical research, informed consent, ethics of research design, confidentiality, diversity in medical research, international research, relationships with industry, publication and authorship, conflict of interest, scientific integrity and misconduct, intellectual property and technology transfer, and social and ethical implications of genetic technologies and research.
- CulAnth 611S/GIHLth560S/Psy 611S. Global Mental Health. Examines epidemiology and social context of mental disorders globally. Topics include basic epidemiology of most common mental disorders; challenges with definition & classification of mental disorders; epidemiological methods; mental disorders in the context of HIV/AIDS; disaster/emergency mental health; special populations; approaches to treatment; & barriers to treatment such as stigma. Course utilizes a social epidemiology perspective; focuses on social, economic, & cultural determinants & consequences of mental health problems across the lifecourse. Course designed for graduate students & advanced undergraduates. Prior research methods course recommended. Instructor: Puffer
- Ethics 562S. Understanding Ethical Crisis in Organizations, occasionally. This course examines the causes and consequences of ethical crisis across business, military, higher education and religious institutions. Emphasis is on identifying why certain organizations are more prone to ethical problems and certain

organizations better able to manage them. A core goal is to develop real-world solutions to ethical challenges organizations face in contemporary societies worldwide. Instructor: Pickus

- Environ 538/ GHIth 538/PubPol 582. Course description under PubPol.
- Environ 577. Environmental Politics. Environmental policy formation and implementation in comparative perspective. Topics include interest groups, environmental movements and parties, public opinion, political systems and institutions. Case students selected from the United States and other advanced industrialized countries and the developing world. Spring. Instructor: Weinthal
- Environ 774. One Health: From Philosophy to Practice. Interdisciplinary course introducing construct of One Health as increasingly important to a holistic understanding of prevention of disease and maintenance of health. Includes discussion of bidirectional impact of animal health on human health, impact of earth's changing ecology on health. Learning objectives include 1) to describe how different disciplines contribute to the practice of One Health, 2) to creatively design interdisciplinary interventions to improve Global Health using a One Health model. Course will include weekly 2-hour multi-campus seminar off-site at NC Biotechnology Center with on-campus discussion section using case studies to supplement the seminar. Instructor: Woods
- Environ 820S. Conservation Ethics. Students will delve into the tension between science and advocacy through the lens of environmental ethics. Students will gain a strong foundation in principles of environmental ethics, drawing from the rich literature on this topic from the fields of philosophy and ethics, environmental communications and education, and conservation ecology. Seminar-style course requires students to actively lead and participate in weekly discussions, write a series of essays and collaboratively design and initiate a semester project. Ultimately, the course is about reflecting on not just the academic literature and individual scenarios but seriously considering the role our own values play in our work. Instructor: Vidra
- Environ 826. Global Environmental Politics. How states and non-states actors cooperate to resolve global environmental problems. Central focus is on the creation of international environmental regimes, their implementation, and effectiveness. Case studies include climate change, ozone depletion, water sharing and dams, fisheries, biodiversity, forestries, oil pollution, sustainable development, environmental security, and trade and the environment. Instructor: Weinthal
- Fuqua HlthMgmt 713. Biotechnology: Management of Drug Discovery. A multi-disciplinary overview of drug development process examining the steps required to bring a novel scientific discovery to market. We focus on the scientific, clinical, ethical and financial aspects of this challenging business environment. Students will be introduced to relevant, real-world issues through examination of current events and industry trends, guest speakers from the industry, and key readings. Given that development of these technologies are characterized by large financial investments with long time horizons, financial analysis of these investments are critical. We have used cutting-edge finance concepts to develop unique analytic models that are used as a backbone for this class. The final project is the development of a strategy document for developing and financing a novel molecule utilizing these models as well as other course material. Instructor: Staff
- Genome 584/Law 584. Genetics and Reproductive Technologies. This course will examine the complex interrelationship between legal, political, ethical, and social issues shaping the intersection of genetics, reproductive technologies and reproductive rights. Course will be graded based upon papers and class participation. Instructor: Farahany
- Genome 590S.06/PubPol 590S.02. Cancer and the Genome. Instructor: Bob Cook-Deegan.
- Genome 590S.07/ Law TBD/PubPol 590S.07. Science Law & Policy. Course description under Law.
- Genome 612/PubPol 634. Responsible Genomics, spring. Survey of ethical, social, economic, and legal issues in genomics. Introduction to ethical reasoning and examination of selected issues calling for such analysis, including: special procedures for research involving human participants, (2) respect for privacy and confidentiality of genetic information; (3) historical and political background of health research

funding, and (4) public-private research interactions such as intellectual property and conflict of interest. Instructor: Chandrasekharan

- GHIth 538/PubPol 582/Environ 538. Course description under PubPol.
- GHIth 540/PubPol 638. Global Health Ethics: Interdisciplinary Perspectives. Same as Global Health 210 but requires an additional paper; not open to students who have taken Global Health 210. Department consent required. Instructor: Whetten
- GHIth560S/CulAnth 611S/Psy 611S. Course description under CulAnth.
- GHIth 570/PubPol 643. Global Health Policy and Policy Making, occasionally. Introduction to essential global health policy concepts, understanding of global health policy-making, how policies affect “reality on the ground” in global health and development. Build critical analytical skills and the ability to translate coursework into broader understanding of policies and policy-making. Includes lectures, analysis, discussion, readings, case studies. Open to juniors, seniors, and Master's students pursuing GH certificate or public policy, MSc in GH, SOM third year. Department consent required. Instructor: Miller
- GHIth 590S/PubPol 590S. Special Topics: Law, Development, and Human Rights
- GHIth 740. Bioethics. Course presents overview of practical and theoretical approaches to bioethics from a range of perspectives, including humanities, law, philosophy, medicine and science. Students apply various resources, terminology and frameworks to case studies, preparing them for their own research. Course includes IRB and responsible conduct of research. Instructor: Stewart
- HlthMgmt 717. Economics and Management of the Pharmaceutical Industry. This course examines a number of economic issues relating to innovation, competition, and regulation in the pharmaceutical industry and their role in management decision making. We concentrate on factors that distinguish pharmaceuticals from other industries such as its strong research intensity, broader ties to the health care system, and the critical role of government regulations and policy. The overall perspective is international, but the emphasis is on current market and policy developments in the United States. Instructor: Ridley and Moe
- Law TBD/PubPol 590S.07/Genome 590S.07. Science Law & Policy. Where does the money for R&D come from? How do new findings from neuroscience and genomics pose new questions for law and policy? What is the history of government funding for research, and how did US science policy emerge after World War II? How did academic institutions become hotbeds of research, and how did the idea of the "market university" fundamental to innovation and economic growth emerge? How will the law contend with findings about brain science from functional imaging? Will neuroscience change conceptions of self, guilt and innocence, and culpability in criminal law? How will ubiquitous use of genomic technologies change policy? Will prospective parents increasingly make decisions about what sort of people there should be, based on genomic information and imaging technologies? Instructors: Farahany & Cook-Deegan
- Law 236. International Human Rights. This course will address the questions concerning the basis for an international human rights system that would pose limits to states' treatment of their own nationals. In particular, discussion will focus on the available fora and forms of jurisdiction for the prosecution of international crimes. Instructor: Helfer
- Law 237G. Reconciling Human Rights and Intellectual Property, summer. This course explores the intersections between intellectual property and human rights law and policy. The first term introduces the key rules and institutions of each legal regime and the conceptual competing frameworks for analyzing their relationship. The second term examines several other interfaces between IP and human rights on the international plane, emphasizing the potentially conflicting approaches that different legal regimes adopt and that international law offers to address such conflicts. The final section of the course deals with indigenous peoples' rights. Instructors: Helfer and Ruse-Khan
- Law 253G. The Law of Energy and the Environment, summer. This course will explore the legal and policy issues regulating the ownership, production and consumption of energy, as well as efforts to address the resulting environmental impacts. The course will consider both domestic (U.S.) and international legal

frameworks. The second term is intended to provide students with a firm understanding of the main legal issues related to the relationship between a foreign investment in the energy sector and the protection of the environment. The course will also explore international environmental treaties. Instructors: Salzman and Gazzini

- Law 259G. International Issues in Biotechnology Law. This course will provide a general overview of the legal issues implicated by advances in biotechnology. It will also focus closely on the intellectual property and technology transfer implications of this scientific field. It will discuss comparative Swiss/European and U.S. patent law, and other issues. Instructor: Staff
- Law 301. AIDS and the Law. This course covers the substantive law issues raised by clients with disabilities, concentrating on those with HIV/AIDS. The course is strongly recommended but not required for those intending to enroll in the AIDS Legal Project. The course is also open to students who do not intend to take the AIDS Clinic course. Instructor: McAllaster
- Law 347. Health Care Law and Policy. Surveys the legal environment of the health services industry in a policy perspective. Instructor: Richman
- Law 364. Global Health. The course is designed to provide students with multidisciplinary theories and techniques for assessing and addressing infectious, chronic, and behavioral health problems in less wealthy areas of the world. Also taught as Public Policy 195 Instructor: Whetten
- Law 524. Health and Medical Research for Lawyers. This seminar will introduce students to specific sources, and strategies for researching a variety of health and medical topics as they pertain to attorneys, including Medicare, and Medicaid regulations, medical malpractice, health insurance procedures, etc. Instructor: Brownfield or Bahnson
- Law 527. Access to Medicines: Intellectual Property and Global Public Health, fall and/or spring. Examines the law and policy governing the availability, price and development of medicines worldwide, providing an overview of the international legal frameworks, national regulations, and innovation policies affecting access to existing medicines and the development of future treatments for global health. It encourages students to critically examine current international law governing pharmaceutical innovation and to engage in efforts to improve incentives for the pharmaceutical sector to better meet global health needs. This seminar is open to non-law graduate students depending on space and prior experience. Instructor: Reichman
- Law 529. Genetics and the Law. In this seminar, we will examine the complex ethical and legal issues arising out of the remarkable advances in the genomic sciences over the past fifty years, particularly knowledge gained from the mapping of the human genome. We will begin by examining the legal issues raised by the use of genetics in medicine, including genetic testing, reproductive technologies, genetic screening, and genetic therapy. We will then examine legal issues raised by genetic research and the commercialization of that research. In the latter part of the course, we will explore the use of genetic information in non-medical areas, such as criminal law, employment, and privacy. The primary focus of the course will be legal issues related to the human genome, (not animal or plant), with an emphasis on American law. No prerequisites. Instructor: Dame
- Law 584/Genome 584. Course description under Genome.
- Law 705. Bioethics. Examination of the complex ethical and legal issues that arise in medical care and research, particularly issues arising from advances in biomedical technology. Focus on a variety of bioethical concerns in three general medical contexts: clinical care, medical research, and genetic science. The seminar concludes with a look at critiques of the current bioethics model, and a discussion of health and human rights. Instructor: Dame
- Law 774.01 Taboo Trades & Forbidden Exchanges. This class examines exchanges and transactions that are traditionally taboo, and sometimes illegal. Importantly, what constitutes a taboo trade is culturally dependent, changing over time and across cultures. For example, typical taboo trades in modern western societies include organs, blood, babies, sexual relations, votes for money, and a wide range of other issues. In other cultures and other times, however, humans were sold as a matter of course,

whereas land was considered inalienable. Students will discuss reading selections from law, economics, anthropology, psychology, and sociology. During most class meetings, we will host speakers (generally visiting faculty from other law schools) who will discuss current projects related to taboo trades.

Instructor: Krawiec

- Neurosci 555S/Phil 555S. Course description under Phil.
- Nursing 405. Health Care Operations, Human Resources, Quality, Law, and Ethics. Students develop a toolkit for continuous improvement within health care organizations and systems and explore selected health law, ethical, and human resources issues in nursing and health care management. Students will apply concepts to practice using relevant theory, quality improvement parameters, ethics modeling, and analysis of landmark legal cases. (Online)
- Phil 502S. Comparative Ethics, fall and/or spring. Chinese and Western ethics compared, including conceptions of the virtues, the good life, right action, and the person. Instructor permission required. Instructor: Wong
- Phil 503S. Contemporary Ethical Theories, occasionally. The nature and justification of basic ethical concepts in the light of the chief ethical theories of twentieth-century British and American philosophers. Consent of instructor required. Instructor: Flanagan or Wong
- Phil 510S. Adversarial Ethics, fall and/or spring. Course attempts to identify general principles for designing the rules & regulations for deliberately adversarial institutions (ie; markets, electoral systems/legislatures, criminal law, warfare, sports). Looks at the special virtues of sportsmanship, professionalism, business ethics, etc. people are expected to follow within these hyper-competitive contexts. By examining ways the criteria for being an ethical businessperson, lawyer, soldier, and so on may differ from the criteria for simply being an "ethical person", this course seeks to prepare students for future professional roles in these adversarial domains. No formal pre-requisites. Instructor: Norman
- Phil 539S/ AAAS 580S. Race Theory. Course description under AAAS.
- Phil 541S/Hist 577S. Historical and Philosophical Perspectives on Science. An integrated introduction to the nature of science and scientific change, and its impact on society. Instructor: Janiak
- Phil 510S. Adversarial Ethics. Course attempts to identify general principles for designing the rules & regulations for deliberately adversarial institutions (ie; markets, electoral systems/legislatures, criminal law, warfare, sports). Looks at the special virtues of sportsmanship, professionalism, business ethics, etc. people are expected to follow within these hyper-competitive contexts. By examining ways the criteria for being an ethical businessperson, lawyer, soldier, and so on may differ from the criteria for simply being an "ethical person", this course seeks to prepare students for future professional roles in these adversarial domains. No formal pre-requisites. Instructor: Norman
- Phil 555S/Neurosci 555S. Topics in Philosophy of Mind, every 2-3 years. One or more topics such as mental causation, animal minds, artificial intelligence, and foundations of cognitive science. Includes relevant literature from fields outside philosophy (for example, psychology, neuroscience, ethology, computer science, cognitive science). Instructor: Neander
- Phil 634S/Bio 555S. Problems in the Philosophy of Biology, occasionally. Selected topics, with emphasis on evolutionary biology: the structure of evolutionary theory, adaptation, teleological or teleonomic explanations in biology, reductionism and organicism, the units of selection, and sociobiology. Consent of instructor required. Instructor: Brandon, Neander, or Rosenberg
- Phil 692S. Bioethics. Course offers a graduate-level intro to bioethics. Topics include the history of bioethics; research ethics; limit setting in health care; and reproductive ethics. Course primarily intended for seniors and graduate students. Instructors Ross McKinney, Sreenivasan, and other faculty from the Trent Center for Bioethics, Humanities, and the History of Medicine
- Phil 711. Philosophy and Medicine. The scope of medicine as a philosophical problem, the concept of health, and investigation of ethical issues arising in medical contexts. Consent of instructor required. Instructor: Golding

- Phil 753S/754S. Principles in Cognitive Neuroscience I/II, fall/spring. Introduction to the cognitive neuroscience of emotion, social cognition, executive function, development, and consciousness. Topics also include cognitive disorders, and computer modeling. Highlights current theories, methodological advances, and controversies. Students evaluate and synthesize findings across a variety of research techniques. Consent of instructor required. Instructor: Cabeza, Labar, Purves, or Woldorff
- Phil 950S. Neurophilosophy. Status of such concepts of the 'self,' 'person,' 'free will' in the age of mind science. Conflict between scientific and humanistic images of persons. Varieties of naturalism, neurophilosophy, and neurophenomenology Explanation, prediction, correlations, identities, reduction, levels, laws, functions, and mechanisms in mind science. The logical relations between neurobiology, cognitive, and affective neuroscience, cognitive science, psychology, and social science(s). Instructor: Flanagan
- Psy 608S. Gender, Pain, and Coping. Examination of recent research on gender differences manifested in severity of pain, in healthcare seeking behaviors for painful conditions, and in responses to pain management interventions such as medications or self-help efforts. Exploration of gender-related factors, psychological, social, spiritual, cultural, and biological, which influence responses to persistent pain. Writing intensive seminar requiring student critiques of recent journal articles focused on sex and gender differences in the pain experience, as well as a review paper analyzing recent research in this area. Instructor: Keefer
- Psy 609S. Psychosocial Determinants of Health. Provides an in-depth understanding of psychosocial determinants of health. Emphasis on the ways psychological factors interact with social, cultural, economic, and environmental contexts of health. Topics include impact of social integration, socioeconomic position, discrimination, health behaviors, and affective states on health outcomes. Students will gain competency through lectures, discussions, written work, and oral presentations. Prerequisite: Psychology 104 or 105, Research Methods. Instructor: Richman
- Psy 611S/ CulAnth 611S/GIHLth560S. Course description under CulAnth.
- Psy 672S. Cognitive Neuroscience of Memory. Research on the neural correlates of memory in humans. Neuropsychological studies with brain-damaged patients and functional neuroimaging studies with healthy individuals. Cognitive neuroscience models of memory, including episodic memory, working memory, semantic memory, priming, and procedural memory. Prerequisite: Psychology 102 or Psychology 106/Neuroscience 101, and consent of instructor. Instructor: Cabeza
- Psy 780S. Foundations of Behavioral and Computational Neuroscience. Survey and in depth discussion of the methods, theory, and current research in the field of behavioral and computational neuroscience. Emphasis on animal models and neurobiological underpinnings of learning, memory, and cognition. Covers the latest developments in research on neuroanatomical, cellular and molecular substrates of behavior with emphasis on the influence of development, environment, and experience across the lifespan. Instructor: Bilbo, Williams, Staff
- PubPol 582/GIHLth 538/ Envir 538. Global Environmental Health: Economics and Policy. Social science perspective on global environmental health. Students will learn to identify primary environmental causes of high burden diseases such as malaria, diarrhea, and respiratory infections; describe how to measure socio-economic impacts of global environmental health diseases; discuss key policies to control global environmental health problems based on private prevention and therapeutic behaviors; and propose frameworks to empirically monitor and evaluate global environmental health policies. A sub-module will focus on climate change and water-borne diseases. Prerequisites: Introductory course in statistics. Instructor: Pattanayak
- PubPol 590S.02/ Genome 590S.06. Cancer and the Genome. Course description under Genome.
- PubPol 590S.07/ Law TBD/ Genome 590S.07. Science Law & Policy. Course description under Law.
- PubPol 634/Genome 612. Responsible Genomics, spring. Course description under Genome 612.
- PubPol 638/GIHLth 540. Global Health Ethics: Interdisciplinary Perspectives. Course description under GIHLth 540.

- PubPol 640S. Value for Money in Health Care, occasionally. Determining which health interventions and programs are "worth it." Resource allocation and priority setting in practice. Analytical topics of cost benefit and cost effectiveness. Prerequisite: Economics 101 or 201D. Instructor: Vigdor
- PubPol 642S. Design Innovative Global Health, spring. Explores the introduction, adaptation, and globalization across borders of health technologies, with emphasis on resource-limited settings. Students will critically examine how policy can influence and funding can enable (or not) their innovation and access in low- and middle-income countries. Topics include policies to minimize inequity, systems for sharing and owning knowledge, approaches to innovative financing, and ethical issues. Instructor: So
- PubPol 643/GIHlth 570. Course description under GIHlth.
- PubPol 674. Media and Democracy. Examines the relationship between mass media and democracy in the United States, other developed democracies, and societies in transition. Seeks to explain how the media cover politics and public policy, examining the nature of media institutions, the economics of news production and consumption, and the strategic interplay of politicians, journalists, editors, and other actors who influence the content of news. Instructor: Mickiewicz
- PubPol 752. Indigenous Peoples, Human Rights and Development, spring. This seminar focuses on indigenous peoples, their basic rights, and their roles in national and international development processes. Through class discussions, case studies and role-playing, students will examine the impact of national policies and global trends on indigenous populations and vice versa, and the dynamics of conflict generation and resolution. Among the issues to be discussed are notions of sovereignty and governance, land and other property rights, community management of natural resources, indigenous social movements, international networks and assistance, culture, access and survival. This seminar is designed for graduate students from diverse fields such as public policy, environmental science, law, religion, education and business, who are concerned with international development issues and processes. Fellows enrolled in the course are expected to participate actively in class sessions and to read the course materials. We will have class discussions of theories relevant to power and participation, case studies, and role playing. Fellows will be required to submit short individual policy papers and one major group paper which will also be presented in class. Consent of instructor required. Instructor: Staff
- PubPol 816. Ethics and Policy-Making, fall. Normative concepts in politics, liberty, justice, and the public interest: historical and philosophical roots, relationship to one another and to American political tradition, and implications for domestic and international problems. Not open to students who have taken Public Policy Studies 302. Graduate status only. Instructor: Charney
- PubPol 825. Topics in Health Policy, occasionally. Seminar introduces students to major health policy concepts and methods of analysis of health policy problems. Focus on domestic and international health policy topics, including: nature of disease, health and economics, health care delivery systems, demography and health. Consent of instructor required. Instructor: D. Taylor
- Sociol 534/ GIHlth 550/PubPol 633. Topics in Population, Health, and Policy. Course description under GIHlth 550.
- Sociol 634S. Making Social Policy, fall. Examines the policymaking process, the role of different sectors in policymaking, policymakers' use of research and communicating with policymakers. Focus on social policy. Includes experiential and written work as well as visits from policymakers and to policymaking "events." Instructor: Owen
- Sociol 641S. Proseminar in Medical Sociology, occasionally. Selected topics in medical sociology: social structure and health; social behavior and health; organization and financing of health care; medical sociology (for example, social epidemiology, stress and coping, health and aging). Instructor: Burton, George, Gold, or Moody
- Sta 504. Statistical Genetics, fall. Mechanisms, probability models and statistical analysis in examples of classical and population genetics, aimed at covering the basic quantitative concepts and tools for biological scientists. This module will serve as a primer in basic statistics for genomics, also involving computing and computation using standard languages. Instructor: Staff



- Sta 613. Statistical Methods for Computational Biology, spring. Methods of statistical inference and stochastic modeling with application to functional genomics and computational molecular biology. Topics include: statistical theory underlying sequence analysis and database searching; Markov models; elements of Bayesian and likelihood inference; multivariate high-dimensional regression models, applied linear regress analysis; discrete data models; multivariate data decomposition methods (PCA, clustering, multi-dimensional scaling); software tools for statistical computing. Prerequisites: multivariate calculus, linear algebra and Statistical Science 611. Instructor: Mukherjee
- WomenSt 519S. Topics in Sexuality and Gender Studies. The study of identity and difference and the representation of bodies, genders, and desires through developments in medicine and anatomy. May include different historical periods. Readings from public to private documents, literary texts, playscripts, medical treatises, and pamphlets. Taught in English. Instructor: Finucci and staff.
- WomenSt 541S. Historical and Philosophical Perspectives on Science. An integrated introduction to the nature of science and scientific change, and its impact on society. Instructor: Staff

## Appendix C: Undergraduate Level Courses Currently Offered at Duke Related to Bioethics

- AAAS 242S. Race, Gender, and Sexuality, occasionally. Gender's relationship to race and sexuality explored through a variety of issues, including health, intimacy, family, the state, economic practices, transnational communities and identities, and social movement. Instructor: Staff
- AAAS 244. Racial & Ethnic Economic Inequality: A Cross National Perspective, fall and/or spring. Explores origins and causes of differences in patterns of economic performance between ethnic and racial groups from a comparative perspective across the globe. Consideration of a variety of accounts for wide disparities in incidence of poverty and affluence across ascriptively differentiated groups, with particular attention to economic problems in ethnically or racially plural societies and use of various social policies to redress intergroup inequalities, including Malaysia's New Economic Policy, India's reservations system for scheduled castes, and affirmative action in U.S. and South Africa. Instructor: Darity
- AAAS 246. Comparative Race & Ethnic Studies, spring. The social, legal and cultural construction of racial and ethnic hierarchies in a comparative international context with the United States and the United Kingdom of central analytical concern. Racial formation and racial segregation in specific historical and national contexts including the normative case of the Anglo-Saxon core in the United States and how its dominance has led to patterns of ethnic antagonism and discrimination; the historical context of racial stereotypes and their representation in various mediums. Social justice movements and public policies designed to challenge racial and ethnic domination including controversial topics such as "positive discrimination" (United Kingdom) and Affirmative Action (United States/South Africa). May include comparative case studies from India, South Africa, Brazil, and continental Europe. Instructor: Bonilla-Silva
- AAAS 251. The Anthropology of Race, fall. Human variation and the historical development of concepts of race; science and scientific racism; folk-concepts of race; and the political and economic causes of racism; ethics of racism. Instructor: Staff
- AAAS 260. United States Racial/Ethnic Health Disparities: Social Determinants and Public Policy Implications, occasionally. The most commonly used indices to measure United States health disparities by race/ethnicity; origins and evolution of racial/ethnic categories in the United States Census; role of poverty, racial residential segregation, and inadequate health care in explaining racial/ethnic health disparities; and the promise and limitations of academic-community partnerships and public policy initiatives designed to reduce and ultimately eliminate those health disparities. Instructor: James
- AAAS 261S/Genomics 258. Race, Genomics, and Society. Integrated analysis of historical and contemporary aspects of 'race and genetics/genomics'. Focus on relevant applications in science, medicine, and society; develop skills required for scientific, sociopolitical, cultural, psychosocial, and ethical evaluation of issues. Topics include: introduction to population genetics/genetic variation; concepts and definitions of race; overview of bioethics; social and political history of race; genomics and health disparities; race, ancestry, and medical practice; genealogy, genetic ancestry, and identity; public perceptions of race and genetics/genomics. Instructor: Royal
- AAAS 350S. U.S. Critical Studies of Race, Law and the Literary Imagination, occasionally. This course explores the intersections of race and law. We'll focus on issues like sexuality, adoption, and marriage, the era and residue of Jim Crow, as well as the meaning and intent of affirmative action in educational contexts. We'll use case law and some literary fiction to expose and explore these issues with a particular interest in understanding how race matters in the construction of US citizenship. Instructor: Holloway
- Art History 590S/Italian 584S/ Medieval & Renaissance 640S. The Body: Anatomy and Gender in the Early Modern Period. (Future title: Medicine and Sexuality: Cultural Intersections). This course will focus on early modern conceptions of the human body and study the period's attitudes toward anatomy, sex, and gender--and the discoveries and experimentations that a newly authorized practice of dissection brought about. Concentrating on Italy, where the first two medical schools of the Renaissance—in Padua and Bologna—were opened (Paris was the only other university offering a medical degree at the time), we will study the developments in medicine and anatomy through public and private documents, literary texts

(such as novellas and poems), playscripts, even drawings, paintings and films, and concentrate on topics such as: the beautiful body, the hyperactive body, the youthful body, the aging body, the virgin's body, the maternal body, the pathological body, the problematic body, and the diseased body as well as on the meanings of paternity and maternity from both a socio-legal and anatomical point of view. Through the semester we will also use the resources of Duke's Medical History Library. Instructor: Finucci

- Bio 153. Ecosystem Health and Human Well-Being, occasionally. Explores interactions between ecosystem health and human well-being in context of global change and human population growth. Effects of climate change on food supply, water availability, land degradation and human well-being; impact of species distribution, disease spread, and human health; ecosystem services and human well-being. Case studies used to illustrate the scientific process and to evaluate supporting evidence. For non-majors. Instructor: Reid
- Bio 156/Genome 156. Genetics, Genomics, and Society: Implications for the 21st Century, spring. Introduction to the foundation of genomic sciences with an emphasis on recent advances and their social, ethical and policy implications. Foundational topics including DNA, proteins, genome organization, gene expression, and genetic variation will be interwoven with contemporary issues emanating from the genome revolution such as pharmacogenetics, genetic discrimination, genomics of race, genetically modified crops, and genomic testing. Genomic sciences and policy science applied to present and future societal, and particularly ethical, concerns related to genomics. Intended for non-Biology majors. Instructor: Hill
- Bio 159. The Past & Future of the Human Genome, spring. Exploration of current DNA technology and potential impacts which are in continual flux because of new scientific findings, medical advances, judicial rulings. Introduction to the structure of the genome, genetic variation, and the genetic basis of disease to study existing and future medical, ethical, and policy issues. Intended for nonmajors. Instructor: Goldstein and Angrist
- Bio 250. Population Genetics, spring. Use of genetic sequence analysis to examine aspects of natural populations of humans and other organisms in the past and present. Topics include molecular phylogenetics; the origin, maintenance, and loss of major features of evolution; the evolutionary process at the molecular level; reconstruction of human origins and paleohistory; and genetic information in forensic studies. Instructor: Uyenoyama
- Bio 255. Philosophy of Biology, fall. An introduction to conceptual and methodological issues raised in contemporary biology, including teleology, reductions, the units of selection, and the structure of evolutionary theory. Prerequisites: Biology 25. Instructor: Brandon or Rosenberg
- Bio 350. Complex Traits and Evolutionary Genetics, spring. Introduction to the principles of evolutionary genetics and variation of complex phenotypic traits. Genetic variation, neutral theory, natural selection, quantitative genetics, human population genetics, phylogenetic reconstruction, evolutionary genomics, and evolutionary bioinformatics. Prerequisites: Biology 20 or 202L. Instructor: Mitchell-Olds
- Bio 410S. Advanced Approaches to Genome Science Research, spring. Exploration of current experimental and computational approaches in genomics and genetics and their applications to contemporary research questions. Formulation and design of interdisciplinary research plans with discussion of implications for biology, medicine and society. Utilizing primary scientific literature, students write critical reviews and research proposals. Prerequisite: Biology 201L or 210FS, 220 or 413L, or consent of instructor. Recommended co- or prerequisite: independent study in genomics or computational biology. Instructor: Willard
- Bio 417S. Genetic Engineering & Biotechnology, occasionally. Applications of recombinant DNA in medicine and in agriculture. Topics include diagnosis of genetic diseases, gene therapy, drugs for AIDS and cancer, DNA fingerprinting, cloning of mammals, phytoremediation, crop improvement, and pharmaceutical protein production in transgenic plants and animals. Social and environmental impacts of biotechnology. Prerequisites: Biology 201L. Recommended: Biology 220 or lab experience or consent of instructor. Instructor: Sun

- CompSci 92L. Technical and Social Analysis of Information and the Internet, fall. Study of standards, software, policy, and the impact of computing and the Internet on science and society. Analysis and creation of software and other computational and digital artifacts to solve problems in many domains using different approaches, including data mining, web-based communication, algorithmic and data-driven approaches, crowd-sourcing. Use of real-world problems in understanding evolving international standards. Analysis of tradeoffs in ethical, economic, and technical areas. Instructor: Astrachan
- CompSci 260. Introduction to Computational Genomics. A computational perspective on the analysis of genomic and genome-scale information. Focus on exploration and analysis of large genomic sequences, but also attention to issues in structural and functional genomics. Topics include genome sequence assembly, local and global alignment, gene and motif finding, protein threading and folding, and the clustering and classification of genes and tissues using gene expression data. Students to learn computational approaches to genomics as well as to develop practical experience with handling, analyzing, and visualizing information at a genome-scale. Instructor: Hartemink
- CompSci 342S. Technical and Social Analysis of Information and the Internet, spring. Technical version of Computer Science 82S. Requires a significant technical project. The development of technical and social standards governing the Internet and information technology in general. The role of software as it relates to law, patents, intellectual property, and IETF (Internet Engineering Task Force) standards. Written analysis of issues from a technical perspective with an emphasis on the role of software and on how standards relate to social and ethical issues. Meets as a seminar with an additional weekly meeting to accommodate guest lectures. Not open to students who have taken Computer Science 82S. Prerequisites: Computer Science 308 and recommended Computer Science 316. Instructor: Astrachan and Forbes
- CulAnth 237. Indigenous Medicine and Global Health. Explores indigenous medicine's role in global health and focuses on four interrelated topics: basic medical paradigms and practices, access and utilization in different regions, cross-cultural health delivery, and the complexities of medical pluralism. Course themes will be explored through lecture, discussion, small group case analyses, comparative analytical exercises, and workshops. Instructor: Boyd
- CulAnth 396AS. Health Policy in Transition: Challenges for China, spring. Critical introduction to the dynamics and challenges of health policy in China, from the early twentieth century to the present, with a particular focus on the reform period. Topics to be addressed: health care and economic development, state responsibility and welfare systems, privatization, and disparities in access to health services; history of state policy on regional health planning, community health services, rural health provisions in poverty areas, and the developments in public health infrastructure urban and rural settings. Instructor consent required. Course taught in China as part of the Global Study Abroad Program. Instructor: Guo
- CulAnth 424T. Medical Anthropology, occasionally. Cross cultural experiences and understanding of health and illness, the body and non-biological aspects of medicine. Culture-specific sickness (like envidia, running amok, attention deficit disorder). Class, race, and gender inflected experiences of health. Various societies' organization of health care specialists, including biomedical doctors, voodoo priestesses, and shamans. Instructor: Davis
- Environ 102. Introduction to Environmental Sciences and Policy, fall and/or spring. An introduction to the study of environmental sciences and policy through exploration of basic environmental principles in the life, physical, and social sciences. Emphasis on understanding how the atmosphere, hydrosphere, lithosphere, cryosphere, and biosphere function, and how these spheres interact with human consumption, production, and technological patterns and processes. Field trips to a local site as well as the Duke University Marine Laboratory. Instructors: Christensen or Meyer
- Environ 201. Integrating Environmental Sciences and Policy, fall. Interaction between the natural and the social systems as they relate to the environment. Focus on ecological and earth system cycles, processes, and fundamental relationships. The environmental impact of human-induced change at the local, regional, and global levels. The role of technology and the policy process in determining how environmental problems evolve and are addressed. Use of ethical analysis to evaluate environmental tradeoffs. Use of case studies to integrate multiple disciplinary perspectives on environmental problems

and to address issues of environmental justice. Not open to first year students. Prerequisite: Environment 102 or consent of instructor. Instructor: Clark

- Environ 214S. Ethical Challenges in Environmental Conservation, fall and/or spring. Ethical challenges in environmental conservation. Topics include the philosophical basis and challenges of mankind's responsibility to the natural world; prioritization of often conflicting conservation efforts; balancing the needs of humans and the environment; the disputed role of scientists as advocates; and the philosophical and political obstacles to conservation efforts. Case studies on local and global issues, especially on the intersection of science and policy. Instructor: Vidra
- Environ 260. Global Disasters: Science and Policy, occasionally. In this interdisciplinary course, students will examine the multifaceted aspects of "global" disasters. Invited experts will first examine the science behind the disasters, discuss the range of meteorologic, hydrologic and geologic factors that cause disasters; explore how societies plan for and/or respond to the immediate and long-term physical, social, emotional and spiritual issues associated with survival; and present case studies of response, recovery and reconstruction efforts. In the second phase of the course, economic experts will address some of the most pressing and rapidly evolving economic calamities. In the third segment of the course, the focus will shift to political "disasters" and how natural and/or economic events can destabilize a political system. Students will attend the lecture and labs components of the course and complete on-line quizzes to demonstrate understanding of the material presented. Additionally, they will prepare one research paper on a relevant topic, the results of which will be presented to the class. Instructor: Schaad
- Environ 282A. Environmental Science and Policy of the Tropics. Investigates major environmental issues facing tropical nations using concepts from the natural and physical sciences, the social sciences, and resource management. Topics include: climatic and biogeographical patterns, trends in human population size and demography, historical and contemporary issues in resource use and conservation, and sociological and ethical concerns regarding the source and distribution of economic wealth. (Given in Costa Rica.) Prerequisite: Biology 25 or equivalent. Instructor: Shelly
- Environ 328S. Science and Technology Policy, occasionally. Review of major political, international, and technical factors which led to current world leadership of the United States in research and development. Examination of trends in federal and industry funding. Reasons for the federal government funding research, ways federal funds should be allocated, relationships among industry, government, and academia. Several current policy issues selected for in-depth analysis. Instructor: Ahearne
- Ethics 204/WomenSt 367. Feminist Ethics. Do women experience the world differently than men? An examination of women's experience, women's ways of knowing, ethical systems and feminist critique, patriarchy, dualistic thinking, gender oppression, care ethics, ethical dilemmas. Lecture version of Women's Studies 367S. Instructor: Rudy
- Ethics 269/Neurosci 267. Neuroethics, spring. Focus on emerging ethical controversies concurrent with advances in neuroscience. Background material covered: concepts and methods in neuroscience; theories of ethics and morality from philosophy, law, and other fields. Ethical topics covered: biological bases of morality; emotions and decision making; neuroeconomics and neuromarketing; pathologies of mind and behavior; volition and legal culpability. Course format: combined lectures, discussion, interactive activities, with case studies and real-world examples (e.g., neuroimaging as legal evidence). Prior coursework in neuroscience and/or ethical inquiry recommended. Instructor: Huettel, Sinnott-Armstrong
- Ethics 360S. Civic Engagements: Reflection and Transformation, fall. Course provides an extended reflection on students' civic engagement experience. Explores meaning of transformation commonly seen as underlying civic engagement. Examines critical questions like who or what is transformed, and when. Considers how transformation is related to negotiation of goals and challenges, to gaining insight into politics and histories of place and person, and to understanding and expressing ethical co-citizenship. Course designed interactively with students over the first two weeks, includes interdisciplinary readings that range from poetry and autobiography to politics and policy. Draws on varied documentary media and guest lectures. Instructor consent required. Instructor: Prasad

- EvAnth 431S. Human Embryology, occasionally. The development of the mammalian embryo. Emphasis on human embryology, the origin of major human teratologies, birth defects, ethical and social issues of reproductive biology, aspects of comparative vertebrate development. The evolution of developmental patterns, and the molecular mechanisms of development. Prerequisites: Biology 330L or 414LS or Evolutionary Anthropology 333L or equivalent. Permission of instructor required. Instructor: Smith and Wall
- Genome 156/ Bio 156. Course description in bio
- Genome 238S. Influential Scientists and Policy Leaders in Science Policy. Explores role of scientist and non-scientist policy-makers and elected officials who have substantially shaped U.S. science research and application of scientific discoveries throughout the 20th century from within and outside the federal government. Science policies examined in larger context of political, cultural, and social events. Instructor: Haga
- Genome 256. Genome Sciences and Society, spring. Parallels Genome 156. Focus on contemporary study of human genome with particular attention given to relationships among structural and functional genomics, genome variation and phenotypic variation. Incorporates discussion of social and policy issues created by the Genome Revolution. Students will develop a final paper addressing the science and societal impact of a genomics topic. Prerequisites: Biology 201L/202L or Biology 210FS or consent of instructor. Instructor: Willard or staff
- Genome 258 and 258S/ AAAS 261S. Course description in AAAS
- Genome 290S-1. Special Topics in Social Impacts of Genomics. Topics in social impacts of genomics. Topics will vary. Instructor: Staff
- GHIth 210. Global Health Ethics: Interdisciplinary Perspectives, fall. Ethical issues of conducting research on or working with marginalized/stigmatized populations, using theoretical frameworks and case studies. Investigations of ethical choices made by multinational, national and local policymakers, clinicians and researchers, and their impact on individuals, families and communities. Emphasis on working with community partners to develop needs assessment programs. Topics include: differential standards of care; protection of human subjects; access to essential medicines; genetic information and confidentiality; pharmaceutical development; health information technology; placebo controlled trials; best outcomes vs distributive justice. Requires a background in Global Health. Instructor: Whetten
- GHIth 212/Sociol 212. Gender, Poverty, and Health, fall and/or spring. Examines interconnections among gender, poverty, and health. Adopts global perspective with focus on resource poor countries. Discusses frameworks for understanding health as well as in depth case studies of particular health areas. Instructor: Watt
- GHIth 241/Phil 281. Global Bioethics. Examines various problems of international ethics, discussing them in the context of general ethical theory and then in the specific context of various controversies concerning the conduct of clinical trials in developing countries. Problems include moral universalism and relativism; poverty relief and international aid; international health disparities; human rights; and exploitation. Instructor: Sreenivasan
- GHIth 340. Social Determinants of U.S. Health Disparities. Introduction to how social factors influence health and well-being, with a particular focus on contemporary U.S. society. Topics include obesity, aging, socioeconomic disadvantage, access to health insurance, public health systems, the role of the media, and racial/ethnic and gender inequalities. The course will provide descriptive assessments of health inequalities and analytic examinations of the mechanisms through which social factors affect health. Instructor: Read
- GHIth 373S. Global Health Service, Research, & Ethics, spring. Introduces ethical and human rights concepts in Global Health and current issues in health ethics. Explores how to understand and engage in ethical health service, intervention, research and education. Requires students analyze and critique ethical choices of individuals, policy-makers and health workers. Engaging in service activities, students improve understanding of how an intellectual approach to ethics can be enhanced as well as

counteracted by emotional impact. Explores standards of care, access to care, best outcomes vs. distributed justice. Focuses on ethics related to infectious diseases; obesity, alcohol & tobacco; and environmental health.

- Neurosci 252. Philosophy and Neuroscience. Explores relevance of recent findings in neuroscience (and cognitive neuroscience) to traditional philosophical areas of inquiry. Also addresses philosophical issues regarding practice of neuroscience and relation to other disciplines/sciences. Possible topics include: epistemology of neuroscience data, relation between neuroscience/psychology, neurolinguistics, neuroethics, neural representations, neuroscience & consciousness. Instructors: Flanagan or Neander
- Neurosci 258. Decision Neuroscience, occasionally. How new research in neuroscience, cognitive psychology, and behavioral economics shapes our understanding of decision making. Topics include functional organization of key brain systems, approaches to measuring and interpreting neuroscience data, methods for measuring decision-making behavior, economic and cognitive modeling, and impact of neuroscience on real-world decision-making. Emerging topics will include applications in policy, marketing, and finance. Prior coursework in neuroscience or decision sciences is strongly recommended. Instructor: Huettel
- Neurosci 267/ Ethics 269. Course description in Ethics.
- Phil 207. Political and Social Philosophy, fall. Basic ethical concepts involved in political organization and in a variety of periods, such as equality, human dignity and rights, source of political obligation, political education. Discussion of contemporary problems. Examination of contemporary viewpoints such as liberalism and feminism. Instructor: Wong
- Phil 208. Introduction to the Evolution of Human Culture, Behavior, and Institutions, occasionally. Interdisciplinary examination of philosophical foundations, anthropological framework, psychological/social ramifications of long term interaction of hereditary and non-inhereditary traits of Homo sapiens with its original and later environments, including those created by human culture. Instructor: Rosenberg
- Phil 215. Applied and Environmental Ethics, occasionally. A critical examination of ethical dimensions of several contemporary individual and political normative problems, including abortion, affirmative action, national and international economic redistribution, and the environmental impact of economic changes and political decisions. Instructor: Staff
- Phil 216. Problems in Ethical Theory, spring. The nature of morality, amoralism, utilitarianism, and deontology. Both historical and contemporary readings. Instructor: Flanagan or Wong
- Phil 218. Philosophical Issues in Medical Ethics, fall and/or spring. Ethical issues arising in connection with medical practice and research and medical technology. Definition of health and illness; experimentation and consent; genetic counseling and biological engineering; abortion, contraception, and sterilization; death and dying; codes of professional conduct; and the allocation of scarce medical resources. Prerequisite: for freshmen, previous philosophy course and consent of instructor. Instructor: Staff
- Phil 222/222S. Philosophical Issues in Feminism, occasionally. Issues in political and moral philosophy in their bearing on feminist concerns, including political equality and rights, preferential treatment, feminist and nonfeminist critiques of pornography, and the morality of abortion. Instructor: Wilson or Wong
- Phil 242. Problems in Philosophy of Science, fall and/or spring. The principal philosophical problems of scientific practice. Explanation, confirmation, instrumentalist and realist conceptions of scientific theory. Laws and indeterminism in modern science. Instructors: Brandon, Janiak, or Rosenberg
- Phil 249. Introduction to Cognitive Neuroscience (B, C), spring. The biological bases of higher brain function, including perception, attention, memory, language, emotion, executive functions and consciousness. Emphasis on human brain function at the macroscopic network-level, and the current theories and controversies in this rapidly growing field. Course is not recommended for Freshmen. Prerequisites (one of the following): Neuroscience 101/Psychology 106, or Psychology 102, or Psychology 275/Neuroscience 201/Biology 224, or Neurobiology 195FS/Neuroscience 195FS, or Neurobiology 193FS/Psychology 193FS/Neuroscience 193FS, or permission of instructor. Instructor: Egner, LaBar

- Phil 281/GIHLth 241. Global Bioethics. Course description under GIHLth.
- Phil 282. Science, Ethics, & Democracy, fall and/or spring. Examines relationships between scientific knowledge, ethics, & formation of public policies in a democratic society. Science influences public policy & public policy shapes scientific enterprise. How can citizens reliably identify genuine scientific expertise? If scientific expertise conflicts with religious views of some citizens, can public policy rely on scientific expertise without violating principles of religious toleration? What are ethical rules of public deliberation- must citizens appeal only to reasons accessible from secular viewpoints? To what extent should science goals be shaped by scientific community versus democratic processes? Instructor: Buchanan
- Phil 314. Philosophy of Biology, fall. An introduction to conceptual and methodological issues raised in contemporary biology, including teleology, reductions, the units of selection, and the structure of evolutionary theory. Prerequisites: Biology 25. Instructor: Brandon or Rosenberg
- Psy 205. Health Psychology and Behavior Change. The interplay of psychological, social, cultural and biological factors in health and disease prevention. Major topics include psychosocial and contextual influences on health and behavior; the design and evaluation of individual treatments and population interventions; stress and coping; psychosocial impacts of disease on patients and families. Emphasis on theory, research design, and causal inference. Students should have basic understanding of social science research methods. Instructor: Bennett, Sikkema
- Psy 210. Behavior, Biases, and Interventions in Global Health, occasionally. Apply multidisciplinary social science research to global health issues. Examine how people think, the cultural, contextual, and cognitive influences to health behavior and decisions, and the influences behind the acceptance or rejection of different interventions. Discuss current global health issues. Explore how to change small details of intervention programs to make them more effective. Investigate ways to effectively address barriers to health promotion. Instructor: Ariely
- Psy 353S. Medical Decision Making, occasionally. Various topics in medical decision making explored from the perspective of behavioral science: emotion and medical decisions; allocation of health care resources; adaptations to changing health states; cognitive shortcuts used by patients and care providers; communication and understanding of risk information; informed consent; and improving the quality of decision making. Prerequisite: include one of the following Psychology courses: 101, 102, 205, 208, 209, or 257, or consent of instructor. Instructor: Weinfurt
- Psy 372S. Neuroscience and Cognitive Aging. Theories of cognitive aging (emphasis on the psychobiological/neurobiological perspectives) focusing on processes of perception, attention, decision making, memory and movement through both text and journal readings. Neurological diseases of aging (i.e., Parkinson's disease, Alzheimer's disease). Focus on developing skills for scientific grant writing. Instructor: Jurkowsk
- PubPol 166. Introduction to Global Health. Introduction to multidisciplinary theories and techniques for assessing and addressing global, infectious, chronic, and behavioral health problems. Global health issues addressed from perspectives such as: epidemiology, biology, engineering, environment, business, human rights, nursing, psychology, law, public policy, and economics. Instructor: Whetten
- PubPol 235. Gender, Race, and Ethnicity in Politics and Public Policy, occasionally. Examines gender, race, and ethnicity as salient and significant cleavages in politics, and explores how they factor into public policies and the policy making process. Also considers the distinctive roles women and racial and ethnic minorities play in the policy process. Topics include courts and the law, legislative processes, public opinion, and voting and elections. Specific policy domains examined may include healthcare, environmental, education, social welfare, affirmative action, and foreign policies. Instructor: Haynie
- PubPol 250FS. Law, Ethics & Responsibility, fall. Examines the intersection of law and neuroscience, including the use of neuroimaging to determine if a witness is telling the truth; the implications of neuroscience for determining the mental competency of defendants, the insanity defense, the imposition of punishment on defendants. Considers the extent to which recent advances in brain science cause us to reevaluate fundamental legal concepts of "intent," "insanity," and responsibility; the ways in which



neuroscience may be applied to these and related issues; and the inherent limitations and incongruities of applying brain science to legal questions. Instructor: Newcity

- PubPol 286S. Science and Technology Policy, occasionally. Review of major political, international, and technical factors which led to current world leadership of the United States in research and development. Examination of trends in federal and industry funding. Reasons for the federal government funding research, ways federal funds should be allocated, relationships among industry, government, and academia. Several current policy issues selected for in-depth analysis. Instructor: Ahearne
- PubPol 330. Global Health Ethics: Interdisciplinary Perspectives, spring. Ethical issues of conducting research on or working with marginalized/stigmatized populations, using theoretical frameworks and case studies. Investigations of ethical choices made by multinational, national and local policymakers, clinicians and researchers, and their impact on individuals, families and communities. Emphasis on working with community partners to develop needs assessment programs. Topics include: differential standards of care; protection of human subjects; access to essential medicines; genetic information and confidentiality; pharmaceutical development; health information technology; placebo controlled trials; best outcomes vs distributive justice. Requires a background in Global Health. Instructor: Whetten
- PubPol 332. Health Policy, spring. Introduction to United States' health care policies and practices. Historical perspectives as backdrop to analyses of current topics. Role of current debates in changes to United States health care system and structure. Ethics of selected health policy and health care decisions. Emphasis on differences in health outcomes and participation in health structures by race, ethnicity, and gender. Consent of instructor required. Instructor: Whetten
- PubPol 334S. Medical Decision Making, occasionally. Various topics in medical decision making explored from the perspective of behavioral science: emotion and medical decisions; allocation of health care resources; adaptations to changing health states; cognitive shortcuts used by patients and care providers; communication and understanding of risk information; informed consent; and improving the quality of decision making. Prerequisite: include one of the following Psychology courses: 101, 102, 205, 208, 209, or 257, or consent of instructor. Instructor: Weinfurt
- PubPol 336S. Long Term Care Policy, occasionally. The aging of the United States population, escalating expenditures, uneven managed care penetration in the Medicare and Medicaid markets, and unresolved public/private relationships; federal policy debates on social security and Medicare, state and local service strategies, and reform agenda for the future. Instructor: Taylor
- PubPol 371. News as a Moral Battleground, fall and/or spring. Ethical inquiry into journalism traditions and its effect on public discourse. Issues include accuracy, transparency, conflicts of interest and fairness. Stories presenting special issues such as national security, reporting on vulnerable people and the privacy of public figures. New challenges in blogging, social media and the 24-hour news cycle. Instructor consent required. Instructor: Bennett or Burness
- PubPol 381S. Science and The Media, spring. Technique and goals of science writing. Introduce different modes, publication outlets, and peculiar editorial demands of each. Making complex, nuanced ideas about science, health and related policy matters understandable to nonscientists in limited space and in engaging ways. Encompasses both deep and broad reading with attention to science stories as told by the best in the field, and writing, on the readings, scientists and their science, and its significance to a public bombarded by, fascinated with and alienated from science. Instructor: Angrist
- Sociol 212/ GHIth 212. Course description in GHIth
- Sociol 356. Global Contexts of Science and Technology, occasionally. National variations in the structure of scientific systems, and their consequences for the production and application of scientific knowledge. Particular attention to how these differences are shaped by cultural values and social institutions based on those values (politics, economics, education). Focus on recent developments in the biomedical sciences, such as genetic engineering and bio-ecology, and how they are incorporated into the scientific agendas of different cultures. Requires research paper addressing cross-cultural comparisons in the context of a selected scientific principle or technological development. Instructor: O'Rand

- Sociol 361. Social Determinants of U.S. Health Disparities, occasionally. Introduction to how social factors influence health and well-being, with a particular focus on contemporary U.S. society. Topics include obesity, aging, socioeconomic disadvantage, access to health insurance, public health systems, the role of the media, and racial/ethnic and gender inequalities. The course will provide descriptive assessments of health inequalities and analytic examinations of the mechanisms through which social factors affect health. Instructor: Read
- Sta 102. Introductory Biostatistics, fall and/or spring. Reading and interpretation of statistical analysis from life and health sciences. Topics include: basic concepts and tools of probability, estimation, inference, decisions analysis, and modeling. Emphasizes role of biostatistics in modern society. Prerequisites: placement test. Not open to students who have credit for another 100-level STA course. Instructor: Schmidler or Stangl
- Sta 350S. Statistical Methods in Bioinformatics, occasionally. Statistical and analytical tools for bioinformatics and genomics. Methods for comparison, database search, and functional inference for DNA, RNA, and protein sequences; analysis of families of molecular sequences and structures; inference in genetic pedigrees and basic linkage analysis; analysis of gene expression experiments. Topics include: sequence comparison algorithms and Karlin-Altschul statistics; Hidden Markov models of families; statistics of protein structure threading; visualization and comparative analyses for oligonucleotide array datasets. Statistical Science 230/Mathematics 230 required. Statistical Science 250/Mathematics 342 suggested. Computer programming and molecular biology required. Instructor: Mukherjee, Schmidler
- SXL 268. Gender, Sexuality, and Human Rights. This course investigates gender and sexual dimensions of human rights, considering key international human rights campaigns and emphasizing the historical and philosophical contexts involved in advocacy for Women's Human Rights and Sexual Rights. Instructor: Staff
- WomenSt 222. Philosophical Issues in Feminism, occasionally. Issues in political and moral philosophy in their bearing on feminist concerns, including political equality and rights, preferential treatment, feminist and nonfeminist critiques of pornography, and the morality of abortion. Instructor: Wilson or Wong
- WomenSt 235S. Clinical Issues for the LGBTQ Community. An introduction to LGBTQ issues in the mental-health field and other people-focused professions, e.g. medicine, education, and law. An examination of the historical treatment of the LGBTQ population in psychological practice, the evolution of mental-health care for members of the LGBTQ community, and the psychological effects of social norms on LGBTQ individuals, couples, and families, including non-pathologizing, heterosexual bias, genderism, self-identification, coming out, multiple-minority identities, parenting, and couple dynamics. Instructor: Long
- WomenSt 239. Women, Gender, and Sexuality in U.S. History, occasionally. Major questions relating to women and women's place in society over the course of U.S. history, broadly defined, from the colonial period to the present: How did different groups of women see themselves as women? How did views of women's sexuality change? How did men's and women's relationships and roles change? How did women understand their connections to the larger society? How did race, ethnicity, and class shape all those issues? Course uses a variety of materials, including novels, movies, images, and music to explore the ethical contours of women's lives in the past, following change over time to better understand women's position today. Instructor: Edwards or Deutsch
- WomenSt 288S. Gender and Sexuality in Africa, occasionally. Constructions of gender and sexuality in different African societies. Related issues of power and inequality. Instructor: Holsey
- WomenSt 303. Gender, Race, and Ethnicity in Politics and Public Policy, occasionally. Examines gender, race, and ethnicity as salient and significant cleavages in politics, and explores how they factor into public policies and the policy making process. Also considers the distinctive roles women and racial and ethnic minorities play in the policy process. Topics include courts and the law, legislative processes, public opinion, and voting and elections. Specific policy domains examined may include healthcare, environmental, education, social welfare, affirmative action, and foreign policies. Instructor: Haynie

- WomenSt 366S. Nature, Culture, and Gender. Understanding human identity through a consideration of the human animal boundary, feminist primatology, animal welfare, the great ape project. Do women view nature differently than men? Ethics of primate research, primate gender roles, human justice and non-human animals, subjectivity and emotional lives of nonhuman animals, the relationship between gender, nature, and animals, new formulations of "nature/culture," women and animals. Instructor: Staff
- WomenSt 367/ Ethics 204. Feminist Ethics. Course description in Ethics
- WomenSt 368. Gender, Sexuality, and Human Rights, occasionally. This course investigates gender and sexual dimensions of human rights, considering key international human rights campaigns and emphasizing the historical and philosophical contexts involved in advocacy for Women's Human Rights and Sexual Rights. Instructor: Staff
- WomenSt 401. Gender and the Law, fall. Examination of issues at the intersection of gender and law through a number of different theoretical lenses. Analyzes policy problems with gender implications from the perspective of formal equality, substantive equality, nonsubordination theory, different voice theory, autonomy, and various poststructural critiques. Engages theory at the level of concrete, easily accessible ethical and policy issues, including such topics as employment equality, pregnancy, domestic violence, rape, reproductive rights, sexual orientation and sexual identity discrimination, family equality, sexual harassment, pornography, education equality, affirmative action, and the justice system. Instructor: Bartlett

## **Appendix D: Letters of Support**



**Catherine L. Gilliss, PhD, RN, FAAN**

Dean and Helene Fuld Health Trust Professor of Nursing

Vice Chancellor for Nursing Affairs

February 27, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University  
CAMPUS

Dear Professor Farahany,

As Dean of the Duke University School of Nursing I am pleased to offer my support of the proposed Master of Arts in Bioethics proposal.

For a number of years, we have been engaged in successful collaboration with the Institute for Genome Sciences & Policy that has led to extramurally funded scientific projects and the development of a series of survey courses on genetics/genomics for students in the health sciences. Our faculty members and students are both curious about and supportive of the development and use of knowledge in an area that is so clearly relevant to the field of nursing.

I have consulted with our academic leaders and our own experts in genetics/genomics and they are very enthusiastic about the opportunities that the proposed degree would provide to our students. Both the second-degree entry students and those studying for one of our graduate degrees (MSN, DNP and PhD) would benefit from the proposed coursework.

I look forward to collaborating with you and your team as your plans develop.

Sincerely,

A handwritten signature in black ink, appearing to read 'Catherine L. Gilliss'.

Catherine L. Gilliss



# Duke University

DURHAM  
NORTH CAROLINA  
27708-0968

AMY LAURA HALL  
ASSOCIATE PROFESSOR OF THEOLOGICAL ETHICS  
THE DIVINITY SCHOOL

BOX 90968  
TELEPHONE (919) 660-3403  
FACSIMILE (919) 660-3473  
E-mail: divalh@duke.edu

March 13, 2013

Nita A. Farahany  
Professor of Law and Philosophy  
Professor of Genome Sciences & Policy  
Duke University  
Box 90362  
Durham, NC 27708

Dear Professor Farahany,

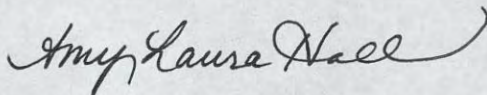
I am writing to offer my enthusiastic support for the proposed Master of Arts in Bioethics and Science Policy.

I believe that this program will significantly enrich Duke and will provide a forum for bringing disparate faculty and students together to explore important issues in our modern lives. My own research fits well with this new program. I focus on theological and biomedical ethics, and I would be particularly enthusiastic about teaching an elective class on: Ethical Issues Represented in Literature and Film, Bioethics and Reproduction, Medical Ethics, or Womanist and Feminist Ethics.

As a scholar in the Divinity School with a specialization in ethics and bioethics, I have had the opportunity to work in interdisciplinary settings, including with faculty and programs in IGSP. I have served on the Steering Committee of Genome Ethics, Law and Policy, and I have been a faculty member for the FOCUS program of the IGSP, both of which I enjoyed immensely. Also pertinent to this program, I have served as a member of the Duke Medical Center's IRB, as an Ethics Consultant to the VA Center in Durham, as a member of the Bioethics Task Force of the United Methodist Church, as a consultant to the World Council of Churches meeting on bioethics, and as a guest lecturer at the American Association for the Advancement of Science and the Center for Bioethics and Human Dignity. My second book focuses on the marketing of biotechnology in the U.S., and it has been favorably reviewed in bioethics, history, and theology journals.

I am eager to contribute to the development of this master's program. Please let me know how I can help as the process moves forward.

Sincerely,



Amy Laura Hall, MDiv, PhD  
Associate Professor of Christian Ethics  
Cell (preferred) 919-616-8642

# Duke University

PHILOSOPHY DEPARTMENT  
201 WEST DUKE BUILDING, BOX 90743  
DURHAM, NORTH CAROLINA 27708-0743

TELEPHONE: (919) 660-3050  
FAX: (919) 660-3060  
<http://philosophy.duke.edu/>

March 11, 2013

Nita A. Farahany  
Professor of Law and Philosophy  
Professor of Genome Sciences & Policy  
Duke University  
Box 90362  
Durham, NC 27708

Dear Nita,

After our recent discussions about a new Master's of Bioethics and Science Policy here at Duke, I was quite excited. I wanted to write you to express in writing my support for the initiative.

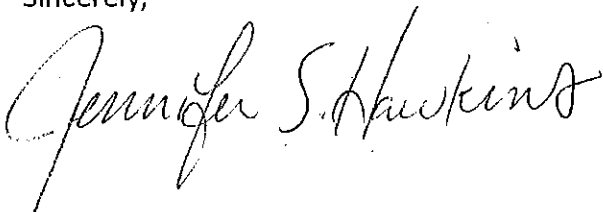
As you know, my work focuses on issues squarely in the field of bioethics and science policy. I have always seen myself as a bioethicist, and have been involved with several strong bioethics programs in the past, first as a postdoctoral fellow at the NIH and then as an Associate Professor at the University of Toronto where I was an active member of the University's Joint Center for Bioethics, and where I taught some of their Master's students. So I would be delighted to contribute to the development of this new Master's program. Both my work on research ethics (which addresses such topics as informed consent, exploitation, and developing world research ethics) and my work on more traditional topics of medical ethics (including ideal doctor-patient relationships, the problems of medical decision-making, understanding the 'best interests' of dementia patients, and the problems associated with the use of advance directives) would fit well with the curricular needs of the program. I would really love teaching in the program, and would be happy to offer regularly one of the program's core classes, Philosophical Foundations of Bioethics.

As a Trent Scholar in Bioethics, an Associate Research Professor in Philosophy, and an Assistant Professor in the Department of Medicine, my own work and experience at Duke is truly interdisciplinary, and I would value highly a program that would engage the cross-section of departments at this intersection at Duke. As you know from our discussions, I am already in the process of starting a bioethics journal club, which will provide another outlet for faculty and students to engage deeply with bioethics and science policy literature. I believe your proposed new Master's in Bioethics and Science Policy will significantly strengthen and enrich the Duke bioethics community. Duke is, and has been for a long time, a recognized leader in bioethics.

This new initiative will, I think, ensure that we maintain and strengthen that position. Moreover, we have the faculty resources here to offer a truly cutting-edge approach to bioethics—one that addresses the most significant emerging issues of our increasingly global world.

I look forward to being an active participant in this program and in working toward its future success. Please let me know if there is anything I can do as the program moves forward.

Sincerely,

A handwritten signature in cursive script that reads "Jennifer S. Hawkins". The signature is written in dark ink and is positioned above the printed name.

Jennifer S. Hawkins

Jennifer Hawkins, PhD

Trent Scholar in Bioethics, Trent Center for Bioethics, Humanities and History of Medicine

Associate Research Professor, Department of Philosophy

Assistant Professor, Department of Medicine





**Richard B. Hays**  
Dean of the Divinity School  
George Washington Ivey Professor of New Testament

April 9, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

I am writing in full support of the proposed Masters in Bioethics and Science Policy.

The Divinity School has long been committed to forming interdisciplinary collaborations, and the prospect of this particular partnership is an exciting opportunity. Several members our faculty (Ray Barfield, Warren Kinghorn, Amy Laura Hall, Allen Verhey, and Richard Payne) already research and teach in areas relevant to such a partnership (medical ethics, healing arts, philosophy of science, the theology of death and dying, etc.), and the Divinity School has just launched a new initiative in Theology, Medicine, and Culture. Hence, this proposed partnership is consonant with activities already under way in the Divinity School, and I believe formal collaboration through the proposed Masters in Bioethics and Science Policy will further strengthen both programs.

I look forward to our work together, and the new doors it might open in both places. Please let me know if there is anything else I can do to support this program.

Cordially,

Richard B. Hays  
Dean, Duke Divinity School

Duke University  
Durham  
North Carolina 27708-0005


Office of the Provost

220 Allen Building  
Box 90005  
Telephone (919) 684-2631  
Fax (919) 684-4421

October 1, 2013

Memorandum

To: Nita Farahany

From: Peter Lange 

Re: Working Capital Loan for MA in Bioethics and Science Policy

I have approved the \$730,890.00 working capital loan (WCL) for the MA in Bioethics and Science Policy with the understanding that the loan will be paid off in five years from net tuition revenue.

If the WCL payments cannot be made from net tuition, the Provost will meet with you and examine the budget to determine if budget adjustments can be made to direct funds to the loan payment. Otherwise, the Provost will make the loan payments or renegotiate the terms of the loan. The Provost is the ultimate backstop for this WCL.

Please let me know if you have any questions.

xc: Jim Roberts  
Amy Oates



DAVID S. LEVIN, DEAN  
DUKE UNIVERSITY SCHOOL OF LAW  
SCIENCE DRIVE AND TOWERVIEW ROAD  
BOX 90160 • DURHAM, NC 27708-7560  
PHONE: 919-613-7000 • FAX: 919-613-7159  
LEVIN@LAW.DUKE.EDU  
WWW.LAW.DUKE.EDU

August 23, 2013

Professor Nita Farahany  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

As the Dean of the Duke Law School, I am pleased to fully endorse the proposed Duke Masters in Bioethics and Science Policy.

We have seen the increasing need for a deep understanding of bioethics and science in shaping current policy and law, and we are eager to see this program's arrival at Duke. The Law School currently offers several related courses, covering such topics as sexuality, health ethics, health policy, neuroscience, and intellectual property; as you well know, several of these courses are taught by you and the future faculty of the MA program. While your students will benefit from enrolling in several of these classes, we have students who are quite invested and focused in the area of science law, and we expect that they will enroll in several of the new classes offered through the MA program. I look forward to seeing students who complete both a JD and an MA.

We have a top-tier law school, which will benefit your new program. In addition, having a Masters in Bioethics and Science Policy will increase the draw of Duke for all other programs, as it offers specialization in this very pertinent area. I hope in the near future to continue discussions on a formalized dual degree option between our two programs as I expect that having this option would help make our already highly-acclaimed law school program even more attractive to potential candidates with interest and expertise in bioethics and science.

I look forward to working with you as you move forward. Please let me know if there is anything I can do to further support your efforts.

Sincerely,



## DUKE UNIVERSITY MEDICAL CENTER

Trent Center for Bioethics, Humanities and History of Medicine

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Re: Bioethics Masters Program

Dear Nita,

This letter is to offer my clear cut and eager support for your proposal to develop a masters degree program in Bioethics. As should be obvious, the idea is near and dear to those of us who are part of the Trent Center for Bioethics, Humanities, and History of Medicine. I can see this degree program appealing to undergraduates who are seeking more depth, and to medical students who want something "more" during their third (and sometimes fourth) year that they spend in research.

Faculty in the Trent Center currently teach classes that could be applicable, including CRTP 253 (my course in Research Ethics that's part of the Masters in Health Sciences in Clinical Research program) and our courses offered through the philosophy department in A&S. For example, there's a course that Gopal Sreenivasan and I co-teach on special topics in bioethics (we've rotated through issues like research ethics and healthcare rationing), and there are the standard ethics and bioethics courses taught in the philosophy department (external to the Trent Center).

My support for the program is, in part, related to the focus that a masters degree program would bring to issues in biomedical ethics, and also to the likelihood that the program would enhance collaborations between the faculty who identify now with the Trent Center, Kenan, the Law School, Divinity School, the Philosophy Department, DIBS, and even the Global Health Institute.

Good luck with your endeavor to put this degree program together! Let me know how I can help.

Sincerely

A handwritten signature in blue ink, reading "Ross McKinney, Jr. MD".

Ross McKinney, Jr, MD  
Professor, Pediatrics  
Director, Trent Center for Bioethics, Humanities, and History of Medicine  
Duke University School of Medicine



DUKE  
INSTITUTE *for*  
BRAIN  
SCIENCES

**Michael L. Platt, PhD, Director**

Professor, Departments of Neurobiology,  
Evolutionary Anthropology,  
and Psychology & Neuroscience  
Rm. B243F LSRC Building  
Duke University  
Durham, NC 27710

February 28, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

As the Director of the Duke Institute for Brain Sciences (DIBS), I am pleased to fully endorse and support this proposal for a Duke Masters degree program in Bioethics and Science Policy.

At DIBS, we are committed to working to advance brain sciences in education, research, and outreach across campus. This new masters program would provide us with an excellent opportunity to do so. We are excited about partnering with IGSP to support this program, and plan to identify existing courses and support the development of new courses to serve the neuroscience and neuroethics concentration in the program. There are very few programs in the country that enable professionals and scholars to gain an understanding in the growing issues at the intersection of neuroscience, ethics and science policy. This program would offer an unparalleled opportunity for Duke to serve that population.

While the participation of DIBS will strengthen the program, this new degree will also benefit DIBS by increasing the breadth of coursework available to students of neuroscience, neurobiology and psychology, drawing even more top students to Duke.

The proposal is clearly robust, and I look forward to my involvement with this interdisciplinary program.

Please let me know if there is anything I can do to further support your efforts.

All the best,

Michael L. Platt

# Duke University

DURHAM  
NORTH CAROLINA  
27708

THE R. TAYLOR COLE PROFESSOR OF PHILOSOPHY  
DEPARTMENT OF PHILOSOPHY  
201 WEST DUKE BUILDING  
BOX 90743

TELEPHONE (919) 660-3047  
FACSIMILE (919) 668-3060  
ALEXROSE@DUKE.EDU

February 22, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

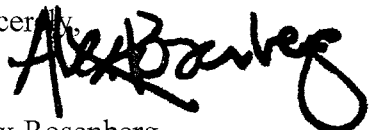
As chair of the department of philosophy I fully support the Master of Arts in Bioethics proposal IGSP is making.

Given the regional and national need for such a program, and the outstanding resources that Duke already has for delivering it, your proposal is more than timely.

The interdisciplinary nature of bioethics will require drawing on many resources across the Duke campus. But at its core there will have to be courses, seminars, and supervision of students by several of the world class specialists in bioethics at work in the philosophy department. Moreover, the current demand for course work in this area by the very best of Duke undergraduates suggests that almost immediately a master's program will acquire critical mass, and keep students at Duke to complete an MA while attracting others from the best programs elsewhere. I also anticipate that just as our doctoral students now take MS degrees in biology, cognitive neuroscience, and other disciplines, many of them will want to equip themselves to work in this field too by taking the M.A. you propose.

Please call on me and my colleagues for participation in any aspect of this effort where we can help. I look forward to working with you as your plans develop further.

Sincerely,



Alex Rosenberg  
R. Taylor Cole Professor of Philosophy  
Professor of Biology, Professor of Political Science  
Chair





June 30, 2013  
Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

As the Acting Director of the Kenan Institute for Ethics, I am writing to offer my enthusiastic support of the Masters in Bioethics and Science Policy at Duke.

I was quite excited to hear about this program, as I feel that offering a master's in bioethics would be a great addition to the Duke community and would be a wonderful compliment to our programs at the Kenan Institute. Like this new program, the Kenan Institute is committed to helping shape policy and practice. However, although we currently feature work on global migration, human rights, regulatory policy, moral attitudes and decision-making, and religions and public life, we do not offer a focus or coursework on bioethics or science policy. Adding this program will provide increased breadth for current Duke students and will serve as a draw for prospective students.

Both of our institutes are dedicated to interdisciplinary work, and this program provides us with a perfect opportunity to build on our synergies to further strength both programs. First, we will plan to co-sponsor workshops and a colloquium series in topics related to ethics and bioethics; that series will be of great mutual benefit to both students and faculty. Second, we will continue our discussions about an ethics track for the master's program. That track will provide your students with an opportunity to focus on issues addressed in coursework offered by Kenan and will be a forum for our students to engage in meaningful dialogue with each other. Finally, I'd be delighted to serve as the Kenan Institute's representative on your faculty council. I hope to both provide curricular and programmatic feedback and serve as a liaison between our programs.

I think our programs will have great opportunity for collaboration, will help strengthen Duke, and will draw even more top students to our university. I look forward to seeing the Masters in Bioethics and Science Policy move forward.

Please let me know if there is anything else I can do to support this program.

Sincerely,

Suzanne Shanahan  
Acting Director, Kenan Institute for Ethics  
Associate Research Professor, Sociology



# Duke University

DURHAM  
NORTH CAROLINA  
27708-0968

DAVID TOOLE  
ASSOCIATE DEAN FOR GLOBAL HEALTH INITIATIVES  
THE DIVINITY SCHOOL

BOX 90968  
TELEPHONE (919) 660-3475  
FACSIMILE (919) 660-3575  
E-MAIL: DTOOLE@DIV.DUKE.EDU

March 14, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

As the Associate Dean for Global Health Initiatives in Duke Divinity School, I enthusiastically endorse the inception of the Duke Master's degree program in Bioethics and Science Policy.

At the Divinity School, we are committed to working across campus with many other departments. Some members of our faculty have joint appointments with the School of Medicine, the VA, the Kenan Institute, and the Law School. Issues in theology, health care, and ethics invariably intersect and can best be understood in an interdisciplinary context. To that end, and as you know, we have just begun a new initiative in Theology, Medicine, and Culture; we welcome your participation as that initiative grows. Further, several of the classes in the Divinity School, such as those taught by Ray Barfield, Warren Kinghorn, and Amy Laura Hall, would serve well as electives in your program.

I am sure our program and faculty can strengthen and broaden the scope of your master's degree, but I expect that our students will also benefit from taking classes in your program. Many of our students seek to explore health care ethics and theology, and how theology and modern technology affect each other. This new master's program will provide us with an excellent opportunity to partner with IGSP—in course offerings, in joint participation in workshops and discussions, in joint degree offerings, and in engaging our faculty and students in conversation and study to further explore the intersection of theology and issues of bioethics and science policy. My colleagues and I in the Divinity School look forward to our collaboration and to seeing this program come to fruition.

Please let me know if there is anything I can do to further support your efforts.

Sincerely,



David Toole, PhD  
Associate Dean for Global Health Initiatives





**Peter A. Ubel**  
Madge and Dennis T. McLawhorn  
University Professor

Duke University  
The Fuqua School of  
Business  
100 Fuqua Drive  
Box 90120  
Durham, NC 27708-0120

Tel (919) 660-8003  
Fax (919) 660-6245  
peter.ubel@duke.edu

March 15, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

I am pleased to offer with enthusiasm my full support for a new Masters in Bioethics and Science Policy at Duke.

As a Professor of Business Administration and Medicine at Fuqua, and a Professor of Public Policy at Sanford, I grapple consistently with issues that arise in science policy, health care, and decision-making. My research—on informed consent, health-care rationing, and the role of values in decision-making in health care—would be enhanced by the energy of the students and new research in the program, and I am enthusiastic about contributing to its success. My expertise and interests align well with the curricular and programmatic focus of the master's program, and I look forward to being engaged with the faculty and students it will attract.

There is a growing demand and need for professionals in positions of decision-making to be better trained in the ethical and policy concerns of those fields. The opportunity to serve that population, while engaging with outstanding other faculty and students with similar interests makes me eager to become involved in and teach in the program. The courses we have discussed that I would be pleased to offer in the program include Ethics and Policy of Health Care Practice or Ethics of Health Care Rationing.

The Masters in Bioethics and Science Policy proposal presents an exciting interdisciplinary opportunity for Duke. Please let me know if there is anything I can do to further support your efforts.

Sincerely yours,

Peter A. Ubel M.D.  
Madge and Dennis T. McLawhorn University Professor  
Schools of Business, Public Policy and Medicine  
Duke University

---

June 6, 2013

Professor Nita Farahany  
Duke Law School  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University

Dear Nita,

I am happy to offer my enthusiastic support for the Masters in Bioethics and Science Policy at Duke.

As you know, my expertise and interests align well with the proposed program, as I have been engaged in science law and policy throughout my career. Specifically, I have worked on legal issues in biomedical research, bioinformatics, conflicts of interest, health sector management, and health care reform. Further, I have enjoyed teaching classes and mentoring students at Duke for many years. I am quite excited about playing an active role in this new program and very much look forward to mentoring masters' students and to teaching one of the core courses, Science Law and Policy.

As I consider the issues that arise in the intersection of science law and policy, I strongly believe that we need better-trained professionals in the field who can fully analyze and understand the ethical and policy issues. Because of its reputation, interdisciplinary nature, and top-notch faculty, Duke University is in a strong position to offer a highly-acclaimed program that will educate the next generation of leaders. I am pleased to be a part of this exciting initiative.

Please let me know if there is anything I can do to further support your efforts.

Sincerely,



Michael B. Waitzkin, JD  
Adjunct Faculty and Senior Scholar, Fuqua School of Business



**Duke Clinical Research Institute**

From Thought Leadership to Clinical Practice

March 8, 2013

Nita A. Farahany  
Professor of Law and Philosophy  
Professor of Genome Sciences & Policy  
Duke University  
Box 90362  
Durham, NC 27708

Dear Nita,

I am pleased to write in strong support of the new Masters in Bioethics and Science Policy being proposed at Duke. I feel this is a critical interdisciplinary field of study that warrants a high quality program.

My extensive experience in several areas—including empirical bioethics; measurement and research design; and the psychology of medical decision making—fit well with the curricular needs and focus tracks of the proposed program. Moreover, as a Professor in Psychiatry and Behavioral Sciences in the Duke Clinical Research Institute, Professor of Psychology and Neuroscience, co-director of the School of Medicine's master's program in Clinical Research Training, I strongly value interdisciplinary research and the emphasis and support at Duke to do so. Duke's strength in the intersection between scientific disciplines and their social impact is growing, and will be further strengthened by this new program.

My research will bring important expertise to the program, including in areas such as the psychology of decision making, the communication of uncertainty, informed consent, conflicts of interest in research, methods for measuring and analyzing patient-reported outcomes, and research design and statistics. Given my own background and research areas of focus, and my passion for teaching and mentoring students, I would be delighted to teach a class in the master's program, including Research Methods in Bioethics and/or the Psychology of Medical Decision Making. I am truly delighted by the prospect of this interdisciplinary program at Duke, and look forward to working toward its future success.

Please let me know if there is anything I can do as the program moves forward.

Sincerely,

A handwritten signature in dark ink, appearing to read 'Kevin Weinfurt', with a stylized flourish at the end.

Kevin Weinfurt, PhD  
Professor in Psychiatry and Behavioral Sciences  
Professor of Psychology and Neuroscience  
Chair of the Interdisciplinary Medical Decision Making Initiative

July 24, 2013

Professor Nita Farahany  
Duke Institute for Genome Sciences & Policy  
Box 3382  
Duke University



Huntington F. Willard, PhD  
Director

**Duke Institute for  
Genome Sciences & Policy**

Duke University  
CIEMAS  
101 Science Drive  
Box 3382  
Durham, NC 27708

T 919-668-4477  
F 919-668-0795

[www.genome.duke.edu](http://www.genome.duke.edu)

Dear Nita,

I am writing to offer you my full and enthusiastic support for the proposed Masters in Bioethics & Science Policy program at Duke.

In discussing this new program with you, I am pleased that we share a vision of continuing to strengthen the "policy" component of the institute and of increasing and broadening the educational offerings associated with the IGSP to include bioethics and science policy. I believe that this program will be of great benefit to IGSP in helping further the collaborations among the science and the policy faculty. In fact, I expect that many of your educational offerings will be of great interest to those who focus on biomedical research, including your proposed workshops that will help scientists make their writing more accessible.

I also believe that the proposed Masters program will help Duke as a whole further its interdisciplinary work and round out its course offerings. I am pleased that you have reached out to faculty all over campus — in the neuroscience community, the Divinity School, Trinity, Medicine and Sanford, to name a few — and that you see the Masters as a truly interdisciplinary program that will bring together a diverse group of faculty and students.

At the same time, the history and profile of the IGSP will help contribute to the establishment and growth of your program. As you know, over the past decade we have built an institute that is uniquely interdisciplinary at the national level, combining and bridging science and policy, medicine and basic science, and faculty with students, with a growing reputation and track-record in both research and education. This solid foundation will, I believe, serve your proposed program well.

As you know, while my own work over the past three decades has focused on human genetics and genome biology, I have a great interest in the impact of genome information on individuals, populations and society as a whole, as well as in education at all levels. I am quite eager to see you launch this program at Duke, and I offer you my full and most enthusiastic support.

Sincerely yours,

A handwritten signature in black ink, appearing to read "H. Willard".

Huntington F. Willard  
Nanaline H. Duke Professor of Genome Sciences  
Director, Institute for Genome Sciences & Policy

## **Appendix E: Jobs of Recent Graduates of Master's of Bioethics Students**

### **Albert Einstein:**

- RN clinician—went back for MA in Bioethics; bioethics clinical consultant
- Assistant Professor of Surgery—went back for MA in Bioethics; doing surgical education, Neonatal Intensive Care Unit

### **Emory**

- neonatologist at Grady Memorial Hospital and Children's Healthcare of Atlanta, bioethics committee at Children's Healthcare of Atlanta, teaches medical ethics of physicians in training and also physicians in practice—degree to strengthen current work

### **NYU:**

- Research Assistant & Ethicist, Biomedical Research Institute, Brigham and Women's Hospital
- Candidate for M.D., Yale University School of Medicine
- Attorney, Medical Practice Group, Motley Rice LLC, Mt. Pleasant, South Carolina Community Representative, Medical University of South Carolina, Ethics Committee and Ethics Consultation Service
- Candidate for B.C.L/LL.B., McGill University
- Junior Research Scientist, Institute of Human Development & Social Change, The Steinhardt School, New York University
- Candidate for M.D., The George Washington University School of Medicine and Health Sciences
- Research Aide, Medical Ethics, Departments of Medicine and Public Health, Weill Cornell Medical College
- Candidate for M.D., Temple University School of Medicine
- Research Technician, Rockefeller University
- Candidate for Ph.D. in Population Health Sciences and Environment & Resources, University of Wisconsin-Madison School of Medicine and Public Health & the Nelson Institute for Environmental Studies
- Resident Physician, Department of Orthopaedic Surgery, Hospital for Joint Diseases, New York University Langone Medical Center
- Senior Research Associate, International Program in Health Policy and Innovation, The Commonwealth Fund
- Candidate for M.D., University of Florida School of Medicine
- Public Health Solutions-MIC Women's Health Services
- Science Educator, Brooklyn Children's Museum, Friends of the High Line, The Intrepid: Sea, Air, and Space Museum, The New York Botanical Garden, and The Science Barge: Environmental Education Center
- Health Services Analyst, Mayo Clinic in Rochester
- Research Project Coordinator, Memorial Sloan-Kettering
- Program Director, Woolly School Garden Program (Largest school garden and nutrition program in the U.S.), Los Angeles, California
- Candidate for Ph.D. in Bioethics and Health Policy, Bloomberg School of Public Health, Johns Hopkins University

- Scientific Research Manager, Institutional Review Board (IRB), Human Research Subject Protection Program, NYU Langone Medical Center
- Editor, BioInform at GenomeWeb LLC
- Validation Specialist, QPharma, Inc.

Stonybrook: complete terminal medical degrees and PhD programs and hold diverse positions in such fields as clinical ethics, hospital administration, patient advocacy, hospice care and the chaplaincy. Many current working professionals use the education they receive in this program to enhance and complement their skills and knowledge in their current profession

Union:

- Research scientist became managing editor of a bioethics journal
- Certified public accountant became a hospital clinical ethicist immediately after earning her Masters
- Some graduates have found that the Masters enhanced their prospects of admission to medical school, or to graduate school.
- Enrolled in the Harvard School of Public Health Doctoral Program in Public Health Ethics

University of Pittsburgh

- Member of the Joint Centre for Bioethics and an Associate Professor and Chair of the Department of Philosophy at the University of Toronto
- Associate in the Litigation Services Department at Schnader Harrison Segal & Lewis, LLP
- Private legal practice focused on criminal and family law
- Law degree candidate at Temple University
- Internal Medicine MD
- Medical school candidate at Case Western Reserve University
- 2 jobs since—The Global Network of People Living with HIV/AIDS (GNP+) in The Netherlands, and the Women's Global Network for Reproductive Rights
- Director of Hospital Based Palliative Care for the Palliative and Supportive Institute of UPMC and Assistant Professor of Medicine at the University of Pittsburgh School of Medicine in the Division of General Medicine in the Section of Palliative Care and Medical Ethics
- Medical school candidate at Lake Erie College of Osteopathic Medicine
- Office of Consumer Litigation at the U.S. Justice Department--conducts investigations and litigates pharmaceutical and adulterated food cases under the federal Food, Drug and Cosmetic Act, and prosecutes abusive telemarketers for violations of the Federal Trade Commission's Telemarketing Sales Rule
- Assistant Professor in the University of Pittsburgh Schools of Nursing (Department of Health and Community Systems) and Medicine (Psychiatry) and a nurse practitioner at the University of Pittsburgh Alzheimer Disease Research Center
- General internist and palliative medicine physician
- Assistant Professor of Surgery, University of Pittsburgh School of Medicine--provides clinical ethics education to medical students and residents. Physician in the Department of Pediatric General and Thoracic Surgery at Children's Hospital of Pittsburgh--serves on the Ethics Committee and the Ethics Consultation Service

- Associate Professor and Director of Graduate Studies in Communication at the University of Colorado Denver
- Assistant Director of Admissions at Rhodes College
- Associate with McGuireWoods in Richmond, Virginia, practices almost exclusively in health law
- editor of the *UPMC Health System Palliative Care and Hospice Newsletter*, an educational resource for UPMC physicians
- Senior Attorney at the Pennsylvania Department of Welfare and has interests in the ethics of health care rationing and issues related to health insurance coverage, as well as the POLST
- Assistant Professor of Medicine in Drexel University's College of Medicine and the Internal Medicine Residency Program Director at Allegheny General Hospital, Pittsburgh (and chair of the ethics committee). Now-Assistant Professor of Medicine, Section of Palliative Care and Ethics, Division of General Medicine, University of Pittsburgh, and Medical Director for Family Hospice and Palliative Care Center – Center for Compassionate Care
- Senior Attorney with the US Department of Health and Human Services (HHS) in the Office of the General Counsel, Public Health Division
- Professor in the Department of Pediatrics, School of Medicine, and in the Department of Health and Physical Activity, School of Education, University of Pittsburgh. Chair of the Ethics Committee at Children's Hospital of Pittsburgh of UPMC
- Research Coordinator for Planned Parenthood of Southwest and Central Florida
- Law clerk to the Deputy Presiding Judge Philip Volland of the Alaska Superior Court in Anchorage, Alaska and a faculty facilitator for Ethics in the Health Professions course at the University of Colorado
- Health Sciences Fellow of the Jewish Health Care Foundation and the Coro Center for Civic Leadership
- internist, health services researcher, and ethicist
- PhD in History and Philosophy of Science in from the University of Pittsburgh in 2007, and then Assistant Professor, Department of Philosophy, and Adjunct Assistant Professor, Division of Medical Ethics and Humanities at the University of Utah
- Adjunct Lecturer, teaching bioethics, in the Department of Philosophy at Spring Hill College in Mobile, AL
- Pittsburgh firm of Buchanan Ingersoll & Rooney. Then taught bioethics and health law as an Adjunct Professor at the University of Pittsburgh School of Law. Then Assistant Professor of Law and Director of the Center for Bioethics & Health Law at the Mississippi College School of Law

#### Wakeforest

- VA/University of Chicago Ethics Consultation Fellowship. This fellowship is a one year intensive training opportunity in health care ethics consultation
- Going to medical school
- bioethics project coordinator for the Wake Forest University Baptist Medical Center

## **Appendix F: CV's of Faculty of MA in Bioethics & Science Policy**



**Curriculum Vitae, Misha Angrist, Ph.D., M.F.A.**  
(March 2013)

**Contact Information:**

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302 Research Drive  
Durham, North Carolina 27708-0141  
tel: 919.684.2872  
email: [misha.angrist@duke.edu](mailto:misha.angrist@duke.edu)

Date/Place of Birth: 5 July 1964, Pittsburgh, PA

Current Positions: Assistant Professor of the Practice, Duke University Institute for Genome Sciences & Policy  
Visiting Lecturer, DeWitt Wallace Center for Media and Democracy, Sanford School of Public Policy, Duke University

**Education:**

1982-1985	B.A. Psychology, Indiana University, Bloomington, Indiana
1988-1990	M.S. Biology, University of Cincinnati, Cincinnati, Ohio (Board-Eligible Genetic Counselor, 1990)
1991-1996	Ph.D. Genetics, Case Western Reserve University, Cleveland, Ohio (Thesis: "Identification of Hirschsprung Disease Susceptibility Genes," Advisor: Aravinda Chakravarti, Ph.D.)
1999-2001	M.F.A. Writing and Literature, The Writing Seminars, Bennington College, Bennington, Vermont

**Honors:**

1984-1987	Member, Psi Phi Psychology Honors Society
1985	Honors Graduate, Indiana University, Bloomington
1989	Visiting Research Fellow, Duke University, Durham, North Carolina
1990	Honors Graduate, University of Cincinnati
1996	Honors Graduate, Case Western Reserve University
2001	Recipient, Individual Artist Fellowship, Ohio Arts Council
2002	Tennessee Williams Scholar, Sewanee Writers' Conference
2003	Semi-Finalist, Iowa Short Fiction Award
2003	Selected for inclusion in <i>Best New American Voices 2004</i>
2004	Pushcart Prize Nominee
2004	Winner, Brenda L. Smart Fiction Prize
2005	Finalist, the Bakeless Literary Prize in Fiction
2007	Partial Fellowship Award, Vermont Studio Center
2013	Cole Memorial Lecturer, Wabash College

## **Memberships in Professional Societies:**

National Association of Science Writers  
American Society of Human Genetics  
Human Genome Organisation  
American Society for Bioethics & Humanities

## **Work Experience:**

1985-1987	Program Assistant, Institute for the Study of Developmental Disabilities, Indiana University, Bloomington, Indiana
1987-1988	Research Assistant, Institute for the Study of Developmental Disabilities, Indiana University, Bloomington, Indiana
1989-1990	Visiting Research Fellow, Duke University, Neurogenetics Unit
1990	Research Fellow, Molecular Diagnostics Lab, West Penn Hospital, Pittsburgh, PA
1996-1998	Research Associate, Case Western Reserve University
1998-2001	Industry Analyst, The Freedomia Group, Cleveland, Ohio
2000-2001	Portfolio Manager, Biotech Horizons Fund, LP, Cleveland, Ohio
2001-2003	Life Sciences Consultant (Ars Vita Consulting, Inc.)
2003-2008	Science Editor, Duke Institute for Genome Sciences & Policy
2008-present	Visiting Lecturer, Duke University Sanford Institute of Public Policy, DeWitt Wallace Center for Media & Democracy
2008-present	Assistant Professor of the Practice, Duke Institute for Genome Sciences & Policy

## **Teaching and Mentorship Experience:**

1988-1989	Graduate Teaching Fellow, Freshman Biology Laboratory, University of Cincinnati, Cincinnati, Ohio
1991-1996	Graduate Student Mentor, Case Western Reserve University
1999-2000	New Student Mentor, Bennington College M.F.A. Program
2005	Guest Lecturer, Talent Identification Program, Duke University
2005	Guest Lecturer, "The Human Genome in Literature, Film & News," Duke University
2005-2007	Guest Instructor, DNA and You, Club Boulevard Humanities Magnet School
2005-2007	Guest Lecturer, Duke IGSP Summer Fellowship Program
2006	Guest Lecturer, "The Gene Revolution and Our Food Supply," Duke University
2006-2007	Guest Lecturer, "Genomes, Biology, Medicine," (Freshman FOCUS Seminar in Biology), Duke University
2007	Guest Lecturer, "The Genome Revolution," (Special Topics in FOCUS), Duke University

2007	Independent Study Advisor to Master of Arts in Liberal Studies student, Megan Mayhew Bergman, Duke University
2008	Instructor, FOCUS 99FCS.06-F2008, Genome Revolution Interdisciplinary Discussion Course
2008-present	Instructor, PUBPOL196.S05/PUBPOL290S/DOCST290S/ENVIRON390S, "Science in the Media: Coverage of Science, Health and Policy in Print and Online," DeWitt Wallace Center for Media and Democracy, Terry Sanford Institute of Public Policy, Duke University
2009	Guest Lecturer, Watson School of Biological Sciences, Cold Spring Harbor Laboratory, Cold Spring Harbor, New York
2009-present	Instructor, GENOME 98FCS/GENOME118FS, "The Secret of Life: DNA, Property Rights and Human Identity," Duke University Institute for Genome Sciences & Policy and the Focus Program
2010	Independent Study Advisor to undergraduate student, Joyce Kim, Duke University
2010-present	Guest Lecturer, BIO280S, "Genetic Engineering and Biotechnology," Duke University
2011	Instructor, BIO44/GENOME44/BIO159/GENOME159, "The Past and Future of the Human Genome," Duke University
2011-2012	Independent Study Advisor to undergraduate student, Grace Baranowski, Duke University
2011-2012	Guest Lecturer, Duke House Course on Personalized Medicine, Duke University
2011-present	Guest Lecturer, PHARM 170S - 01 (PHARM 370S) "Pharmacogenomics and Personalized Medicine" Duke University
2011-present	Instructor, GENOME148, "Genome Sciences and Society," Duke University
2011-present	Guest Lecturer, 01:447:481: "Topics in Human Genetics," Rutgers University
2012	Mentor to Christina Lee, Duke undergraduate
2012	Guest Lecturer, CRTP 253, "Responsible Conduct of Research," Duke University
2012	Guest speaker, "Computational Personal Genomics," MIT
2013	Guest Lecturer, GENOME 612, "Responsible Genomics," Duke University

### Book:

**Angrist M.** *Here is a Human Being: At the Dawn of Personal Genomics*. New York: Harper Books (HarperCollins). 2010.

### Scientific and Scholarly Publications and Abstracts:

**1. Angrist M,** Kauffman E, Slaugenhaupt SA, Matise TC, Puffenberger EG, Washington SS, Lipson A, Cass DT, Reyna T, Weeks DE, et al. A gene for Hirschsprung disease (megacolon) in the pericentromeric region of human chromosome 10. *Nat Genet*. 1993 4:351-6.

**2. Puffenberger EG,** Kauffman ER, Bolk S, Matise TC, Washington SS, **Angrist M,** Weissenbach J, Garver KL, Mascari M, Ladda R, et al. Identity-by-descent and association mapping of a recessive gene for Hirschsprung disease on human chromosome 13q22. *Hum Mol Genet*. 1994 3:1217-25.

3. Hentati A, Pericak-Vance MA, Lennon F, Wasserman B, Hentati F, Juneja T, **Angrist MH**, Hung WY, Boustany RM, Bohlega S, et al. Linkage of a locus for autosomal dominant familial spastic paraplegia to chromosome 2p markers. *Hum Mol Genet.* 1994 3:1867-71.
4. **Angrist M**, Bolk S, Thiel B, Puffenberger EG, Hofstra RM, Buys CH, Cass DT, Chakravarti A. Mutation analysis of the RET receptor tyrosine kinase in Hirschsprung disease. *Hum Mol Genet.* 1995 4:821-30.
5. **Angrist M**, Wells DE, Chakravarti A, Pandey A. Chromosomal localization of the mouse Src-like adapter protein (Slap) gene and its putative human homolog SLA. *Genomics.* 1995 30:623-5.
6. Hofstra RM, Osinga J, Tan-Sindhunata G, Wu Y, Kamsteeg EJ, Stulp RP, van Ravenswaaij-Arts C, Majoor-Krakauer D, **Angrist M**, Chakravarti A, Meijers C, Buys CH. A homozygous mutation in the endothelin-3 gene associated with a combined Waardenburg type 2 and Hirschsprung phenotype (Shah-Waardenburg syndrome). *Nat Genet.* 1996 12:445-7.
7. Bolk S, **Angrist M**, Schwartz S, Silvestri JM, Weese-Mayer DE, Chakravarti A. Congenital central hypoventilation syndrome: mutation analysis of the receptor tyrosine kinase RET. *Am J Med Genet.* 1996 63:603-9.
8. Bolk S, **Angrist M**, Xie J, Yanagisawa M, Silvestri JM, Weese-Mayer DE, Chakravarti A. Endothelin-3 frameshift mutation in congenital central hypoventilation syndrome. *Nat Genet.* 1996 13:395-6.
9. **Angrist M**, Bolk S, Halushka M, Lapchak PA, Chakravarti A. Germline mutations in glial cell line-derived neurotrophic factor (GDNF) and RET in a Hirschsprung disease patient. *Nat Genet.* 1996 14:341-4.
10. **Angrist M**. Does phaster mean better? *Clin Chem.* 1997 43:424-6.
11. **Angrist M**, Jing S, Bolk S, Bentley K, Nallasamy S, Halushka M, Fox GM, Chakravarti A. Human GFRA1: cloning, mapping, genomic structure, and evaluation as a candidate gene for Hirschsprung disease susceptibility. *Genomics.* 1998 48:354-62.
12. **Angrist M**. Less is more: compact genomes pay dividends. *Genome Res.* 1998 8:683-5.
13. **Angrist M**, Bolk S, Bentley K, Nallasamy S, Halushka MK, Chakravarti A. Genomic structure of the gene for the SH2 and pleckstrin homology domain-containing protein GRB10 and evaluation of its role in Hirschsprung disease. *Oncogene.* 1998 17:3065-70.
14. Chadwick BP, Helbling LA, **Angrist M**, Chakravarti A, Gusella JF, Slaugenhaupt SA. Assignment of persephin (PSPN), a human neurotrophic factor, to chromosome 19p13.3 by radiation hybrid mapping and somatic cell hybrid PCR. *Cytogenet Cell Genet.* 1998 83:236-7.
15. Southard-Smith EM, **Angrist M**, Ellison JS, Agarwala R, Baxeavanis AD, Chakravarti A, Pavan WJ. The Sox10(Dom) mouse: modeling the genetic variation of Waardenburg-Shah (WS4) syndrome.

*Genome Res.* 1999 9:215-25.

16. Bolk S, Pelet A, Hofstra RM, **Angrist M**, Salomon R, Croaker D, Buys CH, Lyonnet S, Chakravarti A. A human model for multigenic inheritance: phenotypic expression in Hirschsprung disease requires both the RET gene and a new 9q31 locus. *Proc Natl Acad Sci U S A.* 2000 97:268-73.
17. Blagoev B, Nielsen MM, **Angrist M**, Chakravarti A, Pandey A. Cloning of rat thymic stromal lymphopoietin receptor (TSLPR) and characterization of genomic structure of murine Tslpr gene. *Gene.* 2002 284:161-8.
18. Gabriel SB, Salomon R, Pelet A, **Angrist M**, Amiel J, Fornage M, Attie-Bitach T, Olson JM, Hofstra R, Buys C, Steffann J, Munnich A, Lyonnet S, Chakravarti A. Segregation at three loci explains familial and population risk in Hirschsprung disease. *Nat Genet.* 2002 31:89-93.
19. **Angrist M**. Breast cancer: integrating the patient with her genome. *Trends Biotechnol.* 2005 23:3-5.
20. **Angrist M**, Willard HF. The genome for the masses (book review). *Nat Genet.* 2005 37:114.
21. Willard HF, **Angrist M**, Ginsburg GS. Genomic medicine: genetic variation and its impact on the future of health care. *Philos Trans R Soc Lond B Biol Sci.* 2005 360:1543-50.
22. **Angrist M**, Cook-Deegan RM. Who owns the genome? *New Atlantis.* 2006 11:87-96.
23. Ginsburg GS, **Angrist M**. The future may be closer than you think: a response from the Personalized Medicine Coalition to the Royal Society's report on personalized medicine. *Personalized Medicine.* 2006 3:119-23.
24. Ginsburg GS, **Angrist M**, Cook-Deegan R. Genomics and medicine at a crossroads in Chernobyl. *Science.* 2006 314:62-3.
25. **Angrist M**. Personal genomics: Access denied? *Technology Review.* 2008 September/October <http://www.technologyreview.com/Biotech/21250/page1/>
26. **Angrist M**. High anxiety (book review). *Nat Genet.* 2008 40:1038.
27. **Angrist M**. The stewardess is flying the plane: Genomic determinism and personal genomics gone wild! Abstract and poster presentation, Personal Genomes, Cold Spring Harbor Laboratory, 9 – 12 October 2008.
28. **Angrist M**, Chandrasekharan S, Heaney C, Cook-Deegan R. "Intellectual Property and Its Impact on Genetic Testing for Long QT Syndrome." Peer-reviewed case study submitted for discussion at the Secretary's Advisory Committee on Genetics, Health, and Society, 1 December 2008.

29. **Angrist M**, Chandrasekharan S, Heaney C, Cook-Deegan RM. A tangled web: Exclusive patent rights and genetic testing for long QT syndrome. Abstract and poster presentation, American Society of Human Genetics meeting, 12 November 2008, Philadelphia PA.
30. Cook-Deegan R, Chandrasekharan S, **Angrist M**. The dangers of diagnostic monopolies. *Nature*. 2009 458:405-6.
31. **Angrist M**. We are the genes we've been waiting for: Rational responses to the gathering storm of personal genomics. *Am J Bioeth*. 2009 9(6-7): 30-1.
32. **Angrist M**. Eyes wide open: The Personal Genome Project, citizen science and veracity in informed consent. *Personalized Medicine*. 2009 6(6): 691-9.
33. **Angrist M**. Only connect: Personal genomics and the future of American medicine. *Mol Diagn Ther*. 2010 14(2):67-72.
34. Lunshof JE, Bobe J, Aach J, **Angrist M**, Thakuria JV, Vorhaus DB, Hoehe MR, Church GM. Personal Genomes in Progress: From the *Human* Genome Project to the *Personal* Genome Project. *Dialogues Clin Neurosci*. 2010 12(1):47-60.
35. **Angrist M**, Chandrasekharan S, Heaney C, Cook-Deegan RM. Impact of gene patents and licensing practices on access to genetic testing for long QT syndrome. *Genet Med*. 2010 12(4): S111-S154.
36. **Angrist M**. Urge overkill: Protecting deidentified human subjects at what price? *Am J Bioeth*. 2010 10(9): 1-2.
37. Carbone J, Gold ER, Sampat B, Chandrasekharan S, Knowles L, **Angrist M**, Cook-Deegan R. DNA patents and diagnostics: Not a pretty picture. *Nat Biotech*. 2010 8:784-91.
38. **Angrist M**. You never call, you never write: Why return of "omic" results to research participants is both a good idea and a moral imperative. *Personalized Medicine*. 2011 8:651-7.
39. Øien NC, Katsanis SH, Davis EE, Cope H, Sun J, Kurtzberg J, Ashley-Koch A, Goldberg R, **Angrist M**, Murtha A, Cotton CM, Katsanis N. Multidisciplinary and Translational Task Force for Neonatal Genomics. ACMG Abstract #22, platform presentation, American College of Medical Genetics Annual Clinical Genetics Meeting, 29 March 2012, Charlotte, North Carolina.
40. Ball MP, Thakuria JV, Zaranek AW, Bobe J, Bhak J, Cano C, Clegg T, Chou MF, Chung WK, Douglas SM, Gore A, Hulick P, Labarga A, Lunshof J, Kim BC, Li Z, Nilsen GB, Peshkin L, Robasky K, Rosenbaum AM, Vandeweghe W, Vorhaus D, Yang JL, Yang L, Wu X, Aach J, Ashley EA, Drmanac R, Li JB, **Angrist M**, Seidman CE, Zhang K, Rehm HL, Church GM. A Public Resource Facilitating Clinical Use of Genomes. *Proc Natl Acad Sci U S A*. 2012 109:11920-7.
41. Davis EE, Sabo A, Øien NC, Katsanis SH, Cope H, Sheets K, Sadeghpour A, McDonald K, Kousi M, Willer JR, Kim J, Dugan-Rocha S, Muzny DM, Ashley-Koch A, Hauser E, Hauser M, Sun J,

Kurtzberg J, Murtha A, Boyd B, Gallentine WB, Goldberg R, McDonald MT, Gibbs RA, **Angrist M**, Cotton CM, Katsanis N. Multidisciplinary and Translational Task Force for Neonatal Genomics. ASHG Abstract #3, plenary presentation, American Society of Human Genetics Annual Meeting, 6 November 2012, San Francisco, California.

**42. Katsanis N, Cotten M, Angrist M.** Exome and genome sequencing of neonates with neurodevelopmental disorders. *Future Neurology*. 2012 7:655-658.

**43. Angrist M.** Genetic privacy needs a more nuanced approach. *Nature*. 2013 494:7.

**44. Angrist M.** “Of Helices, HIPAA, Hairballs...and Humans.” In: *The Story Within: Personal Essays on Genetics and Identity*. Baltimore: Johns Hopkins University Press. 2013 (IN PRESS).

#### **Journalism, Op-Eds and Public Information Publications:**

**Angrist M.** *GenomeLIFE*. Duke University Institute for Genome Sciences & Policy bi-monthly magazine. Principal writer and co-editor, 2004-2008. <http://www.genome.duke.edu/genomelife>

**Angrist M.** Genomic medicine on the move. *Duke University Dialogue*. 22 October 2004.

**Angrist M.** Genomes and global health. *INSIDE Duke University Medical System*. 6 December 2004.

**Angrist M.** Reflections on the god gene and ‘hard-wired faith.’ *Duke University Dialogue*. 3 June 2005

**Angrist M.** From genes to vaccines. *INSIDE Duke University Medical System*. 20 February 2006.

**Angrist M.** Putting the DNA into dance. *This Month at Duke*. September 2006.

**Angrist M.** Offensive science: HIV/AIDS education at home and abroad. *This Month at Duke*. March 2007.

**Angrist M.** Let’s decide what to do about our DNA. *The Newark Star-Ledger*. 8 February 2008.

<http://www.nj.com/starledger/stories/index.ssf?/base/news-1/120244896797690.xml&coll=1>

Also published as:

**Angrist M.** Already cruising the genome highway. *The Raleigh News & Observer*. 8 February 2008.

<http://www.newsobserver.com/opinion/columns/story/931766.html>

**Angrist M.** Genomics and the secret ingredient. *Inside Duke University Medical Center & Health System*. 1 July 2008. <http://inside.duke.edu/article.php?IssueID=189&ParentID=18873>

**Angrist M.** School of Hock: Two universities have announced plans to collect students' saliva and analyze their DNA. Is that a good idea? *Slate*. 23 June 2010. <http://www.slate.com/id/2257793/>

**Angrist M.** A chance to help overcome society’s DNA phobia. *The Times*. 11 October 2010. <http://www.thetimes.co.uk/tto/news/uk/article2761107.ece>

**Angrist M.** Everything that I'm made of, I put online. *Salon*. 27 November 2010.  
[http://www.salon.com/life/excerpt/2010/11/27/misha\\_angrist\\_genome\\_sequenced](http://www.salon.com/life/excerpt/2010/11/27/misha_angrist_genome_sequenced)

**Angrist M.** Overcoming Genophobia. *Huffington Post*. 15 December 2010.  
[http://www.huffingtonpost.com/misha-angrist/overcoming-genophobia\\_b\\_796639.html](http://www.huffingtonpost.com/misha-angrist/overcoming-genophobia_b_796639.html)

**Angrist M.** Writing about personal genomics in the postgenomic era. *ReportingonHealth.org*. 11 August 2011. <http://www.reportingonhealth.org/resources/lessons/writing-about-personal-genomics-postgenomic-era>

**Angrist M.** Running on empty: what happens when patients with an orphan disease find themselves orphaned? IN PREPARATION.

#### **Selected Literary Publications:**

**Angrist M.** "Swedish Bricks and Minerals" (2003) *The Michigan Quarterly Review*. **42:1**, pp. 178-194.

**Angrist M.** "So Much the Better" (2003) In: *Best New American Voices 2004* (John Casey, ed.). New York: Harcourt, Inc., pp. 1-20.

**Angrist M.** "Holidays" (2004) *Kerem*. **9**, p. 10.

**Angrist M.** "Venn Diagram" (2005) *Elysian Fields Quarterly*. **22:3**.

**Angrist M.** "Paper Boy" (2006) *The Literary Review*. **49:4**.

**Angrist M.** "Fourth and a Mile" (2006) *The Pittsburgh Post-Gazette*. 24 September 2006.

**Angrist M.** "Orchid Agonistes" (2010) *Nature*. **465:518**.

#### **Invited Presentations:**

"Your Sequence is Showing: A Whirlwind Tour through the Land of Personal Genomics." Duke University Institute for Genome Sciences & Policy, Duke University, Durham, North Carolina. 21 February 2008.

"Your Biological Biography." Panel presentation at the World Science Festival. New York City, New York. 31 May 2008.

"Your Sequence is Showing: A Research Subject's Perspective on Personal Genomics." Beyond Genome: Personal Medicine. San Francisco, California. 10 June 2008.

"Prometheus at Large: The Rise of Personal Genomics." Institute for Pharmacogenomics & Individualized Therapy. University of North Carolina, Chapel Hill, North Carolina. 13 January 2009.

"Prometheus at Large: Personal Genomics and the Transformation of Genetic Testing." Expression Analysis. Durham, North Carolina. 23 January 2009.



“And the Crowd Goes Wild: The Eruption of Personal Genomics.” Keynote Presentation, Synapse 2009. Charleston, South Carolina. 28 March 2009.

“Letting it All Hang Out: The Personal Genome Project.” Science Café, The North Carolina Museum of Natural Sciences. Raleigh, North Carolina. 19 May 2009.

“It’s My Party and I’ll Spit if I Want to.” Genetics & Ethics in the 21st Century Conference. Breckenridge, Colorado. 25 July 2009.

“What I Saw at the Revolution: An Extremely Incomplete, Terribly Biased, Ridiculously Premature, Oral, Visual and Molecular History of Personal Genomics, 2003-2009.” Ethics Panel at Cold Spring Harbor Laboratory Meeting on Personal Genomes. Cold Spring Harbor, NY. 15 September 2009.

“Clinical Integration of Direct-to-Consumer Personal Genome Testing: Perspectives, Experiences, and Challenges.” Panel at American Society for Bioethics + Humanities 11th Annual Meeting. Washington, DC. 18 October 2009.

“Probabilistic Medicine.” Health Horizons 2009 Fall Conference, Health and Health Care 2020 Making the Future: Strategic Action Retreat. Sausalito, California. 16 November 2009.

“The Human Genome: Perpetual Contemplation of an Infinite Glory...or Something.” 2010 AB Duke Speaker Series. Duke University, Durham, North Carolina. 2 February 2010.

“Imputing the Future.” 2010 Duke Prospective Health Care Conference. Duke University, Durham, North Carolina. 10 February 2010.

“Oh, jeez, she’s a real person: Personal genomics and the perpetual struggle for autonomy.” Personal Genomics: From Discovery to the Bedside. Duke University, Durham, North Carolina. 24 March 2010.

“The Future Ain’t What it Used to Be: A Truncated, Biased and Self-Serving History of Personal Genomics, 2003-2010.” UC Santa Cruz Biocuration Workshop. Santa Cruz, California. 27 May 2010.

“Is that your genome or are you just happy to see me?” UC Santa Cruz Biocuration Workshop. Santa Cruz, California. 27 May 2010

“Risks and Benefits of Direct-to-Consumer Access to Genetic Information.” Panel presentation at 23andMe Policy Forum. San Francisco, California. 14 July 2010.

“What Becomes of the Broken-Hearted: Gene Patents and Long QT Syndrome.” Open Science Summit. Berkeley, California. 30 July 2010.

“Old Media in a New Media World.” Panel presentation at the Science Communication Conference at the North Carolina Museum of Natural Sciences. Raleigh, North Carolina. 21 August 2010.

"DIYbio: Origin, Activities, & Scenarios for the Future." Synthetic Biology II Workshop, Building Bridges Around Biotech. Boston, Massachusetts. 31 August 2010.

"What Becomes of the Broken-Hearted: Gene Patents and Long QT Syndrome." Genomic and Personalized Medicine Forum. Duke University, Durham, North Carolina. 16 September 2010.

"Don't Fear the Reaper: Personal Genomics and Living with Uncertainty." The Bloody Crossroads of Science and Policy, American Enterprise Institute. Washington, DC. 24 September 2010.

"I Can Live Without the Singularity." Panel presentation at Technology: Promises & Pitfalls for Advanced Illness Management. Duke Institute for Care at the End of Life Roundtable. Durham, North Carolina. 26 October 2010.

"Great science writing part I: From eureka moment to book." Panel presentation at the National Association of Science Writers Annual Meeting. New Haven, Connecticut. 6 November 2010.

"Here is a Human Being." Knight Science Journalism Fellows, Massachusetts Institute of Technology. Cambridge, Massachusetts. 22 November 2010.

"Here is a Human Being." Center for Genetics Research, Ethics and Law, Case Western Reserve University. Cleveland, Ohio. 16 December 2010.

"Alternative careers for scientists: from grad school to writing for mainstream media." ScienceOnline2011. Research Triangle Park, North Carolina. 16 January 2011.

"Exploring Your Genetic Blueprint." Panel presentation at "A Decade with the Human Genome Sequence: Charting a Course for Genomic Medicine," National Institutes of Health. Bethesda, Maryland. 11 February 2011.

"The Future Ain't What It Used to Be." The Future of Genomic Medicine IV, Scripps Seaside Forum. La Jolla, California. 4 March 2011.

"What's in It for Us: A New Covenant for Human Biomedical Research." BIL Conference. Long Beach, California. 5 March 2011.

"Here is a Human Being." Public Library of Science. San Francisco, California. 10 March 2011.

"Here is a Human Being." Harvard Club. San Francisco, California. 11 March 2011.

"I Shall Be Released: Personal Genomic Data and a New Covenant for Biomedical Research." National Undergraduate Bioethics Conference. Duke University, Durham, North Carolina. 20 March 2011.

"You Never Call, You Never Write: A New Covenant for Human Biomedical Research." Pediatric Pharmacogenomics and Personalized Medicine. Kansas City, Missouri. 31 March 2011.

“It’s Not About You: The Life and Times of a Public Genome.” Duke University Undergraduate Fellows Finalists Luncheon. Durham, North Carolina. 9 April 2011.

“Whole Genome Sequencing.” Panel presentation at ELSI Congress, Exploring the ELSI Universe. Chapel Hill, North Carolina. 13 April 2011.

“You Never Call, You Never Write: Personal Genomic Data and a New Covenant for Biomedical Studies of Real Live Humans.” Duke University Institutional Review Board. Durham, North Carolina. 10 May 2011.

“‘In This Happy Place My Serious Heart Has Made’: Searching For Pittsburgh, the Genome...and What It Means to be Human.” Café Scientifique, Carnegie Science Center. Pittsburgh, Pennsylvania. 6 June 2011.

“The Genomic Era: Hype or Hope?” Panel debate at Genetic Alliance 25th Anniversary Annual Conference. Bethesda, Maryland. 24 June 2011.

“Mama, Don’t Let Your Babies Grow Up to be Cylons: Personal Genomics and Choosing One’s Battles.” Singularity University, Moffett Field, Sunnyvale, California. 3 August 2011.

“Personal Genomics: I Expect Nothing. I Fear Nothing. I Am Free.” Deutscher CFO-Summit. Bad Nauheim, Germany. 22 September 2011.

“Fabrazyme®.” Open Science Summit. Mountain View, California. 22 October 2011.

“Pay It Forward: Why Return of Laboratory Results to Research participants is Both a Moral Imperative and a Good Idea.” Lab Institute 2011. Arlington, Virginia. 21 October 2011.

“What We’ve Got Here is a Failure to Communicate: A Test of Faith in Human Research Participants” Open Science Summit. Mountain View, California. 23 October 2011.

“Took my diamond to the pawnshop...but that don’t make it junk.” Science Communicators of North Carolina. Research Triangle Park, North Carolina. 25 October 2011.

“Personal Genomics: I Expect Nothing. I Fear Nothing. I Am Free.” DRI Annual Meeting. Washington, DC. 27 October 2011.

“When We Were Orphans: The Case of Fabrazyme® Duke Center for Public Genomics fall meeting, Duke University. Durham, North Carolina. 16 November 2011.

“Personal Genomics: I Expect Nothing. I Fear Nothing. I Am Free.” ScienceOnline2012. Raleigh, North Carolina. 21 January 2012.

“My ‘Ome’ is Not My Castle: Turning Genomic Determinism on Its Head.” Circulating Genomes Meeting. Edinburgh, UK. 10 February 2012.

“To Put Away Childish Things: Fomenting Rebellion Among Human Research Participants.” UC Davis Ecology and Evolution Seminar. Davis, California. 7 March 2012.

“Nobody Sees the Wizard: Human Research Participants and the Man Behind the Curtain.” NIEHS/OHRP SANC Conference. Raleigh, North Carolina. 21 March 2012.

“The Least of My Worries: Genomes Personal and Public.” Office of University Scholars & Fellows Finalists Meeting, John Hope Franklin Center, Duke University. Durham, North Carolina. 31 March 2012.

“Genomes for Me and Not for Thee.” Sage Biocommons Congress. San Francisco, California. 20 April 2012.

“Nobody Sees the Wizard: Human Research Participants and the Man Behind the Curtain.” University of Rhode Island. Kingston, Rhode Island. 24 April 2012.

“Genomes: Personal and Public.” South Granville High School. Creedmoor, North Carolina. 27 April 2012.

“Can You See the Real Me: Treating Human Research Participants and Patients Like Human Beings.” Duke Center for Human Genome Variation Retreat. Lake Lure, North Carolina. 8 June 2012.

“Can You See the Real Me: Human Patients, Human Participants.” NCI's Think Tank on the Identifiability of Biospecimens and Genomic Data. Rockville, Maryland. 11 June 2012.

“‘Don’t Try This At Home, Kids’: Genetic Exceptionalism, Personal Genomics and Genetics Education.” Workshop on Using Genetics and Genealogy to Teach Evolution and Human Diversity, The National Evolutionary Synthesis Center. Durham, North Carolina. 22 June 2012.

“Nobody Sees the Wizard: Human Biological Information and the Man Behind the Curtain.” Fletcher Allen Health Care Pathology Grand Rounds. Burlington, Vermont. 27 June 2012.

“The Man Behind the Curtain: Using genomic information in a just and constructive way.” FTNLS Workshop: The Omics (R)evolution. Universiteit Antwerpen, Antwerp, Belgium. 14 September 2012.

“We are the 2 percent...and increasingly, the 93 percent: The past, present and future of clinical sequencing.” Keynote, Undergraduate Faculty Genetics Education Workshop, Annual Meeting of the American Society of Human Genetics, San Francisco, California. 6 November 2012.

“Midwife crisis: A cultural and financial mandate for talking to research participants.” Future of Genomic Medicine VI, La Jolla, California. 7 March 2013.

“An Acre of Tea Leaves: The Past, Present and Future of Clinical DNA Sequencing.” Cole Memorial Lecture, Wabash College, Wabash, Indiana. 11 March 2013.

“Midwife crisis: A cultural and financial mandate for talking to research participants.” Cole Memorial Lecture, Wabash College, Wabash, Indiana. 11 March 2013.

**University/Nonprofit Service and Academic Committees:**

2007-2008	Member, Duke Research Communicators
2007-2008	Member, Advisory Board, <i>Duke Today</i>
2009-present	Member, Institutional Review Board, Duke University Medical Center
2010	Co-convener, Duke University Personal Genomics Working Group
2010-present	Member, Genetics and Genealogy Working Group (convened by Henry Louis Gates, Jr.)
2010-present	Co-convener, Duke University Policy in Genome Sciences Working Group
2012-present	Member, Curriculum Development Group for Genetics and Genealogy: Teaching Evolution and Human Diversity to Middle School Students
2012-present	Member, Personal Genome Project Board of Directors

**Ad Hoc Reviewer 1996-present:**

*Genome Research*  
*Human Molecular Genetics*  
*Nature Biotechnology*  
*Nature Genetics*  
*Oncogene*  
*Personalized Medicine*  
*Trends in Biotechnology*  
*Genetics in Medicine*

**Consultation Activities 2001-2004:**

Cambridge Healthtech Institute  
The Cleveland Clinic  
Ernst & Young LLP  
Walter Greenblatt & Associates LLC

**Current Research Collaborators:**

- Shubha Chandrasekharan, Duke University Institute for Genome Sciences & Policy
- George M. Church, Department of Genetics, Harvard University
- Robert M. Cook-Deegan, Duke University Institute for Genome Sciences & Policy
- C. Michael Cotten, Duke University School of Medicine, Department of Pediatrics, Division of Neonatology
- Nico Katsanis, Duke University Center for Human Disease Modeling
- Sara Katsanis, Duke University Institute for Genome Sciences & Policy

- Jeantine Lunshof, Faculty of Health, Medicine and Life Sciences, Cluster of Genetics & Cell Biology, Maastricht University
- Arti K. Rai, Duke University School of Law
- Mark Sagoff, Institute for Philosophy and Public Policy, George Mason University
- Jennifer K. Wagner, Center for the Integration of Genetic Healthcare Technologies, University of Pennsylvania
- Huntington F. Willard, Duke University Institute for Genome Sciences & Policy

### **Current Support**

2P50-HG003391-06 MINI #5-C2031057 PROJECT #4-PERSONAL GENOMICS; Part of NHGRI-funded P50 Center for Excellence in Ethics Research.

Strategic Grant #20110316 Ewing Marion Kauffman Foundation award to study the Chordoma Foundation.

NIDDK P01 proposal for Whole-Exome Sequencing of Neonates with Renal and/or Urogenital Malformations in conjunction with the Duke Task Force for Exome Sequencing and Return of Results (Nico Katsanis, PhD, Principal Investigator). Start date: 1 July 2012.

### **Completed Support**

Completed Research Support

10/1/07 – 6/30/08

Duke Center for Science Education

(PI: Angrist)

Pilot Grant

9/1/04 - 3/31/11

Center for Public Genomics: Analytical Resources

(PI: Cook-Deegan)

P50-HG 03391-05S2

National Institutes of Health

Role: Paid Consultant

**CURRICULUM VITAE**  
**LAURA MARI BESKOW**

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**CONTACT INFORMATION**

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Durham, North Carolina 27708  
Tel: 919-668-2293; Fax: 919-668-0799  
Email: laura.beskow@duke.edu

**EDUCATION**

- 2001 – 2005 Ph.D. Health Policy & Administration (Epidemiology minor), University of North Carolina at Chapel Hill School of Public Health
- Dissertation title: “Recruiting Research Participants through Cancer Registries: Stakeholder Perspectives” (Chair: Morris Weinberger, PhD, Distinguished Professor)
- 1994 – 1995 M.P.H. Health Law Concentration, Boston University School of Public Health
- 1980 – 1985 B.S. Food & Nutrition (Coordinated Undergraduate Program in Dietetics), Iowa State University

**EXPERIENCE**

Professional

- 2007 – Assistant Research Professor, Duke Institute for Genome Sciences & Policy
- Other appointments:*
- Faculty Associate, Trent Center for Bioethics, Humanities & History of Medicine, Duke University Medical Center
  - Faculty Category B, Duke Clinical Research Institute
  - Faculty Associate, Center for Genomics & Society (a Center of Excellence in ELSI Research), UNC-Chapel Hill
- 2006 Senior Research Scholar, Center for Genome Ethics, Law & Policy, Duke Institute for Genome Sciences & Policy
- 1999 – 2001 Career Development Awardee (through the Association of Teachers of Preventive Medicine), Office of Genetics and Disease Prevention, Centers for Disease Control & Prevention

1996 – 1998 Associate Director and Coordinator, Program in Genomics, Ethics & Society, Stanford University  
Center for Biomedical Ethics

## PUBLICATIONS

### Peer-Reviewed Articles

**Beskow LM**, Burke W, Fullerton SM, Sharp RR. Offering aggregate results to participants in genomic research: benefits and challenges. *Genetics in Medicine*; in press.

**Beskow LM**, Namey EE, Cadigan RJ, Brazg T, Crouch J, Henderson GE, Michie M, Nelson DK, Tabor HK, Wilfond BS. Research participants' perspectives on genotype-driven research recruitment. *Journal of Empirical Research on Human Research Ethics*; in press.

Namey EE, **Beskow LM**. Epilepsy patient-participants and genetic research results as 'answers.' *Journal of Empirical Research on Human Research Ethics*; in press.

Cadigan RJ, Michie M, Henderson GE, Davis AM, **Beskow LM**. The meaning of genetic research results: reflections from individuals with and without a known genetic disorder. *Journal of Empirical Research on Human Research Ethics*; in press.

Tabor HK, Brazg T, Crouch J, Namey EE, Fullerton SM, **Beskow LM**, Wilfond BS. Parent perspectives on pediatric genetic research and the implications for genotype-driven research recruitment. *Journal of Empirical Research on Human Research Ethics*; in press.

**Beskow LM**, Namey EE, Miller PR, Nelson DK, Cooper A. IRB chairs' perspectives on genotype-driven research recruitment. *IRB: Ethics & Human Research*; in press.

DuBois JM, **Beskow LM**, Campbell J, Dugosh K, Festinger D, Hartz S, James R, Lidz C. Restoring balance: the protection of "vulnerable" research participants. *American Journal of Public Health*; in press.

Fabsitz RR, McGuire AL, Sharp RR, Hudson K, Pandey M, **Beskow LM**, Biesecker LG, Bookman E, Burke W, Burchard EG, Church G, Clayton EW, Eckfeldt J, Fernandez C, Fisher R, Fullerton SM, Gabriel S, James C, Jarvik GP, Kittles R, Leib J, O'Donnell C, O'Rourke PP, Rodriguez LL, Romero F, Schully SD, Shuldiner AR, Sze RKF, Thakuria J, Wolf SM, Burke GL. Ethical and practical guidelines for reporting genetic research results to study participants: updated guidelines from an NHLBI Working Group. *Circulation: Cardiovascular Genetics* 2010; 3(6): 574-80 [PMC3090664].

**Beskow LM**, Friedman J, Hardy C, Lin L, Weinfurt KP. Developing a simplified consent form for biobanking. *PLoS One* 2010; 5(10): e13302. doi:10.1371/journal.pone.0013302 [PMC2951917].

Clayton EW, Smith M, Fullerton SM, Burke W, McCarty CA, Koenig BA, McGuire AL, **Beskow LM**, Dressler L, Lemke AA, Ramos EM, Rodriguez LL. Confronting real time ethical, legal, and social issues in the eMERGE (Electronic Medical Records and Genomics) Consortium. *Genetics in Medicine* 2010; 12(10): 616-20 [PMC3090678].

**Beskow LM**, Friedman J, Hardy C, Lin L, Weinfurt KP. Simplifying informed consent for biorepositories: stakeholder perspectives. *Genetics in Medicine* 2010; 12(9): 567-72 [PMCID in process].



McGuire AL, **Beskow LM**. Informed consent in genomics and genetic research. *Annual Review of Genomics and Human Genetics* 2010; 11: 361-81 [PMC3216676].

**Beskow LM**, Burke W. Offering individual genetic research results: context matters. *Science Translational Medicine* 2010; 2(38): 38cm20 [PMC3136874].

**Beskow LM**, Linney KN, Radtke RA, Heinzen EL, Goldstein DB. Ethical challenges in genotype-driven research recruitment. *Genome Research* 2010; 20(6): 705-9 [PMC2877567].

**Beskow LM**, Grady C, Iltis AS, Sadler JZ, Wilfond BS. Points to consider: the relationship between research ethics consultation and institutional review boards. *IRB: Ethics & Human Research* 2009; 31(6): 1-9 [PMC2921073].

**Beskow LM**, Smolek SJ. Prospective biorepository participants' perspectives on access to research results. *Journal of Empirical Research on Human Research Ethics* 2009; 4(3): 99-111 [PMC2892166].

**Beskow LM**, Dame L, Costello EJ. Certificates of Confidentiality and compelled disclosure of data. *Science* 2008; 322(5904): 1054-5 [PMC2694567].

**Beskow LM**, Dean E. Informed consent for biorepositories: assessing prospective participants' understanding and opinions. *Cancer Epidemiology, Biomarkers & Prevention* 2008; 17(6): 1440-51.

Haga SG, **Beskow LM**. Ethical, legal, and social implications of biobanks for genetics research. *Advances in Genetics* 2008; 60: 505-44.

Glickman SW, Anstrom KJ, Lin L, Chandra A, Laskowitz DT, Woods CW, Freeman DH, Kraft M, **Beskow LM**, Weinfurt KP, Schulman KA, Cairns CB. Challenges in enrollment of minority, pediatric, and geriatric patients in emergency and acute care clinical research. *Annals of Emergency Medicine* 2008; 51(6): 775-80.

Carpenter WR, **Beskow LM**, Blocker DE, Forlenza MJ, Kim AE, Pevzner ES, Rose JM, Tran AN, Webber KH, Knight K, O'Malley MS. Towards a more comprehensive understanding of cancer burden in North Carolina: Priorities for intervention. *North Carolina Medical Journal* 2008; 69(4): 275-82 [PMC2743945].

Bailey DB Jr, **Beskow LM**, Davis AM, Skinner D. Changing perspectives on the benefits of newborn screening. *Mental Retardation and Developmental Disabilities Research Reviews* 2006; 12(4): 270-9.

**Beskow LM**, Sandler RS, Weinberger M. Research recruitment through U.S. central cancer registries: balancing privacy and scientific issues. *American Journal of Public Health* 2006; 96(11): 1920-6 [PMC1751818].

**Beskow LM**, Millikan RC, Sandler RS, Godley PA, Weiner BJ, Weinberger M. The effect of physician permission versus notification on research recruitment through cancer registries. *Cancer Causes & Control* 2006; 17(3): 315-23.

Stitzenberg KB, Thomas NE, **Beskow LM**, Ollila DW. Population-based analysis of lymphatic mapping and sentinel lymphadenectomy utilization for intermediate thickness melanoma. *Journal of Surgical Oncology* 2006; 93(2): 100-7.

**Beskow LM**, Sandler RS, Millikan RC, Weinberger M. Patient perspectives on research recruitment through cancer registries. *Cancer Causes & Control* 2005; 16(10): 1171-5.

**Beskow LM**, Botkin JR, Daly M, Juengst ET, Lehmann LS, Merz JF, Pentz R, Press NA, Ross LF, Sugarman J, Susswein LR, Terry SF, Austin MA, Burke W. Ethical issues in identifying and recruiting participants for familial genetic research. *American Journal of Medical Genetics* 2004; 130A: 424-31.

**Beskow LM**, Burke W, Merz JF, Barr PA, Terry S, Penchaszadeh VB, Gostin LO, Gwinn M, Khoury MJ. Informed consent for population-based research involving genetics. *JAMA* 2001; 286(18): 2315-21.

**Beskow LM**, Khoury MJ, Baker TG, Thrasher JF. The integration of genomics into public health research, policy, and practice. *Community Genetics* 2001; 4(1): 2-11.

**McConnell LM**, Koenig BA, Greely HT, Raffin TA. Genetic testing and Alzheimer disease: recommendations of the Stanford Program in Genomics, Ethics, and Society. *Genetic Testing* 1999; 3(1): 3-12.

**McConnell LM**. Understanding genetic testing for Alzheimer disease: medical and epidemiological background. *Genetic Testing* 1999; 3(1): 21-7.

Tobin SL, Chun N, Powell TM, **McConnell LM**. The genetics of Alzheimer disease and the application of molecular tests. *Genetic Testing* 1999; 3(1): 37-45.

**McConnell LM**, Sanders G, Owens DK. Evaluation of genetic tests: APOE genotyping for the diagnosis of Alzheimer disease. *Genetic Testing* 1999; 3(1): 47-53.

**McConnell LM**, Goldstein MK. The application of medical decision analysis to genetic testing: an introduction. *Genetic Testing* 1999; 3(1): 65-70.

**McConnell LM**, Koenig BA, Greely HT, Raffin TA. Genetic testing and Alzheimer disease: has the time come? *Nature Medicine* 1998; 4(7): 757-9.

Koenig BA, Greely HT, **McConnell LM**, Silverberg HL, Raffin TA. Genetic testing for BRCA1 and BRCA2: recommendations of the Stanford Program in Genomics, Ethics, and Society. *Journal of Women's Health* 1998; 7(5): 531-45.

*In process:*

**Beskow LM**, Fullerton SM, Namey EE, Nelson DK, Davis AM, Wilfond BS. Recommendations for ethical approaches to genotype-driven research recruitment; submitted.

Wolf SM, Crock BN, Van Ness B, Lawrenz B, Kahn JP, **Beskow LM**, Cho MK, Christman MF, Green RC, Hall R, Illes J, Keane M, Knoppers BM, Koenig BA, Kohane IS, LeRoy B, Maschke KJ, McGeeveran W, Ossorio P, Parker LS, Petersen GM, Richardson HS, Scott JA, Terry SF, Wilfond BS, Wolf W. Managing incidental findings and research results in genomic research involving biobanks and archived datasets; in process.

Michie M, Cadigan RJ, Henderson G, **Beskow LM**. Am I a control? Genotype-driven research recruitment and self-understandings of study participants; in process.

#### Other Articles (non-peer-reviewed)

**Beskow LM**, Dame L, Costello EJ. Certificates should be retired, Certificates should be strengthened [author reply]. *Science* 2009; 323(5919): 1288-90.

**Beskow LM.** Considering the nature of individual research results [commentary]. *American Journal of Bioethics* 2006; 6(6): 38-40.

Khoury MJ, **Beskow LM**, Gwinn M. Translation of genomic research into health care [letter]. *JAMA* 2001; 285(19): 2447.

**McConnell LM.** Who should take the Alzheimer's test? [editorial] *Stanford Medicine* Winter 1998/99: 13.

#### Book Chapters

**Beskow LM.** Informed consent in genomic and personalized medicine. In HF Willard, GS Ginsburg (eds), *Genomic and Personalized Medicine, Second Edition*. San Diego, CA: Elsevier, Inc., in press.

**Beskow LM**, Burke W. Ethical issues in genetic epidemiology and population genetics. In SS Coughlin, TL Beauchamp, DL Weed (eds), *Ethics and Epidemiology, Second Edition*. New York, NY: Oxford University Press, 2009.

Haga S, **Beskow LM.** Ethical, legal, and social implications of biobanks for genetics research. In DC Rao (ed), *Genetic Dissection of Complex Traits, Second Edition*. San Diego, CA: Academic Press, 2008.

**Beskow LM.** Ethical, legal, and social issues in the design and conduct of human genome epidemiologic studies. In MJ Khoury, J Little, W Burke (eds), *Human Genome Epidemiology: A Scientific Foundation for Using Genetic Information to Improve Health and Prevent Disease*. New York, NY: Oxford University Press, 2003.

**Beskow LM**, Gwinn M, Rothstein MA. Integrating genetics into public health policy and practice. In RA Goodman, RE Hoffman, W Lopez, GW Matthews, MA Rothstein (eds), *Law in Public Health Practice*. New York, NY: Oxford University Press, 2002.

## RESEARCH FUNDING

### Active

Title: *Advancing Collaborative Genetic Research: Ethical and Policy Challenges*  
Role: Co-Investigator, Duke subcontract (PI: Leona Cuttler, Case Western)  
Source: National Human Genome Research Institute (R01-HG-005691)  
Dates: 2011-2014

Title: *Center for Public Genomics 2.0 (a Center of Excellence in ELSI Research (CEER))*  
Role: Principal Investigator, "Linkages" core (overall PI: Robert M. Cook-Deegan, Duke University)  
Source: National Human Genome Research Institute (P50-HG-003391)  
Dates: 2011-2014

Title: *Assessing the Use and Understanding of Certificates of Confidentiality*  
Role: Principal Investigator  
Source: National Human Genome Research Institute (R01-HG-005087)  
Dates: 2010-2012

Title: *Ethical Approaches to Genotype-Driven Research Recruitment*  
Role: Principal Investigator  
Source: NIH Challenge Grants in Health and Science Research (RC1-HG-005787)  
Dates: 2009-2011

Title: *An Open Source Research Permissions Management System for South Carolina*  
Role: Principal Investigator, Duke subcontract, with Kevin P. Weinfurt (overall PI: Jay Moskowitz, Health Sciences South Carolina)  
Source: NIH Research and Research Infrastructure “Grand Opportunities” Grant (RC2-LM-010796)  
Dates: 2009-2011

Title: *Duke Translational Medicine Institute*  
Role: Assoc. Director, Research Ethics, Law & Policy Core (overall PI: Robert M. Califf, Duke University)  
Source: National Center for Research Resources (UL1-RR-024128)  
Dates: 2006-2011

#### Pending

Title: *Testing Simple and Practical Consent Strategies*  
Role: Principal Investigator, Duke subcontract (overall PI: Nancy Kass, Johns Hopkins University)  
Source: NIH R01 (submitted June 2011)  
Dates: 2012-2017 (projected)

Title: *Enhancing the Biobanking Informed Consent Process to Improve Comprehension*  
Role: Principal Investigator, with Kevin P. Weinfurt  
Source: NIH R01 (submitted February 2011)  
Dates: 2012-2015 (projected)

#### Completed

Title: *Programs in Clinical Effectiveness of Cancer Pharmacogenomics*  
Role: Co-Investigator (PI: Geoffrey S. Ginsburg, Duke University)  
Source: NIH Research and Research Infrastructure “Grand Opportunities” Grant (RC2-CA-148041)  
Dates: 2009-2010

Title: *Simplifying Informed Consent for Biorepositories*  
Role: Principal Investigator, with Kevin P. Weinfurt  
Source: David H. Murdock Foundation (private gift to Duke University to establish the MURDOCK Study)  
Dates: 2008-2010

Title: *CTSA National Resource Database for Translational (T1) Research*  
Role: Co-Investigator (Co-PIs: Geoffrey S. Ginsburg, Duke University and Alice Tarantal, UC Davis)  
Source: National Center for Research Resources (supplement to DTMI U54-RR-023469)  
Dates: 2008-2009

Title: *Assessment of the Utility and Efficacy of Using Genomic Profiles of Chemosensitivity to Individualize Care for Patients with Metastatic Cancer*  
Role: Co-Investigator (PI: Philip Febbo, Duke University)  
Source: Duke University Health System (internal funding)  
Dates: 2008

Title: *Informed Consent for Biorepositories*  
Role: Principal Investigator  
Source: Duke Translational Medicine Institute (UL1-RR-024128)  
Dates: 2007

Title: *Center for Public Genomics (a Center of Excellence in ELSI Research (CEER))*  
Role: Co-Investigator (PI: Robert M. Cook-Deegan, Duke University)  
Source: National Human Genome Research Institute (P50-HG-003391)  
Dates: 2006-2010

Title: *Chernobyl Research and Service Project*  
Role: Co-Investigator (PI: Geoffrey S. Ginsburg, Duke University)  
Source: Department of Energy (Research Triangle Institute Subcontract #2-312-0)  
Dates: 2006-2008

Title: *Recruiting Research Participants through Cancer Registries: Stakeholder Perspectives*  
Role: Principal Investigator (dissertation research)  
Source: National Cancer Institute (R25-CA57726) for the UNC-Chapel Hill Lineberger Cancer Control Education Program (pre-doctoral fellowship)  
Dates: 2003-2005

## PROFESSIONAL PRESENTATIONS

*Informed Consent in Biobanking and Biorepositories* at “Engaging the Community for Research Success: What Scientists and IRBs Need to Know,” South Atlantic National Research Conference, Raleigh, NC, March 2012.

*Certificates of Confidentiality: Everything You Wanted to Know but Were Afraid to Ask* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, National Harbor, MD, December 2011.

*Certificates of Confidentiality: Uses and Understanding* at U.S. Department of Health & Human Services’ Certificate Coordinators’ Meeting, Bethesda, MD, October 2011.

*Ethical Approaches to Genotype-Driven Research Recruitment* at the 12th International Congress of Human Genetics/American Society of Human Genetics 61st Annual Meeting, Montreal, Canada, October 2011.

*Participant Perspectives on Data Sharing* at “Challenges in Research Ethics and Policy: Perspectives on Data Sharing,” NHGRI/EMERGE Conference, Bethesda, MD, July 2011.

*The Use and Understanding of Certificates of Confidentiality* at “Research with Vulnerable Populations: Charting the Ethical Terrain,” National Institute of Mental Health Ethics Conference, St. Louis, MO, June 2011.

*Disclosing Individual Research Results in Genotype-Driven Research Recruitment: IRB Perspectives* at ELSI Congress: Exploring the ELSI Universe, Chapel Hill, NC, April 2011.

*Biological Specimens, Biobanking, and Informed Consent Issues* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, San Diego, CA, December 2010.

*Improving Informed Consent* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, San Diego, CA, December 2010.

*Offering Individual Genetic Research Results: Context Matters* at “Release of Research Results to Participants in Biospecimen Studies,” National Cancer Institute Workshop, Bethesda, MD, July 2010.

*Research on Simplifying Consent for Biobanking* at Subpart A Subcommittee Meeting, Secretary's Advisory Committee on Human Research Protections, Rockville, MD, June 2010.

*Biobanks' Handling of Incidental Findings and Individual Research Results* at “Managing Incidental Findings and Research Results in Genomic Biobanks & Archives” Workshop, Minneapolis, MN, January 2010.

*Simplifying Informed Consent: Stakeholder Perspectives* at the 59<sup>th</sup> Annual Meeting of the American Society of Human Genetics, Honolulu, HI, October 2009.

*Certificates of Confidentiality and the Compelled Disclosure of Research Data*, a National Institute of Environmental Health Sciences Seminar, Research Triangle Park, NC, April 2009.

*CEER-CTSA Synergies* at the 5<sup>th</sup> Annual Meeting of the Centers of Excellence in ELSI Research (CEER), Stanford, CA, March 2009.

*Informed Consent Disclosures and Options Concerning Genetic Research Results* at “Ethical and Practical Guidelines for Reporting Genetic Research Results to Study Participants,” National Heart, Lung & Blood Institute Workshop, Bethesda, MD, January 2009.

*Research Participants' Reactions to Biorepository Consent Language* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Orlando, FL, November 2008.

*Ethical and Policy Issues in Large-Scale Research Repositories and Data Sharing* at “Genotype-Tissue Expression (GTEx) Resource,” National Institutes of Health Workshop, Bethesda, MD, June 2008.

*Informed Consent for Biobanks: Research to Translate Policy into Practice* at “Translating ‘ELSI’: Ethical, Legal, and Social Implications of Genomic Research,” Cleveland, OH, May 2008.

*Research Ethics Consultation in the Clinical and Translational Science Awards (CTSA) Consortium* at “Research Ethics Consultation,” Stanford University Center for Integration of Research on Genetics & Ethics Workshop, Stanford, CA, May 2007.

*Access to Potential Subjects in Epidemiological and Health Services Research: Considerations for IRBs* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Washington, DC, November 2006.

*NIH's Proposal for Data Sharing in Genomic Studies: Exploring the Implications for Participants, Investigators, and IRBs* at Advancing Ethical Research Conference, Public Responsibility in Medicine & Research, Washington, DC, November 2006.

*Patient Contact Studies: Results from a National Survey* at “From Registration to Research,” Maryland Cancer Registry 2005 Educational Conference, Baltimore, MD, December 2005.

*Protecting Participants in Population-Based Research Involving Genetics* at “Ethics, Law and Policy,” 5<sup>th</sup> World Congress of Bioethics, London, England, September 2000.

*The Role of Genetics in Public Health Prevention Programs* at “Genetics in Public Health: Connecting Research, Education, Practice and Community,” 3<sup>rd</sup> National Conference on Genetics and Disease Prevention, Ann Arbor, MI, September 2000.

*Translating Advances in Human Genetics into Public Health Action* at Alabama Public Health Association Annual Meeting, Auburn, AL, April 2000.

*Genetic Research: Guidance from the National Bioethics Advisory Commission* at “Prevention 2000,” 17th Annual National Preventive Medicine Conference, Atlanta, GA, March 2000.

*Integrating Genetics into Public Health Research: Developing Guidelines for Informed Consent* for the Excellence in Science Committee, Centers for Disease Control and Prevention, Atlanta, GA, November 1999.

*APOE Genotyping for the Diagnosis of Alzheimer Disease* at the Kaiser Regional Ethics Symposium on Genetics, Berkeley, CA, March 1999.

*Evaluating the Safety and Effectiveness of Genetic Tests* for the Office of Genetics and Disease Prevention, Centers for Disease Control and Prevention, Atlanta, GA, January 1999.

*Targeted Prevention: A New Paradigm in Public Health Practice* at “Individual Genetic Variation: Implications of the Coming Transformation of Medicine,” Stanford Program in Genomics, Ethics, and Society, Stanford, CA, October 1998.

*Genetic Testing and Alzheimer Disease: Ethical, Legal, and Social Implications of Clinical Testing Programs* at “Advances in the Practice of Clinical Genetics,” 5th Annual Meeting of the American College of Medical Genetics, Los Angeles, CA, March 1998.

*Genetic Testing and Alzheimer Disease* at “Genetic Information: Acquisition, Access, and Control,” University of Central Lancashire for the International Association of Bioethics and Euroscreen, Preston, England, December 1997.

## TEACHING

### Courses Taught

Instructor of day-long course, *Examining Complex Issues in Genomics Research*, Centers for Disease Control & Prevention, Atlanta, GA, March 2011.

Co-instructor of 5-week course, *Responsible Conduct of Research for NIH Trainees*, Duke University, Durham, NC, September 2009. My lecture: “Responsible Authorship and Peer Review.”

Co-instructor of 5-week course, *Responsible Conduct of Research for NIH Trainees*, Duke University, Durham, NC, March 2009. My lecture: “Study Design and Ethical Research with Humans.”

Teaching Assistant (as graduate student) for courses on *Ethical Issues in Health Policy and Administration* and on *Health Law*, UNC-Chapel Hill School of Public Health, 2002-2003 (Instructor: Dean Harris, JD)

Academic and Community-Based Lectures

*Genotype-Driven Research Recruitment: Research Participants' Reflections on Return of Results* (with Jean Cadigan and Marsha Michie) for the UNC-Chapel Hill Center Genomics & Society interdisciplinary seminar series, Chapel Hill, NC, March 2011.

*Disclosing Individual Research Results in Genotype-Driven Research Recruitment* (with Emily Namey) for the Trent Center for Bioethics, Humanities & History of Medicine works-in-progress seminar series, Duke University Medical Center, Durham, NC, February 2011.

*Ethical Issues in Genotype-Driven Research Recruitment* for the Duke Institute for Genome Sciences & Policy Annual Retreat, Durham, NC, November 2010.

*Research on Simplifying Consent for Biobanking* for the MURDOCK Study Healthcare Advisory Board, Kannapolis, NC, April 2010.

*Genetic Databases and Privacy Concerns* (with Lauren Dame) for the Responsible Conduct of Research Forum, Duke University Graduate School, Durham, NC, February 2010.

*Research on Simplifying Consent for Biobanking* for the Genomic Medicine Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, February 2010.

*Simplifying Informed Consent for Biospecimen Research* for the UNC-Chapel Hill Center Genomics & Society interdisciplinary seminar series, Chapel Hill, NC, December 2009.

*Informed Consent for Biospecimen Research* for the Duke University Health System Institutional Review Board, Durham, NC, December 2009.

*Genetic Databases and Privacy Concerns* (with Lauren Dame) for the Responsible Conduct of Research Forum, Duke University Graduate School, Durham, NC, February 2009.

*Researchers' Obligations to Disclose Genetic Research Results to Research Participants: What Do You Think?* for the Genomic Medicine Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, December 2008.

*Returning Research Results to Research Participants* for the Duke University Genome Revolution Focus Program, Durham, NC, September 2008.

*Gene Expression to Stratify Cancer Patients and Predict Clinical Outcome: Scientific and ELSI Issues in the Cancer Genome Atlas Project* (panel) for the UNC-Chapel Hill Center Genomics & Society interdisciplinary seminar series, Chapel Hill, NC, April 2008.

*Simplifying Informed Consent for Biorepositories* for the Genomic Medicine Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, February 2008.

*Large-Scale Genomic Databases: Practical and Policy Considerations for Use* for Genomes@4 series, Duke Institute for Genome Sciences & Policy, Durham, NC, May 2007.

*Large-Scale Research Involving Genomics* for the Clinical Research Training Program's Responsible Conduct of Research Course, Duke University School of Medicine, Durham, NC, April 2007.



*Ethical & Policy Issues in Research Involving Human Biospecimens* for the Genome Academy, Duke Institute for Genome Sciences & Policy, Durham, NC, November 2006.

*NIH's Proposed Data Sharing Policy for Genome-Wide Association Studies* for the Cardiovascular Genomic Forum, Duke Institute for Genome Sciences & Policy, Durham, NC, October 2006.

*Recruiting Research Participants through Cancer Registries - Stakeholder Perspectives*: Dissertation presentations for Duke Institute for Genome Sciences & Policy, September 2006; RTI International, April 2006; UNC Center for Excellence in Ethical, Legal & Social Implications Research, April 2006; Indiana University Center for Health Services and Outcomes Research, August 2005; Policy Seminar in Health Policy and Administration (HPAA 360), UNC-Chapel Hill School of Public Health, April 2004.

*Ethical and Policy Issues in Genomics and Public Health*: Guest lectures for “Ethical Issues in Health Policy and Administration” (HPAA 185), UNC-Chapel Hill School of Public Health, February 2002, February 2003, February 2004.

*Assessing Health Care Technologies: Using Genetic Information to Improve Health & Prevent Disease* for “Evolution, Organization, and Financing of Health Services in the United States” (HPAA 220), UNC-Chapel Hill School of Public Health, November 2000.

*Implications of Advances in Molecular Genetics* (with Sara Tobin) for Earthwatch Student Challenge Program, Stanford Human Genome Center, Palo Alto, CA, August 1998.

*Ethical Implications of Advances in Human Genetics* for the Center for Advancement and Renewal of Educators, San Francisco, CA, March 1998.

*Ethical Issues in Genetic Testing for Alzheimer Disease* for Alzheimer's Association Support Group, San Francisco, CA, March 1998.

*Ethics and Alzheimer Genetics* (with Sara Tobin) for the Bay Area Alzheimer's Consortium, San Mateo, CA, October 1997.

*Ethical Issues in Molecular Genetics* (with Sara Tobin and Timothy Caulfield) for Earthwatch Student Challenge Program, Stanford Human Genome Center, Palo Alto, CA, July 1997.

*Genetic Testing for Breast Cancer Susceptibility* (with Sara Tobin) at “Molecular Genetic Methods,” Cold Spring Harbor-sponsored workshop at Foothill College, Los Altos Hills, CA, April 1997.

## **PROFESSIONAL SERVICE**

### **Federal Review Panels**

Source Evaluation Group for Solicitation S10-084, “Cancer Human Biobank (caHUB) Acquisition of Normal Tissues” and Solicitation S10-120, “caHUB Acquisition of Normal Tissues in Support of the Genotype-Tissue Expression (GTEx) Project,” National Cancer Institute, Office of Biorepositories and Biospecimen Research, March-April, 2010.

Special Emphasis Panel/Scientific Review Group 2009/10 ZRG1 HDM-P (58) S for RFA-OD-09-003, “NIH Challenge Grants in Health and Science Research (RC1),” National Institutes of Health, June 2009.

Special Emphasis Panel for RFA-HG-09-004, “Follow-up Consultation to Inform the Design of a Possible Longitudinal Cohort Study of the Role of Genes and Environment in Health and Disease,” National Human Genome Research Institute, March 2009.

Special Emphasis Panel for RFA GD08-801, “Genomic Applications in Practice and Prevention: Translation Programs in Education, Surveillance, and Policy,” Centers for Disease Control & Prevention, July 2008.

National Committees, Advisory Boards, Working Groups: Leadership Roles

Co-Chair (with Lisa Carey), Correlative Science Working Group, Concise Informed Consent Template Project, Cancer Therapy Evaluation Program, National Cancer Institute, 2011.

Advisory Committee, Biobanks Working Group, Clinical Research Ethics Key Function Committee, Clinical and Translational Science Award (CTSA) Consortium, 2010-present.

Co-Chair (with Ross McKinney), Scholarly Collaboration on Research Ethics (SCORE) Workgroup, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2009-2010.

Team Lead, Informed Consent Task Force, Consent and Community Consultation Workgroup, Electronic Medical Records and Genomics (eMERGE) Network, 2008-2011.

- This task force developed model consent language that can be found on NHGRI’s “Informed Consent for Genomics Research” web site at <http://www.genome.gov/27526660>

Chair, Research Ethics Consultation Workgroup, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2007-2009.

National Committees, Advisory Boards, Working Groups: Membership Roles

Working Group, “Disclosing Genomic Incidental Findings in a Cancer Biobank,” an NCI-sponsored study (PI: Gloria M. Petersen, Mayo Clinic), 2011-present.

Subpart A Subcommittee, Secretary's Advisory Committee for Human Research Protections, U.S. Department of Health and Human Services, 2010-present.

Consulting Editor, *Journal of Empirical Research on Human Research Ethics*, 2010-present.

Biobanks Workgroup, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2010-present.

Working Group, “Managing Incidental Findings and Research Results in Genomic Biobanks & Archives,” an NHGRI-sponsored study (PI: Susan M. Wolf, University of Minnesota), 2010-2011.

SCORE Workgroup, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2009-present.

Clinical Research Ethics Key Function Committee, CTSA Consortium, 2007-present.

Consent and Community Consultation Workgroup, eMERGE Network, 2007-2011.

Operations Workgroup, Clinical Research Ethics Key Function Committee, CTSA Consortium, 2007-2010.

Advisory Board, “The Ethics of Consent for the Public Release of Potentially Identifiable DNA Data,” an NHGRI-sponsored study (PI: Amy L. McGuire, Baylor College of Medicine), 2007-2010.

Informed Consent Working Group, Association of American Medical Colleges, 2007-2008.

Advisory Board, “Ethics and Practice of Stored Tissue Genetic Research,” an NCI-sponsored study (PI: Leslie E. Wolf, Georgia State University), 2007.

Committee on Privacy, Blue Ribbon Panel on Human Genetic Technologies, National Conference of State Legislatures; contributing author on “Genetics Policy Report: Privacy,” 2002.

Ethics Working Group, National Children’s Study, 2000-2002.

#### Local Committees, Advisory Boards, Working Groups: Leadership Roles

Team Lead, Regulatory and Compliance Working Group, Duke Biobank Task Force, 2007-2008.

Associate Director, Clinical and Translational Research Ethics, Law & Policy Core, Duke Translational Medicine Institute, 2006-2011.

Chair, Offering Individual and Aggregate Research Results Subcommittee, Ad Hoc Committee on Tissue Banks and DNA Repositories, UNC-Chapel Hill, 2005-2008.

#### Local Committees, Advisory Boards, Working Groups: Membership Roles

Ad Hoc Human Genetics Scientific Review Committee, Duke University, 2011-present.

IGSP Working Committee on Translation and Applications of Genomics, Duke University, 2011.

Duke Biobanking Ethics and Regulations Working Group, Duke University, 2010-present.

Community Engagement Committee, Measurement to Understand Reclassification of Disease of Cabarrus/Kannapolis (MURDOCK) Study, Duke University, 2008-2010.

Oversight Committee, MURDOCK Study, Duke University, 2007-2009.

Ad Hoc Committee on Tissue Banks and DNA Repositories, UNC-Chapel Hill, 2005-2008.

Planning Committee, “Large-Scale Genomic Discovery and Translation,” an NHGRI-funded exploratory grant for the development of a Center of Excellence in ELSI Research (CEER), UNC-Chapel Hill, 2005-2006.

Research Committee, Department of Health Policy & Administration, UNC-Chapel Hill School of Public Health, 2003-2005.

Medical Scientific Advisory Council, Alzheimer’s Association of the Greater San Francisco Bay Area, 1998.

#### Other Professional Activities

Advisor, “Epi4K: Gene Discovery in 4,000 Epilepsy Genomes,” an NINDS-sponsored study (PI: David B. Goldstein, Duke University), 2011-present.

Co-Chair (with Jim Evans), CDC / National Center for Health Statistics Workshop to develop disclosure criteria for return of individual genomic research results to participants in the National Health and Nutrition Examination Survey (NHANES), May 2011.

Consultant, Baylor College of Medicine, for the Cancer Prevention and Research Institute of Texas (CPRIT)-funded Texas Cancer Research Biobank, 2010-2011.

Invited Participant, “Release of Research Results to Participants in Biospecimen Studies” workshop, National Cancer Institute, Bethesda, MD, July 2010.

Conference Abstract: Peppercorn J, Hamilton E, Qiu S, Lipkus I, Marcom PK, **Beskow LM**, Lyman G. Factors influencing use of genetic tests in clinical practice among U.S. oncologists, American Society of Clinical Oncology Annual Meeting, Chicago, IL, June 2010.

Invited Participant and Informed Consent Session Moderator, “Perspectives on Data Sharing and Informed Consent in Genomic Research,” an NHGRI-funded workshop (PI: Amy L. McGuire, Baylor College of Medicine), Houston, TX, March 2010.

Invited Participant, “Managing Incidental Findings and Research Results in Genomic Biobanks & Archives,” an NHGRI-funded workshop (PI: Susan M. Wolf, University of Minnesota), Minneapolis, MN, January 2010.

Conference Abstract: Peppercorn J, Hamilton E, Qiu S, Lipkus I, Marcom PK, **Beskow LM**, Lyman G. Practice and attitudes towards CYP2D6 testing for patients on tamoxifen among U.S. oncologists, 32nd Annual San Antonio Breast Cancer Symposium, December 2009 (available in *Cancer Research* 2009; 69(24): 563S).

Invited Participant, “Ethical and Practical Guidelines for Reporting Genetic Research Results to Study Participants” workshop, National Heart, Lung & Blood Institute, Bethesda, MD, January 2009.

Consultant, Duke Center for Community Research, “Ethics and Community-Engaged Research,” a Collaborative Institutional Training Initiative (CITI) research ethics education module, 2009.

- A copy of this module is available on the Duke Translational Medicine Institute web site at <https://www.dtmi.duke.edu/about-us/organization/duke-center-for-community-research/Resources/Ethics-CommunityEngagedResearch.pdf>

Invited Participant, “Genotype-Tissue Expression (GTEx) Resource” workshop, National Institutes of Health, Bethesda, MD, June 2008.

Key Informant Interview, “Ethics and Safeguards for Psychiatric Genetic Research,” an NIMH-sponsored study (PI: Laura W. Roberts, Medical College of Wisconsin), April 2008.

Member, Advisory Committee on “Whole Genome Sequencing Research – IRB Considerations,” Duke University, Durham, NC, October 2007.

Invited Participant, “Research Ethics Consultation” workshop, Stanford University Center for Integration of Research on Genetics & Ethics, Stanford, CA, May 2007.

Invited Participant, “Reporting Results of Genetic Research” workshop, Stanford University Center for Integration of Research on Genetics and Ethics, Stanford, CA, July 2005.

Consultant, University of Washington Center for Genomics and Public Health, “Asthma Genomics: Implications for Public Health,” a report commissioned by the Centers for Disease Control and Prevention, 2004.

Reviewer, “Pharmacogenetics: Ethical and Regulatory Issues in Research and Clinical Practice,” a report of the Consortium on Pharmacogenetics, 2002.

Invited Participant, “Day of Dialog” Workshop for the development of the National Health Museum, San Francisco, CA, October 1998.

#### Journal Referee

American Journal of Bioethics; AJOB Primary Research; American Journal of Critical Care; American Journal of Epidemiology; American Journal of Managed Care; American Journal of Pharmacogenomics; American Journal of Preventive Medicine; American Journal of Public Health; Annals of Behavioral Medicine; BMC Health Services Research; BMC Medical Ethics; BMC Medical Genomics; Canadian Medical Association Journal; Clinical Trials; Community Genetics; Contemporary Clinical Trials; Critical Reviews in Oncology/Hematology; European Journal of Human Genetics; Genetic Epidemiology; Genetics in Medicine; Genome Research; Health Affairs; Health Education & Behavior; IRB: Ethics & Human Research; JAMA; Journal of Empirical Research on Human Research Ethics; Journal of the National Cancer Institute; Nature Biotechnology; Neuroepidemiology; Optometry & Vision Science; Science; Science Translational Medicine; Trends in Genetics

#### **HONORS AND AWARDS**

Recipient, Pre-Doctoral Fellowship in Cancer Prevention and Control, Cancer Control and Education Program, UNC Lineberger Comprehensive Cancer Center, 2003-2004 and 2004-2005.

Recipient, Graduate School Merit Assistantship, University of North Carolina at Chapel Hill, 2001-2002.

Recipient, Career Development Award, “Integration of Human Genetics into Public Health Education and Training,” Association of Teachers of Preventive Medicine, 1999-2001.

Elected Member, Delta Omega (graduate honor society, Boston University and University of North Carolina chapters), Omicron Nu and Phi Upsilon Omicron (undergraduate honor societies).

Recipient, Wyeth-Ayerst Scholarship for Women in Graduate Medical and Health Business Programs, 1994-1995 and 1995-1996.

Recipient, Public Health Traineeship Grant, 1994-1995; Recipient, Boston University School of Public Health Scholarship, 1995-1996.

Registered Dietician and Member, American Dietetic Association, 1985-2000.

**CURRICULUM VITAE**  
**Subhashini Chandrasekharan, PhD**  
IGSP Center for Genome Ethics Law and Policy  
Phone: 919-684-0417, Email: shubha.c@duke.edu

**EDUCATION**

**PhD Genetics and Molecular Biology, 2001**, University of North Carolina at Chapel Hill, NC, USA  
Curriculum in Genetics & Molecular Biology, University of North Carolina, Chapel Hill

**MSc. (Honors) Biology 1993**, Birla Institute of Technology & Science, Pilani, India

**RESEARCH EXPERIENCE**

**Senior Research Associate, Center for Genome Ethics Law and Policy, IGSP, Duke University** 11/1/2008 – present

**Post-doctoral Research Associate, Center for Public Genomics (CPG), IGSP, Duke University** 10/1/2006 – 10/2008  
**Mentor: Robert Cook-Deegan M.D.**

**Post-doctoral Research Associate, Dept of Genetics, UNC-Chapel Hill** 7/2001 – 9/2006

Defining the biological function of PGE<sub>2</sub> in normal mammary gland physiology and tumorigenesis using transgenic and gene knockout mice for PGE<sub>2</sub> metabolism enzymes and receptors

**Mentor: Beverly H. Koller PhD**

**Doctoral Student, Curriculum in Genetics and Molecular Biology, UNC- Chapel Hill** 12/1995- 5/2001

Dissertation: Targeted Disruption of the Non-Receptor-Tyrosine Kinase, *Frk*.

Generated and characterized mice deficient in the src-like epithelial tyrosine kinase *Frk/rak*

**Mentor: Edison T. Liu M.D.**

**Research Assistant, Department of Microbiology, SUNY Buffalo, NY** 7/1993 – 7/1994

**MSc. (Honors) Thesis Training Program BITS Pilani** 1/93- 6/93

Functional *in vitro* characterization of the VZV ORF 63 gene product

Advisor: John Hay PhD

**GRANTS & FELLOWSHIPS**

**1 R03 HG005026-01** 4/1/2009 – 3/31/2012

**NHGRI, NIH**

**Title: Intellectual Property Challenges for the Development of Genomic Diagnostics**

Role: Principal Investigator (PI)

Co-investigators: Robert Cook-Deegan, Arti K Rai

**Josiah Charles Trent Memorial Foundation, 5/15/08- 5/14/09**

Title: Access to Cervical Cancer Vaccines - An Analysis of Technical Legal, Regulatory and Societal Challenges in India.

Role: Project Director

Principal Investigator: Robert Cook-Deegan

**Department of Defense Breast Cancer Postdoctoral Training Grant, 5/ 03- 10/06**

**Hoechst Callnesse Fellowship, 8/94 – 8/95** Awarded by Hoechst Callnesse Inc. for Merit, Curriculum in Genetics and Molecular Biology, UNC-Chapel Hill

## ACADEMIC HONORS

**National Talent Search Scholar, 1987 - 93** Awarded by the Government of India for Academic Excellence

## PEER REVIEWED PUBLICATIONS

Padmanabhan S, Amin T, Sampat B, Cook-Deegan R, **Chandrasekharan S**. Intellectual Property, Technology Transfer and Developing Country Manufacture of Low-cost HPV vaccines in India. 2010. [\*Nat Biotechnol\*](#). 7:671-8

Carbone J, Gold ER, Sampat B, **Chandrasekharan S**, Knowles L, Angrist M, Cook-Deegan R. DNA patents and diagnostics: not a pretty picture. 2010. [\*Nat Biotechnol\*](#). 8:784-91

**Chandrasekharan S**, Heaney C, James T, Conover C, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing for cystic fibrosis. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S194-211

**Chandrasekharan S**, Fiffer M. Impact of gene patents and licensing practices on access to genetic testing for hearing loss. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S171-93.

**Chandrasekharan S**, Pitlick E, Heaney C, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing for hereditary hemochromatosis. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S155-70

Angrist M, **Chandrasekharan S**, Heaney C, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing for long QT syndrome. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S111-54

Powell A, **Chandrasekharan S**, Cook-Deegan R. Spinocerebellar ataxia: patient and health professional perspectives on whether and how patents affect access to clinical genetic testing. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S83-S110

Colaiaanni A, **Chandrasekharan S**, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing and carrier screening for Tay-Sachs and Canavan disease. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S5-S14

Cook-Deegan R, DeRienzo C, Carbone J, **Chandrasekharan S**, Heaney C, Conover C. Impact of gene patents and licensing practices on access to genetic testing for inherited susceptibility to cancer: comparing breast and ovarian cancers with colon cancers. 2010. [\*Genet Med\*](#). Apr;12 (4 Suppl):S15-38

**Chandrasekharan S**, Kumar S, Valley CM, Rai A. Proprietary science, open science and the role of patent disclosure: the case of zinc-finger proteins. 2009. [\*Nature Biotechnol\*](#). 27(2): 140-44

Cook-Deegan R, **Chandrasekharan S**, Angrist M. The dangers of diagnostic monopolies. 2009. [\*Nature\*](#) 58(7237):405-406

Jania LA, **Chandrasekharan S**, Backlund MG, Foley NA, Snouwaert J, Wang IM, Clark P, Audoly LP, Koller BH. Microsomal prostaglandin E synthase-2 is not essential for in vivo prostaglandin E2 biosynthesis. 2009 [\*Prostaglandins Other Lipid Mediat\*](#). 88(3-4):73-81.

Jason I Herschkowitz, Karl Simin, Victor J. Weigman, Igor Mikaelian, Zhiyuan Hu, Karen E. Rasmussen, Laundette P. Jones, Shahin Assefina, **Subhashini Chandrasekharan**, Michael G. Backlund, Yuzhi Yin et al. Identification of conserved gene expression features across human and murine mammary tumors. 2007. [\*Genome Biology\*](#). 8(5):R76.

**Subhashini Chandrasekharan**, Nicholas A. Foley, Leigh Jania, Laurent P. Audoly and Beverly H. Koller Coupling of COX-1 to mPGES1 for prostaglandin E<sub>2</sub> biosynthesis in the murine mammary gland. 2005. [\*J Lipid Res\*](#).46: 2636-48.

Michael Welsh, Charlotte Welsh, Maria Ekman, Johan Dixelius, Robert Hägerkvist, Cecilia Annerén, Björn Åkerblom, Siavosh Mahboobi, **Subhashini Chandrasekharan**, and Edison T. Liu. The FRK/RAK tyrosine kinase participates in cytokine-induced islet cell toxicity. 2004. [\*Biochem J\*](#). 382(Pt 1): 261-8.

**Subhashini Chandrasekharan**, Tinghu Qiu, Nawal Alkharouf, Kelly Brantley, James B. Mitchell and Edison T. Liu Characterization of Mice deficient in the Src family Non-Receptor Tyrosine Kinase *Frk/rak* 2002. ***Mol Cell Biol.*** 22(14): 5235-47.

Jang-Ming Li, Michael A. Nichols, **Subhashini Chandrasekharan**, Yue Xiong and Xia Fan Wang Transforming Growth Factor  $\beta$  Activates the Promoter of Cyclin-Dependent Kinase Inhibitor p15<sup>INK4B</sup> Through an SP-1 Consensus Site.1995. ***J Biol. Chem.*** 270(45): 26750-3.

### **Case Studies for the Secretary's Advisory Committee of Genetics Health and Society**

Topics for these case studies were chosen in close consultation with the SACGHS Task Force, revised repeatedly, subjected to independent external peer and technical review by the SACGHS staff, and published in a supplement in Genetics in Medicine.

**Chandrasekharan S**, Fiffer M. Impact of gene patents and licensing practices on access to genetic testing for hearing loss. Peer-reviewed case study commissioned by the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS); Released for public comment 2009 March 3. Available from:  
[http://oba.od.nih.gov/SACGHS/sacghs\\_documents.html](http://oba.od.nih.gov/SACGHS/sacghs_documents.html)

**Chandrasekharan S**, Heaney C, James T, Conover C, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing for cystic fibrosis. Peer-reviewed case study commissioned by the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS); Released for public comment 2009 March 3. Available from:  
[http://oba.od.nih.gov/SACGHS/sacghs\\_documents.html](http://oba.od.nih.gov/SACGHS/sacghs_documents.html)

**Chandrasekharan S**, Pitlick E, Heaney C, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing for hereditary hemochromatosis. Peer-reviewed case study commissioned by the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS); Released for public comment 2009 March 3. Available from:  
[http://oba.od.nih.gov/SACGHS/sacghs\\_documents.html](http://oba.od.nih.gov/SACGHS/sacghs_documents.html)

Angrist M, **Chandrasekharan S**, Heaney C, Cook-Deegan R. Impact of gene patents and licensing practices on access to genetic testing for Long QT syndrome. Peer-reviewed case study commissioned by the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS); Released for public comment 2009 March 3. Available from:  
[http://oba.od.nih.gov/SACGHS/sacghs\\_documents.html](http://oba.od.nih.gov/SACGHS/sacghs_documents.html)

### **Invited Articles, Book Chapters and Reports**

**Chandrasekharan S**, Cook-Deegan R. Gene patents and personalized medicine - what lies ahead? 2009.  
***Genome Medicine*** 1(9):92.

**Chandrasekharan S.**, Perin N.C., Wiechers I.R., and Cook-Deegan, R. Public–Private Interactions in Genomic Medicine: Research and Development In: *Genomic and Personalized Medicine*, editors Willard HF, Ginsburg GS, (NY: Elsevier, 2008), pp. 434-444  
Description available from: [http://www.elsevier.com/wps/find/bookdescription.cws\\_home/716375/description#description](http://www.elsevier.com/wps/find/bookdescription.cws_home/716375/description#description)

### **Selected Presentations**

**Subhashini Chandrasekharan** and Cristina Capustij. Intellectual property challenges for the development of novel genomic diagnostics- An emerging picture  
ELSI Congress, UNC-Chapel Hill, North Carolina, April 12, 2011.

**Subhashini Chandrasekharan** and Swathi Padmanabhan. **Harnessing University Technology Transfer to Increase**



#### **Global HPV Vaccine Access.**

**Access to HPV Vaccines Symposium: Human Rights and Global Health**, BU School of Law, Boston, Massachusetts, USA February 7, 2009

**Subhashini Chandrasekharan**, Eric Jiang and Alex Cho. **Intellectual Property and Genomic Diagnostics for Type II Diabetes.**

**Personal Genomes Cold Spring Harbor Meeting**, Cold Spring Harbor New York, October 2008

**Subhashini Chandrasekharan** and Robert Cook-Deegan Intellectual Property Challenges for Development of Multi-gene Diagnostic Tests

Platform presentation, **American Society of Human Genetics Annual Meeting**, November 14, 2008

**Subhashini Chandrasekharan** Patents and Licensing and Access to Genetic Testing in the US

Invited presentation and panel discussant

**Translating Ethical, Legal and Social Implications of Genomic Research**

International conference, Cleveland, Ohio, May 1-3, 2008

Carla Rydholm, **Subhashini Chandrasekharan** and Robert Cook-Deegan The impact of University Licensing Practices and DNA-based patents on Genetic Testing access, Poster presentation

**Changing Horizons, Association of University Technology Managers, Annual Meeting**, San Diego, California, USA, February 28- March 1 2008

**Subhashini Chandrasekharan**, Nicholas A. Foley, Leigh Jania, Laurent P. Audoly and Beverly H. Koller The Role of Prostaglandin E<sub>2</sub> in the Normal development and Mammary Epithelial Transformation, Poster presentation

**DOD Era of Hope Breast Cancer Research Program Meeting**, Philadelphia, PA, USA, June 2005

**Subhashini Chandrasekharan**, Nicholas A. Foley, Beverly H. Koller. The Role of Prostaglandin E<sub>2</sub> in the Normal development and malignant Transformation of Mammary Epithelium, Poster presentation

**Advances in Breast Cancer Research, Genetics, Biology and Clinical Implications, AACR Special Conference**, Huntington Beach, CA, USA, October 2003

#### **PROFESSIONAL TRAINING**

- **Bioethics Training, Intensive Bioethics Course 33: *Decision making in the 21<sup>st</sup> century***, June 4-9 2007, Kennedy Institute of Bioethics, Georgetown University
- **Workshop on Genetics, Evolution and Cognitive ability** June 11-12, 2007, organized by the Center for Integration of Research on Genetics and Ethics, Stanford Center for Biomedical Ethics.
- **NHGRI Training Workshop on ELSI Grant Writing** October 17, 2007. NIH, Bethesda.
- **Leadership Training Certification, Center for Creative Leadership UNC Leadership Symposium**, June 2006, UNC-Chapel Hill
- **Grant Writing Symposium for Biological & Physical Sciences**, June 2005, UNC- Chapel Hill  
Participated in an NIH R01 grant proposal peer-review mock study section exercise
- **Management Strategies: Building a Foundation for Success**, June, 2003 UNC-Chapel Hill

#### **TEACHING**

- Instructor, **Cancer Biology BIO445** University of North Carolina Chapel Hill, May12- June 15 2009,
- Teaching assistant, **PUBPOL240 Responsible Genomics**, Duke University 1/2007- 5 /2007

- **BIO98**, Undergraduate Research Project, Mentor, UNC-Chapel Hill 8/2003 –12/2003 & 12/2004- 5/2004
- **Guest Lectures**  
 Duke University, PUBPOL 240, Responsible Genomics, May 2007  
 Topic: **Genomics and Global Health**  
  
 Duke University, LEAP Summer Program, July 2007  
 Topic: **Breast Cancer Therapy**  
  
 UNC-Chapel Hill, GEN 113, Core course, Curriculum of Genetics and Molecular Biology- 4/2004, 4/2005  
 North Carolina Central University 4/2005, 4/2006  
 Topic: **Mouse Models for Cancer**

## **SERVICE**

- **Coordinator, IGSP, Science and Society Journal Club**, Duke University, November 2007- present. Initiated and currently help co –ordinate this monthly journal club at IGSP
- **Instructor, Responsible Conduct of Research Course**, Trent Center for Bioethics, Duke University September 2009
- **Guest lecturer, Responsible Conduct of Research training, IGSP Dept of Computational Biology and Bioinformatics**, September 18, 2009 & September 20 2008.
- **Invited Panelist “Altruistic Careers”** Women in Science and Engineering , Duke University, March 21, 2008

**Curriculum Vitae**  
**Robert Mullan Cook-Deegan, MD**  
Duke University, Box 90141, Durham, NC 27708-0141  
Phone 919-668-0790, Fax 919-668-0799  
[bob.cd@duke.edu](mailto:bob.cd@duke.edu)

**Current Position**

Director, Center for Genome Ethics, Law & Policy, Institute for Genome Sciences & Policy,  
Duke University

**Education**

B.A. Harvard College, chemistry, *magna cum laude*, 1975  
M.D. University of Colorado, 1979

**Academic Positions**

Research Professor of Public Policy, Department of Public Policy Studies, Duke University,  
2003-present

Research Professor, Department of Medicine, Duke University Medical Center, 2003-  
present

Research Professor, Department of Biology, Duke University, 2006-present

Faculty Associate, Kennedy Institute of Ethics, Georgetown University, 2001-present;  
Senior Research Fellow, 1986-2001

Seminar Director, Stanford-in-Washington ([undergraduate tutorials and seminars on health and  
biomedical research policy](#)), 1996-2003

Cecil and Ida Green Senior Fellow, Green Center for the Study of Science and Society,  
University of Texas, Dallas, February-April 1996

Associate, Department of Health Policy and Management, School of Hygiene and Public Health,  
The Johns Hopkins University, 1988-2001

**Nonacademic Positions**

*Office of Technology Assessment*, U.S. Congress, Washington, DC. OTA Fellow 1982-3, Project  
Director and Analyst 1983-4, Senior Analyst 1985-6, Senior Associate 1987-1988

*Biomedical Ethics Board*, U.S. Congress, and Biomedical Ethics Advisory Committee,  
Washington, DC, 1988-1989. Acting Executive Director (this was a small congressional  
agency that operated for one year)

*National Center for Human Genome Research*, National Institutes of Health, Expert (consultant  
to Center Director, James D. Watson) 1989-1990

*National Academy of Sciences*, Washington, DC. Director, Division of Biobehavioral Sciences  
and Mental Disorders, Institute of Medicine, 1991-1994; Senior Program Officer,  
Committee on Allocation of Federal Funds for Science and Technology ("Press Report"),  
1994-1996; Director, National Cancer Policy Board, National Research Council and  
Institute of Medicine, 1996-2000; Senior Program Officer, Committee on Human  
Research Protection Programs, 2000; Director, Robert Wood Johnson Foundation Health  
Policy Fellowship Program, Institute of Medicine, 2001-2002

**State, National and International Committees and Boards**

Member, AAAS Committee on Science, Engineering and Public Policy, 2011-2014

- Member, The Hinxton Group, in particular, participant in meeting October 2010 at University of Manchester that produced the *Statement on Policies and Practices Governing Data and Materials Sharing and Intellectual Property in Stem Cell Science* (January 2011)
- Chair, External Advisory Committee, REVEAL study (four-site clinical trial of ApoE genetic testing for Alzheimer's susceptibility, Robert Green– Principal Investigator, Boston University), 2000-present
- Member, AAAS Committee on Council Affairs, 2009-2011
- Member, Committee on University Management of Intellectual Property, Board on Science, Technology and Economic Policy and Committee on Science, Technology and the Law, The National Academies, June 2008-February 2010. (Committee produced a report, [Managing University Intellectual Property in the Public Interest](#) [Washington, D.C.: National Academies Press, 2010].)
- Council Delegate and Section X Nominating Committee, AAAS Section on Societal Impacts of Science and Engineering, 2007-present
- Member, NAS-AAAS Committee on Assessing Fundamental Attitudes of Life Scientists as a Basis for Biosecurity Education, National Research Council Committee, 2007-2009 (Committee produced a report, [A Survey of Attitudes and Actions on Dual Use Research in the Life Sciences: A Collaborative Effort of the National Research Council and the American Association for the Advancement of Science](#) [Washington, D.C.: National Academies Press, 2009].)
- Member, Advisory Committee for the Graduate Student Forum on Science, Technology, and Health Policy, National Academies of Science and Engineering and Institute of Medicine, National Academy of Sciences, 2007-present
- Consultant, Gene Patents and Licensing Practices Task Force, Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS), Department of Health and Human Services, 2007-2010 (committee dissolved after final meeting in October of 2010)
- Member, Task Force on Patent Reform, American Association of Universities, Association of American Medical Colleges, Council on Government Relations, American Council on Education, and Association of Public and Land-Grant Universities (APLA, formerly National Association of State Universities and Land Grant Colleges), 2005-2009
- Member, Committee on Alternative Funding Strategies for Department of Defense's Peer-Reviewed Medical Research Programs, Institute of Medicine, January-May 2004 (Committee produced a report, *Strategies to Leverage Research Funding* [Washington, DC: National Academies Press])
- Consultant, Comparative Approach to Genomics of Complex Traits, Department of Health and Human Services Grant, 2003-2004
- Member, Project Advisory Panel on Reprogenetics: A Blueprint for Meaningful Moral Debate and Responsible Public Policy, The Hastings Center, 2001- 2003 (Report: *Reprogenetics and Public Policy: Reflections and Recommendations* by Erik Parens and Lori P. Knowles, *Hastings Center Report Special Supplement*, July/Aug 2003)
- Member, History and Health Policy Cluster Group, Robert Wood Johnson Foundation, 2003-2005
- Member, Task Force for Genomics and Public Health, North Carolina Department of Health and Human Services Office of Genomics, 2002-2005

Member, Expert Advisory Panel, Accessible Genetics Research Ethics Education (AGREE) grant, US Department of Energy, 2002-2005 (J Sugarman– Principal Investigator, The Johns Hopkins University)

Member, Ethical Issues in the Management of Financial Conflicts of Interest in Research in Health, Medicine, and the Biomedical Sciences, The Hastings Center, 2002-2005

Coordinator, WHO Advisory Group on Genomics, 2000-2001

Member, Working Group on Germ Line Gene Therapy, American Association for the Advancement of Science, 1998-2000

Member, Council for the American Association for the Advancement of Science 1998-1999 (as retiring chair of Section X)

Trustee and Secretary, Foundation for Genetic Medicine, 1997-2003

Chair, National Academy of Sciences' Committee to Review Studies on Human Subjects (Institutional Review Board for the National Academies of Sciences and Engineering, the National Research Council, and the Institute of Medicine), 1997-2000

Chair, Section X (Societal Impacts of Science and Engineering), American Association for the Advancement of Science, 1997-1998

National Advisory Board and visiting faculty, Dartmouth College genome curriculum project, 1996-1998, 2000-2003

Advisory Committee, Human Genome Education Model, Project II: Collaborative Education for Allied Health Professionals, Alliance of Genetic Support Groups and Georgetown University, 1996-2002

Chair, Royalty Fund Advisory Committee, Alzheimer's Disease and Related Disorders Association (committee to oversee distribution of research funds derived from tacrine royalties) member 1994; chair 1995-2003

Participant, Committee on Science and Human Values, National Conference of Catholic Bishops, 1995-1999

Advisory Board, Science + Literacy for Health, Human Genome Project (advised on production of [\*Your Genes, Your Choices: Exploring the Issues Raised by Genetic Research\*](#) by Catherine Baker), American Association for the Advancement of Science, 1995-1997

Consultant, [DNA Patent Database](#), Kennedy Institute of Ethics, Georgetown University, 1994-2004

Chair, National Panel workshop on international genomics, Office of Technology Assessment, US Congress, March 1994

Participant, workshop on commercial genomics and patenting DNA sequences, Office of Technology Assessment, US Congress, January 1994

Member, Advisory Panel on *Commercializing Emerging Technologies*, Office of Technology Assessment, US Congress, 1994-1995

Member, Advisory Panel on *The Human Genome Project and DNA Patenting*, Office of Technology Assessment, US Congress, 1993-1995

Founding member, the Dana Alliance on Brain Initiatives, Charles A. Dana Foundation, 1992-present

Joint Working Group on Ethical, Legal, and Social Issues, National Institutes of Health and Department of Energy, 1989-1995

Scientific Coordination Committee on the human genome to the Director General of the United Nations Educational, Scientific, and Cultural Organization (UNESCO), 1988-1991

Member, Technical Advisory Committee, Alzheimer's Medicare Demonstration, Mathematica Policy Research, Inc. (under contract to Health Care Financing Administration), 1987-1988

Member, National Advisory Committee, Robert Wood Johnson Foundation, Dementia Care and Respite Services Program, 1987-1991

Member *ex officio*, Human Gene Therapy Subcommittee, Recombinant DNA Advisory Committee, National Institutes of Health, Liaison member, 1987-1991

Member, Health Services Research Task Force, Alzheimer's Disease and Related Disorders Association (also executive committee), 1987-88

Honorary Board Member, Family Respite Center, Falls Church, Virginia, 1987-2000

National Advisory Board Member, Alzheimer's Research Center, Cleveland, Ohio, 1987-1990

National Coordinator, Health Professionals' Network, Amnesty International USA, 1985-1988; National Steering Committee 1988-1998

Board of Directors, Physicians for Human Rights, 1988-1996; Advisory Board, 1987-88; Treasurer and Executive Committee, 1994-1996; Co-chair, Fundraising Committee, 1994-1996

### **Duke University Service**

Member, Faculty Advisory Committee, Masters in Knowledge and Networks, 2011-present

Member, Fulbright Scholarship faculty interview panel, 2009-present

Faculty Committee, Genome Sciences & Policy Certificate Program, 2008-present

Member, Baldwin Scholars Program Review, 2008-2009

Member, Peter Lange Provost Review Committee, 2007-2008

Chair, Search Committee, Associate Director, Kenan Institute of Ethics, 2007 (separate from similar 2003-2004 search committee below)

Member, Committee to review appointment of Anthony So to Department of Public Policy Studies, Fall 2007

Chair, Committee to review Graham Glenday for reappointment to Department of Public Policy Studies, Spring 2007

Member, Center for Comparative Biology of Vulnerable Populations, 2007-2009

Member, Duke Translational Medicine Institute Cell and Tissue Therapy Steering Committee, 2007-2010

Member, Executive Committee, Duke Global Health Institute, 2007-2010

Faculty and Executive Committee Member, Ethics Certificate Program, 2007-present

Group Advisor, Universities Allied for Essential Medicines (UAEM), 2007-present

Member, Rhodes/Marshall/Mitchell Scholarship faculty interview panels, 2007-present

Member, Truman Scholarship faculty interview panel, 2008-present

Faculty Member, History and Philosophy of Science, Technology and Medicine Program, Departments of Philosophy and History, Duke University, 2006-present

Member, Faculty Council, Kenan Institute of Ethics, 2006-2009

Faculty Affiliate, Race, Ethnicity, & Gender in the Social Sciences, Social Science Research Institute, 2006-present

Faculty Advisor, Physicians for Human Rights, Duke Undergraduate and Medical School Chapters, 2004-2009

Faculty Associate, Trent Center for Bioethics, Humanities and History of Medicine, 2003-present

Faculty-In-Residence, Alspaugh Residence Hall, 2003-2010

Faculty Member, Health Policy Certificate Program, 2006-2010

Faculty Member, Genome Revolution Focus program and selection committee, 2006-2008, 2011-present

Member, Campus Culture Initiative Steering Committee, 2006-2007  
 Member, National Breast Cancer Coalition Foundation (NBCCF's) Working Committee, 2006-2008  
 Member, Duke Translational Medicine Institute Leadership Group, 2006-2010  
 Member, Institute for Genome Sciences & Policy Executive Committee, 2005-2008  
 Co-Chair (with Barton Haynes), Global Health Initiative Steering Committee, November 2004-June 2006  
 Member, Global Health Panel, Inauguration of President Richard Brodhead, September 2004  
 Member, Search Committee, Director of Center for the Study of Medical Ethics and Humanities, 2004-2005  
 Chair, Search Committee, Associate Director, Kenan Institute of Ethics, 2003-2004  
 Member, Working Group, Neurosciences Microarray Center of Duke University Medical Center, June 2002-2006  
 Member, Steering Committee, Making Meaning of Genomic Information grant, Howard Hughes Medical Institute, September 2002-2005 (R Thompson, Principal Investigator, Duke University)

## Teaching

"The Genome and the Internet: Growing Up Together," GENOME 108FCS/PUBPOL 81FCS. For 'Genomes in Our Lives: Science and Conscience.' FOCUS cluster, Fall 2011.  
 "Responsible Genomics," Public Policy 240/Computational Biology and Bioinformatics 212, spring 2004, fall 2005, spring 2007, 2008, 2009, and 2010.  
 "Health Policy Capstone," Public Policy 255S: final course for Health Policy Certificate Program. Undergraduate section, spring 2004. Graduate and professional student section (with Christopher Conover), spring 2007. Undergraduate and graduate/professional students, spring 2010.  
 "Genome Sciences and Policy Capstone," final course for undergraduate Genome Science and Policy Certificate Program, spring 2010 (with Hunt Willard, Director of the Institute for Genome Sciences & Policy, Professor of Biology and of Molecular Genetics and Microbiology).  
 "Evolution in Science and Culture" (with Priscilla Wald, Professor of English), English 193S/Genome 178S, fall 2009.  
 "Social and Political History of Genomics," Public Policy 264, fall 2004. Taught a similar course of the same title for the Focus program The Genome Revolution and Its Impact on Society, as Public Policy 196S/History 105S (fall 2006) and Public Policy 81FCS/History89FCS (fall 2007).  
 "Health, Science, and Human Rights," Public Policy 195S, for Focus program fall 2003, Humanitarian Challenges at Home and Abroad; and for Focus program spring 2006, Global Health.  
 House course faculty sponsor: "The Physician Activist," fall and spring 2005.  
 Stanford-in-Washington Seminar and Tutorial director, "How Policy Decisions Get Made about Health Research and Health Policy," Fall 1996-Winter 2003 (offered 13 quarters as a seminar or tutorial).

## Student thesis supervision

Graduate and Professional Student Supervisor (Duke University)

Julia Carbone, SJD candidate, 2009-Present (Arti Rai, chair)  
 Erin McCarthy, MPP candidate, Nov 2009-May 2010 (Anthony So, chair)  
 Lisa Warner, Biology PhD Candidate, 2008-Present (Gregory Wray, chair)  
 Jeremy Block, Biochemistry PhD candidate, MPP project 2008-2009 (chair of MPP)  
 Matthew DeCamp, Philosophy PhD, July 2002-May 2007 (MD 2008; co-chair for PhD committee with Allen Buchanan)  
 Elana Fric-Shamji, MPP (already had her MD), May 2007-May 2008 (chair of MPP)  
 Deirdre Parsons, MS in Molecular Genetics & Microbiology, May-December 2007 (Hunt Willard, chair)  
 Eric Hoefer, MPP, MBA, Jan-May 2004  
 Noah Perin, MPP, MBA, Jan-May 2005  
 Charles Matthews, MPP, Jan-May 2004

#### Undergraduate Thesis Supervisor (Duke University)

Shreya Prasad, May 2010 (International Comparative Studies, graduation with distinction)  
 Swathi Padmanabhan, May 2010 (Public Policy Studies, graduation with distinction)  
 Matthew Piehl, May 2008 (Biology, graduation with distinction)  
 Sarah Wallace, December 2007 (Public Policy Studies, graduation with distinction)  
 Catherine Alessandra Colaianni, May 2007 (Biology and Philosophy, graduation with distinction)  
 Joe Fore, December 2006 (Public Policy Studies, graduation with distinction)  
 Daidree Tofano, May 2006 (Program II, graduation with distinction)

#### Thesis supervision outside Duke University

Esther van Zimmeren, 2011 PhD (University of Leuven, Geertrui van Overwalle, chair)

### Medical Background

Internship: Pathology, University of Colorado Hospital, 1979-80  
 Residency: Pathology, University of Colorado Medical School, 1980-1982  
 Medical License: State of Maryland, D31433, 1984-1992

### Fellowships and Specialized Coursework

Fellow, Brocher Foundation ([http://www.brocher.ch/pages/appel\\_aux.asp](http://www.brocher.ch/pages/appel_aux.asp)), Hermance, Switzerland, February-July 2011. For the project: "ConSequences: A Social and Political History of DNA Sequencing and Its Implications for Full-Genome Sequencing and Personal Genomics."  
 Fellow, American Association for the Advancement of Science, 1988-present  
 Faculty Affiliate, Georgetown University, Joseph and Rose Kennedy Institute of Ethics, 2007-2009  
 Fellow, Cecil and Ida Green Center, University of Texas, Dallas, January-April 1996  
 Intensive Bioethics Course, Kennedy Institute for Ethics, Georgetown University, June 1983; faculty June 1987-1990; advanced course faculty, December 1987  
 Congressional Science and Engineering Fellowship, 1982-83  
 Neurobiology Course, Marine Biological Laboratories, Woods Hole, June-August 1982  
 NIH National Research Service Award, University of Colorado, 1981-82  
 National Endowment for the Humanities Summer Fellowship, University of Chicago, July 1981



Student Honors and Research Committee Award, University of Colorado Medical School, 1979  
 Chester H. Elliott Award in Pathology, University of Colorado Medical School, 1978  
 Detur Book Prize, Harvard College, 1974  
 Student Summer Fellowship in Nuclear Chemistry, Lawrence Berkeley National Laboratory  
 (Atomic Energy Commission) and University of California at Berkeley, Summer 1974  
 Special Student, Mathematics, University of Colorado, Denver; 1971, 1973, 1977

## Research

Principal Investigator, Center for Public Genomics 2.0. Duke University, Center of Excellence for ELSI Research P50 Center, National Human Genome Research Institute, 2011-2015 (Grant renewed April 2011-March 2015, Overall PI)

Principal Investigator, Ewing Marion Kauffman Foundation, Case Studies in Constructing and Using Open and Collaborative Research Models, 2011-2012

Principal Investigator, Josiah Charles Trent Memorial Foundation, Cervical Cancer Vaccines–Analysis/Technical Legal, Regulatory and Societal Challenges in India, 2008-2011

Principal Investigator, Duke Interdisciplinary Working Group “Cognitive and Behavioral Genomics, Evolution, and Race? What Lies Ahead?” (Provost’s Common Fund) 2007–2009

Principal Investigator, Policy Ethics and Law Core, Duke Translational Medicine Institute (Clinical Translational Science Award), National Center for Research Resources, 2006-2007; Investigator 2007-2010

Principal Investigator, Center for the Study of Public Genomics, Duke University and Georgetown University, Center of Excellence for ELSI Research P50 Center, National Human Genome Research Institute and U.S. Department of Energy, 2004-2009 (Overall PI)

Principal Investigator, Policy, Ethics, and Law Core, Southeast Regional Center of Excellence for Emerging Infections and Biodefense (SERCEB), National Institute of Allergy and Infectious Diseases, 2003-present (Overall SERCEB PI, Fred Sparling, UNC), 2004-2010.

Grantee, Burroughs Wellcome Fund, Stanford-in-Washington, for a [case study on international funding of genomics research](#), in collaboration with the Global Forum for Health Research (Geneva) and the World Health Organization, 2000-2001

Robert Wood Johnson Foundation Investigator Award in Health Policy Research, Georgetown University, 1999-2002

Principal Investigator, grants from Robert Wood Johnson Foundation and National Cancer Institute, on youth tobacco control, 1992-1994

Principal Investigator, Alfred P. Sloan Foundation grant to write a political history of the Human Genome Project, Georgetown University 1988-1991

Principal Investigator, National Science Foundation grant to establish an oral history resource and Human Genome Archive at Georgetown University, 1990-1991

Postdoctoral fellow, molecular biology. Tyrosine kinases encoded by retroviral oncogenes, Raymond L. Erikson, Department of Pathology, University of Colorado (during pathology residency, PGY 2 and 3, supported in part by a National Research Service Award), July 1980-June 1982

Research coordinator and medical student researcher, primarily on Mendelian dominant (inherited) Alzheimer’s Disease: James H. Austin, M.D., mentor, University of Colorado,

Chair, Department of Neurology; also worked in that laboratory 1971-82 (part time in high school, full-time summer 1978, then regularly as medical student 1976-1979, and intermittently as postdoc and resident 1979-1982)

Medical student researcher, D. Carleton Gajdusek Laboratory, National Institute of Neurological and Communicative Disorders and Stroke, National Institutes of Health, November 1979-January 1980; prion and other “slow virus” encephalopathies

### **Editorial Positions**

Board of Reviewing Editors, *Science*, August 2011-Present

Editorial Board, *Human Gene Therapy*, 1989-2009

Editorial Board, *American Journal of Alzheimer's Disease*, 1997-2007

Editorial Advisory Board, *Courts, Health Science, and the Law*, 1989-1992

Special Features Editor, *Genomics*, 1989-1992

## ***Publications***

To request an item that is not available online, email: [gelp@duke.edu](mailto:gelp@duke.edu)

### ***Peer-Reviewed Publications***

#### ***Book***

[\*The Gene Wars: Science, Politics, and the Human Genome\*](#) (New York and London: WW Norton & Co., 1994; paperback 1996). Published also in Korean (translated by Shin Won Literary Agency, published by Minum, 1995) and Japanese (translated by K. and G. Ishidate, published by Kogaku Dojin, 1996). Peer-reviewed and accepted for publication by Oxford University Press, University of California Press, and Harvard University Press. Full text available online (with permission of publisher): <http://www.genome.duke.edu/books/gene-wars/>.

#### ***Articles and Chapters***

##### ***2009-Present***

**Cook-Deegan R.** “[Boosting Health Services Research](#).” *Science* 2011 **333**(9 Sept 2011): 1384-1385.

**Cook-Deegan R.** “Estudios sobre genes-medio ambiente en la era de secuenciación del genoma completo: algunas lecciones de la eugensia y los debates sobre razas-cociente intelectual.” *Perspectivas Bioéticas* 2011 (Primer Semestre) **16**(30): 34-61.

**Cook-Deegan R.** “Gene-Environment Studies in an Era of Full-Genome Sequencing: Some Lessons from Eugenics and the Race-IQ Debates.” Chapter 12 (pp. 235-257) in [Gene-Environment Interactions in Developmental Psychopathology: So What?](#) KA Dodge, M Rutter, eds. New York: Guilford Press, 2011.

Litan RE and **Cook-Deegan R.** “Universities and Economic Growth: The Importance of Academic Entrepreneurship.” Chapter 3 (pp. 55-82) in [Rules for Growth: Promoting Innovation and Growth Through Legal Reform](#). The Kauffman Task Force on Law, Innovation, and Growth. Ewing Marion Kauffman Foundation: Kansas City, 2011.

**Cook-Deegan R**, Heaney C. [Patents in Genomics and Human Genetics](#). *Annual Review of Genomics and Human Genetics*. 2010. 11(17): 1-43. PMC2935940.

Angrist M, Chandrasekharan S, Heaney C, **Cook-Deegan R.** [Impact of gene patents and licensing practices on access to genetic testing for long QT syndrome](#). Peer-reviewed case study commissioned by the Secretary’s Advisory Committee on Genetics, Health, and Society (SACGHS). Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S111-S154. PMC3021512. Available [here](#).

Carbone J, Gold ER, Sampat B, Chandrasekharan S, Knowles L, Angrist M, and **Cook-Deegan R.** [DNA patents and diagnostics: not a pretty picture](#). *Nature Biotechnology*. 2010. 28(8): 784-791. PMC3026778.

Chandrasekharan S, **Cook-Deegan R.** [Gene patents and personalized medicine – what lies ahead?](#) *Genome Medicine*. 2009. 1: 92. PMC2768999. Available [here](#).

Chandrasekharan S, Heaney C, James T, Conover C, **Cook-Deegan R.** [Impact of gene patents and licensing practices on access to genetic testing for cystic fibrosis](#). Peer-reviewed case study commissioned by the SACGHS. Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S194-S211. PMC2914455. Available [here](#).

Chandrasekharan S, Pitlick E, Heaney C, **Cook-Deegan R.** [Impact of gene patents and licensing practices on access to genetic testing for hereditary hemochromatosis](#). Peer-

- reviewed case study commissioned by the SACGHS. Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S156-S171. PMC3131230. Available [here](#).
- Colaianne CA, Chandrasekharan S, **Cook-Deegan R**. [Impact of gene patents and licensing practices on access to genetic testing and carrier screening for Tay-Sachs and Canavan disease](#). Peer-reviewed case study commissioned by the SACGHS. Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S5-S14. PMC3042321. Available [here](#).
- Colaianne CA, **Cook-Deegan R**. [Columbia University's Axel patents: technology transfer and implications for the Bayh-Dole Act](#). *Milbank Quarterly*. 2009. 87(3): 683–715. [PMC2750841](#).
- Cook-Deegan R**, Chandrasekharan S, Angrist M. [The dangers of diagnostic monopolies](#). *Nature*. 2009. 458(7237): 405-406. [PMC2702156](#)
- Cook-Deegan R**, DeRienzo C, Carbone J, Chandrasekharan S, Heaney C, Conover C. [Impact of gene patents and licensing practices on access to genetic testing for inherited susceptibility to cancer: comparing breast and ovarian cancers to colon cancers](#). Peer-reviewed case study commissioned by the SACGHS. Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S15-S38. PMC3047448. Available [here](#).
- Cook-Deegan R**, Heaney C. [Gene patents and licensing: case studies prepared for the Secretary's Advisory Committee on Genetics, Health, and Society \(SACGHS\)](#). Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S1-S2. PMC2917582. Available [here](#).
- Green R, Roberts J, Cupples L, Relkin N, Whitehouse P, Brown T, Eckert S, Butson M, Sadovnick A, Quaid K, Chen C, **Cook-Deegan R**, and Farrer L. [Disclosure of APOE Genotype for Risk of Alzheimer's Disease](#). *New England Journal of Medicine*. 361 (July 16):245-254, 2009. PMC2778270.
- Heaney C, Carbone J, Gold ER, Bubela T, Holman CM, Colaianne A, Lewis T, **Cook-Deegan R**. [The perils of taking property too far](#). *Stanford Journal of Law, Science, and Policy*. 2009. 1: 46-64. [PMC2902196](#)
- Kepler T, Crossman C, **Cook-Deegan R**. [Metastasizing patent claims on BRCA1](#). *Genomics*. 2010. 95(5): 312-4. PMC2857658. Available [here](#).
- Lyerly AD, Steinhäuser K, Voils C, Namev E, Alexander C, Bankowski B, **Cook-Deegan R**, Dodson WC, Gates E, Jungheim ES, McGovern PG, Myers ER, Osborn B, Schlaff W, Sugarman J, Tulskey JA, Walmer D, Faden RR, and Wallach E: [Fertility Patients' Views about Frozen Embryo Disposition: Results of a Multi-Institutional U.S. Survey](#). *Fertility and Sterility* 93(2): 499-509, 2010. PMC2828821.
- Magnus D, Cho MK, **Cook-Deegan R**. [Direct-to-consumer genetic tests: beyond medical regulation?](#) *Genome Medicine*. 2009. 1(2): 17. PMC2664950. Available [here](#).
- Padmanabhan S, Amin T, Sampat B, **Cook-Deegan R**, Chandrasekharan S. [Intellectual property, technology transfer and manufacture of low-cost HPV vaccines in India](#). *Nature Biotechnology*. 2010. 28(7; July): 671-678. PMC3138722.
- Powell A, Chandrasekharan S, **Cook-Deegan R**. [Spinocerebellar ataxia: patient and health professional perspectives on whether and how patents affect access to clinical genetic testing](#). Peer-reviewed case study commissioned by the SACGHS. Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S83-S110. PMC3138714. Available [here](#).
- Skeehan K, Heaney C, **Cook-Deegan R**. [Impact of gene patents and licensing practices on access to genetic testing for Alzheimer's disease](#). Peer-reviewed case study

commissioned by the SACGHS. Republished in *Genetics in Medicine*. 2010. April Supplement; 12(4): S71-S82. PMC2913132. Available [here](#).

Taylor DH, **Cook-Deegan R**, Hiraki S, Roberts JS, Blazer DG, and Green RC: [Genetic Testing for Alzheimer's and Long-Term Care Insurance](#). *Health Affairs* **29** (1; Jan): 102-108, 2010. PMC2931337.

### **Before 2009**

**Cook-Deegan R**, Lohr KN, and Palmer JH: [How Bioethics Can Inform Policy Decisions About Genetic Enhancement](#). Chapter in *Altering Nature*, v. 2: *Religion, Biotechnology and Public Policy*, BA Lustig, BA Brody, and GP, eds. (Springer) pp. 161-198, 2008.

So A, Sampat B, Rai A, **Cook-Deegan R**, Reichman J, Weissman R, and Kapczynski A: [Is Bayh-Dole Good For Developing Countries? Lessons from the U.S. Experience](#). *PLoS Biology* **6**(10):e262, 2008. [PMC2573936](#).

Karp D, Carlin S, **Cook-Deegan R**, Ford D, Geller G, Glass D, Greely H, Guthridge J, Kahn J, Kaslow R, Kraft C, MacQueen K, Malin B, Scheuerman R, and Sugarman J: [Ethical and Practical Issues Associated with Aggregating Databases](#). *PLoS Medicine* **5**(9):e190, 2008. [PMC2553818](#).

Chandrasekharan S, Perin NC, Wiechers IR, and **Cook-Deegan R**: Public-Private Interactions in Genomic Medicine: Research and Development. Chapter 37 of [Genomic and Personalized Medicine](#), Huntington F. Willard and Geoffrey S. Ginsburg, eds. (NY: Elsevier) pp. 434-444, October 2008.

Pohlhaus JR and **Cook-Deegan R**: [Genomics Research: World Survey of Public Funding](#). *BMC Genomics* **9**(10 October):472, 2008. [PMC2576262](#).

Christensen KD, Roberts JS, Royal CD, Fasaye GA, Obisesan T, Cupples LA, Whitehouse PJ, Butson MB, Linnenbringer EP, Relkin NR, Farrer LA, **Cook-Deegan RM**, Green RC: [Incorporating Ethnicity into Genetic Risk Assessment for Alzheimer's Disease: The REVEAL Study Experience](#). *Genetics in Medicine* **10** (March): 207-214, 2008. PMC2483343.

Davidson EM, Frothingham R, and **Cook-Deegan R**: [Science and Security: Practical Experiences in Dual-Use Review](#). *Science* **316** (8 Jun 2007): 1432-1433, 2007.

**Cook-Deegan R** and Dedeurwaerdere T: [The Science Commons in Life Science Research: Structure, Function and Value of Access to Genetic Diversity](#). *International Social Science Journal* (UNESCO) **188** (June): 299-317, 2006. Translated as <<Biens communs scientifiques>> et recherché en sciences de la vie: structure, fonction et valeur de l'accès à la diversité génétique. *Revue internationale des sciences sociales*. 188 (June):317 – 338, 2006.

**Cook-Deegan R**: [The Science Commons in Health Research: Structure, Function, and Value](#). *Journal of Technology Transfer*, **32**:133-156, 2007. Correction at <http://www.springerlink.com/content/d08736m462382715/fulltext.pdf>

Tofano D, Wiechers IR, and **Cook-Deegan R**: [Edwin Southern, DNA Blotting, and Microarray Technology: A Case Study of the Shifting Role of Patents in Academic Molecular Biology](#). *Genomics, Society, and Policy Journal* **2**(2): 50-61, 2006.

Ginsburg GS, Angrist M, **Cook-Deegan R**: [Genomics and Medicine at a Crossroads in Chernobyl](#). *Science* **314**: 62-3, 2006.

Caulfield T, **Cook-Deegan R**, Kieff FS, Walsh JP: [Evidence and Anecdotes: An Analysis of Human Gene Patenting Controversies](#). *Nature Biotechnology* **24**(9): 1091-1094, 2006. [PMC2701726](#).



- Cook-Deegan R** and McGeary M: [The Jewel in the Federal Crown? History, Politics, and the National Institutes of Health](#). Chapter in *History and Health Policy in the United States: Putting the Past Back In*. Rosemary A. Stevens, Charles E. Rosenberg, Lawton R. Burns, eds. New Brunswick, NJ: Rutgers University Press, pp.176-201, 2006.
- Fore J, Wiechers IR, and **Cook-Deegan R**: [The Effects of Business Practices, Licensing, and Intellectual Property on Development and Dissemination of the Polymerase Chain Reaction: Case Study](#). *Journal of Biomedical Discovery and Collaboration* **1**(7): 2006. PMC1523369.
- Shanawani H, Dame L, Schwartz D, and **Cook-Deegan R**: [Non-Reporting and Inconsistent Reporting of Race and Ethnicity in Articles that Claim Associations among Genotype, Outcome, and Race or Ethnicity](#). *Journal of Medical Ethics*, **32** (Dec): 724-728, 2006.
- Lyerly AD, Steinhauer K, Namey E, Tulskey JA, **Cook-Deegan R**, Sugarman J, Walmer D, Faden RR, Wallach E: [Factors that Affect Infertility Patients' Decisions about Frozen Embryos](#). *Fertility and Sterility* **85**(6): 1620-1630, 2006.
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- Cook-Deegan R**: "[How Health Research Got So Big in the United States.](#)" *Research Policy Alert* (formerly "The Blue Sheet" and Washington Fax) Experts Forum (on-line resource), June 22, 2005 (posted as a special feature).
- Cook-Deegan R**: [The Urge to Commercialize: Interactions between Public and Private Research and Development](#). Section in [The Role of Scientific and Technical Data and Information in the Public Domain: Proceedings of a Symposium](#), National Research Council of the National Academies (Washington, DC: National Academy Press) pp. 87-94, 2003.
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## Reports

**Note of Explanation:** The reports below were prepared when I was staff for Washington-based organizations. Most are book-length reports subjected to extensive external review, but not peer-reviewed in the sense usually meant in academia. External peer review is for quality and technical content, and often much more thorough than academic publication peer review; but not part of a process for accepting or rejecting a submission and therefore

not an indicator of competitive achievement. I have described my contribution to these in each case.

### **National Cancer Policy Board Reports**

"CellPro: a case study in intellectual property related to cancer therapeutics." Background memo, June 2001.

[State Programs Can Reduce Tobacco Use](#). February 2000. (Main writer.)

[Expanding Medicare Reimbursement for Clinical Trials](#), H Aaron and H Gelband, eds., Washington, DC: National Academy Press, December 1999. (Supervision only, no authorship. This study was administratively housed with the Board, but the report was formally from IOM as a whole.)

[Ensuring Quality Cancer Care](#), M Hewitt and J Simone, eds., Washington, DC: National Academy Press, April 1999. (Supervision and editing only, no authorship.)

[Taking Action to Reduce Tobacco Use](#). National Academy Press, 1998. (Principal staff writer/editor.)

Letter on tobacco control to Donna Shalala, Bruce Reed, and Members of Congress from the National Cancer Policy Board, July 19, 1997. (Staff writer.)

[Background paper on Tobacco Control](#), July 1997. (Staff writer. Background paper prepared for Board.)

### **National Academy of Sciences Reports**

[Strategies To Leverage Research Funding: Guiding DOD's Peer-Reviewed Medical Research Programs](#), Michael McGeary and Kathi E. Hanna, eds. Washington, DC, The National Academies Press, 2004. This study was supported by the National Academy of Sciences and the U.S. Department of Defense. (Committee member, principal writer of a few short sections; main writers were Kathi Hanna and Michael McGeary; chair was Joseph Pagano, University of North Carolina Cancer Center.)

[Allocating Federal Funds for Science and Technology](#). National Academy Press, 1995. (Senior Program Officer; staff writer for some sections and executive summary, and several background papers. Committee chair, Frank Press; study director, Norman Metzger. Other staff writers: Christopher Hill, Michael McGeary, and Julie Esanu.)

### **Institute of Medicine Reports**

[Preserving Public Trust: Accrediting Human Research Participant Protection Programs](#).

Washington, DC: National Academy Press, 2001. (Primary staff writer for fast-track project; Chair, Daniel Federman, Harvard Medical School; study director, L Rodriguez; Division of Health Sciences Policy, Institute of Medicine.)

The following reports were initiated and substantially completed in the Division of Biobehavioral Sciences and Mental Disorders, 1991-1994, while I was Division Director at the Institute of Medicine, National Academy of Sciences.

[The Development of Medications for the Treatment of Opiate and Cocaine Addictions](#), CE Fulco, CT Liverman, and LE Early, eds. Washington, DC: National Academy Press, 1995. (Supervision only, no authorship.)

[Federal Regulation of Methadone Treatment](#), Richard A. Rettig and Adam Yarmolinsky, eds. Washington, DC: National Academy Press, 1995. (Supervision only, no authorship.)

*Growing Up Tobacco Free: Preventing Nicotine Addiction in Children and Youths*, BS

Lynch and RJ Bonnie, eds. Washington, DC: National Academy Press, 1994. (Co-writer of first and last chapters. Overall supervision. Main writers were study director Barbara Lynch and committee member Richard Bonnie.)

*AIDS and Behavior: An Integrated Approach*, JD Auerbach, C Wypijewska, H Keith and H Brodie, eds. Washington, DC: National Academy Press, 1994. (Wrote one section of one chapter on biology. Main writers were study director Judith Auerbach and her research associate, Christina Wypijewska.)

*The Dynamic Brain*, by Robert Pool for the Institute of Medicine Washington, DC: National Academy Press, 1994. (Supervision and editing only.)

*Reducing Risks of Mental Disorders: Frontiers of Preventive Intervention Research*, PJ

Mrazek and RJ Haggerty, eds. Washington, DC: National Academy Press, 1994. (Wrote one chapter section on specific disorders and sections of two policy chapters and aided in editing; main staff author/editor was study director, Patricia Mrazek.)

*Discovering the Brain*, by Sandra Ackerman for the Institute of Medicine, Washington, DC: National Academy Press, 1992. (I was ghost author of James D. Watson preface and did overall project supervision.)

*Assessing Future Research Needs: Mental and Addictive Disorders in Women*. C Pechura, ed. Washington, DC: Division of Health Sciences Policy and Division of Biobehavioral Sciences and Mental Disorders, Institute of Medicine, 1991. (No authorship. Main writer was study director, Constance Pechura.)

### **Office of Technology Assessment Reports**

Reports are available at Princeton University's "OTA Legacy" website

(<http://www.princeton.edu/~ota/>) and with more recent and higher quality scans at the Federation of American Scientists archive (<http://fas.org/ota/>).

*Mapping Our Genes – Genome Projects: How Big? How Fast?* Project director. April, 1988. Reprinted by The Johns Hopkins University Press, Baltimore, Maryland, 1988; and Human Sciences Press, New York, 1988. Received Notable Documents of 1988 Award, National Library Association, 1989. (Author of executive summary and several chapters. Overall project director. Other staff authors: Patricia Hoben, Gladys White, Jacqueline Courteau and David Guston.)

*Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias*. Project director. April, 1987. Reprinted by JP Lippincott, Philadelphia, PA, as *Confronting Alzheimer's Disease and Other Dementias*, 1988, and by Human Sciences Press, 1988 under its original title. Listed among 20 Federal reports in Godort "Notable Documents" for 1987, and one of 17 "Historic Documents, 1987" by *Congressional Quarterly*. (Project director and author of congressional summary and chapter 3. Other chapter authors: Katie Maslow, L. Val Giddings, Dana Gelb [Safran], Teresa Schwab Myers, David Chavkin, Mary Ann Bailly, Catherine Hawes and Nancy Mace.)

*Technology and Aging in America*, June 1985. (Senior analyst, with primary responsibility for sections on biomedical research, chronic disorders, and medications.)

*Human Gene Therapy*, December 1984. (Study director and principal writer.)

*Impacts of Neuroscience*, March 1984. (Study director and principal writer.)

*Commercial Biotechnology: An International Analysis*. January, 1984. Reprinted by the North Carolina Biotechnology Center, Durham, NC, and Pergamon Press, Elmwood, NY. (Special Contributor. Wrote a few short chapter sections and background papers. Main



staff writers: Nanette Newell, Susan Clymer, Geoffrey Karny, Thomas Bugbee, James A. Thomas, Louise Williams and Raymond Zlinskas.)

## Short Communications and Letters

- Cook-Deegan, R.** "Patenting Nature: What Ruling in Myriad Case Means for Biotechnology and DNA Diagnostics." *The Cancer Letter*. 2011 **37**(31): 7-14. Available from the [Duke briefing page](#) on the BRCA patent lawsuit.
- Cook-Deegan R.** "Gene Patents: The Shadow of Uncertainty." *Science* **331** (18 Feb 2011): 873-74.
- Conley J, Vorhaus D, and **Cook-Deegan R:** [How Will Myriad Respond to the Next Generation of BRCA Testing?](#) *Genomics Law Report*, 1 March 2011.
- Cook-Deegan R**, Chandrasekharan S, Angrist MA, Sampat B, Gold ER, Carbone J, and Knowles L. [Reply to 'Wrong Fixes for gene patents.'](#) *Nature Biotechnology* **28** (No. 12; Dec): 1243, 2010.
- Cook-Deegan R**, and Rai A: [DNA sequence patents not in the grave yet](#). Letter on "A Nail in the Coffin of DNA Sequence Patents?" *Nature Biotechnology*. **27**(2):122, 2009.
- Magnus D, Cho M, and **Cook-Deegan R.** "Genetic-Test Firms Must Follow Law." [San Jose Mercury-News](#). 11 July 2008.
- Cook-Deegan R**, Berkelman R, Davidson EM, Finder S, Heitman E, Kelley MC, King NMP, Moseley R, Thomas JC, Tilden SJ, and Vangsnes NM: [Letter on "Issues in Biosecurity and Biosafety"](#) *Science* 308 (24 June): 1867-1868, 2005.
- Cook-Deegan R** and Hogan B: "[The Future of Human Cloning: Can we reap the benefits of therapeutic cloning without crossing ethical lines?](#)" *DukeMed Magazine* Spring/Summer 2003; pp. 46-47.
- Cook-Deegan R**, Walters L, Pressman L, Pau D, McCormack S, Gatchalian J, and Burgess R: "Preliminary Data about U.S. DNA-Based Patents and Plans for a Survey of Licensing Practices." Paper prepared for the DNA Sampling Conference, September 5-8, 2002 in Montreal, Canada. (Unpublished conference paper.)
- Cook-Deegan R:** "Opportunities for WHO in Genomics." Background paper for World Health Organization, Geneva, Switzerland: 12 July 2000. (Prepared for Director General and her senior administrators; unpublished.)
- Alwan A and **Cook-Deegan R:** Memo on Genomics to World Health Organization Director General Gro Brundtland and her cabinet. 3 July 2000.
- Cook-Deegan R:** "[Inner Sanctum](#)," letter commenting on NIH peer review, *Science* **284** (23 April): 589, 1999.
- Cook-Deegan R:** [Commentary on "Can Patents Deter Innovation? The Anticommons in Biomedical Research,"](#) by Michael A. Heller and Rebecca S. Eisenberg, *Science* **280**: 698-701, 1998. (This is an online commentary, not part of the printed journal.)
- Cook-Deegan R:** [Letter on "Insulin Gene Patent Litigation,"](#) *Science* **278**: 560-561, 1997.
- Press F, Metzger N, **Cook-Deegan R:** [Letter re Robinson's commentary "Budget Battles."](#) *Issues in Science and Technology* **12** (Summer): 5-6, Fall 1996.
- Allen A, Anderson B, Andrews L, Beckwith J, Bowman J, **Cook-Deegan R**, Cox D, Duster T, Eisenberg R, Fine B, Holtzman N, King P, Kitcher P, McInerney J, McKusick V, Mulvihill J, Murray J, Murray R, Murray T, Nelkin D, Rapp R, Saxton M, and Wexler N: "The Bell Curve: Statement by the NIH-DOE Joint Working Group on the Ethical,

- Legal, and Social Implications of Human Genome Research." *Am J Hum Genet* **52** (August):487-488, 1996. PMCID: [PMC1914721](#).
- Cook-Deegan R**, Walters L, Goldstein D, and McCormack S: [Letter on "Ownership of Human Genes."](#) *Nature* **382** (July 4): 17-18, 1996.
- Cook-Deegan R**: Letter: "Research Funding," *Issues in Science and Technology* **12** (Summer): 18, 1996.
- Cook-Deegan R**: "[Introduction](#)." In *Will I Be Next? Bea Gorman's Life Story*. Lois Bristow. Acampo, CA: Hope Warren Press, 1995, pp. 13-14.
- Cook-Deegan R**: "Poison Gas Attacks Against Iraqi Kurds." Testimony and written statement for the Human Rights Caucus, US Congress, 24 October 1989.
- Cook-Deegan R**: Letter: "The Medical Profession and the Prevention of Torture." *New England Journal of Medicine* **314**: 587, 1986.
- Cook-Deegan, R**: Office of Technology Assessment, US Congress: "Long-Term Social Consequences of Artificial Intelligence." Senior Analyst. Workshop transcript, July 1985.
- Cook-Deegan R**, Austin JH: "Implications of normal lymphocyte DNA content in familial Alzheimer's disease." *American Journal of Medical Genetics* **15**: 511-513, 1983.
- Cook-Deegan R**: Letter: "The researcher as a Congressional director." *Trends in Biochemical Sciences* **7**: 434, 1982.
- Cook R**: Letter: "Medicine and Political Death." *The PHAROS of Alpha Omega Alpha Honor Medical Society* **45**: 39, 1982.
- Cook R**: "The Narrow Gauge." *New England Journal of Medicine* **302**: 63-64, 1980.
- Cook R**: "[Memory Loss in Alzheimer Disease](#)." *Annals of Neurology* **5**: 105-106, 1979.

## Book Reviews

- [Review of \*The Art and Politics of Science\* by Harold Varmus](#). *American Scientist*. 97 (March-April): 152-154, 2009.
- Hype and Hope. Introductory essay to "Scientists' Bookshelf Special Edition: Books of Life," in *American Scientist* 89 (Jan-Feb): 62-64, 2001.
- Review of *Brain Policy: How the New Neuroscience Will Change Our Lives and Our Politics* by Robert H. Blank. *Cerebrum*. 1 (Spring): 104-109, 1999.
- Review of *The Baltimore Case: A Trial of Politics, Science, and Character* by Daniel Kevles. *Recent Science Newsletter* 1 (Spring): 8-10, 1999.
- Review of *Clone: The Road to Dolly and the Path Ahead* by Gina Kolata. *Issues in Science and Technology*, 14 (Spring): 90-95, 1998.
- Review of *The Moral Challenge of Alzheimer's Disease*, by Stephen Post. *New England Journal of Medicine*, **334** (2 May): 1204, 1996.
- Review of *Alzheimer's Disease Research: Ethical and Legal Issues*, in *New England Journal of Medicine*, **327**: 60-61, 1992.
- A Landmark in Medical Genetics. Review of *Ethics and Human Genetics: A Cross Cultural Perspective*. Wertz and Fletcher, eds. in *Bioethics Books*, **1** (4): 75-77, 1990.
- Review of *Biotechnology and the Human Genome*. Woodhead and Barnhart, eds. in *Bioscience* **39**: 402-403, 1989.
- Review of *Invisible Frontiers* by Stephen Hall and *Natural Obsessions* by Natalie Angier, in *Journal of the American Medical Association* **261**: 773-773, February 3, 1989.

“Scientists and the Dawn of Industrial Pharmacology.” Review of *Academic Scientists and the Pharmaceutical Industry* by John Swann for *Medical Humanities Review* 3: 84-86, January 1989.

### **Invited Presentations** (Since July 2002, reverse chronological order)

Congressional Briefing, “The Myriad Genetics/Breast Cancer Gene Case: What Just Happened? What Happens Next? What are the Implications for Congress? Thursday, Sept 15, 2011. Washington, DC.

FLEET Work Groups, presentations for flagship grant applications for an EU program of large-scale science projects, coordinated by Mark Milutinovich of the American Association for the Advancement of Sciences, July 20-21, 2011 in Vienna, Austria.

“The Transition to Full-Genome Sequencing: Implications for Human Genetics,” University of Geneva, June 28, 2011.

“Should Human Genes Be Patented?” Interview for *The Mark* (Canada), first [posted online](#) on May 26, 2011.

“Gene Patents and the U.S. Myriad BRCA Case,” Lunch Seminar at the Katholieke Universiteit Leuven, Belgium, May 18, 2011. (Lunch Seminar Topic: “Gene Patents in the U.S. and Europe: The Case of Breast Cancer.”)

“Enabling Sharing: Sage Commons Principles,” plenary session at 2<sup>nd</sup> Sage Congress, William Rutter Building, University of California San Francisco Bayview Campus, 16 April 2011.

Convenor, panel on “Implications of Full-Genome Sequence Analysis,” ELSI Congress, Chapel Hill, NC, April 13, 2011.

Harvard Law School, “The Myriad Case,” panel with Mark Freeman, US Department of Justice and three Harvard Law faculty, symposium for the Harvard Journal of Law and Technology, April 7, 2011.

“ConSequences: History and Implications of Whole-Genome Sequencing,” Fondation Brocher, Hermance, Switzerland, 10 February 2011.

“The Interplay Between Access to Genetic Diagnostics and Biomedical Technology Patents.” Case Western Reserve University School of Law. Hosted by the Center for Law, Technology, and The Arts and the *Journal of Law, Technology, and the Internet (JOLTI)*. The JOLTI Symposium: “Exploring the Current Debate Over Patenting Life.” Cleveland, OH, 28 January 2011. [Webcast](#).

Press release of Hinxton Group Report, *Statement on Policies and Practices Governing Data and Materials Sharing and Intellectual Property in Stem Cell Science*, at the headquarters building of American Association for the Advancement of Science, Washington, DC, January 24, 2011.

“Affordable Whole Genome Sequence Analysis: What Will Change?” Health Canada (federal department responsible for Canadian healthcare), in Ottawa, on 2 December 2010. Invited Lecture similar to 27-28 September OECD Workshop on Biomedicine lecture.

Columbia University Medical Center, “The Topsy-Turvy World of Gene Patents,” November 18, 2010

“Secrets of Life: DNA, Property Rights, and Human Identity,” Invited Lecture for the Genome Revolution FOCUS course cluster, 10 November 2010.

“Global Health and Human Rights,” Invited Lecture, Global Health Masters program, Duke University Class, 8 November 2010.

American Society for Human Genetics (ASHG) 2010 annual meeting, “The REVEAL Study at 10 Years: Lessons for Genetic Risk Disclosure and Personal Genomics,” Panelist, Washington, DC, 4 November 2010.

Organisation for Economic Cooperation and Development (OECD) Workshop on Biomedicine, “Affordable Whole Genome Sequence Analysis: What Will Change?” Berlin, Germany, 27-28 September 2010. Presentation slides available from: <http://www.oecd.org/dataoecd/2/59/46147415.pdf>.

University of Leeds, UK, “Gene Patents and Policy: The Neverending Story,” Intellectual Property and the Biosciences symposium, Devonshire Hall, July 7, 2010.

Genomics Automation Conference 2010, “Medical Practices, Regulation, and Patents: How They Might Affect the Transition to Full-genome Sequence Analysis,” Boston, MA, May 7, 2010.

BIO (Biotechnology Industry Organization) annual meeting, Panelist on “Patenting Genes: In Search of Calmer Waters,” Chicago, IL, May 4, 2010.

BIO (Biotechnology Industry Organization) annual meeting, Panelist on “Commercializing Stem Cell-Based Therapies: Meeting FDA and Other Requirements,” Chicago, IL, May 4, 2010.

Duke University Online Office Hours, “Patenting Genes,” April 2, 2010.

Association of University Technology Managers Annual Meeting, Panelist on “Perspectives on Patenting Genomic Inventions,” New Orleans, LA, March 19, 2010.

Invited Lecture, *Global Health: Human Rights*, Duke University, November 11, 2009.

Plenary Keynote Speaker, “So My Genome Costs Less Than My Bike: What’s the Big Deal?” Cambridge Healthtech Institute’s Exploring Next-Generation Sequencing Conference, Providence, RI, September 21, 2009

Kauffman Foundation Summer Legal Institute, “Patents and the Genome,” Laguna Niguel, July 18, 2009.

National Research Council and American Association for the Advancement of Science, “Intellectual Property Challenges and Organization of Science in Synthetic Biology,” Opportunities and Challenges in the Emerging Field of Synthetic Biology, Washington, DC, July 10, 2009.

“Life in the Era of Full-Genome Sequencing,” Duke University Department of Pediatrics Research Retreat, June 20, 2009.

Personal Genetics Conference, “Cognitive Bias and Network Effects,” Boston, MA, June 10, 2009.

Translational Medicine Alliance Forum, “Patents and Consequences,” Philadelphia, PA, May 13, 2009.

Gordon Research Conference on Nucleic Acids, “Patents and Personal Genomics,” New England University, May 31, 2009.

Gene-Environment Interactions research conference, “Gene-Environment Interactions Research: Lessons from Eugenics,” Sanford Institute of Public Policy and Center for Child and Family Policy, Duke University, May 18, 2009.

University of Texas Southwestern Medical Center, “Personal Genomics” and “The Political Economy of Biomedical Research,” Ethics Grand Rounds and occasional lecture, May 12, 2009.

CEER Investigators Meeting, Panel Moderator, “ELSI Research Challenges Associated with Influencing Policy at Various Levels,” Palo Alto, California, March 5, 2009.

“Mental Health Stability Among Laboratory Workers: Why this Topic is Important to Academic Institutions,” *Workshop on Biosafety, Biosecurity and Mental Health Concerns in the Academic Laboratory Setting*, Cary, NC, February 4, 2009.

University of Montreal, Invited Commentary, *Commercialisation of Genomic Research Workshop*, Montreal, Canada, January 30, 2009.

Bloomberg School of Public Health at Johns Hopkins, “The Changing Face of Genomic Patents: The Future is Complexity, Not Pharma,” January 27, 2009.

Berman Institute of Bioethics Seminar Series, “Public Genomics: Do we need doctors anymore?” Johns Hopkins University, January 26, 2009.

School of Medicine at East Carolina University, “Policy issues entwined in the triple helix: government, academe, and pharma/biotech,” American Medical Student Association regional meeting, January 17, 2009.

Humanities in Medicine Lecture Series, “Personal Genomics: Do We Need Doctors Anymore?” Trent Center for Bioethics, Humanities and History of Medicine, Duke University, January 14, 2009.

Crossroads: Sharing Social Environment and Genetic Data, “Unique Concerns in Sharing Merged Social Environment and Genetics Data,” National Institute of on Drug Abuse, Washington, D.C., December 8, 2008.

Panel Member on *Intensely Human*, Duke University, December 3, 2008.

“Intellectual Property Challenges for the Development of Multigene Diagnostics,” Presentation, Public Policy Studies Faculty Luncheon Series, Duke University, November 19, 2008.

Speaker, *Almost Honest Colloquium*, Kenan Institute for Ethics, Duke University, November 12, 2008.

Invited Lecture, *Genetics & Society – Promise or Peril*, Duke University Writing Program, November 11, 2008.

Genome Medicine Forum, “Do Patents and Licensing Affect Clinical Access to DNA Diagnostics: Can We Tell?” Duke University, October 25, 2008.

Genome Canada International Conference, “Sharing Data, Materials and Intellectual Property in Genomics: Some Implications for Public Policy” at *2020 Vision: The Impact of Science on Society*, British Columbia, Canada, October 22, 2008.

The Sixteenth Annual Joseph B. Brennan Lecture, “Four Decades of Bioethics and Genetics: How Have We Done?” Kennedy Institute of Ethics, Georgetown University, October 16, 2008.

Banbury Center, “Race, Ancestry, Geography, Ethnicity, Disparity, and Population Genetics: Can We Reduce Confusion and the Propensity to Misinterpret Results?” in Banbury Center meeting *Who Are We?: Kinship, Ancestry and Social Identity*, Cold Spring Harbor Laboratory, New York, October 8, 2008.

Universities Allied for Essential Medicine, *Advancing Global Health, Making University Innovations Available in Developing Countries*, Duke University, September 29, 2008.

Stanford Journal of Law, Science, and Policy, “The Bioethics of Biobanking,” at the *Law and Ethics of Biobanking*, annual symposium for the journal in Palo Alto California, September 26, 2008.

“Dual-Use Issues in Biomedical Research: Concerns of Bioterrorism,” Speaker, Duke University Responsible Conduct of Research Forum, September 23, 2008.

Invited lecture, Executive Development Program in Public Policy and Management, Sanford School of Public Policy, September 18, 2008.

“The Prospects for Governing Emerging Technologies,” Concluding Panel Speaker, Gordon Research Conference on Science and Technology Policy, Big Sky, Montana, August 21, 2008.

“Bioethics and the Election,” panel at 20<sup>th</sup> *Annual Bioethics Summer Retreat*, Hilton Sonoma Wine Country, June 21, 2008.

“The History of Gene Transfer Research in Lieu of Cellular Therapy” and “Ethical Issues in Cancer Treatments,” Ethics of Cellular Therapy Conference, June 15 – 16, 2008.

“Race, Medicine and Genetics: What Have They Got to Do with One Another,” Talk at Duke Summer Medical and Dental Education Program, June 10, 2008.

Universities Allied for Essential Medicines, “Universities, technologies, and patents: What role in global health?” UNC-Chapel Hill, Chapel Hill, NC, April 23, 2008.

“Patenting and Licensing - Ownership of Genes,” talk for *Genetics and Public Policy* course organized by Phyllis Frosst for the genetic counseling master’s program, National Human Genome Research Institute and Johns Hopkins School of Public Health, Bethesda, MD, April 11, 2008.

Davidson University, “Digging your own grave: Pharma, biotech and academia in intricate mutualism,” *Davidson University Spring Ethics Symposium*, April 4-5, 2008.

Dickinson College, “Genomics and Intellectual Property: Life in the Information Jungle,” *Clarke Forum*, Carlisle, Pennsylvania, March 18, 2008.

Southeast Regional Center of Excellence for Emerging Infections and Biodefense annual meeting, “Policy, Ethics and Law Core: The SERCEB Experience in Educating the Investigator Community about Dual Use,” talk for *Biosecurity and Dual-use Education Activities* session of the February 28, 2008.

“The Misuse of Genomic Human Variation Data by Scientists and Society,” for Genome Revolution Focus course cluster interdisciplinary discussion course, Nov 5, 2007.

“From the Farm to the Capital: Stanford Faculty in Government,” panelist at *20th Anniversary Celebration, Stanford in Washington*, Washington, DC, 26 – 28 Oct 2007.

Presentation on dual-use review, *Transparency in Current and Emerging Approaches to Biosecurity*, Center for Arms Control and Non-Proliferation, October 19, 2007.

Convenor, “‘Na ‘Oia ‘i‘o’: Multiple Truths—An Indigenous Perspective on Genomics, Intellectual Property and Community Consent,” *Faculty Colloquium*, Maile Tauali‘i, Urban Indian Health Institute (UIHI), September 17, 2007.

“Four meanings of ‘dual use’ policies in pathogen research: for deliberate misuse, for military use, for export, and for saving lives in poor regions,” *19th Annual Bioethics Summer Retreat*, Lake George, NY, July 12, 2007.

National Press Club, “Who Owns Your Genes? Intellectual Property and the Human Genome,” presentation at Washington, DC, Washington, DC, July 10, 2007. Part of the Genetics and Public Policy Center’s *Genetics Perspectives on Policy Seminars* (GenePOPS) series organized Johns Hopkins University (moderator: Kathy Hudson; organizer: Rick Borchelt).

Lawrence Livermore National Laboratory, “Technology-Intensive Biology: A Succession of Controversies,” *Director’s Distinguished Lecturer Series*, Livermore, CA, May 22, 2007.

University of California, Santa Cruz, “Democracy, Justice and Genomics: Promises, Perils and Paradoxes,” *Genomics and Justice Conference*, Santa Cruz, California, May 18, 2007.

University of Washington, “Intellectual Property and Genomic Innovation: DNA Science, Patents and Money,” *Genome Sciences Seminar*, Seattle, Washington, May 15, 2007.

North Carolina Central University Law School, Biotechnology and Pharmaceutical Law Institute, “Stem Cells: Diffusing the Rhetoric,” April 13, 2007.

Centre for Applied Ethics, University of British Columbia, “Topsy Turvy: Science, Money, & the Human Genome,” presentation for *GE<sup>3</sup>LS Genome Canada Project*, “*Dissecting Gene Expression Networks in Mammalian Organogenesis*,” Celebration of Research Week, Vancouver, B.C., March 8, 2007.

“Ethical Implications of Prospective Health Care,” *Second Annual Prospective Health Care Conference*, Duke University, March 30, 2007.

Secretary’s Advisory Committee on Genetics, Health, and Society (SACGHS), “A Primer on DNA Patenting and Its Relevance to Access to Genetic Tests,” presentation to SACGHS Task Force on clinical access to genetic testing, Adelphi, MD, March 26, 2007.

Moderator: Session I: Science and Security; panel on Bioethics and the Dual-Use Dilemma. *Bioethics & Biodefense Meeting*, NIAID Southeast Regional Center of Excellence in Emerging Infections and Biodefense. Hosted by Johns Hopkins School of Advanced International Studies, Washington, DC, February 5, 2007.

Southwestern Medical Center, “Challenges of Collaboration” *Data Sharing and the Bioethics of Collaborative Genetic Research Conference*, NIAID conference on data-sharing and research ethics, Dallas, Texas, January 17-18, 2007.

Council on Foreign Relations, “The Future of Biotechnology in International Relations,” presentation for *Berkeley-Duke Center for America’s Global Strategic Challenges*, New York, December 13, 2006.



*Policy, Ethics, Law (PEL) Core Meeting*, Concurrent Interactive Discussion SERCEB Annual Meeting, University of Florida, Gainesville, Florida, October 18, 2006.

NIEHS-Office for Human Research Protections (OHRP), “Risk of Genetic Testing & Stored Specimens,” presentation for *Crossing the Line: What is Acceptable Risk*, speaker at regional meeting in Research Triangle Park, NC, September 26, 2006.

University of North Carolina at Chapel Hill, Workshop on Privacy, *Into the City with Faculty and Students*, Community Genomics Forum, September 16, 2006.

The National Academies’ Southern Regional Meeting, “Biodefense Policy, Ethics, and Law,” hosted by Georgia Institute of Technology and Emory University, Atlanta, Georgia, June 5-6, 2006.

University of Alberta Law School, *Intellectual Property and Knowledge Translation, What’s the evidence? What’s missing?* Two-day workshop, Banff, Canada, May 24-28, 2006.

American Society for Microbiology (ASM), “The Use and Potential Misuse of Microorganisms: The Impact of Select Agents in Teaching Microbiology” and “Dual Use in the Trenches: The View from the Policy, Ethics & Law Core,” symposium presentations at the *106th Annual General Meeting*, Orlando, Florida, May 22-23, 2006.

Liberty Fund Colloquium, *Intellectual Property in Biotechnology*. Houston, Texas (Baruch Brody, Rice University and Baylor Medical Center, convenor), May 18, 2006.

Presentation at dedication of Wyngaarden Conference Room, CIEMAS/Fitzpatrick Center, Duke University, May 13, 2006.

Cold Spring Harbor Laboratory, “Data Release and Intellectual Property Challenges in the Age of Large-Scale Human Genotyping and Sequencing,” panel discussion at the annual *Biology of Genomes* symposium, New York, May 11-12, 2006.

U.S. Department of Energy (DOE), “Why do we need ethics? What does it actually contribute?” presentation at *Integrated Societal Implications of Science* Workshop: “Dealing with the Societal Implications of DOE Science,” Chantilly, VA, May 2, 2006.

National Breast Cancer Coalition Foundation, “Under Attack: Maintaining the Integrity and Independence of the FDA,” talk for plenary panel, Annual Meeting, May 1, 2006.

“Transcending Disciplinary Boundaries,” presented report on *P50 National Center of Excellence for Ethical, Legal & Social Implications (ELSI) Research, Second Annual Investigator Meeting*, Rockville, MD, April 26-28, 2006.

Carolina Center for Genome Sciences, “Does open science matter? Genomics as a case study,” talk for University of North Carolina, Chapel Hill, April 21, 2006.

Moderator/Speaker, Global Health Symposium. Duke University, April 18, 2006.

University of Alberta School of Law, *Picard Lecture in Health Law*, “Tales of the Genome: Can we tell when patents foster or impede innovation,” Edmonton, Alberta, Canada, March 22-24, 2006.

“Who Owns the Genome?” Radio interview with *Kresta In The Afternoon*, Catholic Radio Network, February 27, 2006.



Duke Medicine in Singapore, "Social Dynamics of Public Engagement in Medical Genetics and Genetic Services," lecture for Singapore General Hospital (SGH) and Prof. Chan Yew Weng, Director of the SGH Postgraduate Medical Institute (PGMI) (videotaped for later use in Singapore), February 4, 2006.

Bogazici University, "The History of the Human Genome Project," *Seminer Odas* lecture for the Department of Genetics and Biochemistry, Kuzey Park, Istanbul, Turkey, December 20, 2005.

US delegation to the European Union, "Emerging Biotechnology Applications: EU, US and Global Regulatory Perspectives" presentation for a meeting in Lille, France, December 3-6, 2005.

National Academies Keck Futures Initiative (NAKFI) Conference, "The Genomic Revolution: Implications for Science and Health," presentation as part of *Ethical, Legal and Social Issues* IOM/NAE/NAS/NRC Project, Beckman Center, University of California, Irvine, November 10-13, 2005.

*Global Health* panel discussion for Rubenstein Hall Dedication ceremonies, Duke University, November 4, 2005.

Johns Hopkins University School of Medicine, "Bioethics, policy analysis, and policy engagement: How does it work? How can it work better?" *Greenwall Fellows Seminar Series*, October 24, 2005.

Camelot Academy, *Cracking the Code of Life* Discussion - BrainPlay 5th-6th grade – requested by Scott Mitchell, President, Durham PAGE, Director of Admissions, October 22, 2005.

McGill University, "Legal Models of Biotechnological Intellectual Property Protections: A Transdisciplinary Approach," *Biotechnology & Intellectual Property: Restructuring for the Public Benefit*, Montreal, Quebec, Canada, September 25-27, 2005.

National Research Council and Institute of Medicine, "Education and Raising Awareness: Challenges for Responsible Stewardship of Dual Use Research in the Life Sciences," presentation for a committee meeting on dual-use research, Washington, DC, Sept 8, 2005.

WUNC Live Broadcast, "Stem Cell Research," with Cory Princell and Frank Stacio, August 30, 2005.

*Kite Runner* panel discussion – Plenary session for ~800 freshman students, Page Auditorium, orientation week, Duke University, August 26, 2005.

Robert Wood Johnson Foundation, *Race and Genetics*. Moderator of panel for RWJF staff in Princeton, New Jersey, July 26, 2005.

University of Leuven, "Genomics and World Health: Surviving in the Information Jungle," talk at *Conference on Microbiological Commons*, Brussels, Belgium, July 7, 2005.

*Global Health Initiative*. Presentation to Executive Committee, Board of Trustees, Duke University, June 17, 2005.

*Global Health Initiative*. Presentation to Deans' Cabinet, Duke University, June 6, 2005.

Interview on *Madey v Duke* Case with David Malakoff, National Public Radio, May 24, 2005.

National Breast Cancer Coalition Foundation, "Intellectual Property Rights: Why They Matter to Breast Cancer Advocates," panel at NBCCF annual meeting, Washington, DC, May 22, 2005.

Rice University, *Altering Natures Policy Group Meeting*. Genetics Enhancement Project subcommittee chair, Houston, Texas, May 19, 2005.

Nemours Annual Symposium on Children's Health, "Ethics and Policy Considerations in Genetics," panel discussion, Jacksonville, FL., May 10, 2005.

University of Minnesota, "Future of the Field of Bioethics," *Bioethics and Consortium on Law and Values in Health, Environment & the Life Sciences*, May 5, 2005.

Rotman School of Business, University of Toronto, "The Science Commons in Health Research: Structure, Function, and Value," at conference *Bringing Science to Life*, April 29, 2005.

Center for the Study of Medical Ethics and Humanities, "Genomics and World Health: Navigating the Information Jungle," *Humanities in Medicine Lecture Series*, Duke University, September 15, 2004.

Gordon Research Conference on Science & Technology Policy, "Science as Expertise, Morality, and Politics II: ELSI-So What?" Big Sky, Montana, August 15-20, 2004.

World Health Organization, "Genomics and World Health: Navigating the Information Jungle," *Genetics, Ethics, and Health Law lunchtime seminar*, Geneva, July 21, 2004.

Vanderbilt University, "Genomics: The Information Jungle," keynote speaker for conference on *Genetics in Literature, Film and Popular Culture*, November 7-8, 2003.

"Open Genomics, Innovation and Fairness," *University Program in Genetics and Genomics with the Institute for Genome Sciences & Policy*, Duke University, November 4, 2003.

"The Public Value of Academic Health Research," *Health Sector Management Faculty Seminar*, Fuqua School of Business, Duke University, October 30, 2003.

Robert Wood Johnson Foundation, Investigator Awards in Health Policy Research, "The Jewel in the Federal Crown? History, Politics and the NIH," paper presented to the *History and Social Policy Research Group*, October 11, 2003.

Howard Hughes Precollege Program in the Biological Sciences, "From Genome Sequence to Making Life Better," Duke University, June 25, 2003.

American Association for the Advancement of Science in collaboration with Resources for the Future, "Patents and Innovation in Cancer Therapeutics: The Story of CellPro," and "Licensing Issues in DNA Based Patents," talks at *Science and Intellectual Property in the Public Interest* meeting *Implications of Gene Patents for Biomedical Research and Clinical Medicine*, June 5, 2003.

Presenter, Duke in Napa Valley Seminar, Napa Valley, CA, May 22, 2003.

Harvard University, "Genomics, Genohype, and Policy Issues Confronting the Future of Genetics," guest lecture for the class *Integrity in Research/Responsible Conduct of Research* Cambridge, MA, May 7, 2003, organized by Raymond Erikson, Dept. Biology.

- “Interactions between Public and Private R&D,” *PhRMA Biologics and Biotechnology Section Meeting*, Boston, Massachusetts, April 9, 2003.
- Wake Forest University School of Medicine, “Ethical, Legal, and Social Implications of the Human Genome Project” talk at April 2, 2003.
- Sigma Xi Scientific Research Society, “The Genome Business: Science, Health, Wealth, and Fairness,” annual meeting at April 1, 2003.
- Goodenough College, keynote for meeting *The Power of the Market in Shaping a New Genomic Order*, London, UK, March 27, 2003.
- North Carolina School of Science and Math, “Ethical Challenges Facing Tomorrow’s Leaders,” talk at March 4, 2003.
- Center for the Study of Medical Ethics and Humanities, “Public and Private Genomics: What’s Going On? What’s Fair?” talk for the Duke University, February 5, 2003.
- German-American Institute, “History of US Bioethics Commissions and The Role of ‘Public’ Bioethics,” Heidelberg, Germany, December 11, 2002.
- Max Planck Institute on Intellectual Property, Competition, and Tax Law, “DNA Patenting and Technology Transfer,” talk for the Munich, Germany, December 10, 2002.
- Max Planck Institute on Biology, Biological Cybernetics, and Developmental Biology “DNA Patenting and Commercialization of Genomics,” talk for the, Tübingen, Germany, December 9, 2002.
- Interdepartmental Center for Ethics in Sciences, “History of U.S. Bioethics Commissions and ELSI Research Programs: The Role of ‘Public’ Bioethics,” talk at the University of Tübingen, Germany, December 9, 2002.
- Knight Science Journalism Fellowship Program, “The Role of Public Bioethics” (with Daniel Wikler, Harvard School of Public Health), talk for *Genes and Cells Boot Camp*, Whitehead Institute and Massachusetts Institute of Technology, Cambridge, MA, December 7, 2002.
- “The Role of a Policy, Ethics, and Law Program as Science Progresses,” keynote talk for conference on religion and genetics, Duke University, November 21, 2002.
- Kennedy Institute of Ethics, “Genome Ethics, Law, and Policy: Building a Program at Duke,” talk at the *Tuesday Seminar Series*, Georgetown University, October 22, 2002.
- The Hastings Center, “The Role of Academic Research Institutions in the Biotechnology Innovation System, Including the Bayh-Dole Act,” talk at the second meeting of the *Project on Ethical Issues in the Management of Financial Conflicts of Interest in Research in Health, Medicine and the Biomedical Sciences*, Garrison, NY, October 17, 2002.
- Institute of Medicine, “From Double Helix to Genomic Sequence: Some Policy Lessons,” plenary lecture for IOM annual meeting, October 14, 2002.
- “Policy, Politics, and Power: Health Research Policy,” briefing for the Robert Wood Johnson Health Policy Fellows, Institute of Medicine, September 18, 2002.
- “Preliminary Data on DNA Patents and Plans for a Survey of Licensing Practices at U.S. and Canadian Academic Research Institutions,” presentation at the *Third International Conference on DNA Sampling*, Montreal, Quebec, September 7, 2002.

National Academies of Science and Engineering and the Institute of Medicine, "The Urge to Commercialize: Interactions between Public and Private R&D," presentation at the *Symposium on the Role of Scientific and Technical Data and Information in the Public Domain*, September 5, 2002.

**Lauren A. Dame, J.D., M.P.H.**

2409 Falls Dr.  
Chapel Hill, NC 27514  
(919) 260-1366  
dame@law.duke.edu

**EDUCATION**

**HARVARD SCHOOL OF PUBLIC HEALTH**, Boston, MA 02115 June 1992  
M.P.H. (Master of Public Health)  
Concentration in Public Management & Community Health, with a focus on Public Health Law.

**HARVARD LAW SCHOOL**, Cambridge, MA 02138 June 1983  
J.D.  
Activities: Harvard Civil Rights-Civil Liberties Law Review, Comments Editor  
Harvard Women's Law Journal, Staff member  
Greater Boston Legal Services, Volunteer  
Harvard Women's Law Association, Executive Committee Member

**STANFORD UNIVERSITY**, Stanford, CA 94305 June 1977  
A.B. Human Biology  
Graduated "With Distinction"  
Phi Beta Kappa

**WORK EXPERIENCE**

**Duke University**, Durham, NC September 2001-- present  
*Associate Director*, Center for Genome Ethics, Law & Policy: Responsible for coordinating the Center's work, and for developing and managing specific activities, such as public symposia, seminars, and course development grant competitions. Tasks include supervising research and administrative staff; preparing annual reports to internal and external funders; and serving as a public representative of the Center within and beyond the university. Serve as a liaison between the Center and interested students, teach relevant undergraduate courses, and provide informal mentoring to students.

**Duke Law School**, Durham, NC Jan. 2001-- present  
*Senior Lecturing Fellow*: Responsible for developing and teaching law school courses on (1) Genetics & the Law, and (2) Bioethics. (Topics include informed consent, the "right to die," reproductive technologies, health care policy; medical privacy, human subject research, and bioethical issues raised by genomics.) Additional tasks include supervising law students writing independent papers.

**Duke University**, Durham, NC Fall Terms 2004, 2005 & 2008  
*Faculty Member*, FOCUS Program: "The Genome Revolution." Responsible for designing and teaching a first-year undergraduate seminar on ethical, legal, and social implications of the genomic sciences. This course was one of a cluster of four seminars, one writing course, and an Interdisciplinary Discussion group focusing on various aspects of the genome revolution.

**Duke University, Durham, NC**

March 2001—Sept. 2001

*Director of the Faculty Colloquium, Center for Genome Ethics, Law & Policy:* Responsible for developing programming for a newly-created interdisciplinary center at Duke, including a monthly faculty colloquium on ethical, legal, and policy issues raised by advances in genomic sciences, with the goal of establishing the new center, and engaging an interdisciplinary group of faculty from across the university.

**Health Law & Policy Consultant, Washington, D.C.**

1999-2000

Assisted non-profit health policy organization in research and advocacy on health policy issues related to access to health care, consumers' rights, "managed care" reform, and other issues.

**Yale Law School, New Haven, Connecticut**

Spring 1999

*Visiting Lecturer in Law:* Co-taught "Professionalism Under Pressure in Law and Medicine." (This course looked at the ways in which recent changes in the organization, delivery and financing of medical and legal services have affected traditional notions of professionalism, ethics, and quality of care.)

**Public Citizen's Health Research Group, Washington, D.C.**

March 1995 - Dec. 1997

*Staff Attorney/Health Care Delivery Researcher:* Conducted research, writing and advocacy work in non-profit consumers' rights organization. Areas of analysis included access to health care, quality of care, hospital regulation, physician discipline, medical records privacy, health insurance, and others. Tasks included writing reports, presenting testimony before federal committees, and providing analysis to news reporters.

**Duke University School of Law, Durham, North Carolina**

Spring 1994

*Lecturing Fellow:* Taught "Topics in Health Law: Autonomy, Community and Reform." Seminar was structured around a number of different health law topics, including issues of bioethics, the rights of individuals and the needs of the community, children and medical decision-making, and health care reform.

**Harvard Law School, Cambridge, Massachusetts.**

Spring 1992

*Teaching Assistant* for "AIDS & the Law." Served as a teaching assistant for Harvard professor in a law school seminar, while attending Harvard School of Public Health.

**Covington & Burling, Washington, D.C.**

1988-1989

*Attorney:* legal work in several areas, including insurance law, hospital reimbursement issues, and Food & Drug law. Most extensive work involved analyses of clients' insurance coverage for product liability suits.

**United States District Court, Baltimore, Maryland.**

1985-1987

*Judicial clerk* to the Honorable Herbert F. Murray: performed a broad range of tasks to assist the Judge, including research and drafting opinions, and attending civil and criminal trials.

**American Bar Association**

Summer 1985

Individual Rights & Responsibilities Section

*Consultant:* hired to write a background paper on privacy and technology.

**American Civil Liberties Union**

1985

Washington Legislative Office, Washington, D.C.

*Legal Associate:* worked for the Privacy & Technology Project; work involved research and writing about the effects of technology on privacy law.

**Continuous Curve Contact Lenses, Inc., San Diego, California.**

1978-1980

*Clinical Research Coordinator:* project manager for a clinical study of a new soft contact lens; responsible for coordinating various aspects of the study, communicating with physician researchers, and assisting with preparation of applications to the U.S. Food and Drug Administration.

**Queen's Medical Center, Cardiovascular Research Lab, Honolulu, Hawaii.**

1977

*Laboratory Researcher:* assisted with medical research projects, including both laboratory work and library research.

**TEACHING EXPERIENCE AT DUKE**Courses

- *Bioethics*, law school course, taught every odd year, 2001-present
- *Genetics & the Law*, law school course, taught every even year, 2004-present
- *Responsible Conduct of Research*, Duke Medical Center course, co-faculty
- *Ethical, Legal & Social Implications of the Genome Revolution*, Undergraduate Public Policy course (Focus program) 2008
- *The Human Genome and the Law*, Undergraduate Public Policy course (Focus program), 2004 & 2005
- *Law and Genomic Sciences*, Undergraduate IGSP course, to be offered Fall 2013

Regular Guest lecturer

- *Summer Medical and Dental Education Program (SMDEP)* course, Duke Medical Center (course for underrepresented minorities planning for a medical career; lecture on health policy and health law)
- *Clinical Research Training Program (CRTP)*, Duke Medical Center course (lecture on genomics research, ethics & law)
- *Genetics, Genomics and Society*, Undergraduate course, Biology 156/Genome 156 (lecture on policy issues raised by genomics research)

**SELECTED PUBLICATIONS**

Leslie E. Wolf, Mayank J. Patel, Brett A. Williams, Jeffrey A. Austin, **Lauren A. Dame**, Certificates of Confidentiality: Protecting Human Subject Research Data in Law and Practice, *Minnesota Journal of Law Science and Technology*, Vol. 14, No. 1, 2013.

Leslie E. Wolf, **Lauren A. Dame**, Mayank J. Patel, Brett A. Williams, Jeffrey A. Austin, Laura M. Beskow, Certificates of Confidentiality: Legal Counsels' Experiences with and Perspectives on Legal Demands for Research Data, *Journal of Empirical Research on Human Research Ethics: An International Journal*, Vol. 7, No. 4 (October 2012), pp. 1-9

Beskow LM, Check DK, Namey EE, **Dame LA**, Lin L, et al. (2012) Institutional Review Boards' Use and Understanding of Certificates of Confidentiality. *PLoS ONE* 7(9): e44050. doi:10.1371/journal.pone.0044050

L Beskow, **L Dame** & EJ Costello, Certificates of Confidentiality and Compelled Disclosure of Data, *Science*, Vol. 322, pp. 1054-55, Nov. 14, 2008. (NIHMSID: NIHMS109393)

H Shanawani, **L Dame**, D A Schwartz, and R Cook-Deegan, "Non-reporting and inconsistent reporting of race and ethnicity in articles that claim associations among genotype, outcome, and race or ethnicity," *J. Med. Ethics*, Dec 2006; 32: 724 - 728.

K. Schulman, D. Seils, J. Timbie, J. Sugarman, **L. Dame** et. al., "A National Survey of Provisions in Clinical-Trial Agreements Between Medical Schools and Industry Sponsors," 347 *The New England Journal of Medicine* 1335, October 24, 2002.

**Lauren Dame** & Jeremy Sugarman, MD, "Blood Money: Ethical and Legal Implications of Treating Cord Blood as Property," 23 *Journal of Pediatric Oncology* 409, October 2001.

**Lauren Dame**, "The Emergency Medical Treatment and Active Labor Act: The Anomalous Right to Health Care," 8 *Health Matrix: Journal of Law-Medicine* 3, Spring 1998.

## PROFESSIONAL ACTIVITIES

Member, Duke Hospital Ethics Committee, February 2006 to December 2011.

Faculty Associate, Trent Center for Bioethics, Humanities and History of Medicine at Duke University Medical Center

Member, Expert Advisory Panel for "Accessible Genetics Research Ethics Education" (AGREE), Duke University Medical Center, September 2002 – July 2005.

Member, Duke University Medical Center Task Force on the Hospital Ethics Committee December 2004 – February 2005.

Chair of the North Carolina Task Force on Genetics and Public Health, September 2002 to December 2003.



## NITA A. FARAHANY

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### ACADEMIC APPOINTMENTS

#### Duke University, Durham, NC

<i>Professor of Law</i> , Duke Law School	2012-present
<i>Professor</i> , Institute for Genome, Sciences, and Policy	2012-present
<i>Professor of Philosophy</i> (by courtesy)	2012-present

#### Stanford Law School, Palo Alto, CA

<i>Leah Kaplan Visiting Professor of Human Rights</i>	Fall 2011
<i>Visiting Associate Professor of Law</i>	Winter-Spring 2011
Courses: Criminal Law; Genetics and Reproductive Technologies (cross-listed in medical school); Current Topics in Bioethics (cross-listed in medical school); Liability, Responsibility & Punishment (cross-listed in philosophy)	

#### Vanderbilt University, Nashville, TN

<i>Associate Professor of Law</i> , <i>Associate Professor of Philosophy</i>	2009-2012
<i>Assistant Professor of Law</i> , <i>Assistant Professor of Philosophy</i>	2006-2009
<i>Vanderbilt Fellow and Instructor in Law</i>	2005-2006
Focus: law & science (behavioral genetics, neuroscience), criminal law, torts, philosophy of law, philosophy of science, philosophy of mind, neuroethics, bioethics	
Courses: Torts; Criminal Law; Constitutional Law of Crime & Punishment; Liability, Responsibility & Punishment; Law and Biosciences; Life of the Law	

### EDUCATION

#### Duke University, Durham, N.C.

*Ph.D. in Philosophy*, Graduate School of Arts and Sciences, 2006

- Dissertation: *Rediscovering Criminal Responsibility through Behavioral Genetics*; Committee: Alexander Rosenberg (Advisor), Martin Golding, Allen Buchanan, James E. Coleman, Jr., Lauren Dame

*M.A. in Philosophy*, Graduate School of Arts and Sciences, 2004

- Master's Thesis: *The Limited Applicability of Estimates of Genetic Heritability*

*J.D.*, School of Law, 2004

- High Honors, Order of the Coif
- Research Assistant to Senior Associate Dean James Coleman, Professors David Lange and Walter Dellinger; Teaching Fellow for Professor Thomas Metzloff, Distinctive Aspects of U.S. Law
- Law and Contemporary Problems*, Executive Board, 2003-04; Staff Editor, 2002-03
- Moot Court Team, Winner of the 2003 National Sutherland Cup Competition; Duke National Team 2003-04 and regional quarter-finalist; Executive Board Member 2002-03
- Amicus Curiae* in *U.S. v. O'Connor* (co-authored brief and presented oral argument before U.S.C.A.A.F.)
- Pro Bono work for N.C. Center for Death Penalty Litigation; Duke University Actual Innocence Project

#### Harvard University, Cambridge, MA

*A.L.M. (Biology)*, Harvard Extension School, 2007

Thesis: *Prescribing Culpability*; Advisor: Charles J. Ogletree

#### Dartmouth College, Hanover, N.H.

*A.B. in Genetics, Cell and Developmental Biology*, 1998

- Rockefeller Public Service Scholarship; Lucas Third World Internship; American College of Obstetrics and Gynecologists Scholarship; Pat Bailey Award for Forensic Excellence

## GOVERNMENT SERVICE

- Presidential Commission for the Study of Bioethical Issues, *Member*** 2010-present
- Georgia State Bar, Labor and Employment Section, Committee on Pattern Civil Jury Instructions for the 11<sup>th</sup> Circuit Federal Court of Appeals, *Member*** Summer 2010
- Hon. Judith W. Rogers, U.S. Court of Appeals, D.C. Circuit, Washington, D.C., *Law Clerk*** 2004-2005

## SCHOLARSHIP

### Publications

- *Law and Behavioral Morality* (in NOMOS LII: YEARBOOK OF THE AMERICAN SOCIETY FOR POLITICAL AND LEGAL PHILOSOPHY XIX, Sanford Levinson, ed., 2012)
- *Searching Secrets*, 160 U. Penn. L. Rev. 1239 (2012)
- *Incriminating Thoughts*, 64 Stanford Law Review 351 (2012)
- *A Neurological Foundation for Freedom*, 2012 STANFORD TECHNOLOGY LAW REVIEW 4 (2012)
- *Introduction*, in THE IMPACT OF BEHAVIORAL SCIENCES ON CRIMINAL LAW (Nita A. Farahany ed., Oxford University Press 2009) (2009)
- *Genetics, Neuroscience, and Criminal Responsibility*, in THE IMPACT OF BEHAVIORAL SCIENCES ON CRIMINAL LAW (Nita A. Farahany ed., Oxford University Press 2009) (2009)
- *Cruel and Unequal Punishment*, 86 Washington University Law Review 859 (2009)
- *Bad Nature, Bad Nurture, and Testimony in Murder Trials*, 52 *Journal of Forensic Sciences* 1362 (William Bernet, M.D., Cindy L. Vnencak-Jones, Ph.D., Nita A. Farahany, J.D., M.A., A.L.M., Ph.D., and Stephen A. Montgomery, M.D.) (2007)
- *Behavioural Genetics in Criminal Cases: Past, Present and Future*, 1 GENOMICS, SOCIETY & POLICY 2 (2006) (Nita Farahany & William Bernet)
- *Genetics and Responsibility: To Know the Criminal from the Crime*, 69 LAW & CONTEMPORARY PROBLEMS 115 (Winter/Spring 2006) (Nita A. Farahany & James E. Coleman, Jr.)
- *Foreword*, 69 LAW AND CONTEMPORARY PROBLEMS 1 (2006)
- Co-Special Editor of *Law & Contemporary Problems* Winter/Spring 2006 symposium on The Impact of Behavioral Genetics on Criminal Law

### Books

- THE IMPACT OF BEHAVIORAL SCIENCES ON CRIMINAL LAW (Nita A. Farahany, ed., Oxford University Press 2009)

### Other Publications

- *What are They Thinking?: The Government is Trying to Wrap its Mind Around Yours*, WASH. POST, April 13, 2008, at B3.

### Works in Progress

- *Empirical use of Behavioral Genetics and Neuroscience in Criminal Law, 2004-2010*
- *Privacy Lost and Found*
- *On Cognitive Liberty*

## INVITED WORKSHOPS & PRESENTATIONS

- *Synthetic Biology and Intellectual Property Law*, invited panelist, American Law Institute Young Scholar Conference on Patent Law, Washington, DC, February 2013
- *"Prohibit Genetically Engineered Babies,"* Invited Debater Against the Resolution, Intelligence Squared U.S./PBS/NPR, New York, NY, February 2013
- *Genetics in the Law*, panelist, UC Hastings, San Francisco, CA, February 2013

- *Privacy Roundtable*, participant, University of Arizona School of Law, Tempe, Arizona, January 2013
- *Behavioral Sciences in U.S. Law*, Federal Judicial Center and Stanford University Conference on Genetics for Judges, Stanford, CA, January 2013
- *Finding Consciousness – Implications for Law and Ethics*, Finding Consciousness Conference, Duke University, Durham, NC, January 2013
- *Behavioral Sciences in U.S. Law*, Accuracy and Errors Conference, Duke Law School, Durham, NC, November 2012
- *Neuroscience and Self*, keynote speaker, International Society for Neuroethics Annual Meeting, New Orleans, LA, October 2012
- *Behavioral Sciences in U.S. Law*, invited speaker, College of Charleston, Charleston, SC, October 2012
- *On Cognitive Liberty*, invited speaker, Neuroscience and Public Policy (N&PP) Seminar, University of Wisconsin, September 2012
- *Neuroscience and Neuroethics*, invited speaker, 21<sup>st</sup> Annual Short Course on Experimental Models for Human Cancer, Cold Springs Harbor, ME, August 2012
- *On Cognitive Liberty*, invited keynote speaker, *Australian Society of Legal Philosophy* annual conference, Macquarie University, Sydney, Australia, July 2012
- *Intellectual Property Frameworks for Synthetic Biology*, invited panelist speaker, Synthetic Biology Symposium hosted by the National Academy of Sciences (NAS), National Academy of Engineering (NAE), Royal Society (RS), Royal Academy of Engineering (RAE), Chinese Academy of Sciences (CAS) and Chinese Academy of Engineering (CAE), Washington, D.C., June 2012
- *Neuroscience and Free Will*, invited panelist speaker, San Francisco Public Defender's Justice Summit, May 2012
- *Decoding the Brain: Ethical and Legal Issues*, invited speaker, Stanford Law School Center for Law and Biosciences, April 2012
- *Incriminating Thoughts*, and *Privacy Lost and Found*, invited speaker, John Hopkins Berman Institute of Bioethics Seminar Series, Washington, DC, April 2012
- *Memories of the Guilty Mind*, panel organizer and invited speaker, 2012 Nevada U.S. District Court Annual Conference, Reno, Nevada, April 2012
- *Incriminating Thoughts*, invited speaker, Duke Law School Faculty Workshop Series, February 2012
- *Biosciences in the U.S. Courtroom*, invited speaker, American Association for the Advancement of Science Annual Meeting, Halifax, Nova Scotia, February 2012
- *Synthetic Biology Roundtable Working Group Meeting*, co-organizer and participant, Stanford University, January 2012
- *Searching Secrets*, invited speaker, Public Law and Theory Workshop, Chicago Law School, January 2012
- *Searching Secrets*, invited speaker, Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics of Harvard Law School, Colloquium Series, Harvard Law School, January 2012
- *Empirical Use of Biosciences in Criminal Law*, invited speaker, Seminar on Law and Genetics for Judges, Co-sponsored by the Federal Judicial Center & Stanford Law School, January 2012
- *Searching Secrets*, invited speaker, Stanford Law School Faculty Workshop Series, December 2011
- *Current Issues for the Presidential Commission for the Study of Bioethical Issues*, Center for Law and Biosciences, Stanford University, November 2011
- *ELSI Issues in Synthetic Biology*, National Research Council Study Committee, UC Irvine, October 2011
- *Behavioral Sciences in US Case Law*, United States Court of Appeals for the Ninth Circuit Judicial Conference, invited speaker, August 2011
- *Empirical Use of Behavioral Sciences in US Case Law*, United States Court of Appeals for the Second Circuit Judicial Conference, invited speaker, June 2011
- *Neuroscience in the Courtroom, Ethical, Legal and Social Implications*, NIH, invited speaker, Chapel Hill, NC, April 2011
- *Incriminating Thoughts*, Yale/Harvard/Chicago Annual Criminal Law Roundtable, invited speaker, New Haven, CT, April 2011
- *Promises and Perils of Emerging Neuroscience*, Duke Law School, invited keynote luncheon speaker, May 2011
- *Confronting Our Memories*, conference organizer and speaker, Law and Memory Conference, Stanford University, April 2011

- *Neuroscience & Behavioral Genetics in the Courtroom: Past, Present & Future*, invited speaker, AAAS Seminar for Judges, Phoenix, AZ, March 2011
- *Neuroscience & Behavioral Genetics in the Courtroom: Past, Present & Future*, invited speaker, DANA Alliance Conference on Law and the Brain, New York, NY, March 2011
- *Incriminating Thoughts*, invited speaker, Stanford Law School Faculty Workshop Series, February 2011
- *Incriminating Thoughts*, invited speaker, Stanford Law & Biosciences Colloquium, February 2011
- *Neuroscience in the Courtroom*, invited speaker, Stanford Law School Judicial Seminar, January 2011
- *Incriminating Thoughts*, Faculty Workshop Speaker, George Washington University Law School, October 2010
- *Empirical Use of Behavioral Sciences in North America*, invited speaker, Neuroscience and European and North American Case Law, Milan, Italy, September 2010
- *Neuroscience & Behavioral Genetics in the Courtroom: Past, Present & Future*, invited speaker, AAAS Seminar for Federal Judges, June 2010
- *Freedom of Action*, invited speaker, Gruter Institute Annual Conference, Squaw Valley, NV, May 2010
- *Freedom of Action*, invited speaker, CIHR Conference on Neuroimaging Ethics: From Theory to Practice, Halifax, Canada, May 2010
- *Neuroscience as a Tool for Legal Taxonomy*, invited speaker, MacArthur Law & Neuroscience Project and the Oxford Neuroethics Centre, AAAS, Washington, DC, May 2010
- *Neuroscience and Freedom*, speaker, *Moral Biology Conference*, Harvard Law School, April 2010
- *Law & Biosciences*, moderator and conference organizer, Vanderbilt Law School, March 2010
- *Neuroscience & Behavioral Genetics in the Courtroom: Past, Present & Future*, invited speaker, Seminar on Law and Neuroscience for Judges, Co-sponsored by the Federal Judicial Center; hosted by the Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics of Harvard Law School, Harvard Law School, March 2010.
- *Judging Neuroscience*, speaker, Neuroscience in the Courtroom: What Judges Need to Know, AAAS Program, Halifax, Canada, February 2010
- *Neuroscience and Free Will*, selected speaker, criminal law panel, Association of American Law Schools, New Orleans, LA, January 2010
- *Neuroscience & Behavioral Genetics in the Courtroom: Past, Present & Future*, invited speaker, National Judicial College Seminar for Judges, Nashville, TN, November 2009
- *New Technology, New Society?*, invited panelist, Global Women's Forum, Deauville, France, October 2009
- *Junior Criminal Law Scholars Conference*, Workshop Participant, George Washington University Law School, July 2009
- *Incriminating Thoughts*, invited speaker, Fourteenth Annual Current Legal Issues Inter-Disciplinary Colloquium, University College London, London, UK, July 2009
- *Neuroscience & Behavioral Genetics in the Courtroom: Past, Present & Future*, invited speaker, National Judicial College Seminar for Judges, Nashville, TN, June, 2009
- *Neuroscience and National Security*, invited symposium speaker and participant, *Stanford Technology Law Review Conference*, Stanford University Law School, February 2009
- *Cruel and Unequal Punishment*, invited Faculty Workshop, Stanford University Law School, February 2009
- *Neurosecurity*, invited speaker, Center for Law and Biosciences, Stanford University Law School, February 2009
- *Neuroscience Judges Seminar*, invited participant, hosted by AAAS, November 2008
- *Cruel and Unequal Punishment*, invited Faculty Workshop, Duke Law School, October 2008
- *Neuroscience, Law and Policy*, invited speaker, Beyond Belief III, Salk Institute, October 2008
- *Law, Neuroscience, and Behavioral Morality*, Neuroscience, Law & Government Symposium, University of Akron School of Law, September 2008
- *Law and Behavioral Morality*, invited speaker, American Society for Political and Legal Philosophy Annual Conference, August 2008
- *Junior Criminal Law Scholars Conference*, Workshop Participant, George Washington University Law School, August 2008
- *Incriminating Thoughts*, invited speaker, Stanford University, April 2008
- *Neuroscience in the Criminal Justice System*, invited speaker, National Association of Criminal Defense Lawyers Mid-winter meeting, February 2008

- *Criminal Law Overview, MacArthur Law and Neuroscience Project*, invited presentation to NDM working group session, hosted at Vanderbilt University Law School, February 2008
- Invited Roundtable Participant for *Judging Genes: Implications of the Second Generation of Genetic Tests in the Courtroom*, University of Maryland, January 2008
- Invited panelist for workshop on *Neuroethics and the Ethical Implications of Augmented Cognition*, University of Florida, October 2007
- *Science and the Eighth Amendment*, Amherst College, Evidentiary Processes in Law & Science Series, October 2007
- *Behavioral Sciences in the Law*, 2007 Second Circuit Judicial Conference, invited speaker, June 2007
- *Recent Use of Behavioral Genetics in Criminal Cases*, invited speaker, Interpreting Complexity: The Scientific and Social Meaning of Behavior Conference, hosted by CIRGE, Stanford University, June 2006
- *Bad Nature, Bad Nurture, and Testimony regarding MAOA and SLC6A4 Genes at Murder Trials*, presentation, American Academy of Forensic Sciences Annual Meeting, February 2006
- *Legal Precedents, Culpability, and MAOA and SLC6A4 genotyping of criminal defendants*, presentation, Psychiatric Grand Rounds, Vanderbilt Medical School, January 2006
- *Genetic Predispositions in Criminal Law*, invited speaker, CSI: Nashville, Vanderbilt University, September 2005
- *Rediscovering Criminal Responsibility through Behavioral Genetics, Law & Contemporary Problems* Conference on The Impact of Behavioral Genetics on Criminal Law, Duke University, April 2005
- *Science or Science Fiction? Behavioral Genetics of Criminal Behavior*, Genome, Ethics, Law & Policy Series, Duke University, April 2004

#### **MEMBERSHIPS**

U.S. Supreme Court Bar, New York State Bar, U.S. Court of Appeals for the D.C. Circuit Bar, American Bar Association, International Society for Neuroethics (Board Member), American Association for the Advancement of Science (AAAS)

#### **HONORS AND AWARDS**

2013 Paul M. Bator Award Recipient (awarded annually by the Federalist Society for Law and Public Policy Studies to a scholar under 40 who has made a “significant public impact through their work and demonstrate excellence in legal scholarship, a commitment to teaching, and a concern for students.”)

#### **SERVICE**

American Association of Law Schools, Secretary (January 2011-2012); Chair Elect (January 2012-2013); Member, Dartmouth Alumni Council (August 2010-present); Board Member, Duke Law Alumni Association (July 2011-August 2012)

**AMY LAURA HALL**

Associate Professor of Christian Ethics

Duke Divinity School  
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Durham, N.C. 27708

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[alhall@div.duke.edu](mailto:alhall@div.duke.edu)

**EDUCATIONAL BACKGROUND**

B.A. Political Science and Sociology	Emory University	1990
M.Div.	Yale Divinity School	1993
Ph.D. Religious Ethics	Yale University	1999

**COURSES TAUGHT**

Introduction to Theological Ethics; American Protestantism in Literature and Film; Masculinity and Ministry; War and American Christianity; Sin and Redemption in North American Literature; Sex, Gender, and Discipleship; Womanist and Feminist Ethics; Medical Ethics; Bioethics and Reproduction; Feminist Theology and Ethics; Justice and the Family; Love in the Christian Tradition; Kierkegaard and Continental Philosophy.

**BOOKS**

*Kierkegaard and the Treachery of Love*. Cambridge: Cambridge University Press, 2002.

*Conceiving Parenthood: American Protestantism and the Spirit of Reproduction*. Grand Rapids, MI: Eerdmans, 2008.

*Good Housekeeping with Lady Julian*. Grand Rapids, MI: Eerdmans. Forthcoming.

*Erecting the Pulpit: Muscular Christianity from Victoria to Viagra*. (Current research project.)

**JOURNAL ARTICLES**

“Complicating the Command: Agape in Scriptural Context.” *Annual of the Society of Christian Ethics* 19 (1999): 97-113.

- “Self-Deception, Confusion, and Salvation in Fear and Trembling with Works of Love.” *Journal of Religious Ethics* 28 (2000): 37-61.
- “Poets, Cynics and Thieves: Vicious Love and Divine Protection in Kierkegaard’s Works of Love and Repetition.” *Modern Theology* 16 (2000): 215-236.
- “Prophetic Vulnerability and the Strange Goodness of God: A Reading of Numbers 22 and 1 Kings 17.” *Sewanee Theological Review* 46 (2003): 340-350.
- “Public Bioethics and the Gratitude of Life: Joanna Jepson’s Witness against Negative Eugenics.” *Studies in Christian Ethics* 18 (2005): 15-31.
- “Ruth’s Resolve: On Care at the End of Life.” *Christian Bioethics* 11 (2005): 35-50.
- “Welcome to Ordinary? Masculinity and ADHD.” Open Peer Commentary, *American Journal of Bioethics* 5.3 (2005): 59-60.
- “Whose Progress? The Language of Global Health.” *Journal of Medicine and Philosophy* 31 (2006): 285-304.
- with Kara Slade. “The Single Individual in Ordinary Time.” *Studies in Christian Ethics* 26.1 (2013): 66-82.
- “American TV and Torture.” *The Muslim World* 103.2. Forthcoming.

## CHAPTERS IN BOOKS & ENTRIES IN REFERENCE BOOKS

- “Agape.” In *Dictionary of Feminist Theologies*, ed. Letty M. Russell and J. Shannon Clarkson, 3-4. Louisville: Westminster/John Knox, 1996.
- “Stages on the Wrong Way.” *Stages on Life’s Way: International Kierkegaard Commentary*, Vol. 11, ed. Robert L. Perkins, 9-47. Macon, GA: Mercer University Press, 2000.
- “A Dispatch from Security.” In *Strike Terror No More: Theology, Ethics, and the New War*, ed. Jon L. Berquist, 292-295. St. Louis: Chalice Press, 2002.
- “‘The Law of Love’ – Repentance and the Restoration of Love.” In *The Wesleyan Tradition: A Paradigm for Renewal*, ed. Paul W. Chilcote, 175-188. Nashville: Abingdon Press, 2002.
- “Men at Work: Embodied Discipleship and Post-Industrial Masculinity.” In *The Blackwell Companion to Christian Ethics*, ed. Samuel Wells and Stanley Hauerwas, 82-94. Oxford: Blackwell, 2004.

- “The House of Mirth and a Rebuke of False Wisdom: A Case for Women’s Studies.” In *Conflicting Allegiances*, ed. Michael L. Budde and John Wright, 75-90. Grand Rapids: Brazos Press, 2004.
- “Ethics.” In *The Encyclopedia of Protestantism*, ed. Hans J. Hillerbrand, 687-693. New York: Routledge, 2004.
- “Love: A Kinship of Affliction and Redemption.” In *The Oxford Handbook of Theological Ethics*, ed. Gilbert Meilaender and William Werpehowski, 472-488. New York: Oxford University Press, 2005.
- “Mainline Protestantism and the Popularization of Eugenics.” In *Theology, Disability and the New Genetics: Why Science Needs the Church*, ed. Brian Brock and John Swinton, 75-94. New York: T and T Clark, 2007.
- “You Better Find Somebody to Love: Kierkegaard and Bioethics.” In *Transforming Philosophy and Religion: Love’s Wisdom*, ed. Bruce Benson and Norman Wirzba, 239-255. Bloomington: Indiana University Press, 2008.
- “Charles Kingsley’s Christian Darwinism.” In *Theology After Darwin*, ed. Michael S. Northcott and R. J. Berry, 41-57. Colorado Springs, CO: Paternoster, 2009.
- “Parenthood.” In *The Dictionary of Scripture and Ethics*, ed. Joel B. Green, Jacqueline E. Lapsley, Rebekah Miles, and Allen Verhey, 578-580. Grand Rapids, MI: Baker Academic, 2011.
- “The Trinity and Moral Life: Julian’s Trinitarian Logic of Love and Contagion.” In *The Oxford Handbook of the Trinity*, ed. Gilles Emery and Matthew Levering, 493-504. Oxford/New York: Oxford University Press, 2011.
- with Kara Slade, “What Would You Do If Someone Were Attacking a Loved One?” In *A Faith Not Worth Fighting For: Responses to Common Questions on Christian Nonviolence*, ed. Tripp York and Justin Bronson Barringer, 31-43. Eugene, OR: Cascade Books, 2011.
- “Justice.” *Global Wesleyan Dictionary of Theology*, ed. Al Truesdale, 285-287. Kansas City: Beacon Hill, 2013.
- “A Ravishing and Restful Sight: Seeing with Julian of Norwich.” In *Disability in the Christian Tradition: A Reader*, ed. Brian Brock and John Swinton, 152-183. Grand Rapids, MI: Eerdmans, 2012.
- “Wesleyan Ethics” and “Imitation of Christ.” In *The Westminster Dictionary of Christian Ethics*, ed. J. Childress, C. Mathewes, and Mohrmann. Louisville, KY: Westminster/John Knox Press. Forthcoming.



## **SERVICE (selected)**

- Core Faculty, Institute on Care at the End of Life, Duke Divinity School, 1999-2012
- Faculty Associate, Duke Center for the Study of Medical Ethics and the Humanities, 2000-2011
- Consultant, Caring Communities, Theology and Medicine Program, Duke Divinity School
- Institutional Review Board, Duke University Medical Center, 2000-2001
- Ethics Consultant, Veterans Administration Medical Center, Durham, NC, 2001-2002
- Bioethics Task Force, United Methodist Church, 2001-2003; 2005-2006
- Respondent as Senior Sage to bioethics project of the National Council of Churches, 2005
- Core Faculty, Institute on Genome Sciences and Policy Focus Program, Trinity College, 2006-2009.
- Co-Convener, Biblical and Contextual Ethics Group, AAR, 2008-2011
- Participant and Contributor, The Child in Religion and Ethics Project, 2005-2006
- Faculty-in-Residence, Trinity College, Duke University, 2000-2003
- Pre-Major Advisor, Trinity College, Duke University, 2000-2003
- Lecturer, Duke Youth Academy, 2000-2012
- Admissions Committee for Graduate Program in Religion, Duke University, 2001, 2008
- Executive Committee for Graduate Program in Religion, Duke University, 2002-2004
- Curriculum Review Committee, for full revision of curriculum, Duke Divinity, 2002-2004
- Kenan Ethics Institute Project, Changing Institutional Cultures, Duke University, 2005-2006
- Reconciliation Center Vision Casting Team, Duke University Divinity School, 2005-2006
- Director, Th. D. program, Duke University Divinity School, 2006-2007
- United Methodist Elder, Southwest Texas Conference
- Sunday School Teacher, Trinity United Methodist Church, Durham, 1999-2012
- Visiting Scholar and Lecturer, Christ Church Episcopal, Raleigh, 2000-2005
- Organizing Team, Durham CAN (Industrial Areas Foundation), 2002-2006
- Steering Committee, Center for Class, Labor, and Social Solidarity, 2011-2013
- Advisory Board, Duke Center for Civic Engagement, 2007-2013

# Jennifer S. Hawkins

## CURRICULUM VITAE

Department of Philosophy, Duke University  
Room 201 C, West Duke Building  
Durham, North Carolina 27708  
jen.hawkins@duke.edu

## APPOINTMENTS

Associate Research Professor, Philosophy, Duke University, 2010—  
Trent Scholar in Bioethics, Trent Center for Bioethics, Duke University, 2010—  
Associate Professor of Philosophy, University of Toronto, 2009-2010  
Assistant Professor of Philosophy, University of Toronto, 2002-2009  
Visiting Assistant Professor of Philosophy, Georgetown University, 2001-02  
Assistant Professor of Philosophy, Washington University in St. Louis, 2000-01  
Instructor in Philosophy, Washington University in St. Louis, 1999-2000

## EDUCATION

Ph.D. in philosophy, 2000 Princeton University.  
M.A. in philosophy, 1997 Princeton University.  
B.A. in philosophy, 1994 Reed College, Portland, Oregon.

## POST-GRADUATE FELLOWSHIPS

Faculty Fellowship, Harvard University, Center for Ethics and the Professions, 2004-05  
Postdoctoral Fellowship in Clinical Bioethics, National Institutes of Health, 2000-01

## PAPERS

1. "Well-Being, Time, and Dementia," Forthcoming, *Ethics*.
2. "Well-Being: What Matters Beyond the Mental?" Forthcoming, *Oxford Studies in Normative Ethics*.
3. "The Subjective Intuition," *Philosophical Studies* 148 (2010): 61-68.
4. "Well-Being, Autonomy, and the Horizon Problem," *Utilitas* 20 (2008): 143-168.
5. "Desiring the Bad Under the Guise of the Good," *The Philosophical Quarterly* 58 (2008): 244-264.
6. "Justice and Placebo Controls," *Social Theory and Practice* 32 (2006): 467-96.
7. "Clarifying Confusions About Coercion," *Hastings Center Report* 35 (2005): 16-19. First author with Ezekiel J. Emanuel.
8. "The Ethics of Zelen Consent," *Journal of Thrombosis and Haemostasis* 2 (2004): 882-3.

## BOOK CHAPTERS

9. "Exploitation and Placebo Controls." In Hawkins and Emanuel (eds.) *Exploitation and Developing Countries: The Ethics of Clinical Research* (2008).
10. "Research Ethics, Developing Countries and Exploitation: A Primer." In Hawkins and Emanuel (eds.) *Exploitation and Developing Countries: The Ethics of Clinical Research* (2008).
11. "Why Exploitation?" Introduction to Hawkins and Emanuel (eds.) *Exploitation and Developing Countries: The Ethics of Clinical Research* (2008). First author with Ezekiel J. Emanuel.

## EDITED BOOK

*Exploitation and Developing Countries: The Ethics of Clinical Research* (Princeton University Press, 2008). Co-edited with Ezekiel J. Emanuel.

## CONTRIBUTIONS TO ANTHOLOGIES

12. "Making Autonomous Decisions: Million Dollar Baby." In Colt, Quadrelli, and Friedman (eds.) *The Picture of Health: Medical Ethics at the Movies* (Oxford University Press, 2011), 39-43.

## REVIEWS

1. Review of D. Haybron, The Pursuit of Unhappiness: The Elusive Psychology of Well-Being. Oxford University Press, 2008. *Utilitas* (2011): 237-241.
2. Review of D. DeGrazia, Human Identity and Bioethics. Cambridge University Press, 2005. *Notre Dame Philosophical Reviews* (2006): 2825 words.  
<http://ndpr.nd.edu/review.cfm?id=6983>

## WORK IN PROGRESS

"Well-Being, Ill-Being and Public Policy"  
Under review, *International Journal of Well-Being*

"A New Theory of Well-Being."

"What Role (If Any) Does Suffering Play in a *Good Life*?"  
Invited contribution, special issue *Philosophical Topics*

"Asymmetrical Welfare: Why the Importance of Happiness Varies"

"Subjective and Objective in Theories of Welfare."

"What Aspects of the Philosophical Theories of Well-Being Actually Matter for Welfare-

Based Public Policy?”

Book Manuscript: *Benefiting Persons: A New Theory of Well-Being*

“Post-Trial Access to Care: Limited Duties and the Problem of Harm”

“Quality of Life and the Minimally Conscious Patient.”

## RECENT TALKS

Well-Being, Time, and Dementia

1. New England Consequentialism Workshop, Edmond J. Safra Center for Ethics, Harvard University, April 3, 2013.
2. 1st Annual Rocky Mountain Ethics Conference (RoME), University of Colorado Boulder, August 8, 2008.
3. Northwestern University Society for Ethical Theory and Political Philosophy, 2nd Annual Conference, Northwestern University, May 16, 2008.

A New Theory of Well-Being

1. SMU, Workshop on The Philosophy of Well-Being, March 2, 2013.
2. British Society for Ethical Theory, Nottingham, UK July 2010.

Well-Being: What Matters Beyond the Mental?

1. American Philosophical Association, Central Division, New Orleans, Louisiana, February 20-23, 2013.
2. Fourth Annual Arizona Workshop in Normative Ethics, Tuscon, Arizona, Saturday January 5, 2013.
3. Joint Session of the Aristotelian Society and the Mind Association, Stirling, Scotland, July 7, 2012.
4. 4th Annual Rocky Mountain Ethics Conference (RoME), University of Colorado Boulder, August 8, 2011.

What Aspects of the Philosophical Theories of Well-Being Actually Matter for Welfare-Based Public Policy?

1. Duke Law Journal, 43rd Annual Administrative Law Symposium, “A Happiness Approach to Cost-Benefit Analysis,” Duke Law School, February 15, 2013.

Well-Being, Ill-Being and Public Policy

1. Conference: Measures of Subjective Well-Being for Public Policy: Philosophical Perspectives, University of Leeds, July 15, 2012.

Post-Trial Access to Care: Limited Duties and the Problem of Harm

1. Workshop on Post-Trial Access to Trial Drugs: Legal, Ethical, and Practical Issues, Brocher Foundation, Geneva Switzerland, December 15, 2011.
2. Rethinking the Ethics of Clinical Research, A Workshop on Core Issues of Clinical Research, Duke University, February 24, 2012.

The Subjective Intuition

1. American Philosophical Association, Pacific Division, Vancouver, B.C. April 2009.

# Scott A. Huettel, Ph.D.

Jerry G. and Patricia Crawford Hubbard Professor  
Department of Psychology and Neuroscience  
Duke University  
Box 90999, Durham, NC 27708

email: [scott.huettel@duke.edu](mailto:scott.huettel@duke.edu)  
office telephone: 919-668-5286

## **Professional Experience**

2012-2017	Duke University	<b>Jerry G. and Patricia Crawford Hubbard Professor of Psychology and Neuroscience</b>
2012-present	Duke University	Professor, Psychology and Neuroscience
2008-2011	Duke University	Associate Professor, Psychology and Neuroscience, Neurobiology (secondary), Psychiatry (tertiary)
2006-2008	Duke University	Associate Professor, Dept. of Psychiatry
2002-2006	Duke University	Assistant Professor, Dept. of Psychiatry, Neurobiology (secondary), Psychology (tertiary)
2000-2002	Duke University	Research Associate (NIH NRSA), Psychology
1999-2000	Duke University	Research Associate (NIH Training Grant), Neurobiology
1996-2001	Duke University	Instructor, Dept. of Psychological & Brain Sciences
1994-1999	Duke University	Graduate Student, Dept. of Psychological & Brain Sciences

## **Academic Leadership**

2010-present	Duke University	<b>Director, Center for Interdisciplinary Decision Sciences</b>
2011	Duke University	Interim Co-Director, Duke Institute for Brain Sciences
2009-2010	Duke University	Director, Center for Neuroeconomic Studies
2005-2009	Duke University	Co-Director, Center for Neuroeconomic Studies
2010-present	Duke University	Senior Advisor to the Director, Brain Imaging and Analysis Center
2006-2010	Duke University	Associate Director, Brain Imaging and Analysis Center

## **Education**

Ph.D., Duke University, May, 1999  
Department of Psychology: Experimental  
Advisor: Dr. Gregory Lockhead

B.A., University of Texas at Austin, June, 1994  
Plan II (Liberal Arts Honors Program; Humanities/Classics) with Special Honors  
Psychology with Honors

Scott A. Huettel, Ph.D.

## **Research Funding**

[\*approximate total costs, †approximate direct costs]

### **Extramural Funding**

*Sleep-Deprivation Modulation of the Neural Responses to Reward and Risk*

(Duke-NUS GMS Collaborative Fund: Singapore, 1/10-12/11; †\$150,000). Principal Investigator.

*Neural Mechanisms of Social Reward Valuation and Decision Making*

(NIMH R01-86712; 8/09-8/14; \*\$3,000,000). Co-Investigator, with PI Michael Platt.

*Patterns of Information Processing in Risky Decision Making*

(Institute for Research on Gambling Disorders; 10/10-9/11; \*\$35,000). Principal Investigator.

*Neurobiological Underpinnings of Decision Making*

(NIMH NRSA; 7/09-3/12; †\$82,000). Supports predoctoral work of David Smith.

*From Phenotype to Mechanism: Mapping the Pathways underlying Risky Choice*

(NIMH RC1-88680; 9/09-9/11; \*\$1,000,000). Principal Investigator, with Co-PI Elizabeth Brannon.

*Human Functional Brain Anatomy; Proj. #3, Decision Making and Affective Processing.*

(NINDS P01-41328; 9/06-9/11; \*\$900,000). Principal Investigator

*Neuroeconomics of Drug Addiction*

(NIDA P30-28803; 9/09-9/11; \*\$1,500,000). Co-Investigator, with PI David Fitzpatrick.

*Center for the Neuroscience of Depression; Proj. #3, Cognitive Abnormalities & Emotional Dysregulation*

(NIMH Conte P50-60451; 7/06-6/11; \*\$1,100,000). Principal Investigator

*Using Neuroscience to Inform Phenotype Assessment: From Impulsivity to Identity*

(NIDA P30-23026 subproject: Duke University; 8/10-5/11; †\$56,000).

*Neural mechanisms for the construction of subjective value and preferences*

(NIMH NRSA; 5/09-12/11; †\$80,000). Supported pre-doctoral work of John Clithero

*From Brain to Behavior: Using Neuroscience to inform Phenotype Assessment*

(NIDA P30-23026 subproject: Duke University; 5/09-5/10; †\$50,000). Principal Investigator.

*Neural Compensation and Economic Decision Making in Aging*

(NIA R21-30771; 8/07-8/10; \*\$550,000). Principal Investigator.

*Neuroimaging of Executive Processing*

(NIMH R01-070685; 1/05-12/08; \*\$1,100,000). Principal Investigator.

*A Teaching Laboratory for Functional Brain Imaging*

(Hewlett Packard Philanthropy; 4/04; †\$184,000). Co-PI, with PI Gregory McCarthy.

*Functional Neuroimaging of Executive Processing*

(NIDA I/START R03; DA-16214; 9/02-9/03; \*\$150,000). Principal Investigator.

*Functional Neuroimaging Studies of Object Perception*

(National Research Service Award, NIMH F32-12541; 6/00-2/02; †\$70,000). Principal Investigator.

Investigator on additional NIH grants (selected)

2006-2008: *Functional Neuroimaging of Strategic Retrieval* (NIMH R01-73982; PI Dobbins)

2004-2009: *High-Fidelity fMRI* (NINDS R01-50329; PI: Song)

2005-2009: *Frontal function in Adolescent Cannabis Use Disorders* (NIDA R01-020989; 6/05-5/09; PI DeBellis, Co-PI Huettel)

### **Intramural Funding (Competitive)**

*Decisions under risk: From mechanism to phenotype*

(Incubator Award, Duke Institute for Brain Sciences, 7/07-6/10; †\$350,000). Co-Principal Investigator, with Co-PI Michael Platt

*Neuroeconomics of Decision Making*

(Provost's Common Fund, Duke University, 6/04-6/05; †\$43,000). Co-Principal Investigator, with Co-PIs Michael Platt and Christina Stowe

*A Virtual Environment for Teaching Neuroanatomy*

(Ctr. for Instruct. Tech., Duke, 6/06-5/07; †\$5,000). Principal Investigator, with Co-PI Michael Platt

## **Awards**

Fellow, Bass Society for Excellence in Research and Teaching (2012-present), Duke University  
Dean's Award for Excellence in Mentoring, 2010, Duke University Graduate School  
Top 5% of all undergraduate instructors in Arts & Sciences (course evaluations), 2010, Duke University  
NIH Postdoctoral Fellowship in Neurobiology, 1999-2000, Duke University  
Fellow, McDonnell Foundation Summer Institute in Cognitive Neuroscience, 1999  
Gregory Kimble Instructorship Dissertation Fellowship, 1998-1999, Duke University  
National Science Foundation Graduate Fellowship, 1995-1998, Duke University  
James B. Duke Fellowship, 1994-1998, Duke University  
National Merit Scholar, 1990-1994, University of Texas  
Texas Excellence Scholar, 1990-1994, University of Texas

## **Service: Disciplinary**

Past-President, Society for Neuroeconomics, 2011-2012  
President (Elected), Society for Neuroeconomics, 2010-2011  
Executive Board (Elected), Society for Neuroeconomics, 2008-2012  
Slide Session Review Committee, Cognitive Neuroscience Society, 2011-2013  
Technical Review Committee, National Longitudinal Surveys (Bureau of Labor Statistics), 2010-2012  
Co-Organizer, *Neuroscience, Free Will, and Responsibility* conference, 2011  
Journal Editor Search Committee, American Psychological Association, 2010  
Program Committee, Society for Neuroeconomics annual meeting, 2009, 2010  
Co-Organizer, 2009 *Decision Neuroscience* short course for the Master Mediation Institute  
Social Neuroscience and Neuroeconomics of Aging Subcommittee, National Institute of Aging, 2008

### Society Membership:

- Association for Psychological Science
- Cognitive Neuroscience Society
- Organization for Human Brain Mapping
- Society for Neuroscience
- Society for Neuroeconomics

## **Service: Institutional**

### Leadership Committees and Boards

- Chair, Academic Programs Committee (University-wide), Duke University, 2012-2013
- Steering Committee (Elected), Social Science Research Institute, 2010-11, 2012-2013
- Duke IDEAS faculty council, Duke University, 2012-2013
- Co-Leader of *Brain and Society* theme within Duke IDEAS, 2012-present
- Academic Programs Committee (University-wide), Duke University, 2009-2013
- University Priorities Committee (University-wide), Duke University, 2012-2013
- Academic Affairs Committee, Board of Trustees of Duke University, 2012-2013
- Departmental Advisory Committee (Elected), Psychology and Neuroscience, 2009-2011
- Faculty Council, Kenan Institute for Ethics, 2010-present
- Executive Board Member, Duke Institute for Brain Sciences, 2008-present
- Advisory Board, Social Science Research Institute, 2010-present

### Other Committee Membership

- Academic Committee on Online Education (University-wide), 2012-present
- Reappointment Review Committee, Department of Biomedical Engineering, 2012
- SSRI strategic planning group (University-wide), 2012
- Interdisciplinary Teaching strategic planning committee (University-wide), 2011-2012
- Tenure Review Committee (chair), Department of Psychology & Neuroscience, 2011
- Steering Committee, Postdoctoral Training Program in Neurobiology, 2010-present
- Steering Committee, Cognitive Neuroscience admitting program, 2005-2011
- Grant Reviewer, DIBS Incubator Award Program, 2010



Scott A. Huettel, Ph.D.

Interdisciplinary Studies Strategic Planning Committee (University-wide), 2009  
Space Committee, Center for Cognitive Neuroscience, 2009-present  
Curriculum Committee, Arts & Sciences, 2008-2010  
Committee for Academic Visualization, 2008-2009  
Reappointment Review Committee, Department of Psychology & Neuroscience, 2008  
Committee for Social Psychology Laboratory, 2008  
BIAC Scientific Review Committee, 2002-2008

#### Faculty Searches

*Director, Duke Institute for Brain Sciences* Search Committee (Duke University), 2011  
*Dean of Arts and Sciences* Search Committee (Duke University), 2010-11  
Faculty Search Committee (co-chair), *Neuroeconomics* (Fuqua/DIBS), 2009-2010  
Faculty Search Committee, *Cognitive Neuroscience* (Psychology & Neuroscience), 2008-2009  
Faculty Search Committee, *Social Neuroscience* (Psychology & Neuroscience), 2006-2007  
Faculty Search Committee, *MRI Physics* (Brain Imaging & Analysis Center), 2006-2007

#### Miscellaneous Service

Keynote Speaker, Responsible Conduct of Research Symposium for incoming graduate students, 2012, 2011  
Conference Organizer, Decision Making across Disciplines, Duke University, 2012  
Discussion Leader, Responsible Conduct of Research Symposium for graduate students, 2011  
Co-Convener, SSRI Faculty Fellows program, 2008-2010,  
“Decision-Making: From Behavior to the Brain (and back again)”  
Theme Leader for *Brain to Society*, Duke Institute for Brain Sciences, 2008-present  
Teaching and Learning Center Fellow, Center for Instructional Technology, 2008  
Fellow, *Almost Honest* Symposium Series, 2008-2009  
Conference Organizer, *Transcending the Boundaries*, Duke Inst. for Brain Sciences, 2008  
Senior Fellow, Center for the Study of Aging and Human Development, 2004-present  
Organizer, Topics in Cognitive Neuroscience Series, 2004  
Co-Organizer, Cortex Club, 2003-2004  
Local Organizing Committee, meeting of the Assoc. for Scientific Study of Consciousness, 2001  
Organizer, Invited Workshop on Change Blindness, 2001

### **Journal, Grant, and Book Reviewing**

Co-Editor in Chief, *Frontiers in Decision Neuroscience* (2011-present)  
Associate Editor, *Frontiers in Decision Neuroscience* (2010-2011)  
Editorial Board, *Journal of Neuroscience, Psychology, & Economics* (2008-2011)  
Peer Reviewer, *American J. of Roentgenology, Biological Psychiatry, Brain, Brain Research, Cerebral Cortex, Cognition, Cognitive Brain Research, Consciousness & Cognition, Developmental Psychobiology, Developmental Science, Emotion, Experimental Brain Research, Frontiers in Behavioral Neuroscience, Frontiers in Human Neuroscience (Review Editor), Human Brain Mapping, International J. of Advertising, J. of Cognition and Development, J. of Cognitive Neuroscience, J. of Finance, J. of Marketing Research, J. of Neuroscience, J. of Neurophysiology, J. of Neuroscience Methods, J. of Neuroscience Psychology & Economics, Microscopy Research and Technique, Nature, Nature Neuroscience, Neurobiology of Aging, NeuroImage, Neuron, Neuropsychologia, Neuropsychopharmacology, Neuroscience Letters, Philosophical Transactions of the Royal Society, Proceedings of the National Academy of Sciences, Psychiatry Research: Neuroimaging, Psychological Medicine, Psychological Science, Science, Social Cognitive and Affective Neuroscience, Trends in Cognitive Sciences, Trends in Neurosciences*  
Grant Reviewer (NIH), *NIH CSR: Community Influences on Health Behavior* (2012), *NIH CSR: CP Special Emphasis Panel* (2010), *NIH Conte Awards: Special Emphasis Panel* (2010), *NIH CSR: Grand Challenges Special Emphasis Panel* (2009), *NIH CSR: NIMH Special Emphasis Panel* (2007, Chair), *NIH CSR: NIA Special Emphasis Panel* (2007), *NIH CSR: COG Special Emphasis Panel* (2007), *NIH CSR: Learning and Memory Special Emphasis Panel* (2006), *NIH CSR: Minority Institution Drug Abuse Research Projects* (2006), *NIH CSR: Neurobiology of Behavioral Treatment Review Panel* (2005), *NIH CSR: Cognitive Neuroscience* (2005), *NIH*

CSR: NIDA I/START Program (2005), NIH CSR: Central Visual Processing Study Section (2005), NIH CSR: Research Training Special Emphasis Study Section (2004), NIH CSR: Cognition and Perception Study Section (2004)

Grant and Protocol Reviewer (other): *Institute for Research on Gambling Disorders* (USA, 2012, 2012, 2011, 2010), *AXA Research Fund* (France, 2011), *National University of Singapore* (2011), *Social Sciences and Humanities Research Council* (Canada, 2010), *Wellcome Trust* (Britain; 2009, 2003), *Grants Research Council* (Hong Kong, 2009), *National Institutes of Health Institutional Review Board* external reviewer (2009, 2008), *National Research Council* (Switzerland, 2008), *Canada Foundation for Innovation* (2006, 2005), *NOW VIDI Program* (Netherlands, 2006), *National Science Foundation* (ad hoc, 2005, 2004, 2003), *South Carolina EPSCoR* (2005), *NWO Research Programme in Cognitive Sciences* (Netherlands; 2004)

Book Reviewer: 2004-2010, *Choice* (American Library Association): Reviewer for books in neuroscience, neuroimaging, neuroethics, and consciousness (15+ published reviews); 2009, Dana Foundation (1 published review)

## **Books Published**

4. Purves, D., Cabeza, R., **Huettel, S.**, LaBar, K., Platt, M., Woldorff, M. (2012). *Principles of Cognitive Neuroscience* (2<sup>nd</sup> Edition). Sunderland, MA: Sinauer Associates. [Undergraduate/Graduate Textbook]
3. **Huettel, S.A.**, Song, A.W., & McCarthy, G. (2009). *Functional Magnetic Resonance Imaging* (2<sup>nd</sup> Edition). Sunderland, MA: Sinauer Associates. [Undergraduate/Graduate Textbook]
2. Purves, D., Brannon, E., Cabeza, R., **Huettel, S.**, LaBar, K., Platt, M., Woldorff, M. (2007). *Principles of Cognitive Neuroscience*. Sunderland, MA: Sinauer Associates. [Undergraduate/Graduate Textbook]
1. **Huettel, S.A.**, Song, A.W., & McCarthy, G. (2004). *Functional Magnetic Resonance Imaging*. Sunderland, MA: Sinauer Associates. [Undergraduate/Graduate Textbook]

## **Manuscripts/Chapters Published or in Press**

[h-index: 32 (Google Scholar), 27 (Web of Science)]

95. Libedinsky, C., Massar, S.A.A., Ling, A., Chee, W., **Huettel, S.A.**, Chee, M.W.L. (in press). Sleep Deprivation Alters Effort Discounting but not Delay Discounting of Monetary Rewards. *Sleep*.
94. Coutlee, C.G., & **Huettel, S.A.** (in press). Rules, Rewards, and Responsibility: A Reinforcement Learning Approach to Action Control. In *Moral Psychology, Volume 4: Free Will and Moral Responsibility* (Sinnott-Armstrong, W., ed).
93. Kragel, P.A., Carter, R.M., & **Huettel, S.A.** (2012). What makes a pattern? Matching decoding methods to data in multivariate pattern analysis. *Frontiers in Brain Imaging Methods*. doi: 10.3389/fnins.2012.00162.
92. Levallois, C., Clithero, J.A., Wouters, P., Smidts, A., & **Huettel, S.A.** (2012). Translating upwards: linking the neural and social sciences via neuroeconomics. *Nature Reviews Neuroscience*, 13, 789-797.
91. Paulsen, D.J., Platt, M., **Huettel, S.A.**, & Brannon, E.M. (2012). From Risk-seeking to Risk-averse: The Development of Economic Risk Preference from Childhood to Adulthood. *Frontiers in Psychology*, 3:313. doi: 10.3389/fpsyg.2012.00313.
90. Carter, R.M., Bowling, D.L., Reeck, C.C., & **Huettel, S.A.** (2012). A distinct role of the temporal-parietal junction in predicting socially guided decisions. *Science*, 337, 109-111.
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8. McCarthy, G., & **Huettel, S.** (2001). A functional brain system for face processing revealed by event-related potentials and functional MRI. In Shibasaki, H., et al., (eds), *Inter-areal Coupling of Human Brain Function*. Elsevier Science, p. 5-16.
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6. **Huettel, S.A.**, & Needham, A. (2000). Effects of balance relations between objects on infants' object segregation. *Developmental Science*, 3 (4), 415-427.
5. **Huettel, S.A.**, & McCarthy, G. (2000). Evidence for a refractory period in the hemodynamic response to visual stimuli as measured by MRI. *NeuroImage*, 11 (5), 547-553.
4. Lockhead, G.R. & **Huettel, S.A.** (1999). Isomorphism and subjective colors. *Behavioral and Brain Sciences*, 22, 959-960.
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2. **Huettel, S.A.**, & Lockhead, G.R. (1998). A framework for feature creation. *Behavioral and Brain Sciences*, 21, 29-30.
1. Sandstrom, N.J., Kaufman, J., & **Huettel, S.A.** (1998). Males and females use different distal cues in a spatial navigation task. *Cognitive Brain Research*, 6 (4), 351-360.

## **Invited Presentations (External)**

### **2013**

Neuroeconomics: Why does the brain matter for investing? Keynote address, CFA Institute Asset & Risk Allocation conference (April).

Scott A. Huettel, Ph.D.

## **2012**

Neuroeconomics. Society for Neuroscience (October).  
Promotion, Tenure, and Beyond (Invited Panelist). Conference on Advancing STEM through the  
Participation of Women Faculty of Color, Texas A&M University (October).  
Experience, Price, and the Brain. BLUEMiND, Outer Banks, NC (June).

## **2011**

Embedding Decision Making in a Lifespan Context. Bronfenbrenner Conference on Risky Decision  
Making, Cornell University (September).  
Why bother with the brain? Guidelines for using neuroscience data to understand (consumer) behavior.  
Symposium on Decision Neuroscience, Temple University (September).  
From choices to strategies: Linking Neuroeconomics to Cognitive Neuroscience. Colloquium, University  
of British Columbia (June).  
New directions for research and interventions in the science of aging (Invited Discussant). Workshop,  
Washington, DC. (sponsored by the National Institute for Aging; May).  
From choices to strategies: Linking Neuroeconomics to Cognitive Neuroscience. Colloquium, Princeton  
University (February).

## **2010**

The Neural Mechanisms of Strategic Decision Making. Neuroeconomics symposium, New York  
University (November).  
Foundations of Neuroeconomics: Moving Beyond Models. Invited Workshop talk on “Debates in  
Neuroeconomics”, CSCA Summer School. Amsterdam, Netherlands (June).  
The Neural Mechanisms of Strategic Decision Making. Invited Symposium talk. Amsterdam,  
Netherlands (June).  
Neuroeconomics: Our brains, our decisions. Keynote address: Mercer University Undergraduate  
Research Symposium (April)  
Decision Making and the Brain. Neuroscience program, Elon College (April)

## **2009**

Neuroeconomics: How our brains shape our decisions. Keynote address: Conference on Gambling and  
Addiction, Las Vegas. (November)  
Neural Compensation and Economic Decision Making in Aging. Conference on Neuroeconomics of  
Aging, Chicago. (September)  
Understanding decision making under risk: What is the role for neuroscience? Killam Lecture Series,  
Montreal Neurological Institute, Canada. (September)  
How can decision scientists use neuroscience? Workshop on Decision Neuroscience, Ann Arbor,  
Michigan. (August)  
Risk and Uncertainty in Decision Making. Workshop on Decision Neuroscience, Ann Arbor, Michigan.  
(August)  
Decision making and aging: Why (bother with) neuroeconomics? Invited Symposium talk, International  
Society for Behavioral Neuroscience. (May)  
Neuroeconomics of Individual Choice. Symposium on Decisions and Emotions. Nijmegen, Netherlands.  
(sponsored by the Helmholtz Institute; April).

## **2008**

A Neuroscience of Individual Choice. Conference on the Neurobiology of Political Conflict, Washington  
D.C. (sponsored by Emory Center for Neuropolicy; December).  
Neuroeconomics of Risky Choice. Brain, Mind, and Society lecture series, California Institute of  
Technology (October).  
Neuroeconomics: Decision Making and the Brain. Invited lecture to Park Scholars program, North  
Carolina State University (August).  
Neuroscience of Strategic Decision Making. Invited lecture to A-STAR scholars program, National  
University of Singapore (August).  
The Next Frontiers of Decision Making: the Future of Neuroeconomics. International Symposium on  
Attention and Performance XXII (July).

Scott A. Huettel, Ph.D.

Risky choice reconsidered: Decisions, traits, and their interaction. Invited Symposium on Psychology and Economics, Association for Psychological Science (May).  
Neuroimaging the Aging Brain. Invited Symposium, Association for Psychological Science (May).  
Psychology, Neuroscience and Economics: An Interdisciplinary Collaboration Toward Understanding Decision Making and Economic Behavior Over the Lifespan. Panel Discussion, Association for Psychological Science (May).  
Decision Neuroscience. Neuroeconomics and Decision Making Workshop, National University of Singapore (by videoconference; April).  
Neuroeconomics & Financial Decision Making. Marketing/Public Affairs executives, TIAA-CREF (April).  
Risky choice reconsidered: Decisions, traits, and their interaction. Asia meeting of the Economic Science Association, Singapore (February).  
Neuroeconomics of Risky Choice. Neuroeconomics Seminar, New York University (January).

## **2007**

Neuroeconomics of Risky Choice. Neuroscience Program, Emory University (October).  
Neural substrates for decision making under risk. Symposium on Neurofinance, University of Zurich (July).  
Resolving Uncertainty: the Neural Correlates of Economic Decision Making. Invitational Choice Symposium, Wharton School of Business, University of Pennsylvania (June).  
Resolving Uncertainty: the Neural Correlates of Economic Decision Making. Yale University, Magnetic Resonance Research Center (April).  
Altruism and Agency. Yale University, Department of Psychology (April).  
Using Neuroimaging to Understand Decision Making. Workshop on Neuroimaging and Behavior, MITRE corporation (April).

## **2006**

Resolving Uncertainty: the Neural Correlates of Economic Decision Making. The MIND Institute, University of New Mexico (October).  
Principles of Brain Imaging. Workshop on Decision Neuroscience, Association for Consumer Research (September).  
Principles of Brain Imaging. Society for Prevention Research (May).  
Prefrontal Contributions to Economic Decision Making. University of British Columbia (April).  
Neuroimaging the Aging Brain: Methodological Insights from Cognitive Neuroscience. NIA Neuroeconomics and Aging meeting (March).  
Resolving Uncertainty: the Neural Correlates of Economic Decision Making. Stanford University (February).  
Resolving Uncertainty: the Neural Correlates of Economic Decision Making. University of South Carolina (January).

## **2005-earlier**

FMRI Experimental Design and Data Analysis. Society for Neuroeconomics (September, 2005).  
Non-linearities in the blood-oxygenation-level dependent (BOLD) response measured by functional magnetic resonance imaging (fMRI). IEEE Engineering in Medicine and Biology Society (September, 2004).  
Prediction and the brain: Dynamic lateral prefrontal cortex. University of North Carolina, Chapel Hill (April, 2002).  
Local context writ large: Dynamic processing of event structure in prefrontal cortex. University of Illinois (October, 2001).  
Local context writ large: Understanding information processing in prefrontal cortex using functional MRI. University of California: San Diego (June 2001).  
Functional neuroimaging of change blindness. Assoc. for Scientific Study of Consciousness (May 2001).

## **Conference Presentations (partial list)**



- Clithero, J.A., Carter, R.M., Venkatraman, V., Smith, D.V., Harsch, A.E.W., Huettel, S.A. (2011, October). Large-Sample Identification of Multiple Risk and Motivational Measures in the Human Brain. Poster (by J.A. Clithero), Society for Neuroeconomics.
- Meade, C.S., Bevilacqua, L.A., **Huettel, S.A.**, & Robertson, K.R. (2011, July). Effects of HIV infection and cocaine dependence on cognitive processes related to impulsivity and risk taking. Poster (by C. Meade), HIV Infection and the Central Nervous System.
- Winecoff, A., Clithero, J., Bergman, S., He, Y., Carter, M., Wang, L., **Huettel, S.** (2011, April). Contributions of the ventromedial prefrontal cortex to emotion regulation. Poster (by A. Winecoff), Cognitive Neuroscience Society.
- Smith, D.V., Clithero, J.A., Boltuck, S.E., & **Huettel, S.A.** (2010, November). Ventromedial prefrontal cortex interacts with posterior superior temporal cortex during valuation of social rewards. Poster (by D. Smith), Society for Neuroscience.
- Smith, D.V., Clithero, J.A., Boltuck, S.E., & **Huettel, S.A.** (2010, October). Ventromedial prefrontal cortex interacts with posterior superior temporal cortex during valuation of social rewards. Poster (by D. Smith), Society for Neuroeconomics.
- Carter, R.M., Bowling, D.L., **Huettel, S.A.** (2010, October). Social Components of Motivated Deception. Poster (by R.M. Carter), Society for Neuroeconomics.
- Clithero, J.A., Carter, R.M., Venkatraman, V., Smith, D.V., & **Huettel, S.A.** (2010, October). Motivational and Neural Differences in Reward and Risk Anticipation. Poster (by J.A. Clithero), Society for Neuroeconomics.
- Paulsen, D.P., Carter, R.M., **Huettel, S.A.**, Platt, M.L., Brannon, E.M. (2010, October). Risky decision making and development: neural recruitment from childhood to adulthood. Poster (by D. Paulsen), Society for Neuroeconomics.
- Smith, D.V., Venkatraman, V., Carter, R.M., Clithero, J.A., Meyer, J.R., Skene, J.H.P., Platt, M.L., & **Huettel, S.A.** (2010, June). Neural Predictors of Self and Charity Framing Effects. Poster (by D.V. Smith), Organization for Human Brain Mapping.
- Wang, L., Newell, B., Mullette-Gillman, O., Gadde, K.M., Kuhn, C.M., McCarthy, G., & **Huettel, S.A.** (2010, May). Modulation Effect of Rumination Trait and Low Tryptophan on Default-Mode Network Connectivity. Poster (by L. Wang), Society of Biological Psychiatry.
- Clithero, J.A., Reeck, C.C., Carter, R.M., Smith, D.V., Venkatraman, V., Meyer, J.R., Skene, J.H.P., Platt, M.L., **Huettel, S.A.** (2010, April). Individual Differences in Anticipation of and Preferences for Distinct Reward Categories. Poster (by J. Clithero), Cognitive Neuroscience Society.
- Venkatraman, V., Payne, J.W., Chee, M.W.L., & **Huettel, S.A.** (2010, April). Mechanisms Underlying Strategic Variability in Economic Decision Making. Talk (by V. Venkatraman), Cognitive Neuroscience Society.
- Smith D.V., Venkatraman V., Carter R.M., Clithero J.A., Meyer J.R., Skene J.H.P., Platt M.L., **Huettel S.A.** (2010, April). Individual Differences in Relative Susceptibility to Self and Charity Framing Effects. Poster (by D.V. Smith), Cognitive Neuroscience Society.
- Venkatraman, V., Payne, J.W., & **Huettel, S.A.** (2009, November). Individual Differences in Strategic Variability during Risky Choice. Talk (by V. Venkatraman), Society for Judgment and Decision Making.
- Nanton, A., Carter, R.M., Bowling, D., & **Huettel S.A.** (2009, October). fMRI of Deception in a Poker Paradigm vs. Human and Computer. Poster (by A. Nanton), American Academy of Psychiatry and the Law.
- Winecoff, A., LaBar, K., Madden, D., Cabeza, R., **Huettel, S.** (2009, November). Contributors to emotion regulation in aging. Poster (by A. Winecoff), Society for Neuroscience.
- Newell, B., Wang, L., Mullette-Gillman, O. A., McCarthy, G., & **Huettel, S. A.** (2009, October). Neural Substrates of Emotional Distraction and Inhibition Under Acute Tryptophan Depletion. Poster (by B. Newell), Society for Neuroscience.
- Carter, R.M., Cirulli, E.T., Clithero, J.A., Meyer, J.R., Mullette-Gillman, O.A., Smith, D.V., Taren, A., Venkatraman, V., Goldstein, D.B., Platt, M.L., Skene, J.H.P., & **Huettel, S.A.** (2009, September). Individual Differences in Risk and Reward Sensitivity for Self and Others. Poster (by R.M. Carter), Society for Neuroeconomics.
- Mullette-Gillman, O.A., Schiabor, K.M., Cirulli, E.T., Goldstein, D.B., Platt, M.L., Skene, J.H.P., & **Huettel S.A.** (Sept, 2009). Individual and Genetic Differences in Risk Preference and Loss Aversion. Poster (by O.A. Mullette-Gillman), Society for Neuroeconomics.

- Clithero, J.A., Reeck, C.C., Carter, R.M. Smith, D.V., Venkatraman, V., Meyer, J.R., Platt, M.L., and **Huettel, S.A.** (2009, September). Individual Differences in Reward Anticipation. Poster (by J.A. Clithero), Society for Neuroeconomics.
- Smith, D.V., Venkatraman, V., Carter, R.M., Meyer, J.R., Clithero, J.A., Skene, J.H.P., Platt, M.L., **Huettel, S.A.** (2009, September). Mechanisms of Social and Non-social Framing Effects. Poster (by D.V. Smith), Society for Neuroeconomics.
- Paulsen, D.J., Carter, R.M., **Huettel, S.A.**, Platt, M.L., Brannon, E.M. (2009, September). Neurometrics of Risky Decision-Making in 6- to 7-year-old Children. Poster (by D.J. Paulsen), Society for Neuroeconomics.
- Smith, D.V., Brav, A., **Huettel, S.A.** (2009, June). Global and local factor structure in neuroimaging data. Poster (by D.V. Smith), Organization for Human Brain Mapping.
- Clithero, J.A., Smith, D.V., Carter, R.M., Platt, M.L., **Huettel, S.A.** (2009, June). Local Neural Signal Decodes Reward Properties and Preferences. Poster (by J.A. Clithero), Organization for Human Brain Mapping.
- Paulsen, D., **Huettel, S.**, Platt, M., Brannon, E. (2009, April). Heterogeneity in risky decision making in 6- to -7-year-old children. Poster (by D. Paulsen), Society for Research in Child Development.
- Henninger, D.E., Madden, D., **Huettel, S.A.** (2008, November). Age-Related Cognitive Decline Predicts Changes in Risk Preference. Poster (by D.E. Henninger), Gerontological Society of America.
- Han, S., **Huettel, S.A.**, Raposo, A., Adcock, R.A., & Dobbins, I.G. (2008, November). Memory as reward: Goal-directed reward processes during episodic recognition. Poster (by S. Han), Society for Neuroscience.
- Carter, R.M., Bowling, D.L., & **Huettel, S.A.** (2008, November). Bluffing and folding in a simplified poker task against human and computer opponents. Poster (by R.M. Carter), Society for Neuroscience.
- Venkatraman, V., Chuah, L.Y.M., Payne, J.W., **Huettel, S.A.**, & Chee, M.W.L. (2008, November). Sleep deprivation modulates risky decision -making strategies. Talk (by V. Venkatraman), Society for Neuroscience. [selected for SFN press book and press conference].
- Clithero, J.A., Smith, D.V., Carter, R.M., Platt, M.L., **Huettel, S.A.** (2008, September). Local Differences in the Neural Encoding of Facial and Monetary Rewards. Poster (by J.A. Clithero), Society for Neuroeconomics.
- Mullette-Gillman, O.A., **Huettel, S.A.** (2008, September). Neurally Dissociating Valuative and Non-Valuative Contingency Learning. Poster (by O.A. Mullette-Gillman), Society for Neuroeconomics.
- Venkatraman, V., Chuah, Y.M., Payne, J.W., **Huettel, S.A.**, Chee, M.W.L. (2008, September). Sleep Deprivation Modulates Risky Decision-making Strategies. Poster (by V. Venkatraman), Society for Neuroeconomics.
- Paulsen, D., **Huettel, S.**, Platt, M., Brannon, E. (2008, September). Heterogeneity in risky decision making in 6- to -7-year-old children. Poster (by D. Paulsen), Society for Neuroeconomics.
- Bechara, A., Ansari, A., Bockenholt, U., Dube, L., Fisher, R., & **Huettel, S.** (2008, June). Towards biologically plausible models of motivated behaviour: Sequential sampling process models. Talk (by A. Bechara), Marketing Science.
- Yaxley, R.H., Van Voorhees, E.E., **Huettel, S.A.**, & De Bellis, M.D. (2008, May). Brain Activation During Decisions Involving Behavioral Risk: Adolescents v. Adults. Poster (by R. Yaxley), Society for Biological Psychiatry.
- Tankersley, D., Ooi, C., & **Huettel, S.A.** (2008, April). Altruism and Functional Specificity of the Superior Temporal Cortex. Poster (by D. Tankersley), Cognitive Neuroscience Society.
- Mullette-Gillman, O.A., **Huettel, S.A.** (2008, April). Neurally Dissociating Outcomes into Effect and Value Components. Poster (by O.A. Mullette-Gillman), Cognitive Neuroscience Society.
- Wang L, Mullette-Gillman, O.A., Gadde, K., Kuhn, C., McCarthy, G., and **Huettel, S.A.** (2008, April). Acute Tryptophan Depletion Alters Neural encoding of Emotional Distractors. Poster (by L. Wang), Cognitive Neuroscience Society.
- Clithero, J.A., Carter, R.M., & **Huettel S.A.** (2008, April). Pattern Classification of fMRI Data to Predict Valuation for Probabilistic and Intertemporal Outcomes. Poster (by J.A. Clithero), Cognitive Neuroscience Society.
- Smith, D.V., Hayden, B.Y., Chen, J.A., Meyer, J., Truong, T-K, Song, A.W., Platt, M.L., & **Huettel, S.A.** (2008, April). Neural mechanisms of social and non-social reward processing. Poster (by D.V. Smith), Cognitive Neuroscience Society.

- Venkatraman, V., Merison, K., Payne, J.W., Bettman, J.R., Luce, M.F., & **Huettel, S.A.** (2008, April). To Maximize or Satisfice: Neural predictors of heuristic use in risky decision making. Poster (by V. Venkatraman), Cognitive Neuroscience Society.
- Weber, B., & **Huettel, S.A.** (2007, November). Neuroimaging of multiple forms of risk. Poster (by B. Weber), Society for Judgment and Decision Making.
- Tankersley, D., Englander, Z., **Huettel, S.A.** (2007, November). Superior temporal cortex activation predicts both altruistic tendencies and perceptual abilities. Poster (by D. Tankersley), Society for Neuroscience.
- Smith, D.V., Hayden, B. Y., Chen, J., Truong, T., Song, A.W., Platt, M.L., **Huettel, S.A.** (2007, November). Unattractive faces and financial losses activate the same brain regions. Poster (by D. Smith), Society for Neuroscience. [selected for SFN press book]
- Goyer, J.P., Woldorff, M.G., **Huettel, S.A.** Rapid electrophysiological brain responses are influenced by both valence and magnitude of monetary rewards. Poster (by J. Goyer), Society for Neuroscience. [selected for SFN press book]
- Vicens, L., Dobbins, I.G., **Huettel, S.A.** (2007, November). Contributions of frontopolar cortex to judgments about self, others, and relations. Poster (by L. Vicens), Society for Neuroscience.
- Huettel, S.A.** (2007, October). Motivational and affective processes in decision making. Discussant, Association for Consumer Research.
- Huettel, S.A.** (2007, September). To satisfice or maximize: Neural predictors of decision strategy. Talk, Society for Neuroeconomics.
- Madden, D.J., Costello, M.C., White, L.E., Provenza, J.M., Cabeza, R., & **Huettel, S.A.** (2007, August). Cerebral white matter fiber tracking: Adult age and attention. Poster (by D. Madden), American Psychological Association.
- Tankersley, D., Stowe, C.J., & **Huettel, S.A.** (2007, May). Neural systems underlying agency perception predict the propensity toward altruism. Poster (by D. Tankersley), Neural Systems for Social Behavior.
- Hayes, S.M., Dennis, N.A., Prince, S.E., **Huettel, S.A.**, Madden, D., Cabeza, R. Effects of aging on neural correlates of item and relational memory. Poster (by S. Hayes), Cognitive Neuroscience Society.
- Costello, M.C., Madden, D.J., Dawes, L.C., White, L.E., Cabeza, R., Provenza, J.M., **Huettel, S.A.** (2007, May). Age-Related Changes in Cerebral White Matter Integrity: Fiber Tracking from DTI. Poster (by M. Costello), Cognitive Neuroscience Society.
- Weber, B., & **Huettel, S.A.** (2006, October). Differences in brain activation in decisions involving risk and delay. Talk (by B. Weber), Society for Judgment and Decision Making.
- Tankersley, D., Stowe, C.J., & **Huettel, S.A.** (2006, October). Social perception and reward systems that predict tendency toward altruistic behavior. Poster (by D. Tankersley), Society for Neuroscience. [selected for SFN press book]
- Weber, B., & **Huettel, S.A.** (2006, October). The neural relations between risky and intertemporal choices in decision making. Poster (by B. Weber), Society for Neuroscience.
- Han, S., **Huettel, S.A.**, Dobbins, I.G. (2006, October). Dorsolateral prefrontal cortex and implicit classification. Poster (by S. Han), Society for Neuroscience.
- Detwiler, J.M., Douglas, E.A., Dobbins, I. G., & **Huettel, S.A.** (2006, October). Modulation of executive control systems by task-irrelevant reward information. Poster (by J. Detwiler), Society for Neuroscience.
- Venkatraman, V., Chuah, L.M.Y., **Huettel, S.A.**, & Chee, M.W.L. (2006, October). Effects of sleep deprivation on decision making involving risk studied using fMRI. Poster (by V. Venkatraman), Society for Neuroscience.
- Tankersley, D., Stowe, C. J., & **Huettel, S.A.** (2006, September). Altruism and the Perception of Agency in the Superior Temporal Sulcus. Poster (by D. Tankersley), Society for Neuroeconomics.
- Huettel, S.A.**, Bearden, J. N., & Schultz-Mahlendorf, W. (2006, June). The Neural Correlates of Bluffing in a Simplified Poker Game. Poster, Organization for Human Brain Mapping.
- Marks, B.L., Madden, D.J., Bucur, B., Provenza, J.M., White, L.E., Cabeza, R., & **Huettel, S.A.** (2006, May). Role of Aerobic Fitness and Aging on Cerebral White Matter Integrity. Poster (by B. Marks), Imaging the Aging Brain: New York Academy of Sciences.
- Bearden, J. N., Schultz-Mahlendorf, W., & **Huettel, S.A.** (2006, March). The neuroeconomics of poker. Poster (by N. Bearden), Cognitive Neuroscience Society.
- Tankersley, D., & **Huettel, S.A.** (2006, March). Neural substrates of the processing of monetary and social rewards. Poster (by D. Tankersley), Cognitive Neuroscience Society.

- Bucur, B., Madden, D.J., Spaniol, J., Provenzale, J.M., White, L.E., Cabeza, R., & **Huettel, S.A.** (2006, March). White Matter Integrity as a Mediator between Age and Memory Retrieval: Implications for Disconnection Theories of Cognitive Aging. Poster, Cognitive Neuroscience Society.
- Dagenbach, E.M., & **Huettel, S.A.** (2005, November). Probability transitions in a decision making under risk paradigm. Poster (by E. Dagenbach), Society for Neuroscience.
- Huettel, S.A.**, Stowe, C.J., Platt, M.L., Gordon, E.G., & Warner, B.T. (2005, November). Decision ambiguity modulates activation of the posterior inferior frontal sulcus. Poster, Society for Neuroscience. [selected for SFN press book]
- Huettel, S.A.** (2005, September). Neural substrates for the resolution of uncertainty. Poster, Society for Neuroeconomics.
- Warner, B.T., Gordon, E.M., Stowe, C.J., Platt, M.L., & **Huettel, S.A.** (2005, June). Differential effects of ambiguity and risk upon brain systems for decision making. Poster (by B. Warner), Human Brain Mapping.
- Gordon, E.M., Warner, B.T., Smith, J.K., & **Huettel, S.A.** (2005, June). Effects of risk-reward context upon the evaluation of monetary rewards. Poster (by E. Gordon), Human Brain Mapping.
- Madden, D.J., Spaniol, J., Whiting, W.L., Bucur, B., Provenzale, J.M., Cabeza, R., & **Huettel, S.A.** (2005, March). Adult Age Differences and Similarities in the Functional Neuroanatomy of Visual Attention: Evidence from fMRI. Poster (by D. Madden), Cognitive Neuroscience Society.
- Bucur, B., Madden, D.J., Spaniol, J., Provenzale, J.M., White, L.E., Cabeza, R., & **Huettel, S.A.** (2005, March). Age-Related Decreases in Cerebral White Matter Integrity: Implications for Episodic and Semantic Retrieval Processes. Poster (by B. Bucur), Cognitive Neuroscience Society.
- Huettel, S.A.**, Stowe, C.J., Platt, M.L., Gordon, E.G., & Warner, B.T. (2005, March). Choices between gambles: Effects of certainty, risk, and ambiguity upon brain systems for decision making and reward evaluation. Poster, Cognitive Neuroscience Society.
- Madden, D.J., Whiting, W.L., Provenzale, J.M., Spaniol, J., White, L.E., Bucur, B., Cabeza, R., & **Huettel, S.A.** (2004, October). Diffusion tensor imaging of cerebral white matter: Implications for age-related changes in visual attention. Talk (by D. Madden), ISMRM Aging Connections.
- Huettel, S.A.**, Smith, J.K., & Gordon, E.M. (2004, October). Evaluation of monetary rewards under different risk-reward contexts. Talk, Society for Neuroscience.
- Song, A.W., Woldorff, M.G., Smith, J.K., & **Huettel, S.A.** (2004, October). Evidence for a capillary origin of the fMRI BOLD refractory effect. Poster (by A. Song), Society for Neuroscience.
- Smith, J.K., Gordon, E.M., Sheu, R.D., & **Huettel, S.A.** (2004, April). Reward uncertainty and decision uncertainty independently modulate activity in brain systems for decision making. Poster (by J. Smith), Cognitive Neuroscience Society.
- Berghorst, L.H., **Huettel, S.A.**, & McCarthy, G. (2004, April). Spatial specificity of impoverished face and object stimuli in the fusiform gyrus. Poster (by L. Berghorst), Cognitive Neuroscience Society.
- Madden, D.J., Whiting, W.L., Provenzale, J.M., Spaniol, J., White, L.E., Bucur, B., Cabeza, R., and **Huettel, S.A.** (2004, April). Diffusion tensor imaging of cerebral white matter: Implications for age-related changes in visual attention. Poster (by D. Madden), Cognitive Aging.
- Spaniol, J., Madden, D.J., Cabeza, R., and **Huettel, S.A.** (2004, April). Aging and retrieval in episodic and semantic memory tasks. Poster (by J. Spaniol), Cognitive Aging.
- McClernon, F. J., Hiott, F. B., **Huettel, S.A.**, Wong, J. & Rose, J. E. (2004, February). Smoking deprivation and satiety alter thalamic responses to smoking and control cues: An fMRI investigation. Poster (by F. McClernon), Society for Research on Nicotine and Tobacco.
- Huettel, S.A.**, Mack, P.B., & McCarthy, G. (2003, November). Brain systems associated with violations of expectation. Talk, Society for Neuroscience.
- McCarthy, G., Viola, R., Song, A., & **Huettel, S.A.** (2003, November). Common neural substrates of behavioral selection and working memory: Evidence from functional MRI. Talk (by G. McCarthy), Society for Neuroscience.
- Obembe, O., Woldorff, M., Song, A., **Huettel, S.A.** (2003, November). Adaptation of the fMRI BOLD signal in human motion area V5 is specific to the direction of stimulus motion. Poster (by O. Obembe), Society for Neuroscience.
- Michelich, C., **Huettel, S.**, McCarthy, G., MacFall, J. (2003, July). Evaluating fMRI Spatial Extent in Groups with Different CNR. Poster (by C. Michelich), International Society for Magnetic Resonance in Medicine.
- Huettel, S.A.**, & Misiurek, J. (2003, June). Executive processes of rule and response selection: Evidence from event-related fMRI. Poster, Human Brain Mapping.

- McCarthy, G., Miller, B., Song, A., Mack, P., & **Huettel, S.** (2003, June). Domain Specificity and Domain Switching in a Sequential Judgment Task. Poster (by G. McCarthy), Human Brain Mapping.
- Provenzale, J.M., Whiting, W.L., **Huettel, S.A.**, White, L.E., Harlan, N.J., MacFall, J.R., & Madden, D.J. (2003, May). Age-related change in corpus callosum anisotropy values in healthy volunteers. Poster (by J. Provenzale), American Society of Neuroradiology.
- Madden, D.J., Whiting, W.L., **Huettel, S.A.**, White, L.E., Harlan, N.J., MacFall, J.R., & Provenzale, J.M. (2003, April). Age-related change in functional integrity of white matter pathways obtained from tensor diffusion-weighted imaging. Poster (by D. Madden), Cognitive Neuroscience Society.
- Huettel, S.A.**, Jurkowski, A., Misiurek, J., & McCarthy, G. (2002, November). Dynamic and strategic aspects of executive processing: A comparison of blocked and event-related fMRI measures. Talk, Society for Neuroscience.
- Huettel, S.A.**, McKeown, M.J., Hart, S., Song, A.W., Allison, T., & McCarthy, G. (2002, April). The effects of stimulus duration upon visual cortical activation: Evidence from functional MRI and intracranial ERPs. Poster, Cognitive Neuroscience Society.
- Madden, D.J., **Huettel, S.A.**, Langley, L.K., Harlan, N.J., Whiting, W.L., Provenzale, J.M., & McCarthy, G. (2002, April). Adult age differences in the hemodynamic response during visual target detection measured by functional MRI. Poster (by D. Madden), Cognitive Neuroscience Society.
- Huettel, S.A.**, Mack, P.B., & McCarthy, G. (2001, November). Prefrontal cortex activation is evoked by the violation of local stimulus expectancies. Talk, Society for Neuroscience.
- Huettel, S.A.**, Mack, P.B., & McCarthy, G. (2001, March). Prefrontal cortex activation reflects moment to moment changes in response processing: Evidence from functional MRI. Poster, Cognitive Neuroscience Society.
- Huettel, S.A.**, Singerman, J. & McCarthy, G. (2000, November). Spatial and temporal variability of the fMRI hemodynamic response in young and elderly subjects. Poster, Society for Neuroscience.
- Huettel, S.A.**, Singerman, J. & McCarthy, G. (2000, June). Effects of aging on the refractory period of the fMRI hemodynamic response. Poster, Human Brain Mapping.
- Huettel, S.A.**, & Güzeldere, G. (2000, April). Consciously controlled vs. automatic attentional processes. Talk, Toward a Science of Consciousness conference.
- Huettel, S.A.**, & McCarthy, G. (2000, April). Regional differences in the refractory period of the fMRI hemodynamic response evoked by faces. Poster, Cognitive Neuroscience Society.
- Huettel, S.A.**, & McCarthy, G. (1999, November). A refractory period in the hemodynamic response: Evidence from a paired-stimulus fMRI study. Poster, Society for Neuroscience.
- Huettel, S.A.**, & Lockhead, G.R. (1998, November). Effects of a randomly behaving opponent in Wolf's Dilemma. Poster, Psychonomic Society.
- Sandstrom, N.J., **Huettel, S.A.**, & Kaufman, J. (1998, November). Human sex differences in sensitivity to geometric cues when navigating in virtual environments. Poster, Society for Neuroscience.
- Huettel, S.A.**, & Lockhead, G.R. (1998, August). Sequence effects reveal differences between classification tasks. Poster, International Society for Psychophysics.
- Kaufman, J., **Huettel, S.A.**, & Sandstrom, N. J. (1998, April). Virtual environments in spatial navigation. Poster, Carolina Cognitive Consortium.
- Huettel, S.A.**, & Lockhead, G.R. (1997, November). The source of Garner interference. Poster, Psychonomic Society.
- Sandstrom, N. J., **Huettel, S.A.**, & Kaufman, J. (1997, November). Human navigation in virtual environments. Talk (by N. Sandstrom), Society for Computers in Psychology.
- Lockhead, G.R., Dragoi, V., & **Huettel S.A.** (1996, July). Context and judgment. Talk (by G. Lockhead), International Society for Psychophysics.
- Huettel, S.A.**, & Lockhead, G.R. (1996, June). Sequence effects in classification. Poster, Western Attention
- Huettel, S.A.**, & Needham, A. (1996, April). Infants' use of support information in object segregation. Poster, International Conference on Infant Studies.

## **Media and External Coverage of Research (selected examples)**

**Neuroscience, Neuroeconomics (2002-present).** ABCnews.com, CBS Sunday Morning, Carolina Connection (WCHL), CNN Headline News, Educational Broadcasting System (Korea), Epoca Negocios (Brazil), Geoff Adler Show (Canada), Irish Times, Kiplinger's Personal Finance, Money Magazine,

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MSNBC, Newsmax Magazine, Real Simple Magazine, Scientific American, Times of London, WRAL-TV.

**Social decision making in a simple poker game (2012).** AAAS Podcast, ArsTechnica, Bloomberg Businessweek, Boston Herald, CBSNews.com, Daily Mail (UK), LiveScience, Scientific American podcast.

**Neuroscience and financial decision making (2011).** Television Feature: CNN *Your Bottom Line*, special episode on “Your Money and Your Mind”.

**Testosterone and decision making (2011).** Radio interview: WUNC (North Carolina NPR).

**Sleep deprivation and decision making (2011).** Radio interview: *NPR Science Friday*, National Public Radio. Articles: Healthday News, New Scientist, The Independent (UK), Time Magazine (Healthland, online), Los Angeles Times, healthfinder.gov.

**Risk vs. Cognition in Older Adults (2010).** USAToday.com, Businessweek.com, healthfinder.gov, HHS HealthBeat.

**Strategic biasing in decision making (2009).** Newsweek, Huffington Post, Science World – Public Radio International, Folha (Brazil).

**Neural correlates of altruism (2007).** Interviews: ABC News, BBC 4 News (UK), BBC 5 Live (UK), BBC World Service, CBS Radio, Chronicle of Philanthropy, Daily Mail (London), KCBS, La Repubblica (Italy), Le Quotidien du Medecin (France), Newstalk Ireland, Reader’s Digest Canada, Reuters, UPI, WCHL, WEOL, WMQX, WNYC. [Total of >100 news articles.]

**Perceiving patterns in randomness (2002).** CNN (Your Health), CNN Headline News, Faculty of 1000, Money Magazine, Nature Views, Science News, Seoul Broadcasting System (Korea).

## **Teaching Experience**

Primary Instructor [Undergraduate, Graduate; Spring, Fall, Winter; \*original course]

*Neuroethics*\* [U]: 2012S, 2011S

*Decision Neuroscience*\* [U]: 2012F, 2011F, 2010F, 2010S

*Functional Magnetic Resonance Imaging*\* [G]: 2008F, 2007F, 2005F, 2004F, 2003F, 2002F

*Functional Magnetic Resonance Imaging* [U]: 2008F

*Neuroeconomics*\* (FOCUS Program) [U]: 2009F, 2008F, 2007F, 2006F

*Exploring the Mind IDC* (FOCUS Program) [U]: 2002F, 2001F, 2000F

*The Study of Consciousness*\* [U]: 2001S, 2000S, 1999S

*Consciousness, Complexity, and Cognitive Science*\* [U]: 1998S, 1997S

Lecturer in Courses

*Cognitive Neuroscience* [G]: 2012F,S – 2001F,S (3-5 sessions per year)

*Neuroscience, Juries, and Decision Making* [G]: 2012W (Law School, short course co-organizer)

*Introduction to Cognitive Neuroscience* [U]: 2008S, 2006S, 2002S (2-3 sessions per year)

*Cognitive Neuroscience* (for Psychiatry Residents): 2007, 2006, 2004 (1-2 sessions per year)  
(Guest lectures in > 10 other courses at Duke and area colleges)

Guest Lecturer in Programs

Summer Program in Empirical Implications of Theoretical Models [G]: 2008

Talent Identification Program (High School): 2012, 2008, 2002, 2001, 1999

Mechanisms of Behavior Summer Program [U]: 2001, 2000, 1999

Howard Hughes Precollege Program (High School): 2005

Teaching Assistant

*Statistics* [U]: 1997F

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*Perception Laboratory* [U]: 1995S

Materials Development

*Functional Magnetic Resonance Imaging*. Textbook, figures, and course slides are used by >100 courses internationally, at all levels.

*VirtualBrain*. Virtual reality neuroanatomy program within the Duke Immersive Virtual Environment (DiVE). Used in undergraduate courses and as part of the neuroanatomy training for 1<sup>st</sup> year medical students.

## **Mentoring Experience**

NSF ADVANCE Program (External Mentor)

Dr. Sherece Fields (2011-present): Assistant Professor of Psychology, Texas A&M University

K-award recipients:

Dr. Joseph McClernon (2004-2008): Associate Professor of Psychiatry, Duke University

Dr. Christina Meade (2009-2013): Assistant Professor of Psychiatry, Duke University

Postdoctoral fellows, as primary or secondary mentor:

Dr. Youngbin Kwak (2011-present)

Dr. Steve Stanton (2008-present; co-mentor w/Dr. Kevin LaBar)

Dr. McKell Carter (2007-present); recipient of 2012 “Outstanding Duke Postdoc” award

Dr. Richard Yaxley (2007-2011; co-mentor w/Dr. Michael DeBellis)

Dr. O’Daniel Mullette-Gillman (2007-2011); Assist. Prof. Psychology, National Univ. Singapore

Dr. Debra Henninger (2007-2009); Analyst, Cigna Healthcare

Dr. Ana Raposo (2006-2008, co-mentor w/Dr. Ian Dobbins): Investigator, University of Lisbon

Dr. Bethany Weber (2005-2008): Assistant Professor of Psychology, Iowa State

Dr. J. Neil Bearden (2005-2006): Associate Professor of Decision Sciences, INSEAD

Graduate students, as primary mentor:

Rosa Li (2012-present), Ph.D. in Psychology & Neuroscience, expected 2016

Rene San Martin (2010-present), Ph.D. in Psychology & Neuroscience, expected 2015

Lawrence Ngo (2010-present), Ph.D. in Neurobiology, expected 2015

Amy Winecoff (2010-present), Ph.D. in Psychology & Neuroscience, expected 2014

Chris Coutlee (2009-present), Ph.D. in Psychology & Neuroscience, expected 2014

Dr. David Smith (2007-2012), Ph.D. in Psychology & Neuroscience ; now Post-Doc, Rutgers

Dr. Vinod Venkatraman (2007-2011), Ph.D. in Psychology & Neuroscience;

Assistant Professor of Marketing, Temple University

Dr. John Clithero (2006-2011), Ph.D. in Economics; now Post-Doc, Caltech

Dr. Dharol Tankersley (2005-2008), Ph.D. in Philosophy

Dr. Olufolajimi Obembe (2002-2003), Master’s in Neurobiology / M.D.

Eunice Chang (2003-2004), Master’s in Neurobiology

Graduate students (other), as committee member or secondary mentor:

Jana Brizante (2012-2013, visiting from University of São Paulo)

Phil Kragel (2012-present)

Jeff MacInnes (2012-present)

Jiefeng Jiang (2011-present)

Courtnea Rainey (2011-present)

Amy Bland (2010, visiting from Leeds University)

Crystal Reeck (2009-present)

Betsy Johnson (2008-present)

Irina Kozyrkov, M.A. (2012)

Dr. David Paulsen (2008-2012)

Dr. Megan McCrudden (2008)

Dr. Simon Davis (2007-2011)

Dr. Melissa Libertus (2007-2010)

Scott A. Huettel, Ph.D.

Dr. Jeff Klein (2006-2010)  
Dr. Arwen Long (2005-2009)  
Jacqui Detwiler (2007-2008)  
Dr. Sanghoon Han (2005-2008)  
Dr. Joseph Crozier (2006-2007)  
Dr. Michele Diaz (2003-2005)  
Dr. Deborah H. Due (2000-2001)

Advisor to 20+ undergraduate independent study projects, undergraduate graduation with distinction awardees, and post-graduate research assistants. Selected examples as primary mentor:

Parker Goyer (Duke, '08), 2009 recipient of a Rhodes Scholarship.  
Anjali Bhatia (Duke, '10), Program II graduate in *Neuroeconomics*.  
Nazanin Amini (Duke, '13), Program II candidate in *Neuroscientific Approaches to Political Behavior*  
Evan Gordon (Duke, '04; research assistant, '04-05), cognitive neuroscience Ph.D. program, Georgetown  
Lisa Berghorst (Duke, '04), clinical psychology Ph.D. program, Harvard  
Brandi Newell (research assistantship, '08-10), psychology Ph.D. program, Harvard  
Adrienne Taren (research assistantship, '08-10), M.D./Ph.D. program, Pittsburgh



# **Kimberly D. Krawiec**

*Duke University Law School*  
Science Drive and Towerview Road  
Durham NC 27708  
919-613-7006  
krawiec@law.duke.edu

## ***EXPERIENCE***

### **COURSES:**

Business Associations  
Securities Regulation  
Financial Derivatives  
Corporate Crime

Corporate Finance  
Advanced Seminars in  
Securities and Derivatives  
Issues

Taboo Trades and  
Forbidden Markets  
Theories of Governance  
and Civic Association

**Duke Law School, Durham NC**  
*July 2009-Present*  
Professor of Law

**University of North Carolina School of Law, Chapel Hill NC**  
*August 2001-July 2009*  
Professor of Law

**University of Virginia School of Law**  
*January 2005-May 2005*  
Visiting Professor of Law

**Georgetown University Law Center**  
*August 2004-December 2004*  
Visiting Professor of Law

**Harvard Law School**  
*August 2003-May 2004*  
Bruce W. Nichols Visiting Professor of Law

**University of Pennsylvania School of Law Philadelphia, PA**  
*January 2001 - May 2001*  
Visiting Professor of Law

**University of California at Los Angeles School of Law** Los Angeles, CA  
*August 2000 - December 2000*  
Visiting Professor of Law

**Northwestern University School of Law** Chicago, IL  
*August 1999 - May 2000*  
Visiting Associate Professor of Law

**University of Oregon School of Law** Eugene, OR  
*August 1997 - May 2001*  
Associate Professor of Law with Tenure

**University of Tulsa College of Law** Tulsa, OK  
*August 1995 - August 1997*  
Assistant Professor of Law

**Sullivan & Cromwell** New York, NY  
*October 1992 - August 1995, Summer 1991*  
Associate, Commodity and Derivatives Group

## ***PUBLICATIONS***

*Dangerous Categories: Narratives of Corporate Board Diversity*, 89 N.C. L. REV. \_\_\_\_  
(forthcoming, 2011) (with Lissa Broome and John Conley)

*Does Critical Mass Matter? Views From The Boardroom*, SEATTLE L. REV. (forthcoming, 2011)  
(with Lissa Broome and John Conley)

*The Dark Side of Commodification Objections: A Response to Silbaugh*, WASH U. J. L. & Policy  
(forthcoming 2011)

*Narratives of Diversity in the Corporate Boardroom: What Corporate Insiders Say about Why  
Diversity Matters*, in DISCOURSE PERSPECTIVES ON ORGANIZATIONAL COMMUNICATION  
(Fairleigh Dickinson University Press, 2010) (with Lissa Broome and John Conley)

*A Woman's Worth*, 88 N.C.L. REV. 1739 (2010).

*Price and Pretense in The Baby Market*, in BABY MARKETS: MONEY AND THE NEW POLITICS OF  
CREATING FAMILIES (Cambridge University Press, 2010).

*Sunny Samaritans & Egomaniacs: Price-Fixing in the Gamete Market*, 72 L. & CONTEMP.  
PROBS. 59 (2009).

*Show Me The Money: Making Markets in Forbidden Exchange*, 72 L. & CONTEMP. PROBS. i  
(2009).

*Why We Should Ignore the "Octomom,"* 104 NW. U. L. REV. COLLOQUIY 120 (2009)

*The Return of the Rogue,* 51 AZ. L. REV. 127 (2009).

*Altruism and Intermediation in the Market for Babies,* 66 WASH. & LEE L. REV. 203 (2009).

*Operational Risk Management: An Emergent Industry,* in OPERATIONAL RISK TOWARDS BASEL III: BEST PRACTICES AND ISSUES IN MODELING, MANAGEMENT AND REGULATION (John Wiley and Sons, 2009).

*Signaling Through Board Diversity: Is Anyone Listening?* 77 U. CINN. L. REV. 431 (2008) (with Lissa Broome).

*Incomplete Contracts in a Complete Contract World,* 33 FL. ST. L. REV. 725 (2006) (with Scott Baker).

*Common Law Disclosure Duties and the Sin of Omission: Testing the Meta-Theories,* 91 VA. L. REV. 1795 (2005) (with Kathryn Zeiler).

*Organizational Form as Status and Signal,* 40 WAKE FOREST L. REV. 977 (2005).

*The Economics of Limited Liability: An Empirical Study of New York Law Firms,* 2005 U. ILL. L. REV. 107 (2005) (with Scott Baker).

*Organizational Misconduct: Beyond the Principal-Agent Model,* 32 FL. ST. L. REV. 571 (2005).

*The Penalty Default Canon,* 72 GEO. WASH. L. REV. 663 (2004) (with Scott Baker).

*Cosmetic Compliance and the Failure of Negotiated Governance,* 81 WASH. U. L. Q. 487 (2003).

*Fairness, Efficiency & Insider Trading: Deconstructing the Coin of the Realm in the Information Age,* 95 NW. U. L. REV. 443 (2001).

*Foreword, The Regulation of Derivatives and Other Complex Financial Products,* 21 NW. J. INT'L. L. & BUS. 565 (2001).

*Privatizing "Outsider Trading,"* 41 VA. J. INT'L. L. 693 (2001).

*Derivatives on TV: A Tale of Two Derivatives Debacles in Prime Time,* 4 GREEN BAG 2d 257 (2001) (with Peter H. Huang & Frank Partnoy).

*Accounting for Greed: Unraveling the "Rogue Trader" Mystery,* 72 OR. L. REV. 301 (2000).

*Derivatives, Corporate Hedging and Shareholder Wealth: Modigliani-Miller Forty Years Later,* 1998 U. ILL. L. REV. 201 (1999)

*Don't Ask, Just Tell: Insider Trading After United States v. O'Hagan,* 84 VA. L. REV. 153 (1998) (with Richard Painter and Cindy Williams)

*More Than Just New Financial Bingo: A Risk-based Approach to Understanding Derivatives,* 23 J. CORP. L. 1 (1997)

*SEC Promulgates New Insider Trading Rules*, 15 BNA CORP. COUNSEL WEEKLY 8 (Nov. 1, 2000) (with Richard W. Painter).

*Building the Basic Course Around Intra-Firm Relations*, 34 GA. L. REV. 785 (2000).

*Fiduciaries, Misappropriators and the Murky Outlines of the Den of Thieves: A Conceptual Continuum for Analyzing United States v. O'Hagan*, 33 TULSA L. J. 163 (1997) (Symposium)

*Corporate Debt Restructurings in Mexico: For Foreign Creditors, Insolvency Law Is Only Half the Story*, 17 N.Y.L. SCH. J. INT'L. & COMP. L. 481 (1997) (Symposium)

*Gustafson v. Alloyd Co.: The Wrong Decision, But it is Still Business As Usual in the Securities Markets*, 31 TULSA L. J. 509 (1996) (Symposium)

*Electronic Surveillance*, 79 GEO. CRIM. PROC. PROJECT 678 (1991)

### **WORKING PROJECTS**

*Board Diversity & Corporate Performance: Filling in the Gaps* (with Lissa Broome & John Conley). **Project Description:** This study seeks to fill gaps in our understanding of whether and how the racial and gender diversity of corporate boards of directors impacts board processes and corporate performance, through a series of in-depth interviews with approximately 75 corporate directors, senior executives, executive search firms, activists, shareholders, and regulators.

*Re-Regulation Post Dodd-Frank*, J. CORP. L. (forthcoming, 2011)

### **SELECTED RECENT CONFERENCES AND SPEAKING ENGAGEMENTS**

Faculty Workshops (*Dangerous Categories*, 2010): Illinois, Florida, and Tulane law schools

Presenter/Co-organizer, *Board Diversity and Corporate Performance: Filling in the Gaps*, University of North Carolina School of Law (April 16, 2010)

Commenter/Co-organizer, *For Love or Money: Defining Relationships in Law and Life*, Wash. U. Law School (March 26-27, 2010)

University of British Columbia, The National Centre for Business Law, *Narratives of Diversity in the Corporate Boardroom: What Corporate Insiders Say About Why Diversity Matters* (March 12, 2010)

Faculty Workshops (*A Woman's Worth*, 2009-10): Bar-Ilan, Duke, Georgia, Northwestern, and Tel Aviv law schools

Presenter, *Globalization, Families, and the State*, University of North Carolina (Oct. 2009)

Presenter, *Behavioral Analysis of Law: Markets, Institutions, and Contracts*, University of Haifa (Dec. 2009)

Faculty Workshops (*Operational Risk Management*, 2008-09): Duke Law School-Fuqua School

of Business, University of Arizona Law School

Faculty Workshops (*Sunny Samaritans & Egomaniacs*, 2008-09): University of Chicago, Duke, Indiana-Bloomington, University of Iowa, UCLA, and University of Oregon law schools

Presenter, *The Opposite(s) of Property*, Duke Law School (Jan. 17, 2009)

Commenter, *3<sup>rd</sup> Annual Law & Entrepreneurship Retreat*, Drexel University School of Law (Oct. 24, 2008)

Presenter, *The (Dys)functional Board: Causes and Cures*, University of Cincinnati School of Law (March 14, 2008)

Faculty Workshops (*Board Diversity & Corporate Performance*, 2007-08): University of Alabama, Duke University Law & Markets Speaker Series, University of North Carolina

Faculty Workshops (*Price and Pretense in the Baby Market*, 2006-07): University of Alabama, University of Illinois, Vanderbilt University, Washington & Lee University, and the University of North Carolina Schools of Law

Presenter, *Baby Markets: Money, Morals, and the Neopolitics of Choice*, DePaul University College of Law (November 10, 2006)

Faculty Workshops (*Organizational Form as Status and Signal*, 2005): University of Virginia School of Law

Presenter, *The Future of Closely Held Business Entities*, at Wake Forest University School of Law (April 15, 2005)

Presenter, *Default Rules in Public and Private Law*, at Florida State University School of Law (March 25, 2005)

Faculty Workshops (*Common Law Disclosure Duties and the Sin of Omission*, 2004-2005): University of Virginia School of Law, Georgetown University Law School, Cornell Law School, Lewis & Clark Law School, Washington University School of Law, University of Illinois School of Law, Emory Law School

Faculty Workshops (*The Economics of Limited Liability*, 2003-2004): Georgetown University Law Center, Fordham University School of Law, Harvard Law School

Faculty Workshops (*Organizational Misconduct: Beyond the Principal-Agent Model*, 2003-2004): Harvard Business School, Boston University School of Law, Roger Williams School of Law

Presenter, *Enron and What Has Gone Wrong With Corporate Culture* at the 2004 American Constitutional Society Annual Convention (June 18, 2004)

Presenter, *Uncorporations: A New Age?*, University of Illinois School of Law (April, 2004)

Presenter, *The Behavioral Analysis of Legal Institutions*, Florida State Univ. (March 26-27,

2004)

Faculty Workshops (*The Penalty Default Canon*, 2003-2004): Georgetown University Law Center, Florida State University School of Law, The University of North Carolina School of Law, University of Cincinnati School of Law

Commentator, *Eugene P. and Delia S. Murphy Conference on Corporate Law*, Fordham Univ. School of Law (Nov. 21, 2003)

Presenter, *Law and Society Annual Meeting*, Pittsburgh, PA (June 2003)

Presenter, *F. Hodge O'Neal Corporate and Securities Law Symposium*, Washington University School of Law (Feb. 21, 2003)

### ***COMPETITIVE GRANTS, FELLOWSHIPS, AND AWARDS***

University of North Carolina Pogue Leave (awarded by University Provost -- fall 2008 leave with full salary)

Robertson Scholars Collaboration Fund Grant (awarded \$3600 to support the Duke-UNC Law & Finance Speaker Series for spring 2008; awarded \$1900 to support the Duke-UNC Law & Finance Speaker Series for Spring 2009)

Corporate Practice Commentator's Best Corporate and Securities Law Articles of 1999 (for *Derivatives, Corporate Hedging and Shareholder Wealth*)

Robert Childres Memorial Award for Teaching Excellence (1999-2000, Northwestern University School of Law)

Nominee, University of Tulsa Outstanding Teacher Award (1996)

### ***EDUCATION***

**Georgetown University Law Center** Washington, DC

J.D., *Cum Laude*, May 1992

*Honors/Awards*: Georgetown Law Journal

American Jurisprudence Award (Contracts)

Legal Research and Writing Honors

Dean's List

**North Carolina State University** Raleigh, NC

B.A., *Cum Laude*, May 1987

### ***OTHER PROFESSIONAL ACTIVITIES***

AALS Section on Business Associations, Executive Council (2010-present)

Commentator, Central and East European Law Initiative (CEELI) of the American Bar Association (1997 - Present)

\*Reviewed and commented on the Draft Law on Public Offering of Securities for the Republic of Bulgaria

\*Reviewed and commented on the Draft Law on Derivative Securities for the Ukraine

Faculty, *NASD Institute for Professional Development*, Wharton School of Business (2001 - 2002) (Philadelphia PA)

*United States v. O'Hagan*, cert. granted by 117 S.Ct. 759 (Jan. 13, 1997), Brief Amicus Curiae in Support of Respondent (with Richard Painter and Cindy Williams)

*Hille v. Storaska, et. al.*, NASD Office of Dispute Resolution, No. 98-04063 (Consultant and expert witness for claimants, Jo Bob and Mary Ann Hille) (April, 1999 - May 2000) (Churning and suitability issues)

*Tubular Corporation of America, Inc., et. al. v. Tyler-Dawson Supply Company*, Tulsa County District Court, Civ. No. C-83-570-Wiseman (Consultant and expert witness for defendant, Bank of America Illinois) (Nov. 1996-Jan. 1997) (registration, private placement exemption, rule 144 resale, prospectus delivery and antifraud issues)

LawyersEd.com, Board of Advisors and Content Writer/Reviewer (March 2000 - 2003)

Co-Editor, Oregon Business Law Digest (1997-2001)

Executive Committee, Business Law Section of the Oregon State Bar (1997-2001)

### ***PROFESSIONAL MEMBERSHIPS/BAR ADMISSIONS***

American Bar Association

Business Law Section

Securities Law Section

American Law and Economics Association

Law and Society Association

State Bar of New York (Admitted 1993)

### ***UNIVERSITY SERVICE*** (since 2000)

Faculty Council, Kenan Institute For Ethics (2010-present)

Kenan-Flagler Business School, Dean Search Committee (2007-08)

Chair, Faculty Workshop Committee (2006-8, 2010-11)

Appointments Committee (1996-97, 2001-2003, 2009-11)

Academic Standing Committee (1998-2001)

Lectures and Awards Committee (1998-2001)

**Alexander Rosenberg**  
The R. Taylor Cole Professor of Philosophy

Department of Philosophy  
Duke University  
PO box 90743  
Durham, North Carolina, 27708  
(919) 660 3047      Email: alexrose@duke.edu  
[www.duke.edu/~alexrose](http://www.duke.edu/~alexrose)

**Education:**    B.A.    City College of New York, 1967  
                      Ph.D., The Johns Hopkins University, 1971

**Academic Positions:**

1970-72	Killam Post Doctoral Fellow, Dalhousie University, Halifax, Canada
1972-76	Assistant Professor of Philosophy, Dalhousie University
1975	Visiting Assistant Professor, Fellow of the Center for Philosophy of Science, University of Minnesota, Twin Cities
1976-81	Associate Professor of Philosophy and Social Science, College of Arts and Sciences, and Maxwell School of Public Affairs, Syracuse University
1978-79	Visiting Associate Professor of Philosophy, University of California, Santa Cruz
1981-86	Professor of Philosophy and Social Science, Syracuse University
1986-95	Professor of Philosophy, step IV-VIII, University of California, Riverside
1994-95	Visiting Lecturer, Philosophy sub-faculty, Oxford University (Balliol College)
1995-2000	Professor of Philosophy, University of Georgia
2000-2003	Professor of Philosophy, Duke University
2003-	R. Taylor Cole Professor of Philosophy

**Honors, Awards and Fellowships (selected):**

1967	Phi Beta Kappa
1968	NSF Graduate Fellowship
1970-72	Isaac Walton Killam Post-Doctoral Fellowship
1981-82	American Council of Learned Societies Study-Fellowship
1982-83	John Simon Guggenheim Foundation Fellow
1983	National Science Foundation Research Grant
1987	National Science Foundation Senior Scholar Award
1991	National Science Foundation Research Grant
1993	Lakatos Award for Philosophy of Science
1994	University of California Faculty Research Lecturer
1995	Sigma Psi
2000	Senior Visiting Fellow, Social Philosophy and Policy Center
2003	Appointed to named chair
2005	Dean's Award for Graduate Mentoring
2006-07	National Humanities Center Fellowship
2006-07	United Chapters Phi Beta Kappa Romanell Lecturer in Philosophy

**Institutional Grants:**

1989-91	Department of Education, Fund for Improvement of Post Secondary Education Grant for Honors Program (\$ 270,000)
---------	--



- 1991 National Endowment for the Humanities, Challenge Grant Award (\$ 235,000)  
 1997 Department of Education, Fund for the Improvement of Post Secondary Education Grant for Center for Undergraduate Research Opportunities (\$170,000)  
 2004-2007 National Science Foundation, Duke Center for Philosophy of Biology (\$ 296,000)  
 2006-2008 Cambridge Templeton Consortium Grant for Complexity/Sociality in Biological Systems, with D.McShea (\$ 190,000)

**Editorial Boards:** American Philosophical Quarterly (1988-91), Philosophy of Science(1987 - ), Behavior and Philosophy,(1988-1998 ), Economics and Philosophy (1987-96 ), Philosophy of Social Science (1984-93 ), Journal of Economic Methodology (1996-99), Philosophy of Biology (2006- )

### **Bibliography:**

- Books: Microeconomic Laws: A Philosophical Analysis, University of Pittsburgh Press, 1976  
Sociobiology and the Preemption of Social Science, Johns Hopkins University Press, 1980, Basil Blackwell, 1981  
Hume and the Problem of Causation, Oxford University Press, 1981 (with T.L. Beauchamp)  
The Structure of Biological Science, Cambridge University Press, 1985  
Philosophy of Social Science, Clarendon Press, Oxford and Westview Press, Boulder, 1988, Second Edition, Revised, enlarged, 1995  
Economics: Mathematical Politics or Science of Diminishing Returns?, Chicago, University of Chicago Press, 1992  
Instrumental Biology or the Disunity of Science, Chicago, University of Chicago Press, 1994.  
Darwinism in Philosophy, Social Science and Policy, Cambridge, Cambridge University Press, 2000  
Philosophy of Science: A Contemporary Introduction, London, Routledge, 2000, second edition, 2005  
Darwinian Reductionism, or How to Stop Worrying and Love Molecular Biology, University of Chicago Press, 2006.  
Atheist's Guide to Reality, NY: Norton, 2011.
- Anthologie: Philosophy of Science: Contemporary Readings, with Y. Balashov, London, Routledge, 2002  
Philosophy of Biology, with Robert Arp, Blackwell's, 2009.
- Translation: Formal Thought and the Sciences of Man, by Gilles-Gaston Granger, Boston, Studies in Philosophy of Science, Dordrech, Reidel, 1984
- Articles: Approximately 170 papers (full bibliography available on line at [www.duke.edu/~alexrose](http://www.duke.edu/~alexrose))

# DUKE UNIVERSITY MEDICAL CENTER

## CURRICULUM VITAE

**Name:** Philip Martin Rosoff, M.D., M.A.

**Primary Academic Appointment:** Department of Pediatrics

**Primary Academic Department:** Department of Pediatrics  
Division of Hematology-Oncology

**Secondary Appointment:** Department of Medicine

**Present Academic Rank and Title:** Professor of Pediatrics (with Tenure)  
Professor of Medicine

**Date and Rank of First Duke Faculty Appointment:** Associate Professor of Pediatrics (with Tenure): 11-1995  
Assistant Professor of Medicine: 11-1995

**Medical Licensure:** North Carolina License #: 9501398  
Date of License: 9-16-1995

**Specialty Certification(s) and Dates:** 10/1/1984 Diplomat, American Board of Pediatrics (#31249)  
11/1/1994 Sub-Board in Pediatric Hematology-Oncology (#001162)  
11/1/2000 Recertified, Sub-Board in Pediatric Hematology-Oncology  
3/14/2009 Recertified, Sub-Board in Pediatric Hematology-Oncology

**Date of Birth:** 10/17/1952 **Place:** Philadelphia, PA

**Citizen of:** USA **Visa Status:** N/A

## EDUCATION

<u>Education</u>	<u>Institution</u>	<u>Date</u>	<u>Degree</u>
High School	Friends Select School	1970	HSD
College	New York University	1974	B.A.
Medical School	Case Western Reserve University School of Medicine	1978	M.D.
Graduate School	Duke University (Philosophy)	2008	M.A.

**SCHOLARLY SOCIETIES:**

*Alpha Omega Alpha* Medical Honor Society                      1977  
 (Case Western Reserve U. School of Medicine)

**PROFESSIONAL TRAINING AND ACADEMIC CAREER:**

<u>Institution</u>	<u>Position/Title</u>	<u>Dates</u>
Children's Hospital, Boston MA	Resident in Pediatrics	1978-1980
Children's Hospital, Boston MA Dana-Farber Cancer Institute, Boston MA	Clinical Fellow in Pediatric Hematology/Oncology	1980-1981
Children's Hospital, Boston MA Dana-Farber Cancer Institute, Boston MA	Research Fellow in Pediatric Hematology/Oncology	1981-1984
Dept. Cellular and Developmental Biology, Harvard University, Cambridge MA	Postdoctoral Fellow (Dr. Vicki Sato)	1981-1982
Dept. Biochemistry and Molecular Biology, Harvard University, Cambridge, MA	Postdoctoral Fellow (Dr. Lewis Cantley)	1982-1985
Harvard Medical School, Boston MA	Instructor in Pediatrics	1984-1985
Children's Hospital, Boston MA	Assistant in Medicine (Hematology-Oncology)	1983-1985
Floating Hospital for Infants and Children, New England Medical Center, Boston MA	Assistant Professor of Pediatrics (Hematology-Oncology)	1985-1989
Tufts University School of Medicine	Assistant Professor of Physiology	1985-1989
Sackler School of Graduate Biomedical Sciences, Tufts University	Member, Graduate Program in Immunology	1987-1995
Tufts University School of Medicine	Associate Professor of Pediatrics	1989-1995
Tufts University School of Medicine	Associate Professor of Physiology	1989-1995
Tufts University School of Medicine	Associate. Professor of Medicine	1992-1995
Duke University Medical Center	Associate Professor of Pediatrics (Hematology/Oncology)	1995-2008
Duke University Medical Center	Assistant Professor of Medicine	1996-present
Duke University Medical Center	Professor of Pediatrics Professor of Medicine	2008-present

**PUBLICATIONS:**

**REFEREED JOURNALS:**

1. Newburger, P.E., Robinson, J.M., Pryzwansky, K.R., Rosoff, P.M., Greenberger, J.S., and Tauber, A.I. (1983) "Neutrophil dysfunction with giant granules and defective activation of the respiratory burst." **Blood** **61**: 1247-1257.
2. Rosoff, P.M. and Cantley, L.C. (1983) "Increasing the intracellular Na<sup>+</sup> concentration induces differentiation in a pre-B lymphocyte cell line." **Proc. Natl. Acad. Sci. USA** **80**: 7547-7550.
3. Rosoff, P.M., Stein, L.F., and Cantley, L.C. (1984) "Phorbol esters induce differentiation in a pre-B lymphocyte cell line by enhancing Na<sup>+</sup>/H<sup>+</sup> exchange." **J. Biol. Chem.** **259**: 7056-7060.
4. Oettgen, H.C., Terhorst, C., Cantley, L.C., and Rosoff, P.M. (1985) "Stimulation of the T3-T cell receptor complex induces a membrane potential-sensitive Ca<sup>2+</sup> influx." **Cell** **40**: 583-590.
5. Rosoff, P.M. and Cantley, L.C. (1985) "Lipopolysaccharide and phorbol esters induce differentiation but have opposite effects on phosphatidylinositol turnover and Ca<sup>2+</sup> mobilization in 70Z/3 pre-B lymphocytes." **J. Biol. Chem.** **260**: 9209-9215.
6. Rosoff, P.M. and Cantley, L.C. (1985) "Stimulation of the T3-T cell receptor-associated Ca<sup>2+</sup> influx enhances the activity of the Na<sup>+</sup>/H<sup>+</sup> exchanger in a leukemic human T cell line." **J. Biol. Chem.** **260**: 14053-14059.
7. Rosoff, P.M. and Terres, G. (1986) "Cyclosporine A inhibits Ca<sup>2+</sup>-dependent stimulation of the Na<sup>+</sup>/H<sup>+</sup> antiport in human T cells." **J. Cell Biol.** **103**: 457-463.
8. Rosoff, P.M., Burakoff, S.B., and Greenstein, J. (1987) "The role of the L3T4 molecule in mitogen and antigen-initiated signal transduction." **Cell** **49**: 845-853.
9. Rosoff, P.M., Walker, R., and Winberry, L. (1987) "Pertussis toxin stimulates second messenger production in human T lymphocytes." **J. Immunol.** **139**: 2419-2423.
10. Rosoff, P.M., Savage, N., and Dinarello, C.A. (1988) "Interleukin-1 stimulates diacylglycerol production in T lymphocytes by a novel mechanism." **Cell** **54**: 73-81.
11. Rosoff, P.M., Hall, C., Gramates, S., and Terlecky, S. R. (1988) "DIDS (4,4'-diisothiocyanatostilbene-2,2'-disulfonic acid) inhibits the CD3-T cell antigen receptor-stimulated Ca<sup>2+</sup> transporter in human T cells." **J. Biol. Chem.** **263**: 19535-19540.
12. Melton, L.B., Lakkis, F., Moskovitz-Lopatin, M., Smith, B.R. Williams, J.M., Rosoff, P.M., and Strom, T.B. (1989) "Antibody valence and induced signal transduction: the role of antibody valence in anti-CD3-induced signal transduction in isolated normal T cells." **Clin. Immunol. and Immunopath.** **50**: 171-183.

13. Corey, S.J. and Rosoff, P.M. (1989) "Granulocyte-macrophage colony stimulating factor (GM-CSF) primes neutrophils by modulating the activity of a pertussis toxin-sensitive G protein". **J. Biol. Chem.** **264**: 14165-14171.
14. Rosoff, P.M. (1989) "Characterization of the Interleukin-1-stimulated phospholipase C activity in human T lymphocytes". **Lymphokine Res.** **8**: 407-413.
15. Rogers, T.S., Corey, S.J. and Rosoff, P.M. (1990) "Identification of a 43-Kilodalton membrane protein as the pertussis toxin receptor in human T lymphocytes." **J. Immunol.** **145**: 678-683.
16. Corey, S.J. and Rosoff, P.M. (1991) "Unsaturated fatty acids and lipoxygenase products regulate phagocytic NADPH activity by non-detergent membrane interactions." **J. Lab. Clin. Med.** **118**: 343-351.
17. Rosoff, P.M. and Mohan, C. (1992) "Unidirectional, heterologous desensitization of the pertussis toxin receptor by the CD3-TCR complex." **J. Immunol.** **149**: 3191-3199.
18. Prasad, K.R. and Rosoff, P.M. (1992) "Characterization of the energy-dependent, mating factor-activated  $\text{Ca}^{2+}$  influx in *Saccharomyces cerevisiae*." **Cell Calcium****13**: 615-626.
19. O'Riordan, C. and Rosoff, P.M. (1993) "Reconstitution of a T cell receptor-stimulated plasma membrane calcium transporter: lack of dependence on inositol phosphates." **Cell Calcium** **14**: 119-133.
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21. Rosoff, P.M. (1995) "Brief report: Congenital bone marrow failure with myelodysplasia in siblings" **J. Ped. Hematol/Oncol.** **17**: 56-60.
22. Zhang, X-M., Berland, R. and Rosoff, P.M. (1995) "Differential regulation of accessory mitogenic signaling receptors by the T cell antigen receptor." **Molec. Immunol** **32**: 323-332.
23. Rosoff, P.M. (1995) "Myelodysplasia and UDP-galactose-4-epimerase deficiency." **J. Peds.** **127**: 605-608.
24. Wong, W.S., Simon, D.I., Rosoff, P.M., Rao, N.K. and Chapman, H.A. (1996) "Mechanisms of pertussis toxin-induced myelomonocytic cell adhesion: role of MAC-1 (CD11b/CD18) and urokinase receptor (CD87)". **Immunology** **88**: 90-97.
25. Wong, W.S. and Rosoff, P.M. (1996) "Pharmacology of pertussis toxin B-oligomer". **Canadian J. Physiol. Pharmacol.** **74**: 559-564.

26. Trede, N.S., Warwick, A.B., Rosoff, P.M., Rohrer, R., and Guinan, E. (1997) "Tacrolimus (FK506) in allogeneic bone marrow transplantation for severe aplastic anemia following orthotopic liver transplantation." **Bone Marrow Transplantation 20**: 257-260.
27. Castellino, S., Traweek, T. and Rosoff, P.M. (1998) "Ewing's sarcoma and papillary adenocarcinoma of the thyroid in a teenage girl." **J. Ped. Hematol/Oncol. 20**: 177-180.
28. Warwick, A., Haver, K. and Rosoff, P.M. (1998) "Cystic fibrosis and homozygous sickle cell disease in a patient from the Dominican Republic: report of a case." **Ped. Pulm. 26**: 224-7.
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32. Rosoff, P.M., Hatcher, S. and West, D. (2000) "A Biphenotypic Sarcoma with Characteristics of Both a Ewing's Sarcoma and a Desmoplastic Small Round Cell Tumor: Case Report and Review of the Literature": **Med. Ped. Oncol. 34**: 407-412.
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34. McGregor, L.M. and Rosoff, P.M. (2001) "Follicle-derived Thyroid Cancer in Young People: The Duke Experience." **Pediatric Hematology and Oncology 18**: 89-100.
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37. Sugarman, J. and Rosoff, P.M. (2001) "Ethical issues in gamete preservation for children undergoing treatment for cancer" **J. Andrology 22**: 732-737.
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41. Rosoff, P.M., Tuttle-Newhall, E., and Treem, W.R. (2003) "Successful treatment of immune thrombocytopenic purpura with anti-D antibody following a cadaveric liver transplant for hepatoblastoma". **Med. Ped. Oncol.** **40**: 402-404.
42. Bayliff, S., Horvatinovich, J.M., Gong, J., and Rosoff, P.M. (2003) "Normal infants do not have detectable circulating megakaryoblasts; validation of a detection method using flow cytometry." **J. Ped. Hematol./Oncol.** **25**: 721-725.
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45. Uram, R. and Rosoff, P.M. (2003) "Isolated IgA deficiency after chemotherapy for acute myelogenous leukemia." **Ped. Hematol. and Oncol.** **20**: 487-492.
46. Tirado, C.A., Lager J.J., Rosoff, P.M., Golembiski-Ruiz, V.Gong, J. and Goodman, B.K. (2004) "Inversion/insertion of MLL into the MLLT10 gene on chromosome 10 in a case of an infant with acute lymphoblastic leukemia". **Cancer Gen. Cytogen.** **154**: 57-59.
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51. Rosoff, P.M. and Rosenberg, A. (2006) "How Darwinian Reductionism Refutes Genetic Determinism". **Studies In History And Philosophy Of Biological And Biomedical Sciences** **37**: 122-135.
52. Rosoff, P.M. (2006) "A Central Role for Palliative Care in an Influenza Pandemic". **J. Palliative Med.** **9**: 1051-1053.

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55. Rosoff, P.M. (2008) "Does Physician Responsibility for Patient Care Extend Beyond the Clinic?" **Virtual Mentor**. 2008;8(6):401-403. <http://virtualmentor.ama-assn.org/2008/06/pdf/msoc1-0806.pdf> Accessed June 3, 2008.
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58. LeBlanc, T. and Rosoff, P.M. (2009) "Commentary on 'Is there a duty to inform patients of Phase 1 trials?'" **Virtual Mentor (AMA J. Ethics)** **11** (3): 207-214.
59. Rosoff, P.M. (2010) "In Search of the Mommy Gene: Behavioral Genetics and Modern Molecular Biology." **Sci. Technol. Human Values** **35** (2): 200-243.
60. Paxton, R.J., Jones, L.W., Rosoff, P.M., Bonner, M., Ater, J.L., and Demark-Wahnefried, W. (2010) "Associations between leisure-time physical activity and health-related quality of life among adolescent and adult survivors of childhood cancers". **J. Psycho-Oncology** **19** (9): 997-1003.
61. Rosoff, P.M. (2010) "Is Palliative Care a Necessity or a Luxury During an Overwhelming Health Catastrophe?" **J. Clin. Ethics** **21** (4): 312-320.
62. Rosoff, P.M. (2011) "Is medical ethics education effective?" **Lebanese Med. J.** **59** (1): 12-16.
63. Rosoff, P.M. (2011) "I'll be a monkey's uncle: a moral challenge of genetic enhancement research." **J. Med. Ethics** **37**: 611-615.
64. Rosoff, P.M. and Coleman, D.L. (2011) "The case for legal regulation of physicians' off-label prescribing." **Notre Dame Law Rev.** **86** (2): 649-691.
65. Rosoff, P.M. and Decamp, M. (2011) "Preparing for an influenza pandemic: are some people more equal than others?" **J. of Healthcare for the Poor and Underserved** **22** (3 Supplement): 19-35.



66. Rosoff, P.M. (2012) "Unpredictable Drug Shortages: An Ethical Framework for Short-term Rationing in Hospitals." **Amer. J. of Bioethics** **12** (1): 1-9.
67. Arawi, T. and Rosoff, P.M. (2012) "Competing duties: medical educators, underperforming students and social accountability." **J. Bioethical Inquiry** **9** (2): 135-147.
68. Rosoff, P.M. (2012) "The myth of genetic enhancement." **Theoretical Med. Bioethics** **33** (3): 163-178.
69. Rosoff, P.M., Patel, K., Scates, A., G. Rhea, Bush, P., and Govert, J. A. (2012) "Coping with critical drug shortages: a procedural approach for allocating scarce resources in hospitals." **Arch. Int. Med.**: 172(19): 1494-9.
70. Rosoff, P.M. (2012) "Institutional futility policies are inherently unfair." **HEC Forum**: DOI 10.1007/s10730-012-9194-9.
71. Fuemmeler, B.F., Clark, K., Moriarty, L., Pendzich, M.K., Lovelady, C., Rosoff, P., Blatt, J., Demark-Wahnefried, W. (2013) "Diet, physical activity, and body composition changes during the first year of treatment for childhood acute leukemia and lymphoma." **J. Ped. Hematol/Oncol.**: in press.
72. Raizis, A.M., Van Mater, D., Aaltonen, L.A., Lohmann, D., Bickley, V., George, P.M., Zhou, Y., and Rosoff, P.M. (2013) "Trilateral Retinoblastoma in a Patient with Peutz-Jeghers Syndrome." **Amer. J. Med. Gen.**: in press.
73. Coleman, D. L. and P. M. Rosoff (2013) "The authority of 'mature minors' to consent to medical treatment." **Pediatrics**: in press.
74. Rosoff, P.M. (2013) "Winners and losers in healthcare rationing.": submitted.
75. Rosoff, P.M. (2013) "Should surrogate decision-makers be licensed?": submitted.
76. Rosoff, P.M., R. Maher, and D. L. Coleman (2013) "Are children entitled to organ transplants (no matter what)?": submitted.

**BOOKS:**

1. Rosoff, P.M. (2014) "**Rationing is Not a Four-Letter Word**" MIT Press, Cambridge (MA): forthcoming.

**CHAPTERS IN BOOKS:**

1. Rosoff, P.M. and Cantley, L.C. (1985) "Ion fluxes and differentiation in transformed cell lines." in **Regulation and Development of Membrane Transport Processes** (J.S. Graves, ed.). John Wiley: New York. pp 193-204.
2. Cantley, L.C., Rosoff, P.M., Levenson, R., Macara, I.G., Yeh, L-A., Ling, L., and English, L. (1985) "Na<sup>+</sup> and Ca<sup>2+</sup> fluxes and differentiation on transformed cells." in

**Calcium in Biological Systems** (R.P. Rubin, G.B. Weiss, & J.W. Putney, eds.). Plenum: New York. pp 173-178.

3. Rosoff, P.M. and Cantley, L.C. (1985) "The role of ion fluxes in hematopoietic cell differentiation." in **Stem Cell Physiology** (J. Palek, ed.). Alan R. Liss, Inc.: New York. pp 331-340.
4. Rosoff, P.M. and Cantley, L.C. (1986) "B lymphocyte differentiation: role of phosphoinositides, C kinase, and  $\text{Na}^+$ - $\text{H}^+$  exchange." in  **$\text{Na}^+$ - $\text{H}^+$  Exchange, Intracellular pH and Cell Function** (P. Aronson & W. Boron, eds.). Academic Press: New York. pp 193-199.
5. Whitman, M., Fleischman, L., Chahwala, S.B., Cantley, L., and Rosoff, P. (1986) "Phosphoinositides, mitogenesis, and oncogenesis." in **Phosphatidylinositol Turnover and Receptor Function** (Putney, J.W., Jr., ed.). Alan R. Liss, Inc.: New York. pp 197-217.
6. Rosoff, P.M. (1988) "Regulation of  $\text{Na}^+$ / $\text{H}^+$  exchange - rapid effectors: effects of phorbol esters on  $\text{Na}^+$ / $\text{H}^+$  exchange." in  **$\text{Na}^+$ / $\text{H}^+$  Exchange** (Grinstein, S., ed.). CRC Press, Boca Raton. pp 235-242.
7. Corey, S.J. and Rosoff, P.M. (1989) "Phagocyte Activation" in **Phagocytes in Health and Disease** (M.S. Klempner, Styrt, B., and Ho, J.L., ed.). MTP Press, pp 25-42.
8. Rosoff, P.M. and Cantley, L.C. (1990) "Regulatory Mechanisms" in **Hematology: Basic Principles and Practice** (Benz, E.J.Jr., Cohen, H.J., Furie, B., Hoffman, R., and Shattil, S.J. eds.) Churchill Livingstone: pp 51-58.
9. Rosoff, P.M. and Potter, D. A. (1994) "Regulatory Mechanisms" in **Hematology: Basic Principles and Practice, 2nd Ed.** (Hoffman, R., Benz, E.J. Jr., Shattil, S.J., Furie, B., Cohen, H.J., and Silberstein, L.E., eds.) Churchill Livingstone, New York: pp60-69.
10. Rosoff, P.M. (1999) "Adult Survivors of Childhood and Adolescent Cancer: Successes and Challenges". The In Remembrance Project, Hamilton College, NY.  
<http://www.inremembrance.org>.

#### OTHER:

#### A. PUBLISHED SCIENTIFIC REVIEWS (FOR MASS DISTRIBUTION)

1. Dinarello, C.A., Clark, B.D., Puren, A., Savage, N., and Rosoff, P.M. (1989) "The Interleukin-1 receptor." **Immunol. Today** **10**: 49-51.
2. Rosoff, P.M. (1990) "IL-1 Receptors: Structure and Signals" in **Seminars in Immunology** **2**: 129-137.

3. Rosoff, P.M. and Kreissman, S.G. (2002) "Late Effects of Treatment in Survivors of Neuroblastoma" in **NB Journal (Fall Issue)**: 3.
4. Rosoff, P.M. (2006) "The Two-Edged Sword of Curing Childhood Cancer". **New Engl. J. Med.** **355**: 1522-1523.
5. Saini, S. and Rosoff, P.M. (2007) "Are We Finally Ready For Outpatient Management Of Febrile Neutropenia?" **Pediatr. Blood Cancer** **49**: 765-766.

**B. SELECTED ABSTRACTS: NONE**

**C: EDITORIALS, POSITION, AND BACKGROUND PAPERS**

1. Rosoff, P.M. (2002) "A better lifetime for cancer survivors". **Durham Herald-Sun**: October 21.
2. Rosoff, P.M. and DeCamp, M. (2006) "Pandemic Tests." **Raleigh News and Observer**: February 23, 2006, page 13A.
3. Rosoff, P.M. (2000) "Letter to the Editor". **New Engl. J. Med.** **342**: 2002.
4. Rosoff, P.M. (2003) "Letter to the Editor". **New Engl. J. Med.**: **348**: 863.
5. Coleman, D. and Rosoff, P. (2008) "FDA Offers a Dangerous Gift to Drug Companies." **Raleigh News and Observer**: March 6, 2008, page 9A; **Orlando Sentinel**, March 23, 2008.
6. Rosoff, P.M. (2008) "Letter to the Editor". **New Engl. J. Med.** **358**: 20.
7. Rosoff, P.M. (2009) "Doctors should not participate in state executions", **Durham Herald-Sun**: May 7, 2009, page A7; "Despite ruling, doctors should not participate in executions", **Charlotte Observer**, May 10, 2009.
8. Rosoff, P.M. (2009) "Who decides who lives and who dies?" **Durham Herald-Sun**: November 6.
9. Rosoff, P.M. (2011) "Who Shall Live and Who Shall Die?" **DukeMed Magazine** **10 (2)**: 38-39.
10. Rosoff, P.M. (2011) "What kind of morality targets the poor?" **Raleigh News and Observer**; March 9, page 9A.

**CONSULTANT APPOINTMENTS:**

National Science Foundation Program in Cell Biology      1985-1987

T Cell Sciences, Inc., Cambridge, MA	1987 - 1989
California Tobacco-Related Disease Research Program	1992 – 1998
The Children’s Cancer Foundation (Baltimore, MD)	1997
Molecular Pharmaceuticals, Inc. Thousand Oaks, CA	1994 - 1998
NIH/NCI Clinical Oncology Study Section	2000 - 2003
Member, North Carolina Institute of Medicine Taskforce on Ethics and Influenza Pandemic Planning	2006-2007
Novo Nordisk (Copenhagen, Norway)	2012

**PROFESSIONAL AWARDS AND SPECIAL RECOGNITIONS:**

<i>Alpha Omega Alpha</i> Medical Honor Society	1977
Award of the Department of Pediatrics, Case Western Reserve University School of Medicine	1978
David Abraham Postdoctoral Fellow, Dana-Farber Cancer Institute	1983-1984
Pew Scholar in the Biomedical Sciences	1987-1991
Scholar of the Leukemia Society of America	1990-1995
Stohlmann Scholar of the Leukemia Society of America	1995-1996
Pew Science and Society Institute Scholar	2001-2002
Fellow, American Academy of Pediatrics	2004 – present
Inclusion in “America’s Top Doctors”	2001- present
Visiting Professor, American University of Beirut	9/2009
Featured Speaker, DeVos	9/2009
Medical Ethics Colloquy on “Nature and Nurture. Their contribution to Behavior”	
Fellow in Residence, Foundation Brocher, Hermance (Switzerland)	11/2010
American Society of Bioethics & Humanities,	10/2011
Chair of the subcommittee on Clinical Ethics (annual Meeting)	10/2012

**ORGANIZATIONS AND PARTICIPATION:**

American Association for the Advancement of Science	1979 - 2005
Society for Pediatric Research	1988 - 2004
American Association of Immunologists	1989 - 2000
American Society for Biochemistry & Molecular Biology	1989 - 2004
American Society of Hematology	1991 - 2004
American Society of Pediatric Hematology/Oncology	1996 - 2005
Pediatric Oncology Group (Full Member)	1996 - 2000
Children’s Oncology Group (Full Member)	2000 – present
American Society of Clinical Oncology	1997 – 2005
American Society for Bioethics and Humanities	2004 – present
American Academy of Pediatrics (Fellow)	2004 – present
North Carolina Pediatric Society	1995 – present
Executive Committee	2003 - 2006
North Carolina Medical Society Ethics & Judicial Affairs	2007- present

Committee

Durham County Medical Reserve Corps

2011 - present

**TEACHING RESPONSIBILITIES INCLUDING CONTINUING EDUCATION:****MENTORING**

<b>NAME</b>	<b>AFFILIATION</b>	<b>DATES</b>	<b>STATUS</b>
T. S. Rogers, Ph.D.	Dept. Physiology, Tufts School of Medicine	1986-1988	Research Scientist Southern Research Inst. Birmingham, AL
S. Corey, M.D.	Dept. Physiology, Tufts School of Medicine	1987-1989	Murphy-Rosen Chair in Pediatrics and Cancer Biology, Northwestern University & Children's Memorial Hospital, Chicago
C. O'Riordan, Ph.D.	Dept. Physiology, Tufts School of Medicine	1987-1989	Research Scientist Genzyme Corp Framingham, MA
K. R. Prasad, Ph. D.	Dept. Physiology, Tufts School of Medicine	1990-1992	Research Associate Div. Heme/Onc., Dept. Med. New England Medical Ctr, Boston, MA
J. Zhang, M.D., Ph.D.	Dept. Physiology, Tufts School of Medicine	1992-1995	Research Associate Dept. Physiology, Tufts School of Medicine
R. Berland, Ph.D.	Dept. Physiology, Tufts School of Medicine	1992-1995	Research Associate Dept. Pathology, Tufts School of Medicine
E. Cifuentes, Ph.D.	Dept. Physiology, Tufts School of Medicine	1993-1995	Postdoctoral Fellow Dept. Medicine St. Elizabeth's Hospital Boston, MA
H. Zheng, M.D.	Dept. Pediatrics, DUMC	1998	Senior Scientist Beijing Children's Hospital Beijing, PRC
S. Bayliff, MD	Fellow, Pediatric Heme- Onc, DUMC	1999-2001	Asst. Prof. Pediatrics University of KY (Lexington)
Ilana Ressler	Senior Student Human Development Certificate Program, Duke	2000	Medical Student Case Western Res. University
Rachel Masi	Senior Student Human Development Certificate Program, Duke	2001	Private Workforce
Adrienne McFaden	3 <sup>rd</sup> Yr. DUSM Student Clinical Ethics Internship	2003-4	Graduated 2004

Alexis Sheaffer	Senior Student Human Development Certificate Program, Duke	2005	Graduated 2005
Jesse Waggoner	2 <sup>nd</sup> Yr. DUSM Student Clinical Preceptor	2005	Graduated 2006
Yaolin Zhou	Senior Student Human Development Certificate Program, Duke	2006	Graduated 2006
Sarah Lofgren	1 <sup>st</sup> Yr. DUSM Student Pediatric Interest Group Preceptor	2007	Graduated 2011
Ashley Presar	3 <sup>rd</sup> Yr. DUSM Student Continuity Clinic Preceptor	2006-7	Graduated 2008
Rachel Hughes	3 <sup>rd</sup> Yr. DUSM Student Continuity Clinic Preceptor	2011-12	
Dr. Abhay Singh	Urology Resident (Duke) Law, Medicine & Ethics GME Concentration Mentor)	2012-13	

**FORMAL TEACHING:**

Hematology-Oncology Lectures to Pediatric Residents	1995-present
Ethics Lectures to housestaff and faculty	2005-present
Ethics Lectures to medical students	2005-present
Medical School Capstone Course	2005 - 2008
Nursing Clinical Ethics Resource Mentor Course	2007- present
“Conversations about Care & Conflict: A Nursing Ethics Forum”	2006 - 2008
Ethics Lectures @ Duke Raleigh Hospital	2007 - present
Clinical Ethics Grand Rounds, Duke Hospital	2010 - present
Philosophy 292 (Duke): “Rationing and the Healthcare System”	2011 (Fall)

**AREAS OF RESEARCH INTERESTS:**

Rationing and Clinical Decision-making  
Clinical Medical Ethics

**EXTERNAL SUPPORT - GIFTS, GRANTS, AND CONTRACTS:**

	<u>PI</u>	<u>% Effort</u>	<u>Purpose</u>	<u>Amount</u>	<u>Approximate Duration</u>
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	<u>PI</u>	<u>% Effort</u>	<u>Purpose</u>	<u>Amount</u>	<u>Approximate Duration</u>
<b>a) Past:</b>	PM Rosoff	100	David Abraham Postdoctoral Fellowship	\$25,000	7/1/83-6/30/84
	PM Rosoff	75	Physician Investigator Development Award (NCI #KO8-CA01156)	\$142,518	7/1/84-6/30/87
	PM Rosoff	15%	American Cancer Society Research Grant #BC-513 ("Protein kinase C regulation of Na <sup>+</sup> /H <sup>+</sup> exchange")	\$150,000	7/1/85-6/30/87
	PM Rosoff	No salary support	Pew Scholars Program ("Biochemical characterization of the pertussis toxin receptor")	\$200,000	7/1/87-6/30/91
	PM Rosoff	40	NIH Grant RO1- GM41076 ("Isolation of the human pertussis toxin receptor")	\$750,000	3/1/88 – 2/28/1996
	PM Rosoff	25	American Cancer Society Research Grant #BE-19 ("Purification of the T cell activated Ca <sup>2+</sup> channel")	\$200,000	1/1/90-12/31/91
	PM Rosoff	No salary support	Leukemia Society of America Scholar Award ("Purification of the T cell activated Ca <sup>2+</sup> channel")	\$200,000	7/1/90-6/30/95
	PM Rosoff	No salary support	Pardee Foundation ("Molecular cloning of the pertussis toxin receptor")	\$90,000	4/1/93-3/31/94
	PM Rosoff	5	Pediatric Oncology Group (NCI: 5U10- CA-15525-28): local site	\$940,399	1/1/96-12/31/01
	PM Rosoff	No salary support	APS/SPR Multicenter Clinical Trial Initiative	\$2500	5/2000
	PM Rosoff	No salary	NIH/NCI "PREP" Award ("Down	\$21,600	7/2000

	<b><u>PI</u></b>	<b><u>% Effort</u></b>	<b><u>Purpose</u></b>	<b><u>Amount</u></b>	<b><u>Approximate Duration</u></b>
		support	Syndrome and Leukemia")		
	PM Rosoff	No salary support	Orthobiotech #PR99-11-034/044 (Epoitin-Alpha)	\$200,000	10/1/00-6/30/2003
	D. Wendler	No salary support	NCI/NIH Subcontract (Assent in Clinical Trials)	\$20,000	2002-2004
	PM Rosoff	No salary support	Trent Foundation (Gamete Cryopreservation)	\$2500	1/1/2002-12/31/2004
	R. Califf	8.5	CTSA Ethics Core		9/30/06-6/30/08
	P.Rosoff	No salary support	Brocher Foundation Residential Fellowship	N/A	11/2010

**CLINICAL ACTIVITY:**

<b><u>Type of Practice</u></b>	<b><u>Time Commitment</u></b>
--------------------------------	-------------------------------

Outpatient services	15%
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Inpatient services	5%
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**PARTICIPATION IN ACADEMIC AND ADMINISTRATIVE ACTIVITIES OF THE  
UNIVERSITY AND MEDICAL CENTER:**

Chief, Div. Pediatric Hematology- Oncology	1995 - 2005
Director, Fellowship Program in Pediatric Hematology-Oncology	1995 - 2000
Director, Pediatric Oncology, Duke Comprehensive Cancer Center	1995 - 2005
Steering Committee Duke Comprehensive Cancer Center	1995- 1998
Chair, Search Committee for Chief, Division of Pediatric Allergy/Immunology	2001 - 2002
Member, Dept. Medicine Chair Search Committee	2002 - 2003
Director, Young Cancer Survivors Program	1998 - present
Member, Clinical Ethics Consultation Committee (Chair since 2005)	1999 – present
Member, Psychosocial Oncology Research: Cancer Prevention, Detection & Control Program	2000 – 2009
Faculty, Undergraduate Program in Human Development	2001 - 2006
Member, Mentorship Program North Carolina School of Science and	2001 - 2006



Mathematics	
Faculty Scholar Duke Institute on Care at the End of Life	2001 – present
Clinical Sciences Faculty Council	2002 - 2006
Medical School Honor Council	2004 - present
Chair, DU Hospital Task Force on Clinical Medical Ethics	2004 – 2005
Director, Duke Hospital Program in Clinical Ethics & Chair, Ethics Committee	2005 – present
Faculty Scholar, Trent Center for Bioethics, Humanities and History of Medicine	2005 – present
Faculty Member, 3 <sup>rd</sup> Year Humanities Research Track, DUSM	2009 - present
Special Taskforce on Promotions Policy, DUSOM	2009 - 2010
Faculty Hearing Committee (Duke University)	2009 - 2012
Member, Duke University Academic Council	2010 - 2012
Member, Duke University Athletic Council	2010 - 2013
Dept. Pediatrics Site-Based Research Unit Advisory Board	2010 - present
Member, DUSOM Promotions Committee (Chair)	2010 - present
Member, DUH Critical Drug Shortage Taskforce	2011 - present
Vice-Chair, DUH Utilization Management Committee	2011 - present
Advisory Committee for a GME Concentration – Law, Ethics & Health Policy	2012 - present

**HOSPITAL/UNIVERSITY POLICIES AUTHORED:**

1. Policy For Clinical Care Of Unbefriended Patients
2. Revised Policy For “Do Not Attempt Resuscitation”
3. Revised Policy for Removal of Life Sustaining Measures
4. Policy For Temporary Suspension Of DNAR
5. Policy For Critical Medication Shortages
6. Policy For Discriminatory Requests By Patients Or Families.
7. Policy on Providing Non-Beneficial Care (Pending)

02/02/2011

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## Education and Training

09/1980-06/1984	BA, Carleton College, <i>Magna Cum Laude</i> (Philosophy)
09/1984-06/1988	MD, University of Minnesota

### *Postdoctoral Training*

07/1988-06/1991	Internal Medicine Residency Training Program, Mayo Graduate School of Medicine, Rochester, MN
07/1991-06/1992	Fellowship in Medical Ethics, University of Chicago Center for Clinical Medical Ethics
07/1992-06/1994	Fellowship in General Medicine, University of Pittsburgh, Department of Medicine

## Academic, Administrative and Clinical Appointments

### *Academic Appointments*

07/1994-06/2000	Assistant Professor of Medicine, Department of Medicine, University of Pennsylvania School of Medicine
07/1994-06/2000	Senior Fellow, The Leonard Davis Institute of Health Economics, University of Pennsylvania School of Medicine
07/1994-06/2000	Faculty, Center for Bioethics, University of Pennsylvania School of Medicine
07/1995-06/2000	Assistant Professor of Epidemiology, University of Pennsylvania School of Medicine (Secondary Appointment)
08/2000-08/2004	Associate Professor of Medicine, Department of Medicine, University of Michigan, School of Medicine
08/2002-08/2004	Adjunct Associate Professor of Psychology, College of Literature, Science and Art, University of Michigan, School of Medicine
09/2004-06/2010	Professor of Medicine, Department of Medicine, University of Michigan
09/2004-06/2010	Adjunct Professor of Psychology, School of Literature, Science and the Arts, University of Michigan

01/2008-06/2010	George Dock Collegiate Professor of Medicine, University of Michigan
07/2010-present	John O. Blackburn Professor of Marketing, Fuqua School of Business, Duke University
07/2010-present	Professor of Public Policy, Sanford School of Public Policy, Duke University
01/2011-present	Faculty Associate, Trent Center for Bioethics, Duke University

#### *Administrative Appointments*

07/1999-07/2000	Director, General Medicine Research Fellowship, University of Pennsylvania
08/2000-06/2003	Director, General Medicine Research Fellowship, University of Michigan
08/2000-12/2003	Core faculty, Robert Wood Johnson Clinical Scholars Program, University of Michigan and Ann Arbor VAMC
08/2000-06/2010	Director, Center for Behavioral and Decision Sciences in Medicine, Ann Arbor VAMC and University of Michigan
12/2003–06/2007	Associate Director, Robert Wood Johnson Clinical Scholars Program, University of Michigan and Ann Arbor VAMC
07/2007-06/2010	Co-Director, Robert Wood Johnson Clinical Scholars Program, University of Michigan and Ann Arbor VAMC

#### *Clinical Appointments*

07/1994-07/2000	Staff Physician, VAMC, Philadelphia
07/1994-07/2000	Staff Physician, Hospital of the University of Pennsylvania
08/2000-06/2010	Staff Physician, VAMC, Ann Arbor

## **Research Interests**

My research explores controversial issues about the role of values and preferences in health care decision making, from decisions at the bedside to policy decisions. I use the tools of decision psychology to explore ethical debates about topics like informed consent and health care rationing.

## **Honors and Awards**

1984	Phi Beta Kappa.
1984	Dana Award (academic achievement, leadership, character), Carleton College, Northfield MN
1994	Mack Lipkin Associates Award for outstanding scientific presentation at national meeting: “Elevator Talk: Observational Study of Inappropriate Conversations in a Public Space.” SGIM national meeting, Washington, DC
1994	Lee Lusted Award for outstanding scientific presentation, honorable mention: “Why Oregon's Cost-effectiveness List

	Failed: Evidence that Individual Utilities do not Predict Rationing Choices.” Society for Medical Decision Making national meeting, Cleveland, OH
1994-1997	Measey Foundation Faculty Fellow, Department of Medicine, University of Pennsylvania School of Medicine
1996-1998	Health Services Research and Development Career Development Award, Department of Veterans Affairs
1997-2001	Robert Wood Johnson Foundation Generalist Physician Faculty Scholar Award
1997	Rockefeller Foundation, recipient of an award to stay at Bellagio Conference Center, Bellagio, Italy.
1997	Outstanding Paper by a Young Investigator, Society for Medical Decision Making.
1998	Nellie Westerman Prize in Clinical Research Ethics, American Federation for Medical Research.
1999-2001	Senior Research Associate, Health Services Research Program, Department of Veterans Affairs.
2000-2005	Presidential Early Career Award for Scientists and Engineers (PECASE)
2000	Labelle Lecturer, McMaster University, Hamilton, Ontario
2000	Mayers Endowment Lecture, Penn State.
2004	Mother Marianne Cope Lectureship in Ethics, The St. Francis International Center for Healthcare Ethics.
2004	Fellow, Hastings Center
2004	Sadoff Lectureship, University of Minnesota
2005	Moore Lectureship, Simon Fraser University; Vancouver, BC, Canada
2007	Stevens Lectureship, Rochester General Hospital, Rochester, NY
2008	David Brin Visiting Professor, Johns Hopkins University, School of Medicine, Baltimore, MD
2008-2010	George Dock Collegiate Professorship, University of Michigan
2008-2011	Robert Wood Johnson Foundation Health Policy Investigator
2008	Member, World Economic Forum, Global Health Committee
2008	Eugene Sullivan Memorial Lecturer, Northwest Society of Colon and Rectal Surgeons, Orcas Island, WA
2009	Distinguished Alumni Achievement Award, Carleton College
2010	John O. Blackburn Professor of Marketing

## Bibliography

### *Books*

1. Ubel PA. Pricing life: Why it's time for health care rationing. Bradford Books a division of MIT Press, Cambridge, 2000.

2. Ubel PA. You're stronger than you think: Tapping the secrets of emotionally resilient people. McGraw-Hill. New York, 2006.
3. Ubel PA. Free Market Madness: Why Human Nature is at Odds with Economics—and Why it Matters. Harvard Business School Press. Boston, 2009.

#### *Peer-Reviewed Publications*

1. Ubel PA, Arnold RM, Caplan AL. Rationing failure: Retransplantation of scarce, vital organs in the US. JAMA. 270:2469-2474, 1993.
2. Ubel PA. Assisted suicide and the case of Quill and Diane. Issues in Law and Medicine. 8; 4:487-502, 1993.
3. Ubel PA, Arnold RM. The unbearable rightness of bedside rationing: Physician duties in a climate of cost containment. Archives Internal Medicine 155:1837-1842, 1995.
4. Ubel PA, Zell M, Fischer G, Miller D, Peters-Stefani D, Arnold, RM. Elevator talk: Observational study of inappropriate conversations in a public space. American Journal Medicine. 99:190-194, 1995.
5. Ubel PA. Doctor talk: Technology and modern conversation. American Journal Medicine. 98:587-588, 1995.
6. Ubel PA, Arnold R, Gramelspacher G, Hoppe R, Landefeld CS, Levinson W, Tierney W, Tolle S. Acceptance of external funds by physician organizations: Issues and policy options. Journal General Internal Medicine. 10:624-630, 1995.
7. Ubel PA, Loewenstein G. The efficacy and equity of retransplantation: An experimental survey of public attitudes. Health Policy. 34:145-151, 1995.
8. Ubel PA, Loewenstein G. Distributing scarce livers: The moral reasoning of the general public. Social Science Medicine. 42:1049-1055, 1996.
9. Ubel PA, Loewenstein G. Public perceptions of the importance of prognosis in allocating transplantable livers to children. Medical Decision Making. 16:234-241, 1996.
10. Ubel PA, Kamlet M, Scanlon D, Loewenstein G. Individual utilities are inconsistent with rationing choices: A partial explanation of why Oregon's Cost-effectiveness List failed. Medical Decision Making. 16:108-119, 1996.
11. Ubel PA. Can we continue to afford organ transplants in an era of managed care? American Journal of Managed Care. 2:293-297, 1996.
12. Ubel PA, Dekay ML, Baron J, Asch DA. Cost-effectiveness analysis in a setting of budget constraints: Is it equitable? New England Journal Medicine. 334:1174-1177, 1996.
13. Ubel PA, DeKay ML, Baron J, Asch DA. Public preferences for efficiency and racial equity in kidney transplant allocation decisions. Transplantation Proceedings. 28:2975-2980, 1996.
14. Beumont MG, Graziani A, Ubel PA, MacGregor RR. Safety of Dapsone as *Pneumocystis carinii* pneumonia prophylaxis in HIV infected patients with allergy to TMP/SMX. American Journal of Medicine. 100:611-616, 1996.

15. Ubel PA, Goold SD. Recognizing bedside rationing: Clear cases and tough calls. Annals of Internal Medicine. 126:74-80, 1997.
16. Ubel PA, Loewenstein G. The role of decision analysis in informed consent: Choosing between intuition and systematicity. Social Science Medicine. 44:647-656, 1997.
17. Ubel PA. Transplanting alcoholics: Separating prognosis and responsibility from social biases. Liver Transplantation and Surgery. 3:1-5, 1997.
18. Farber NJ, Berger M, Davis EB, Weiner J, Boyer EG, Ubel PA. Confidentiality and health insurance fraud. Archives of Internal Medicine. 157:501-504, 1997.
19. Asch DA, Ubel PA. Rationing by any other name. New England Journal Medicine. 336:1668-1671, 1997.
20. Louis ON, Sankar P, Ubel PA. Kidney transplant candidates' views of the transplant allocation system. Journal General Internal Medicine. 12:478-484, 1997.
21. Ubel PA, Asch DA. Semantic and moral debates about hastening death. Journal of Clinical Ethics. 8:242-249, 1997.
22. Silver-Isenstadt A, Ubel PA. Medical student name tags: Identification or obfuscation? Journal General Internal Medicine. 12:669-671, 1997.
23. Ubel PA, Goold S. Does bedside rationing violate patients' best interests? An exploration of "moral hazard." American Journal of Medicine. 104:64-68, 1998.
24. Asch DA, Christakis NA, Ubel PA. Conducting physician mail surveys on a limited budget: A randomized trial comparing \$2 bill versus \$5 bill incentives. Medical Care. 36:95-99, 1998.
25. Ubel PA, Spranca M, DeKay M, Hershey J, Asch, DA. Public preferences for prevention versus cure: What if an ounce of prevention is worth only an ounce of cure? Medical Decision Making. 18:141-148, 1998.
26. Ubel PA, Merz JF, Shea J, Asch DA. How preliminary data affect people's stated willingness to enter a hypothetical randomized controlled trial. Journal of Investigative Medicine. 45:561-566, 1998.
27. Ubel PA, Goold SD. "Rationing" Health Care: Not All Definitions Are Created Equal. Archives of Internal Medicine. 158:209-214, 1998.
28. Ubel PA, Loewenstein G, Scanlon D, Kamlet M. Value measurement in cost-utility analysis: Explaining the discrepancy between analog scale and person trade-off elicitation. Health Policy. 43:33-44, 1998.
29. Farber NJ, Berger MS, Davis EB, Weiner J, Boyer EG, Ubel PA. Physicians' experiences with patient-initiated health insurance fraud. Delaware Medical Journal. 70:329-334, 1998.
30. Ubel PA, Caplan AL. Geographic favoritism in liver transplantation: Unfortunate or unfair? New England Journal Medicine. 339:1322-1325, 1998.
31. Parsons GN, Kinsman, Ubel PA. Encourage qualitative research to improve students' clinical skills! Academic Medicine. 73:933-934, 1998.

32. Ubel PA, Baron J, Asch DA. Social responsibility, personal responsibility, and prognosis in public judgments about transplant allocation. Bioethics. 13:57-68, 1999.
33. Nord E, Pinto JL, Richardson J, Menzel P, Ubel PA. Incorporating societal concerns for fairness in numerical valuations of health programs. Health Economics. 8:25-39, 1999.
34. Menzel P, Gold MR, Nord E, Pinto Prades JL, Richardson J, Ubel PA. Towards a broader view of values in cost-effectiveness analysis in health care. Hastings Center Report 29:7-15, 1999.
35. Silver-isenstadt A, Ubel PA. Erosion in medical students' attitudes about telling patients they are students? Journal General Internal Medicine. 14:481-487, 1999.
36. Ubel PA. How stable are people's preferences for giving priority to severely ill patients? Social Science Medicine. 49:895-903, 1999.
37. Ubel PA. The challenge of measuring community values in ways appropriate for setting health care priorities. Kennedy Institute of Ethics Journal. 9:263-284, 1999.
38. Ubel PA, Richardson J, Pinto Prades JL. Life saving treatments and disabilities: Are all QALYs created equal? International Journal of Technology Assessment in Health Care. 15:738-748, 1999.
39. Armstrong K, Berlin M, Propert K, Schwartz JS, Ubel PA. Educational content and the effectiveness of influenza vaccination reminders. Journal General Internal Medicine. 14:695-697, 1999.
40. Ubel PA, Baron J, Nash B, Asch DA. Are preferences for equity over efficiency in health care allocation "all or nothing?" Medical Care. 38:366-373, 2000.
41. Ubel PA, Richardson J, Menzel P. Societal value, the Person Trade-Off, and the dilemma of whose values to measure for cost-effectiveness analysis. Health Economics. 9:127-136, 2000.
42. DeKay ML, Nickerson CAE, Ubel PA, Hershey JC, Spranca MD, Asch DA. Further explorations of medical decisions for individuals and groups. Medical Decision Making. 20:39-44, 2000.
43. Green MJ, Farber N, Ubel PA, Arnold R. Lying to each other: When internal medicine residents use deception with their colleagues. Archives of Internal Medicine 160:2317-2323, 2000.
44. Ubel PA, Nord E, Gold M, Menzel P, Pinto Prades JL, Richardson J. Improving value measurement in cost-effectiveness analysis. Medical Care. 38:892-901, 2000.
45. Conigliaro J, Good, CB, Macpherson DS, Lofgren RP, Allman R, Passman LJ, Ubel PA, O'Connor M, Hanusa B, Whittle J. Understanding racial variation in the use of coronary revascularization procedures: The role of clinical factors. Archives of Internal Medicine. 160:1329-1335, 2000.
46. Armstrong K, Popik S, Guerra C, Ubel PA. Beliefs about breast cancer risk and use of postmenopausal hormone replacement therapy. Medical Decision Making. 20:308-313, 2000.



47. Ubel PA, Bryce CL, Siminoff LA, Caplan AL, Arnold RM. Pennsylvania's voluntary benefits program: Evaluating an innovative approach to increasing organ donation. Health Affairs. 19:206-211, 2000.
48. Ubel PA, Silver-Insensadt A. Are patients willing to participate in medical education? Journal of Clinical Ethics. 11:230-235, 2000.
49. Farber NJ, Davis EB, Weiner J, Jordan J, Boyer EG, Ubel PA. Physicians' attitudes about involvement in lethal injection for capital punishment. Archives of Internal Medicine. 160:2912-2916, 2000.
50. Neuberger J, Ubel PA. Finding a place for public preferences in liver allocation decisions. Transplantation. 70(10): 1411-1413, 2000.
51. Green MJ, Fong S, Mauger DT, Ubel PA. Rationing HIV medications: What do patients and the public think about allocation policies? Journal of Acquired Immune Deficiency Syndromes. 26:56-62, 2001.
52. Ubel PA, Jepson C, Baron J. The inclusion of patient testimonials in decision aids: Effects on treatment choices. Medical Decision Making. 21:60-68, 2001.
53. Armstrong KA, Berlin M, Schwartz JS, Probert K, Ubel PA. Barriers to influenza immunization in a low-income urban population. American Journal of Preventive Medicine. 20:21-25, 2001.
54. Ubel PA, Baron J, Asch DA. Preference for equity as a framing effect. Medical Decision Making. 21:180-189, 2001.
55. Ubel PA, Loewenstein G, Hershey J, Baron J, Mohr T, Asch DA, Jepson C. Do nonpatients underestimate the quality of life associated with chronic health conditions because of a focusing illusion? Medical Decision Making. 21:190-199, 2001.
56. Baron J, Ubel PA. Revising a priority list based on cost-effectiveness: The role of the prominence effect and distorted utility judgments. Medical Decision Making. 21:278-287, 2001.
57. Peck BM, Asch DA, Goold SD, Roter DL, Ubel PA, McIntyre LM, Abbott KH, Hoff JA, Koropchak CM, Tulskey JA. Measuring patient expectations: Does the instrument affect the satisfaction or expectations? Medical Care. 39:100-108, 2001.
58. Halpern SD, Metzger DS, Berlin JA, Ubel PA. Who will enroll? Predicting participation in a phase II AIDS vaccine trial. Journal of AIDS. 27:281-288, 2001.
59. Ubel PA. Physicians, thou shalt ration: The necessary role of bedside rationing in controlling health care costs. Healthcare Papers. 2:10-21, 2001.
60. Ubel PA. Putting bedside rationing back into perspective. Healthcare Papers. 2:69-75, 2001.
61. Parsons GN, Kinsman SB, Bosk CL, Sankar P, Ubel PA. Between two worlds: Medical student perceptions of humor and slang in the hospital setting. Journal General Internal Medicine. 16:550-553, 2001.
62. Armstrong K, Fitzgerald G, Schwartz SJ, Ubel PA. Using survival curve comparisons to inform patient decision making: Can a practice exercise improve understanding? Journal General Internal Medicine. 16:544-549, 2001.

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64. Ubel PA, Jepson C, Baron J, Mohr T, McMorrow S, Asch DA. Allocation of transplantable organs: Do people want to punish patients for causing their illness? Liver Transplantation. 7:600-607, 2001.
65. Armstrong KA, Schwartz JS, Fitzgerald G, Ubel PA. Effects of framing as gain vs. loss on hypothetical treatment choices: Survival and mortality curves. Medical Decision Making. 22:76-83, 2002.
66. Farber NJ, Aboff BM, Weiner J, Davis EB, Boyer EG, Ubel PA. Physicians' willingness to participate in the process of lethal injection for capital punishment? Annals of Internal Medicine. 135:884-888, 2001.
67. Alexander GC, Werner RM, Fagerlin A, Ubel PA. Gaming the system: Public preferences that doctors play? Journal of General Internal Medicine. 16(Supplement 1): 185, 2001.
68. Ubel PA. "What should I do doc?" Should physicians ever make clinical recommendations? Archives of Internal Medicine. 162:977-980, 2002.
69. Werner RM, Alexander GC, Fagerlin A, Ubel PA. The "hassle factor": What motivates physicians to manipulate reimbursement rules? Archives of Internal Medicine. 162:1134-1139, 2002.
70. Gurmankin AD, Baron J, Hershey JC, Ubel PA. The role of physicians' recommendations in medical treatment decisions. Medical Decision Making. 22:262-271, 2002.
71. Ubel PA, Richardson J, Baron J. Exploring the role of order effects in Person Trade-off elicitations. Health Policy. 61:189-199, 2002.
72. Armstrong K, Weber B, Ubel PA, Guerra C, Schwartz JS. Interest in BRCA 1/2 testing in a primary care population. Preventive Medicine. 34:590-595, 2002.
73. Ballard DW, Li Y, Evans J, Ballard RA, Ubel PA. Fear of litigation may increase resuscitation of infants born near the limits of viability. Journal of Pediatrics. 140:713-718, 2002.
74. Halpern SD, Ubel PA, Caplan AL. Solid organ transplantation for HIV-positive patients: The time is now. New England Journal of Medicine. 347:284-287, 2002.
75. Nord, E, Pinto, JL, Richardson, J, Menzel, P, Ubel PA. Comments to "A note on cost-value analysis." Health Economics Letters. 6:12-14, 2002.
76. Halpern SD, Ubel PA, Berlin JA, Asch DA. Randomized trial of \$5 versus \$10 monetary incentives, envelope size, and candy to increase physician response rates to mailed questionnaires. Medical Care. 40:834-839, 2002.
77. Ubel PA. Is information always a good thing? Helping patients make "good" decisions. Medical Care. 40:39-44, 2002.
78. Halpern SD, Ubel PA, Berlin JA, Townsend R, Asch DA. Physicians' preferences for active-controlled versus placebo-controlled trials of new antihypertensive drugs. Journal of General Internal Medicine. 17:689-695, 2002.

79. Baron, J. and Ubel PA. Types of inconsistency in health-state utility judgments. Organizational Behavior and Human Decision Processes. 89:1110-1118, 2002.
80. Boulis A, Goold SD, Ubel PA. Responding to the immunoglobulin shortage: A case study. Journal of Health Politics, Policy and Law. 27:977-999, 2002.
81. Hershey J, Asch DA, Jepson C, Baron J, Ubel PA. Incremental and average cost-effectiveness ratios: Will physicians make a distinction? Risk Analysis. 23:81-89, 2003.
82. Ubel PA, Jepson C, Silver-Isenstadt A. Don't ask, don't tell: A change in medical student attitudes after obstetrics/gynecology clerkships toward seeking consent for pelvic examinations on an anesthetized patient. American Journal of Obstetrics and Gynecology. 188:575-579, 2003.
83. Alderman AK, Chung KC, Kim HM, Fox DA, Ubel PA. Effectiveness of rheumatoid hand surgery: Contrasting perceptions of hand surgeons and rheumatologists. Journal of Hand Surgery – American Volume. 28:3-11, 2003.
84. Alexander GC, Werner RM, Fagerlin A, Ubel PA. Support for physician deception of insurance companies among a sample of Philadelphia residents. Annals of Internal Medicine. 138:472-475, 2003.
85. Ubel PA, Jepson C, Baron J, Hershey JC, Asch DA. The influence of cost-effectiveness information on physicians' cancer screening recommendations. Social Science and Medicine. 56:1727-1736, 2003.
86. Alderman A, Ubel PA, Kim H, Fox D, Chung K. Surgical management of the rheumatoid hand: Consensus and controversy among rheumatologists and hand surgeons. The Journal of Rheumatology. 30:1464-1472, 2003.
87. Ubel PA, Hirth RA, Chernew M, Fendrick, AM. What is the price of life and why doesn't it increase at the rate of inflation? Archives of Internal Medicine. 163:1637-1641, 2003.
88. Johri M, Ubel PA. Setting organ allocation priorities: should we care what the public cares about? Liver Transplantation Worldwide. 9(8):878-880, 2003.
89. Ubel PA, Loewenstein G, Jepson C. "Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public." Quality of Life. 12:599-607, 2003.
90. Baron J, Asch DA, Fagerlin A, Jepson C, Loewenstein G, Riis J, Stineman MG, Ubel PA. Effect of assessment method on the discrepancy between judgments of health disorders people have and do not have: A Web study. Medical Decision Making. 23(5):422-434, 2003.
91. Beach MC, Asch DA, Jepson C, Hershey JC, Mohr T, McMorro S, Ubel PA. Public response to cost-quality tradeoffs in clinical decisions. Medical Decision Making. 23(5):369-378, 2003.
92. Asch DA, Jepson C, Hershey JC, Baron J, Ubel PA. When money is saved by reducing health care costs, where do physicians think the money goes? American Journal Managed Care. 9(6):438-442, 2003.

93. Heisler M, Vijan S, Anderson RM, Ubel PA, Bernstein SJ, Hofer TP. When do patients and their physicians agree on diabetes treatment goals and strategies, and what difference does it make? Journal of General Internal Medicine. 18(11):893-902, 2003.
94. Ubel PA, Jepson C, Asch DA. Misperceptions about beta blockers and diuretics: a national survey of primary care physicians. Journal of General Internal Medicine. 18(12):977-983, 2003.
95. Zikmund-Fisher B, Fagerlin A, Ubel PA. "Is 28% good or bad?": Evaluability and preferences reversals in health care decisions. Medical Decision Making. 24(2):142-148, 2004.
96. Damschroder LJ, Baron J, Hershey JC, Asch DA, Jepson C, Ubel PA. The validity of person tradeoff measurements: A randomized trial of computer elicitation versus face-to-face interview. Medical Decision Making. 24(2):170-180, 2004.
97. Alexander GC, Werner RM, Ubel PA. The costs of denying scarcity. Archives of Internal Medicine. 164(6):593-596, 2004.
98. Scanlon DP, Hollenbeak CS, Woolton L, Loh E, Ubel PA. Does competition for transplantable hearts lead to gaming of the waiting list? Health Affairs. 23(2):191-198, 2004
99. Jasper JD, Nickerson C, Ubel PA, Asch DA. Altruism, incentives, and organ donation: Attitudes of the transplant community. Medical Care. 42(4):378, 2004
100. Underwood W, DeMonner S, Ubel PA, Fagerlin A, Sanda MG, & Wei JT. Racial disparities in the treatment of localized/regional prostate cancer. Journal of Urology. 171(4): 1504-1507, 2004.
101. Peck, BM, Ubel PA, Roter DL, Door Gold, S, Asch, DA, Jeffreys, AS, Grambow, SC, Tulsky, JA. Do unmet expectations for specific tests, referrals, and new medications reduce patients' satisfaction? Journal of General Internal Medicine. 19:1080-1087, 2004.
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103. Jepson C, Asch DA, Hershey JC, Ubel PA. In a mailed physician survey, questionnaire length had a threshold effect on response rate. Journal of Clinical Epidemiology. 58:103-105, 2005.
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106. Johri M, Damschroder LJ, Zikmund-Fisher BJ, Ubel PA. The importance of age in allocating health care resources: Does intervention type matter? Health Economics. 14(7):669-678, 2005. (Published online October 20, 2004 in advance of print edition)

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109. Ubel PA, Loewenstein G, Schwartz N, Smith D. Misimagining the unimaginable: The disability paradox and healthcare decision making. Health Psychology. 24(4 Suppl.):S57-S62, 2005.
110. Fagerlin A, Wang C, Ubel PA. Reducing the influence of anecdotal reasoning on people's health care decisions: Is a picture worth a thousand statistics? Medical Decision Making. 25(4):398-405, 2005
111. Smith DM, Langa KM, Kabeto MU, Ubel PA. Health, wealth, and happiness: Financial resources buffer subjective well-being after the onset of a disability. Psychological Science. 16:663-666, 2005.
112. Ubel PA, Jankovic A, Smith DM, Langa KM, Fagerlin A. What is perfect health to an 85-year-old?: Evidence for scale recalibration in subjective health ratings. Medical Care. 43(10): 1054-1057, 2005.
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2. Gollust SE, Lantz P, Ubel PA. Images of illness: How causal claims and racial associations influence public preferences for diabetes research spending. Journal of Health Politics, Policy and Law. (In Press)
3. Ubel PA, Silbergleit R. Behavioral equipoise: A way to resolve ethical stalemates in clinical research. American Journal of Bioethics.(In Press)
4. Kozminski MA, Neumann PJ, Nadler ES, Jankovic A, Ubel PA. How long and how well: Oncologists’ attitudes toward the relative value of life-prolonging versus quality of life-enhancing treatments. Medical Decision Making. (In Press)

5. Zikmund-Fisher BJ, Fagerlin A, Ubel PA. Risky feelings: Why a 6% risk of cancer doesn't always feel like 6%. Patient Education and Counseling. (In Press)
6. Volk ML, Ubel PA. Better off not knowing: importing clinical care by limiting physician access to unwanted diagnostic information. Archives of Internal Medicine. (In Press)
7. Zikmund-Fisher BJ, Angott AM, Ubel PA. The Benefits of Discussing Adjuvant Therapies One At A Time Instead of All At Once. Breast Cancer Research and Treatment. (In Press)
8. Ubel PA, Angott AM, Zikmund-Fisher BJ. Recommend Unto Others: Physicians Recommend Different Treatments for Patients than They Would Choose for Themselves. Archives of Internal Medicine. (In Press)
9. Lacey H.P, Loewenstein G, Ubel PA. Compared to What? A Joint Evaluation Method for Assessing Quality of Life. QoL Research. (In press)
10. Zikmund-Fisher BJ, Windschitl PD, Exe N, Ubel PA. "I'll Do What They Did": Social Norm Information and Cancer Treatment Decisions. Patient Education and Counseling. (In press)

#### *In Submission*

1. Zikmund-Fisher BJ, Fagerlin A, Kerr EA, Ubel PA. Misperception of the risk reduction from the first steps of behavior change. (In Submission)
2. Smith DM, Damschroder L, Kim S, Ubel PA. What's it worth? Public willingness to pay for treatment of mental, versus physical, health conditions. (In Submission)
3. Ubel PA, Berry SR, Nadler E, Bell CM, Kozminski M, Jankovic A, Palmer J, Evans WK, Strevel EL, Neumann P. What price for a year of life? Insensitivity to drug cost and value among U.S. and Canadian Oncologists. (In Submission)
4. Ubel PA, Exe N, Zikmund-Fisher BJ. When death pales: Reflection on mortality salience can decrease aversion to mortality. (In Submission)
5. Fagerlin A, Dillard AJ, Smith DM, Zikmund-Fisher BJ, Pitsch R, McClure JB, Greene S, Alford SH, Nair V, Hayes DF, Wiese C, Ubel PA. Women's interest in taking tamoxifen and raloxifene for breast cancer prevention: Response to a tailored decision aid. (In Submission)
6. Ubel PA. Beyond knowledge: Figuring out how to help patients make "good" decisions. (In Submission)
7. Peeters Y, Smith DM, Loewenstein G, Ubel PA. After adversity strikes: Predictions, recollections and reality among people experiencing the onset of adverse circumstances. (In submission)
8. Dillard AJ, Ubel PA, Smith DM, Zikmund-Fisher BJ, Nair V, Derry HA, Zhang A, Pitsch RK, Alford SH, McClure JB, Fagerlin A. The influence of comparative risk perceptions on the decision to take a breast cancer prevention medication. Psychology and Health. (In submission)

9. Dillard A. J, Ubel PA, Canevello A, Smith DM, Zikmund-Fisher BJ, & Fagerlin A, et al. Breast cancer anxiety influences information processing and decision-making in chemoprevention context. (In submission)
10. Singer E, Couper MP, Fagerlin A, Fowler Jr FJ, Levin CA, Ubel PA, Van Hoewyk J, Zikmund-Fisher BJ. The role of perceived benefits and costs in patients' medical decisions. (In submission)
11. Dillard AJ, Ferrer RA, Ubel PA, Fagerlin A. Risk perception measures' association with behavior, affect, and cognition following colon cancer screening messages. (In submission)
12. Jaggi R, DeCastro R. Griffith KA, Rangarajan S, Churchill C, Stewart A, Ubel PA. Similarities and Differences in the Career Trajectories of Male and Female Physician-Researchers (In submission)
13. Fagerlin A, Zikmund-Fisher BJ, Ubel PA. Helping Patients Decide: Ten Steps to Better Risk Communication (In submission)

#### *Chapters in Books*

1. Ubel PA, Siegler M. Living donors for renal transplantation: Ethical considerations. (Review) In International Yearbook of Nephrology. 1993.
2. Parsons GN, Ubel PA. "Advocating for patients under managed care: Case commentary." (Book Chapter) In Gervais KG, Priester R, Vawter DE, Otte KK, Solberg MM eds. Ethical Challenges in Managed Care: A Casebook. Georgetown University Press. 1999.
3. Cohen JP, Asch DA, Ubel PA. "Accounting for fairness in health care." (Book Chapter) In The Social Economics of Health Care. Rutledge Press, London. 2000.
4. Cohen JP, Asch DA, Ubel PA. "Bioethics and medical decision making: What can they learn from each other?" (Book Chapter) In Chapman GB, Sonnenberg FA. Decision Making In Health Care. Cambridge University Press. 2000
5. Ubel PA. "Elevator etiquette: When is communication too effective?" (Book Chapter) In Woods D. Communication for Doctors: How to improve patient care and minimize legal risks. Radcliff Publishing, Oxford, San Francisco. 2004
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11. Ubel PA. "Shrinking Liberty to Combat Expanding Waistlines." (Book Chapter) In Batra R, Keller PA, Strecher VJ, eds. Leveraging Consumer Psychology for Effective Health Communications: The Obesity Challenge. M.E. Sharpe Inc., Armonk, NY. In Press.

#### *Editorials, Reviews, Commentaries*

1. Ubel PA, Arnold RM. Euthanasia debates and empirical evidence: Separating burdens to others from one's own quality of life. (Editorial) Journal of Clinical Ethics, 5:155-8, 1994.
2. Ubel PA. Review of *Spare parts: Organ replacement in American society*, by Fox R and Swazey JP. Journal of Clinical Ethics 5:171, 1994.
3. Ubel PA, Mahowald M. Ethical and legal aspects of live human tissue and organ donation. (Review) in Encyclopedia of Bioethics, 3rd Edition. 1994.
4. Ubel PA. Elevator etiquette: When is communication too effective? (Editorial) Medical Practice Communicator, 3:5, 1996.
5. Ubel PA. Informed consent: From bodily invasion to the seemingly mundane. (Editorial) Archives of Internal Medicine, 156:1262-3, 1996.
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7. Ubel PA. Review of *Justice and health care: Comparative perspectives*, edited by Grub A and Mehlman MJ. Social Science & Medicine, 44:1767, 1997.
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9. Ubel PA. Physicians' duties in an era of cost containment: Advocacy or betrayal? (Editorial) msJAMA, 282:1675, 1999.
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11. Ubel PA. Review of *The ethical QALY: Ethical issues in health care resource allocations*. Medical Decision Making. 20: October-December, 2000.
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15. Ubel PA, Engel K. Scenario: How should you answer the “What would you do” question? (Ethics Forum) AM News, 2003.
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17. Ubel PA. Tough questions, even harder answers. Journal of General Internal Medicine (Editorial), 2006 November; 21 (11): 1209-1211.
18. Ubel PA. The ethics of swimming pools. The Hastings Center Report 2007: 51-55.
19. Altman L, Mussallem M, Dresser J, Lombardo P, Ubel P, White C. Outside the operating room: economic, regulatory, and legal challenges. Proceedings of the Ethical Challenges in Surgical Innovation Summit. Cleveland Clinic Journal of Medicine. 2008: 75(6): S61-S73.
20. Ubel PA. Authorship battles: An outsider’s view. APS Observer. 22(8): October, 2009. <http://www.psychologicalscience.org/observer/getArticle.cfm?id=2563>

#### *Alternative Media*

1. Ubel PA. Mickey Mantle’s liver. Technology Times, August 1995.
2. Ubel PA. The role of community values in health care policy. University of Pennsylvania Center for Bioethics Newsletter, Summer 1996.
3. Ubel PA. HMO’s offer is legal, but is it ethical? The Philadelphia Daily News. Dec. 18, 1996.
4. Ubel PA, The role of community values in setting health care priorities. Medical Laboratory Observer. 29:90-93, 1997.
5. Caplan A, Ubel PA. Any organ donor list must be fair. Newsday. June 1, 1998, Op-Ed Page.
6. Ubel PA. Thinking about our relationships with industry. Neuronetwork Newsletter. Volume 1 January, 1999.
7. Ubel PA. Keeping politics out of the doctor’s office. Physicians Weekly. October 11, 1999.
8. Ubel PA. Malpractice laws would harm, not help, patient hurt by HMOs. Detroit Free Press. September 4, 2001, Op-Ed Page.
9. Ubel PA, Boulis A. Facing the vaccine shortage. The New Leader. July/August, 2002; 85:18-20.
10. Ubel PA. A fine line between ask and tell. The New York Times, Science Times Section. April 13, 2004. Section F, Page 5.
11. Hummel E K., Ubel PA. Policy Forum. Cost and clinical practice guidelines: Can two wrongs make it right? Virtual Mentor, December 2004. <http://www.ama-assn.org/ama/pub/category/14285.html>.
12. Ubel PA. Thoughts on Koch’s postulates. Virtual Mentor, February 2005. <http://www.ama-assn.org/ama/pub/category/14561.html>.

13. Ubel PA. When the unknown is not so bad. Sometimes patients choose to continue suffering, believing the alternative to be worse. Los Angeles Times. August 28, 2006. Part F, Page 6.
14. Ubel PA. When bad advice is the best advice. New York Times, Science Times Section. April 27, 2009. [http://www.nytimes.com/2009/04/28/health/28case.html?\\_r=3&ref=views](http://www.nytimes.com/2009/04/28/health/28case.html?_r=3&ref=views).
15. Kvedar JC, Hwang J, Moorhead T, Orlov LM, Ubel PA. Roundtable Discussion—Up from crisis: Overhauling healthcare information, payment, and delivery in extraordinary times. Telemedicine and e-Health. September, 2009. <http://www.liebertonline.com/doi/pdfplus/10.1089/tmj.2009.9948>
16. Ubel P.A. Economics Behaving badly. The New York Times Op-Ed Page, July 14, 2010

### *Letters*

1. Ubel PA. Third-party payers and investigational therapy. New England Journal Medicine. 319:1228, 1988.
2. Ubel PA. Fever: Blessing or curse? Annals of Internal Medicine. 121:982, 1994.
3. Ubel PA. Will running the numbers first violate the principles of patient-centered care? Annals of Internal Medicine. 149(11): 839.

## **Memberships in Professional Societies**

1988-1993	American Medical Association, Resident Delegate, 1989 Annual Meeting
1989-2001	American College of Physicians
1992-1994	Society for Health and Human Values
1992-1995	American Society for Law, Medicine and Ethics
1993-present	Society of General Internal Medicine Member Ethics Committee 1994-1998 Chair, Ethics Committee 1996-1998 Chair, Elnora Rhodes Service Award Committee 1999-2001
1993-present	Society for Medical Decision Making Member Publications Committee 1996-2001 Council Member 2000-2003 Chair, Publications Committee 2001-2004
1998-2002	American Society of Bioethics and Humanities Member Publications Committee 2000-2002
2004-present	Fellow, The Hastings Center
2005-2007	AACR Task Force on Behavioral Science and Cancer
2007-present	Member, ASCO Task Force on The Cost of Cancer Care Co-Director, Subcommittee on Research
2008	Member, World Economic Forum, Global Health Committee

## Editorial Positions, Boards and Peer-Review Service

### *Editorial Boards*

1996-2005	Editorial Board, Social Science and Medicine
1998-1999	Associate Editor, Journal of General Internal Medicine
1998-2001	Editorial Board, Medical Decision Making
1999-2002	Editorial Board, American Journal of Bioethics
2002-2005	Editorial Board, Population Health Metrics
2006-present	Editorial Board, Journal of Judgment and Decision Making
2007-present	Editorial Board, The Patient

### *Reviewer of Manuscripts*

American Journal of Bioethics	Journal of Clinical Ethics
American Journal of Law, Medicine, & Ethics	Journal of General Internal Medicine
American Journal of Medicine	Journal of Health, Politics, Policy and Law
Annals of Internal Medicine	Kennedy Institute Ethics Journal
Archives of Internal Medicine	Medical Decision Making
Current Perspective in Psychological Science	Milbank Quarterly
British Medical Journal	MIT Press
Hastings Center Report	New England Journal of Medicine
Health Affairs	Oxford University Press
Health Economics	Psychological Science
Health Economics Letters	Quality of Life Research
Health Policy	Social Problems
Health Psychology	Social Science and Medicine
John Hopkins University Press	
Journal of American Medical Association	

### *Grant Proposal Reviewer*

National Institutes of Health  
Medical Research Council of Canada  
Agency for Health Care Policy and Research/AHRQ  
National Science Foundation  
Burroughs Wellcome Foundation (UK)  
Alberta Heritage Foundation for Medical Research (Alberta, Canada)  
Department of Veterans Affairs – Health Services Research and Development  
Journal National Cancer Institute  
Swiss National Science Foundation  
Health Care Efficiency Research Programme (Netherlands)

### *Study Sections*

2000-2002	National Institutes of Health - Health Services Research Study Section
2003-2004	National Institute of Child Health and Human Development Special Emphasis Panel RFA HD-02-024 “Dynamic Health Assessments for Medical Rehabilitation Outcome”
2003-2004	N.C.I. – Program Project: Special Study Section



### *Institute of Medicine*

09/2005	External reviewer of report on cost-effectiveness measurement
05/2006	Invited to present at workshop on Risk Communication and Pharmaceuticals

## **Teaching**

### *Medical Student Research Mentoring*

1994-1995	Okiki N. Louis (UPenn)
1994-1995	Ari Silver-Isenstadt (UPenn)
1996-1997	Genevieve Noone (UPenn)
1998-1999	David Shih (UPenn)
1999-2000	Catherine Magid (UPenn)
1999-2000	Scott Halpern (UPenn)
1999-2001	Duffy Ballard (UPenn)
2008-2010	Michael Kozminski (UM)
2008-2009	Emily Wu (UM)
2009-2010	Kevin Duan (UM)
2009-2010	Eunice Yu (UM)

### *Fellow Research Mentoring*

1996-1998	Katrina Armstrong (UPenn, General Medicine)
1997-1998	Sundar Natarajan (UPenn, General Medicine)
1998-1999	John Hsu (UPenn, General Medicine)
1999-2000	Susan Moran (UPenn, General Medicine)
2000-2002	Willie Underwood (UM, Clinical Scholar)
2000-2002	Michelle Heisler (UM, Clinical Scholar)
2000-2002	Amy Alderman (UM, Clinical Scholar)
2002-2003	Rachel Perlman (UM, Health Services)
2002-2004	Kirsten Engel (UM, Clinical Scholar)
2002-2004	Sonia Angell (UM, Clinical Scholar)
2002-2004	Tracy Richmond (UM, Clinical Scholar)
2004-2006	Ellen Hummel (UM, Clinical Scholar)
2005-2008	Michael Volk (UM, Clinical Scholar)

### *Medical Resident Mentoring*

1999-2000	Caleb Alexander (UPenn, Internal Medicine)
1999-2000	Rachel Werner (UPenn, Internal Medicine)

### *Doctoral Student Mentoring*

2000-2002	Andrea Gurmankin (UPenn, Psychology)
2000-2002	Scott Halpern (UPenn, Epidemiology)
2001-2003	Jason Riis (UM, Psychology)
2002-2004	Jennifer Amsterlaw (UM, Psychology)
2009-2010	Yvette Peeters (Leiden University, Psychology)

2010-present	Avni Shah (Duke University, Marketing)
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#### *Dissertation Committees*

2003	Jason Riis (UM, Psychology)
2005	Hannah Chua (UM, Psychology)
2006	Jing Xsu (UM, Marketing)
2008	Sarah Gollust (UM, Public Health)
2010	Yvette Peeters (Leiden University, Psycholog, Netherland)

#### *Post-Doctoral Fellow Mentoring*

1998-2000	Joanne Buzaglo, PhD (Philadelphia VAMC, Psychology)
1999-2001	Jacqueline Hart, PhD (Philadelphia VAMC, Sociology)
1999-2002	Andrew Siderowf, MD (Upenn, Neurology)
2000-2001	Angie Fagerlin, PhD (UM, Psychology)
2001-2002	Dylan Smith, PhD (Ann Arbor VAMC, Psychology)
2002-2004	Brian Zikmund-Fisher, PhD (Ann Arbor VAMC, Psychology)
2003-2006	Heather Lacey, PhD (Ann Arbor VAMC, Psychology)
2004-2006	Jordana Muroff, MSW, PhD (Ann Arbor VAMC, Psychology)
2006-2009	Amanda Dillard, PhD (Ann Arbor VAMC, Psychology)
2006-2008	Michael Poulin, PhD (Ann Arbor VAMC, Psychology)
2009-present	Holly Witteman, PhD (UM)
2009-present	Andrea Fuhrel-Forbis (UM, Social Psychology)
2010-present	Andrea Angott (DukeUniversuty, Psycology)
2010-present	Sunita Sah (Duke University, Organizational Behavior)

#### *Junior Faculty Mentoring*

2002-2006	Ken Langa, MD, PhD (UM, Internal Medicine, Beeson Award)
2002-2006	Maria Silveria, MD, MA(UM, Internal Medicine, VA Career Development Award)
2006-present	Fold Odetola (UM, Pediatrics, K Award)
2007-present	Reshma Jagsi (UM, Radiation Oncology)
2008-present	Michael Volk (UM, Gastroenterology)
2010-present	Clara Lee (UNC, Plastic Surgery)

## **Committee, Organizational and Volunteer Services**

#### *Department*

2005-2010	General Internal Medicine Research Advisory Committee
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#### *Medical School*

1996-2000	Member, IRB, Philadelphia VAMC
1999-2000	Chair, Ethics Committee, Philadelphia VAMC
2001	Member, Health Services Research Advisory Committee (Chair–Larry McMahon)
2002-2010	VA HSR&D Promotions Committee

2000-2003	Core Faculty – RWJ Clinical Scholars Program
2004-2007	Associate Director – RWJ Clinical Scholars Program
2007-2010	Co-Director - RWJ Clinical Scholars Program

#### *University*

2000-2003	Advisory Board of the Life Sciences, Values and Society Program
2005	Executive Advisory Board, University of Michigan Press

#### *National*

2002-2003	Department of Veterans Affairs – Task force on research ethics
2001-2004	Chair, Publications Committee, Society Medical Decision Making
2005-present	Fellows Council, Hastings Center
2005-2008	Task force on Behavioral Science, AACR
2007-present	Cost of Cancer Care Task Force, ASCO

#### *International*

2008-present	International Patient Decision Aid Standards (IPDAS) Steering Committee
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## **Visiting Professorships**

#### *Visiting Professorships*

2000	Visiting Professor, Johns Hopkins School of Public Health and Hygiene
2001	Visiting Professor, University of Chicago School of Public Policy
2003	Visiting Professor, Carleton College, Northfield, Minnesota
2003	Visiting Professor, University of Montreal
2004	Visiting Professor, Ohio State University
2004	Visiting Professor, University of Toronto, School of Public Health
2004	Visiting Professor, Wharton School of Business, University of Pennsylvania, Philadelphia, Pennsylvania
2007	Visiting Professor, University of Pittsburgh School of Medicine
2007	Visiting Professor, Johns Hopkins University, Department of Oncology
2009	Visiting Professor, Baylor College of Medicine

DUKE UNIVERSITY MEDICAL CENTER  
CURRICULUM VITAE  
for  
Permanent Record  
and the  
Appointments and Promotions Committee

Dated: February 12, 2013

**Name:** Kevin Phillip Weinfurt, Ph.D.

**Primary academic appointment:** Professor, Department of Psychiatry and Behavioral Sciences, Duke University

**Secondary appointment:** Professor, Department of Psychology and Neuroscience, Duke University  
Senior Fellow, Center for the Study of Aging and Human Development, Duke University Medical Center  
Faculty Associate, Trent Center for Bioethics, Humanities & History of Medicine

**Present academic rank and title:** Deputy Director, Center for Clinical and Genetic Economics  
Duke Clinical Research Institute, Duke University Medical Center

**Date and rank of first Duke Faculty appointment:** September 1, 1999, Assistant Research Professor

**Date of birth:** January 23, 1970,

**Place:** Brookfield, WI, USA

**Citizenship:** United States of America

**Education:**

Loyola University, Chicago, IL	1992	B.S.	Psychology
Georgetown University, Washington, DC	1995	M.A.	Psychology
Linacre College, Oxford, England	1995		History of Science, Philosophy of Mind
Georgetown University, Washington, DC	1997	Ph.D.	Cognitive Psychology

**Kevin P. Weinfurt, Ph.D.**

**Scholarly societies:** Sigma Xi, Psi Chi, Alpha Sigma Nu  
1991 - 1992 President, Alpha Sigma Nu (National Jesuit Honor Society)  
1996 - present Sigma Xi (Science Honor Society)

**Professional training and academic career:**

<u>Institution</u>	<u>Position/Title</u>	<u>Dates</u>
Georgetown Univ. Med Center	Assistant Research Professor/Psychiatry	1998-1999
Georgetown Univ. Med Center	Assistant Research Professor/Dept of Medicine	
Georgetown University	Adjunct Professor/Dept of Psychology	
University of Maryland	Special Member/Graduate Faculty	
Duke Univ. Med Center	Deputy Director/CCGE	1999-Present
Duke University	Asst Research Professor/Dept of Psychiatry and Behavioral Science	1999-Present
Duke University	Adjunct Professor/Psychology	1999-2000
Duke University	Asst Research Professor/Psychology	2001-Present
Duke Univ. Med Center	Senior Fellow/Center for Aging	2002-
Duke Univ. Med Center	Faculty Associate Center for the Study of Medical Ethics and Humanities	2004-Present
Duke University	Associate Professor Psychiatry and Behavioral Sciences	2006 - Present
Duke University	Associate Professor Psychology-Social & Health Sciences	2006 - Present
Duke University	Faculty Associate Trent Center for Bioethics, Humanities & History of Medicine	2008
Duke University	Professor, Psychiatry and Behavioral Sciences Professor, Department of Psychology and Neuroscience	2011
Duke University	Co-Director, Clinical Research Training Program (CRTP)	2012

**Publications:**

1. **Weinfurt KP.** The ability of the Sweeping Model to explain human attention. *J Mind Behav*, 1993; 14(2):207-213.
2. **Weinfurt KP.** Some uncertainty regarding uncertainty reduction. *Theor and Philosophical Psychol.* 1994; 14(2):401-407.
3. **Weinfurt KP,** Bryant FB, Yarnold PR. A measurement model for the affect intensity measure. *J Res Pers*, 1994; 28(3):314-331.
4. Bush PJ, **Weinfurt KP,** Iannotti RJ. Families versus peers: developmental influences on drug use from grade 4-5 to grade 7-8. *Appl Psychol Dev.* 1994; 15(3): 437-456.
5. **Weinfurt KP,** and Bush PJ. Peers' assessments of early adolescents who are solicited to help

sell crack: A longitudinal analysis. *J Appl Soc Psychol.* 1995; 25 (24): 2141-2157.

6. **Weinfurt KP**, Bush PJ. Contradictory subject response in longitudinal research. *J Stud Alcohol.* 1996; 57(3): 273-282.

7. Swain SM, Rowland JH, **Weinfurt KP**, Honig SF, et al. Quality of life and toxicity assessment during intensive adjuvant treatment for breast cancer. *J Clin Oncol.* 1996; 14(5):1565-1572.

8. Epstein SA, Gonzales JJ, Onge JS, Carter-Campbell J, **Weinfurt KP**, et al. Leibole M, and Goldberg RL. Practice patterns in the diagnosis and treatment of anxiety and depression in the medically ill: A survey of psychiatrists. *Psychosomatics.* 1996; 37(4):356-366.

9. Iannotti RJ, Bush PJ, **Weinfurt KP**. Perceptions of friends' use of alcohol, cigarettes, and marijuana among urban schoolchildren: A longitudinal analysis. *Addict Behav.* 1996; 21(5):615-632.

10. Richardson FJ, **Weinfurt KP**. Death education: A comparison of two programs for mothers of young children. *Omega.* 1997; 34(2):149-162.

11. Ostrander R, **Weinfurt KP**, Nay WR. The role of age, family support, and negative cognitions in the prediction of depressive symptoms. *School Psychol Rev.* 1998; 27(1):121-137.

12. Crystal DS, Watanabe H, Chin W, **Weinfurt KP**. Perceptions of human differences and intolerance of nontypical peers: A cross-cultural and developmental comparison. *Dev Psychol.* 1998; 34 (4):714-722.

13. Ostrander R, **Weinfurt KP**, Yarnold PR, August G. Diagnosing attention deficit Disorders using the BASC and the CBCL: test and construct validity analyses using optimal Discriminant Classification Trees. *J Consult and Clin Psych.* 1998; 66(4):660-672.

14. **Weinfurt KP**, Willke R, Glick H, Schulman K. Toward a composite scoring solution for the Neurobehavioral Functioning Inventory. *Qual Life Res.* 1999; 8:17-24.

15. Goodman L, Thompson K, **Weinfurt KP**, Corl S, et al. Reliability of reports of violent victimization and posttraumatic stress disorder among men and women with serious mental illness. *J Trauma Stress.* 1999; 12(4): 587-599.

16. Freeman VG, Rathore SS, **Weinfurt KP**, Schulman KA, Sulmasy DP. Lying for patients: Physician deception of third party payers. *Arch Intern Med.* 1999; 159:2263-2270.

17. Rathore SS, Berger AK, **Weinfurt KP**, Schulman KA, et al. Acute Myocardial Infarction Complicated by Atrial Fibrillation in the Elderly: Prevalence and outcomes. *Circulation.* 2000; 101: 969-974.

18. **Weinfurt KP**, Willke RJ, Glick MA, Freimuth WW, Schulman KA. The relationship between CD4 count, viral burden, and quality of life over time in HIV-1 infected patients. *Med Care.* 2000; 38(4): 404-410.

19. Rathore SS, Lenert LA, **Weinfurt KP**, Tinoco A, Taleghani CK, Harless W, Schulman KA. The effects of patient sex and race on medical students' ratings of quality of life. *Am J Med.* 2000; 108(7): 561-566.
20. Rathore SS, Berger AK, **Weinfurt KP**, Feinleib M, Oetgen WJ, Gersh BJ, Schulman KA. Race, sex, poverty and the medical treatment of acute myocardial infarction in the elderly. *Circulation.* 2000; 102(6): 642-648.
21. Sheifer SE, Rathore SS, Gersh BJ, **Weinfurt KP**, Oetgen WJ, Breall JA, Schulman KA. Time to presentation with acute myocardial infarction: associations with race, gender, and socioeconomic status. *Circulation.* 2000; 102(14):1651-1656.
22. **Weinfurt KP**, Moghaddam A. Measuring social distance: A case study of methodological cautions. *J Soc Psychol.* 2001; 141(1):101-110.
23. Rathore SS, Gersh BJ, Berger PB, **Weinfurt KP**, WJ, Schulman KA, Solomon AJ. Acute myocardial infarction complicated by advanced heart block: prevalence and outcomes. *Am Heart J.* 2001; 141(1): 47-54.
24. Polsky D, **Weinfurt KP**, Kaplan B, Kim J, Fastenau J, Schulman KA. An economic and quality of life assessment of Simulect versus ATGAM based induction therapies. *Nephrol Dial Transpl.* 2001; 16(5):1028-1033.
25. Rathore SS, **Weinfurt KP**, Gersh BJ, Oetgen WJ, Schulman KA, Solomon AJ. Treatment of patients with myocardial infarction who present with a paced rhythm. *Ann Intern Med.* 2001; 134(8): 644-651.
26. Epstein SA, Gonzales JJ, **Weinfurt KP**, Boekeloo B, Yuan N, Chase G. Are psychiatrists' characteristics related to how they care for depression in the medically ill: results from a national case-vignette survey? *Psychosomatics.* 2001; 42(6): 482-489.
27. Rathore SS, Gersh BJ, **Weinfurt KP**, Oetgen WJ, Schulman KA, Solomon AJ. The role of reperfusion therapy in paced patients with acute myocardial infarction. *Am Heart J.* 2001; 142(3): 516-519.
28. Weaver CH, Buckner CD, Curtis LH, Bajwa K, **Weinfurt KP**, Wilson-Relyea BJ, Schulman KA. Economic evaluation of filgrastim, sargramostim, and sequential sargramostim and filgrastim after myelosuppressive chemotherapy. *Bone Marrow Transpl.* 2002; 29(2):159-164.
29. **Weinfurt KP**, Trucco SM, Willke RJ, Schulman KA. Measuring agreement between patient and proxy responses to multidimensional health-related quality of life measures in clinical trials: an application of psychometric profile analysis. *J Clin Epidemiol.* 2002; 55(6): 608-618.
30. LaPointe NM, Kramer JM, **Weinfurt KP**, Califf RM. Practitioner acceptance of the dofetilide risk-management program. *Pharmacotherapy.* 2002; 22(8):1041-1046.

31. **Weinfurt KP.** Events on health-related quality of life of patients with metastatic prostate cancer. *Annals of Oncology*, 2002;13(5); 662P;180.
32. **Weinfurt KP,** Olsen MK, Coombs L, Gnanasakthy A, Schulman KA. Comparing methods for treating item-level missing data. *Quality of Life Research*; 2002;11(7): 648.
33. Schulman,KA, Seils DM, Timbie JW, Sugarman J, Dame LA, **Weinfurt KP,** Mark DB, Califf RM. A national survey of provisions in clinical-trial agreements between medical schools and industry sponsors. *New Engl J Med.* 2002; 347(17):1335-1341.
34. Onken JE, Friedman JY, Subramanian S, **Weinfurt KP,** Reed SD, Malenbaum JH, Schmidt T, Schulman KA. Treatment patterns and costs associated with sessile colorectal polyps. *Am J Gastroenterol.* 2002;97(11):2896-2901
35. Rathore SS, **Weinfurt KP,** Gross CP, Krumholz HM. Validity of a simple ST-Elevation acute myocardial infarction risk index: are randomized trial prognostic estimates generalizable to elderly patients? *Circulation.* 2003; 107(6):811-816.
36. **Weinfurt KP.** Outcomes research related to patient decision making in oncology. *Clin Ther.* 2003; 25(2): 671-683.
37. Goodman L, Dutton MA, **Weinfurt KP,** Cook S. The intimate partner violence strategies index. *Violence Against Women*, 2003; 9(2): 163-186.
38. **Weinfurt KP,** Castel LD, Li Y, Sulmasy DP, Balshem AM, Benson AB 3rd, Burnett CB, Gaskin DJ, Marshall JL, Slater EF, Schulman KA, Meropol NJ. The correlation between patient characteristics and expectations of benefit from Phase I clinical trials. *Cancer.* 2003; 98(1):166-175.
39. Meropol NJ, **Weinfurt KP,** Burnett CB, Balshem A, Benson AB 3rd, Castel L, Corbett S, Diefenbach M, Gaskin D, Li Y, Manne S, Marshall J, Rowland JH, Slater E, Sulmasy DP, Van Echo D, Washington S, Schulman KA. Perceptions of patients and providers regarding phase I cancer clinical trials: implications for physician-patient communication. *J Clin Oncol.* 2003; 21(13):2589-2596.
40. **Weinfurt KP,** Sulmasy DP, Schulman KA, Meropol NJ. Patient expectations of benefit from phase I clinical trials: linguistic considerations in diagnosing a therapeutic misconception. *Theor Med Bioeth.* 2003; 24(4):329-344.
41. **Weinfurt KP,** Li Y, Castel LD, Saad F, Timbie JW, Glendenning GA, Schulman KA. The impact of skeletal-related events on preferences and health-related quality of life of patients with metastatic prostate cancer. *EJC Supplements*; 2003;1(3), S9 (OP36).
42. **Weinfurt, KP.** Discursive versus information-processing perspectives on a bioethical problem: the case of “unrealistic” patient expectation. *Theor Psychol*, 2004;14(2):191-203.



43. **Weinfurt KP**, Castel LD, Li Y, Timbie JW, Glendenning GA, Schulman KA. Health-related quality of life among breast cancer patients receiving zoledronic acid or pamidronate disodium for metastatic bone lesions. *Med Care*. 2004; 42(2):164-175.
44. Hong TB, Oddone EZ, **Weinfurt KP**, Friedman JY, Schulman KA, Bosworth HB. The relationship between perceived barriers to healthcare and self-rated health. *Psychol Health Med*. 2004;9(4):476-482.
45. Friedman JY, Reed SD, **Weinfurt KP**, Kahler KH, Walter EB, Schulman KA. Parents' reported preference scores for childhood atopic dermatitis disease states. *BMC Pediatr*. 2004;4(1):21.
46. Gaskin DF, **Weinfurt KP**, Castel LD, DePuy V, Li Y, Balshem A, Benson A, Burnett CB, Corbett S, Marshall J, Slater E, Sulmasy DP, Van Echo D, Meropol NJ, Schulman KA. An exploration of relative health stock in advanced cancer patients. *Med Decis Making*, 2004;24(6):614-624.
47. **Weinfurt KP**, DePuy V, Castel LD, Sulmasy DP, Schulman KA, Meropol NJ. Understanding of an aggregate probability statement by patients who are offered participation in Phase I clinical trials. *Cancer*. 2005;103(1):140-147.
48. Voils CI, Oddone EZ, **Weinfurt KP**, Friedman JY, Schulman KA, Bosworth HB. Who trusts healthcare institutions? Results from a community-based sample. *Ethnicity and Disease*, 2005;15(1); 97-103.
49. **Weinfurt KP**, Li Y, Castel LD, Saad F, Timbie JW, Glendenning GA, Schulman KA. The significance of skeletal-related events for the health-related quality of life of patients with metastatic prostate cancer. *Ann Oncol*. 2005;16(4):579-584.
50. Van Houtven CH, Voils CI, Oddone EZ, **Weinfurt KP**, Friedman JY, Schulman KA, Bosworth HB. Perceived discrimination and reported delay of pharmacy prescriptions and medical tests. *J Gen Intern Med*. 2005;20(7):578-583.
51. Goodman LA, Dutton MA, Vankos N, **Weinfurt KP**. Women's resources and use of strategies as risk and protective factors for re-abuse over time. *Violence Against Women*. 2005; 11(3):311-336.
52. Dutton MA, Kaltman S, Goodman LA, **Weinfurt KP**, Vankos N. Patterns of intimate partner violence: correlates and outcomes. *Violence and Victims*, 2005;20(5):483-497.
53. Reed SD, Radeva JI, **Weinfurt KP**, McMurray JJ, Pfeffer MA, Velazquez EJ, Allsbrook JS, Masselink LE, Sellers MA, Califf RM, Schulman KA; VALIANT Investigators. Resource use, costs, and quality of life among patients in the multinational Valsartan in Acute Myocardial Infarction Trial (VALIANT). *Am Heart J*. 2005;150(2):323-332.
54. Friedman JY, Anstrom KJ, **Weinfurt KP**, McIntosh M, Bosworth HB, Oddone EZ, Bright CM, Schulman KA. Perceived racial/ethnic bias in health care in Durham County, North Carolina: a comparison of community and national sample. *N C Med J*. 2005;66(4):267-275.

55. Rathore SS, **Weinfurt KP**, Foody JM, Krumholz HM. Performance of the Thrombolysis in Myocardial Infarction (TIMI) ST-elevation myocardial infarction risk score in a national cohort of elderly patients. *Am Heart J*. 2005;150(3):402-410.
56. Rasiel EB, **Weinfurt KP**, Schulman KA. Can prospect theory explain risk-seeking behavior by terminally ill patients? *Med Decis Making*. 2005;25(6):609-613.
57. Voils CI, Oddone EZ, **Weinfurt KP**, Friedman JY, Bright CM, Schulman KA, Bosworth H. Racial differences in health concern. *J Natl Medl Assoc*. 2006;98(1):36-42
58. **Weinfurt KP**, Dinan MA, Allsbrook JS, JY, Hall MA, Schulman KA, Sugarman J. Policies of academic medical centers for disclosing financial conflicts of interest to potential research participants. *Acad Med*. 2006;81(2):113-118.
59. **Weinfurt KP**, Anstrom KJ, Castel LD, Schulman KA, and Saad F. Effect of zoledronic acid on pain associated with bone metastasis in patients with prostate cancer. *Ann Oncol*. 2006;17(16):986-98.
60. **Weinfurt KP**, Friedman JY, Allsbrook JS, Dinan MA, Hall MA, Sugarman J. Views of potential research participants on financial conflicts of interest: barriers and opportunities for effective disclosure. *J Gen Intern Med*. 2006;21(9):901-906.
61. **Weinfurt KP**, Friedman JY, Dinan MA, Allsbrook JS, Hall MA, Dhillon JK, Sugarman J. Disclosing conflicts of interest in clinical research: views of institutional review boards, conflict of interest committees, and investigators. *J Law Med Ethics*. 2006;34(3):581-591.
62. Dinan MA, **Weinfurt KP**, Friedman JY, Allsbrook JS, Gottlieb J, Schulman KA, Hall MA, Dhillon JK, Sugarman J. Comparison of conflict of interest policies and reported practices in academic medical centers in the United States. *Account Res*. 2006;13(4):325-342.
63. Hall MA, Camacho F, Lawlor JS, DePuy V, Sugarman J, **Weinfurt K**. Measuring trust in medical researchers. *Med Care*. 2006;44(11):1048-1053.
64. **Weinfurt KP**. Value of high-cost cancer care: a behavioral science perspective. *J Clin Oncol*. 2006;25(2):223-227.
65. **Weinfurt KP**, Allsbrook JS, Friedman JY, MA, Hall MA, Schulman KA, Sugarman J. Developing model language for disclosing financial interests to potential clinical research participants. *IRB*. 2007;29(1):1-5.
66. Revicki DA, Gnanasakthy A, **Weinfurt K**. Documenting the rationale and psychometric characteristics of patient reported outcomes for labeling and promotional claims: the PRO Evidence Dossier. *Qual Life Res*. 2007;16(4):717-723.
67. Shea AM, DePuy V, Allen JM, **Weinfurt KP**. Use and perceptions of clinical practice guidelines by internal medicine physicians. *Am J Med Qual*. 2007;22(3):170-176.

68. Friedman JY, Sugarman J, Dhillon JK, DePuy V, Pierre CK, Dinan MA, Allsbrook JS, Schulman KA, **Weinfurt KP**. Perspectives of clinical research coordinators on disclosing financial conflicts of interest to potential research participants. *Clin Trials*. 2007;4(3):272-278.
69. DePuy V, Anstrom KJ, Castel LD, Schulman KA, **Weinfurt KP**, Saad F. Effects of skeletal morbidities on longitudinal patient-reported outcomes and survival in patients with metastatic prostate cancer. *Support Care Cancer*. 2007;15(7):869-876.
70. Garcia SF, Cella D, Clauser SB, Flynn KE, Lai JS, Reeve BB, Smith AW, Stone AA, **Weinfurt K**. Standardizing patient-reported outcomes assessment in cancer clinical trials: a Patient-Reported Outcomes Measurement Information System initiative. *J Clin Oncol*. 2007;25(32):5106-5112.
71. **Weinfurt KP**, Seils DM, Tzeng JP, Lin L, Schulman KA, Califf RM. Consistency of financial interest disclosures in the biomedical literature: the case of coronary stents. *PLoS ONE*. 2008;3(5):e2128.
72. Fleisher L, Buzaglo J, Collins M, Millard J, Miller SM, Egleston BL, Solarino N, Trinastic J, Cegala DJ, Benson III AIB, Schulman KA, **Weinfurt KP**, Sulmasy D, Diefenbach MA, Meropol NJ. Using health communication best practices to develop a web-based provider-patient communication aid: the CONNECT(TM) study. *Patient Educ Couns*. 2008;71(3):378-387.
73. **Weinfurt KP**, Hall MA, Dinan MA, DePuy V, Friedman JY, Allsbrook JS, Sugarman J. Effects of disclosing financial interests on attitudes toward clinical research. *J Gen Intern Med*. 2008;23(6):860-866.
74. Glickman SW, Anstrom KJ; Lin L, Chandra A, Laskowitz DT, Woods CW, Freeman DH, Kraft M, Beskow LM, **Weinfurt KP**, Schulman KA, Cairns CB. Challenges in enrollment of minority, pediatric, and geriatric patients in emergency and acute care clinical research. *Ann Emerg Med*. 2008; 51(6):775-780.
75. **Weinfurt KP**, Seils DM, Tzeng JP, Compton KL, Sulmasy DP, Astrow AB, Solarino NA, Schulman KA, Meropol NJ. Expectations of benefit in early-phase clinical trials: implications for assessing the adequacy of informed consent. *Med Decis Making*. 2008; 28(4):575-581.
76. Flynn KE, **Weinfurt KP**, Seils DM, Lin L, Burnett CB, Schulman KA, Meropol NJ. Decisional conflict among patients who accept or decline participation in phase I oncology studies. *J Empir Res Hum Res Ethics*. 2008;3(3):69-77.
77. **Weinfurt KP**, Hall MA, Friedman JY, Hardy C, Fortune-Greeley AK, Lawlor JS, Allsbrook JS, Lin L, Schulman KA, Sugarman J. Effects of disclosing financial interests on participation in medical research: a randomized vignette trial. *Am Heart J*. 2008;156(4):689-697.
78. Hooper LM, **Weinfurt KP**, Cooper LA, Mensh J, Harless W, Kuhajda MC, Epstein SA. Virtual standardized patients: an interactive method to examine variation in depression care among primary care physicians. *Prim Health Care Res Dev*. 2008;9(4):257-268.

79. Epstein SA, Hooper LM, **Weinfurt KP**, Depuy V, Cooper LA, Harless W, Tracy CM. Primary care physicians' evaluation and treatment of depression: Results of an experimental study. *Med Care Res Review*, 2008; 65(6):674-695.
80. Abernethy AP, Herdon II JE, Wheeler JL, Patwardhan M, Shaw H, Lysterly HK, **Weinfurt K**. Improving health care efficiency and quality using tablet personal computers to collect research-quality patient-reported data. *Health Serv Res*, 2008; 43(6); 1975-1991.
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70. **Weinfurt K.** Conflict of interest oversight in non-academic research settings. *Abstract presentation presented at the Society of General Internal Medicine Annual Meeting (SGIM)*, Miami Beach, FL, May 15, 2009.

71. Cella D (Chair), Reeve B, **Weinfurt K.** Advances in cancer outcomes measurement: the Patient-Reported Outcomes Measurement Information System (PROMIS). *Presented at the ASCO Annual Meeting*; Orlando FL; May 31, 2009.

72. **Weinfurt K.** The PROMIS Sexual Function Measure for Cancer Patients and Survivors: Development and Preliminary Findings. *Presented at the American Psychosocial Oncology Society (APOS) 7<sup>th</sup> Annual Conference*; New Orleans LA; February 19, 2010.

73. **Weinfurt K.** Analyzing the relationship between changes in pros and clinical endpoints. *Presented as a poster at the ISPOR 15<sup>th</sup> Annual International Meeting*; Atlanta GA; May 19, 2010.
74. **Weinfurt K.** The use and understanding of Certificate of Confidentiality. *Presented at the 2011 ELSI Congress: Exploring the ELSI Universe*; UNC-Chapel Hill; April 12-14, 2011.
75. Czajkowski S, Riley W, Pilkonis P, **Weinfurt K**, Kaplan R. Patient-Reported Outcomes Measurement Information System (PROMIS): using new theory and technology to improve measurement of patient-reported outcomes in clinical research. *Presented at the 32<sup>nd</sup> Annual Meeting & Scientific Sessions of the Society of Behavioral Medicine*; Washington DC; April 27-30, 2011.
76. **Weinfurt K.** Longitudinal changes in emotional distress among cervical cancer survivors. *Presented at the 18<sup>th</sup> Annual International Society for Quality of Life Research Conference*; Denver CO; October 27, 2011.
77. **Weinfurt K.** Validity of 1-month Recall for components of sexual function. *Presented as a poster at the 18<sup>th</sup> Annual International Society for Quality of Life Research Conference*; Denver CO; October 28, 2011.
78. **Weinfurt K.** Mood and gender effects on the accuracy of 30-day recall of sexual function. *Presented at the 18<sup>th</sup> Annual International Society for Quality of Life Research Conference*; Denver CO; October 29, 2011.
79. **Weinfurt K** (moderator), Schneider C, Whitney S, Joffe S, and London AJ. Rethinking the IRB's role. *Presented at the Research Ethics: Re-examining Key Concerns Conference*; Winston-Salem NC; November 10-11, 2011.
80. **Weinfurt K.** The PROMIS experience. *Presented at the Meeting on Measurement of Urinary Symptoms*; Washington DC, November 15, 2011.
81. **Weinfurt K.** and Stephen Van Den Eeden. How to validate the new measurement instrument. *Presented at the Meeting on Measurement of Urinary Symptoms*; Washington DC, November 15, 2011.
82. **Weinfurt K.** Improving the assessment of patient-reported health using PROMIS instruments. *Presented at the 44<sup>th</sup> NACCAM Meeting*; Washington DC, Feb 3, 2012.
83. **Weinfurt K.** Patients' high expectations of benefit from investigational therapies: should we be concerned? *Presented at the LDI Health Policy Lecture Series*; Philadelphia PA, March 8, 2012.
84. Check D, Flynn K, **Weinfurt K.** The use of central IRBs for multicenter clinical trials. *Presented at the Society for Clinical Trials 33rd Annual Meeting*; Miami FL; May 22, 2012.

85. Check D, Seils D, **Weinfurt K**. Understanding Patient Expectations in Early-Phase Oncology Trials. *Presented as a poster at the AcademyHealth Annual Research Meeting*; Orlando FL; June 25, 2012.
86. **Weinfurt K** (moderator), Hernandez A. Updates in clinical research. *Presented at the Changing Politics in Healthcare Lecture Series*; Durham NC; June 5, 2012.
87. **Weinfurt K**. Reasons for sexual inactivity: results from a national survey. *Presented at the World Meeting on Sexual Medicine 2012*; Chicago IL; August 27, 2012.
88. **Weinfurt K**. Development and validation of the PROMIS Sexual Function Measure. *Presented at the World Meeting on Sexual Medicine 2012*; Chicago IL; August 27, 2012.
89. **Weinfurt K** (moderator), Krubert C, Neidigh V, Nusimow M, Patel Y, Rege O. The role of the patient. *Presented as a panel discussion at the 4<sup>th</sup> Annual Wireless Technologies & Consumer Health Care: The Next Generation of Patient Engagement Conference*; Durham NC; September 27, 2012.
90. Birk NA, DeVries R, Kim SY, , Goold SD, Walter JK, **Weinfurt KP**, Anspach RR. Improving your skills in empirical ethics: from apprentice to artisan. *Presented as a workshop at the 14<sup>th</sup> Annual ASBH Meeting*; Washington DC; October 18, 2012.
91. Flynn K, Kramer J, Check D, Hahn C, Dombeck C, **Weinfurt K**. Use of Central Institutional Review Boards for Multicenter Clinical Trials. *Presented as a poster at the PRIM&R 2012 Advancing Ethical Research Conference*; San Diego CA; December 5, 2012.
92. Kappelman M, Cross R and **Weinfurt K**. Sexual Interest and Satisfaction in an Internet Cohort of Patients with Inflammatory Bowel Diseases". *Presented as a poster at the 2012 Advances in Inflammatory Bowel Diseases: Crohn's & Colitis Foundation's Clinical and Research Conference*; Hollywood Florida; December 13 – 15, 2012.

#### **Invited Addresses:**

1. **Weinfurt K**. "Statistics in clinical medicine." *Presented to the Department of Nephrology, Georgetown University Medical Center, Washington DC, March 26, 1998.*
2. **Weinfurt K**. "Using optimal discriminant analysis in clinical research: making life easier and more interesting." *Presented to the Department of Psychology, University of Maryland, College Park, MD; March 9, 1998.*
3. **Weinfurt K**, Rathore SS, Lenert LA, Tinoco A, Taleghani CK, Harless W, and Schulman KA. "Medical students' bias in the evaluation of angina: Role of race and gender." *Presented in the Georgetown University Institute for Health Care Policy and Research Lecture Series, Washington, DC, October, 1998.*
4. **Weinfurt K**. "Agreement between patient and proxy responses to the Functional Status Questionnaire: an application of psychometric profile analysis." *Presented in the Georgetown*



*University Institute for Health Care Policy and Research Lecture Series, Washington, DC, March, 1999.*

5. **Weinfurt K.** “An introduction to random effects regression modeling in health services research.” *Presented at the 13<sup>th</sup> Annual Conference on Mental Health Problems in the General Health Care Sector, Washington, DC, July, 1999.*

6. **Weinfurt K.** “Put up or shut up: Psychotherapy outcomes research.” *Lecture given to the Department of Psychology, Georgetown University, Washington, DC; February 15, 2000.*

7. **Weinfurt K.** “The Psychology of Medical Decision Making.” *Seminar given as part of the Robert Wood Johnson Clinical Scholars Program Core Curriculum; University of North Carolina-Chapel Hill; February 28, 2000.*

8. **Weinfurt K.** “Utility Theory.” *Seminar given as part of the Robert Wood Johnson Clinical Scholars Program Core Curriculum; University of North Carolina-Chapel Hill; September 15, 2000.*

9. **Weinfurt K.** “Health-Related Quality of Life in Economic Evaluations of Clinical Trials.” *Short course at the Annual Meeting of the Society for Medical Decision Making; Cincinnati OH; September 24, 2000.*

10. **Weinfurt K.** “Multimedia Simulations in Medical Decision Making Research and Education.” *Presented at the Tufts Roundtable Conference on Interactive Multimedia Decision Simulations; Medford MA; October 28, 2000.*

11. **Weinfurt K.** “Health-Related Quality of Life.” *Clinical Research Program Course 444; Duke University Medical Center; Durham NC; October 30, 2000.*

12. **Weinfurt K.** “The Psychology of Medical Decision Making.” *Seminar given as part of the Robert Wood Johnson Clinical Scholars Program Core Curriculum; University of North Carolina-Chapel Hill; February 16, 2001.*

13. **Weinfurt K.** “William James and the Sentiment of Rationality.” *Department of Psychology: Social and Health Sciences; Duke University; Durham NC; January 18, 2002.*

14. **Weinfurt K.** “Missing Data Issues in Quality of Life Evaluations.” *Presented at the Biostatistics Division, Novartis Pharmaceuticals; East Hanover NJ; March 12, 2002.*

15. **Weinfurt K.** “Missing Data Issues in Quality of Life Evaluation.” *Presented at Novartis Pharmaceuticals; Basel Switzerland; April 11, 2002.*

16. **Weinfurt K.** “Patient expectations of benefit in Phase I trials: psychological, philosophical, and statistical perspectives.” *Presented at the Psychiatry Grand Rounds; Duke University; Durham NC; January 29, 2004.*

17. **Weinfurt K.** “How to write a convincing R01?” *Presented at the Professional Development Series; Duke University; October 5, 2004.*

18. **Weinfurt K.** "Hope, understanding, and informed consent in Phase I clinical trials." *Presented at the Psychiatry Grand Rounds*; Georgetown University; Washington DC; November 11, 2004.
19. **Weinfurt K.** "Psychological Principles Underlying Marketing to Physicians." *Presented at the Psychiatry Grand Rounds*; Duke University Medical Center; July 14, 2005.
20. **Weinfurt K.** "Psychological Principles Underlying Marketing to Physicians." *Presented at the Psychiatry Grand Rounds*; John Umstead Hospital; Butner NC; July 14, 2005.
21. **Weinfurt K** and Luce MF. "Pharmaceutical Marketing and Clinical Judgment." *Presented at the Department of Medicine Grand Rounds*; Duke University Medical Center; February 3, 2006.
20. **Weinfurt K** and Pfeifer S. "Writing an R01." *Presented at the Professional Development Seminar Series*; Duke University; June 7, 2006.
21. **Weinfurt K.** "Disclosing Financial Conflicts of Interest in Clinical Research: Why and How Should We Tell Subjects?" *Presented at the DCRI Research Conference*; July 19, 2006.
22. Grambow S and **Weinfurt K.** "Working with Quantitative Scientists." *Lecture for the Spring 2007 CRP 254, Research Management Class, Clinical Research Training Program/NIH-Duke Training Program in Clinical Research*, Duke University Medical Center; January 18, 2007.
23. Govert J, Kussin P, Luce MF, and **Weinfurt K.** "Madison Avenue Meets Severe Sepsis: A Case Study on the Interaction Between Guidelines and Marketing." *Presented at the Department of Medicine Grand Rounds*; Duke University Medical Center; February 9, 2007.
24. **Weinfurt K.** "Some Difficulties in Evaluating Informed Consent in Early Phase Trials." *Presented at the DCRI Research Conference*; April 10, 2007.
25. **Weinfurt, K.** "Recent Developments in the Measurement of Patient Reported Outcomes." *Presented at the Post-doc Seminar in Mental Health Services and Systems Research*; Duke University Medical Center; May 1, 2007.
26. **Weinfurt, K.** "Constructing Patient-Reported Outcome Measures for Clinical Research." *Presented at the July 2007 Psychiatry Grand Rounds*; Duke University Medical Center; July 12, 2007.
27. **Weinfurt, K.** "Constructing Patient-Reported Outcome Measures for Clinical Research." *Presented at the John Umstead Hospital Psychiatry Grand Rounds*; John Umstead Hospital, Butner NC; July 12, 2007.
28. Govert J, Kussin P, Luce MF, and **Weinfurt K.** "Madison Avenue Meets Severe Sepsis: A Case Study on the Interaction Between Guidelines and Marketing." *Presented at the Department of Medicine Grand Rounds*; Duke University Medical Center; October 16, 2007.

29. "Research Participants' Reactions to Standard Informed Consent Language." **Weinfurt K**, Lawlor J, Fortune-Greeley A, and Hardy C. *Presented at the DCRI Research Conference*, November 6, 2007.
30. Hall Mark and **Weinfurt K**. "Financial Disclosures and Trust in Health Care Professionals." *Presented at the Institute of Medicine, Committee on Conflict of Interest in Medical Research, Education, and Practice*; Washington DC; May 22, 2008.
31. **Weinfurt K**. "Compliance & Quality Seminar Series: Current Research on Conflict of Interest." *Presented at the University of Missouri, Conflict of Interest Series*; Columbia MO; June 18, 2008.
32. **Weinfurt K**. "The Challenge of Unrealistic Optimism in Early Phase Oncology Trials." *Presented at the Trent Center Colloquium Series*; Duke University Medical Center; October 28, 2008.
33. **Weinfurt K**. "Conflicts of Interest." *Presented at the Dept of Medicine/Health Policy Lecture Series*; Duke University Medical Center; November 3, 2008.
34. **Weinfurt K**. "Conflicts of Interest." *Presented at the Clinical Core in Health Policy and Economics*; Terry Sanford Institute of Public Policy, Duke University; Durham NC; December 17, 2008.
35. Joy SV, Pleasants R, **Weinfurt K** and Luce MF. "Trust me, I'm a doctor" The impact of conflict of interest on expert opinion: case study on the safety of inhaled anticholinergics." *Presented at the Internal Medicine Grand Rounds Pharmacy and Therapeutics Committee*; Duke University Medical Center; February 20, 2009.
36. **Weinfurt K**. "Disclosing financial relationships to research participants: goals, evidence, and recommendations." *Presented to the National Institute of Environmental Health Sciences/ National Institute of Health (NIEHS/NIH)*; RTP NC; March 12, 2009.
37. **Weinfurt K** and Lin Li. "Clinical Research at Duke University and the Role of Patient-Reported Outcomes." *Presented at the Chinese Academy of Chinese Medical Sciences*; Beijing China; August 10, 2009.
38. **Weinfurt K**, and Lin, Li. "Using Qualitative Data in PRO Measure Development." *Presented at the Chinese Academy of Chinese Medical Sciences*; Beijing China; August 11, 2009.
39. **Weinfurt K**, and Lin, Li. "Using Quantitative Data in PRO Measure Development." *Presented at the Chinese Academy of Chinese Medical Sciences*; Beijing China; August 12, 2009.
40. **Weinfurt K** and Friedman J. "Who is CCGE?" *Presented at the DCRI Business Development Lunch and Learn Meeting*; Durham NC; October 27, 2009.
41. **Weinfurt K** and Ariely D. "Biases & Medical Decision-Making." *Presented at the GME Global Health, Law, Ethics Panel*; Duke University Medical Center; Durham NC; December 1, 2009.

42. **Weinfurt K.** "The Science of Influence and Conflicts of Interest in Medicine." *Presented at the National Health Policy Forum*; Washington DC; December 11, 2009.
43. **Weinfurt K.** "Disclosing Conflicts of Interest to Potential Trial Participants: What Do the Data Say?" *Presented at the ACRP*; Durham NC; December 14, 2009.
44. Schulman K, **Weinfurt K**, Friedman J. "CCGE economic and PRO capabilities." *Presented at the Associate Director's Lunch Meeting*; DCRI; Durham NC; January 25, 2010.
45. **Weinfurt K.** "Things You Already Know About the Psychology of Medical Decision Making." *Presented at the Psychiatry Grand Rounds*; Duke University Medical Center; March 18, 2010.
46. **Weinfurt K.** "Things You Already Know About the Psychology of Medical Decision Making." *Presented at the Psychiatry Grand Rounds*; John Umstead Hospital; Butner NC; March 18, 2010.
47. **Weinfurt K** and Flynn K. "Improving the Measurement of Patient-Reported Outcomes: NIH PROMIS and a bit of sex." *Presented at the DCRI Research Conference*; Durham NC; January 25, 2011.
48. **Weinfurt K.** "Grant Writing 101: How to Write a Convincing Research Plan." *Presented at the Professional Development Seminar*; Durham NC; January 27, 2011.
49. **Weinfurt K.** "What do patients understand about the benefits of early-phase trials?" *Presented at the Dana-Farber Cancer Institute Ethics Grand Rounds*; Boston MA; May 16, 2011.
50. **Weinfurt K.** "Improving the Measurement of Sexual Outcomes in Cancer: The NIH PROMIS Approach." *Presented at the Dana-Farber Cancer Institute Ethics Grand Rounds*; Boston MA; May 17, 2011.
51. **Weinfurt K** and Grambow S. "Effective Presentation Skills." *Presented at the Duke Professional Development Seminar*; Durham NC; June 1, 2011.
52. **Weinfurt K.** "Prospect Theory and the Demand for High Cost Cancer Care." *Presented at the Cancer EPI Group Lecture Series*; Durham NC; June 2, 2011.
53. **Weinfurt K.** "Grant Writing 101: How to Write a Convincing Research Plan." *Presented at the Professional Development Seminar*; Durham NC; January 26, 2012.
54. **Weinfurt K.** "Improving the assessment of Patient-Reported Health using NIH PROMIS Instruments." *Presented at the NACCAM 44<sup>th</sup> Annual Meeting*; Washington DC, February 3, 2012.
55. **Weinfurt K.** "Patients' high expectations of benefit from investigational therapies: should we be concerned?" *Presented at 2011-2012 LDI Health Policy Seminar Series*; Philadelphia PA, March 9, 2012.

56. **Weinfurt K.** “Conflicts of Interest.” *Presented at the Dept of Medicine/Health Policy Lecture Series*; Duke University Medical Center; March 13, 2012.

57. **Weinfurt K** and Grambow S. “Working with Biostatisticians.” *Presented at the Collaboration with Statisticians Seminar Series*; Durham NC; March 21, 2012.

58. **Weinfurt K.** “Patients' high expectations of benefit from investigational therapies: should we be concerned?” *Presented at CBSSM Seminar Series*; Univ. of Michigan, May 2, 2012.

#### **Consulting Appointments:**

1999	Putnam Investments Department of Psychology, Boston University
1998	Division of Radiology, Georgetown University Medical Center
1997	University of Aarhus, Denmark Department of Psychology, University of Maryland-College Park Kennedy-Krieger Institute, Johns Hopkins University Medical Center
1996	Department of Psychology, University of Maryland-College Park Department of History, Georgetown University
2000	Department of Psychology: Social and Health Sciences, Duke University Department of Psychiatry, Georgetown University Medical Center Pharmacia and Upjohn Pharmaceuticals Global Health Economics, Novartis Pharmaceuticals, East Hanover, NJ Department of Psychology, Boston University
2001	CancerConsultants.Com Department of Psychiatry, Georgetown University Medical Center Pharmacia and Upjohn Pharmaceuticals Department of Psychology, Boston University Global Health Economics, Novartis Pharmaceuticals, East Hanover, NJ
2002	CancerConsultants.Com
2003	CancerConsultants.Com
2004	Harvard Pilgrim Healthcare CancerConsultants.com

#### **Professional awards and special recognitions:**

**Kevin P. Weinfurt, Ph.D.**

- 1992 Collegiate and Departmental Honors, Loyola University  
Thomas M. Kennedy Award for Outstanding Service (Psychology)
- 1996 - 1997 American Psychological Foundation Graduate Research Scholarship
- 1997 Georgetown University Graduate Scholarship

**Professional activities:**

- 2007 Clinical and Translational Science Award (CTSA)  
Ethics Subcommittee, Duke University
- 2007 Data Safety Monitoring Board (DSMB) Committee, Duke University
- 2007 Member, Outcomes Executive Committee, Duke Clinical Research  
Institute
- 2008 Member, Cancer Prevention, Detection and Control Research  
Duke Comprehensive Cancer Center, Duke University Health System
- 2008 Laura Beskow, PhD Mentorship Committee, Duke University
- 2012 D-CIDES Steering Committee, Duke University
- 2012-2013 Research Advisory Committee, Duke University

**Organizations and participation:**

- 1991 - Present Private Consultant, *Statistics and Research Methodology*
- 1993 - 1995 SAS Consultant, *Georgetown University Academic Computing Center*
- 1993 Ad hoc Software Reviewer, *SPSS Inc. (UniODA for DOS 1.1)*
- 1993 Ad hoc Book Reviewer, *Sage Publications (Discursive Psychology by G. Gillette and R. Harré)*
- 1993 - 1994 Simulated Patient Instructor, *District of Columbia Aids Education and Training Center, Georgetown University Medical Center, Washington, D.C.* Played a simulated patient in programs given to medical students and psychiatric hospital staff to train health care professionals how administer HIV/STD risk assessment and counseling interviews. Provided feedback to program participants in small group settings.
- 1994 Ad hoc Book Reviewer, APA Press (*Reading and Understanding Multivariate Statistics*, L. Grimm and P. R. Yarnold, eds.)
- 2006 Consultant, *Usability Testing of Model Medical Device Patient Labeling* (Food and Drug Administration Contract A71742-00-99)

2008	Member, Board of Directors, <i>PROMIS Health Organization, Inc.</i> Abstract Reviewer, <i>Society for Medical Decision Making</i>
2008-2011	Member, Editorial Board, <i>Medical Decision Making</i>
2009	Consultant and Reviewer, <i>Eastern Research Group of Lexington, and James Bell Associates of Arlington, VA, on AHRQ's conflict of interest policies and procedures.</i>
2009-2012	Member and Reviewer, <i>Health Services Organization and Delivery Study Section (HSOD), Center for Scientific Review</i>
2012-2014	Chair, <i>Health Services Organization and Delivery Study Section (HSOD), Center for Scientific Review</i>
2009-2010	Member and Reviewer, ZRG1 HDM-C (95) S - <i>Center for Scientific Review Special Emphasis Panel</i>
2009	Honorary Member, Editorial Board, <i>Patient Related Outcomes Measures</i>
2010	Steering Committee Member, <i>NCI-ASCO Science of Clinical Trial Accrual Symposium</i>
2010	Reviewer, <i>NIH Director's Opportunity for Research in Five Thematic Areas applications</i>
2011	Editorial Board, <i>Optimal Data Analysis.</i>
2011	Planning Committee Member, <i>NIH Meeting on Measurement of Urinary Symptoms (MOMUS)</i>
2012	Associate Editor, <i>Quality of Life Research</i>

Review Work:

Ad hoc Reviewer, *Journal of Traumatic Stress.*  
 Manuscript Editor, *Niels Bohr and the Rise of the Quantum Theory in the Light of German Metaphysics of Nature* (S. Brock, University of Aarhus, Denmark). Edited a translation from Danish to prepare for publication as a book in English.  
 Institutional Review Board Committee, Georgetown University  
 Ad hoc Reviewer, National Institute of Mental Health  
 Reviewer, *HIV Clinical Trials*  
 Reviewer, *W.W. Norton and Company*  
 Reviewer, *American Heart Journal*  
 Reviewer, *American Journal of Psychiatry*  
 Reviewer, *Annals of Internal Medicine*  
 Reviewer, *British Medical Journal*

Reviewer, *Computer Methods & Programs in Biomedicine*  
 Reviewer, *Journal of the Society for Clinical Trials*  
 Reviewer, *Journal of Statistics Education*  
 Reviewer, *Journal of Complementary and Alternative Medicine*  
 Reviewer, *Journal American Medical Association*  
 Reviewer, *Journal of Clinical Epidemiology*  
 Reviewer, *Journal of General Internal Medicine*  
 Reviewer, *Medical Care*  
 Reviewer, *Medical Decision Making*  
 Reviewer, *Quality of Life Research*  
 Reviewer, *Pediatrics*  
 Reviewer, *Social Science & Medicine*  
 Reviewer, *Theoretical Medicine and Bioethics*  
 Reviewer, *Health Psychology*  
 Reviewer, *Swiss National Science Foundation*  
 Reviewer, *ISPOR*  
 Reviewer, *International Journal of Idiographic Science*  
 Reviewer, *IRB: Ethics and Human Research*  
 Reviewer, *The Milbank Quarterly*  
 Reviewer, *New Ideas in Psychology*  
 Reviewer, *Health Affairs*  
 Reviewer, *The Oncologist*  
 Abstract Reviewer, *Society for Medical Decision Making*  
 Reviewer, *Journal of Consulting and Clinical Psychology*  
 Reviewer, *Hastings Center Report*

#### **Organizations:**

1990	American Psychological Association
1991	American Psychological Society
1993	Division 1: General Psychology
1993	Division 24: Theoretical and Philosophical Psychology
1996	Division 5: Evaluation, Measurement, and Statistics
1997	Society for Judgment and Decision Making
1997	Brunswikian Society
1997	American Association for the Advancement of Science
1997	Society for Medical Decision Making
2000	Drug Information Association
2003	Hastings Center
2003	American Society for Bioethics and Humanities
2005	International Society for Pharmacoeconomics and Outcomes Research
2013	International Society for Sexual Medicine

#### **Teaching responsibilities:**

Fall, 1992	Teaching Assistant to Dr. D. N. Robinson for <i>The Idea of Human Nature</i> , Georgetown University, Washington D.C.
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Spring, 1993	Teaching Assistant to Dr. D. N. Robinson for <i>General Psychology</i> , and <i>Theoretical Psychology</i> , Georgetown University, Washington D.C.
1993 - 1995	SAS Instructor, Academic Computing Center, Georgetown University, Washington, D.C.
Fall, 1995	Independent Study Supervisor, Department of Psychology, Georgetown University, Washington DC. Directed and supervised an undergraduate's independent study on multiple regression and applied computer statistics packages.
	Private Tutorial Instructor. Taught correlation/regression, path analysis, and structural equation modeling in bi-weekly sessions to three clinical psychology professors from George Washington University and the University of Maryland.
Spring, 1995	Independent Study Supervisor, Department of Psychology, Georgetown University, Washington, DC. Directed and supervised an undergraduate's independent research study on personality perception and social cognition.
Spring, 1996	Research Practicum Supervisor and Lecturer (Undergraduate), Departments of Psychiatry and Psychology, Georgetown University, Washington, DC. Supervised undergraduates' work in clinical and health psychology research; gave lecture on applied statistics and data management.
Spring, 1999	Psychology of Decision Making (Undergraduate), Department of Psychology, Georgetown University, Washington, DC
	Statistics and Methodology for Clinical Research (Research Fellows), Department of Medicine, Georgetown University Medical Center, Washington, DC
Fall, 2000	Psychology of Thinking (Undergraduate), Department of Psychology, Duke University, Durham, NC
Spring, 2001	Multivariate Statistics (Graduate), Department of Psychology, Duke University, Durham, NC
Spring, 2002	Introductory Psychology (Undergraduate), Department of Psychology, Duke University, Durham NC
	Undergraduate Honors Thesis Committee Member (Matthew Hays), Department of Psychology, Duke University, Durham NC
Fall, 2002	Multivariate Statistics (Graduate), Department of Psychology, Duke University, Durham NC

Spring, 2003	Introductory Psychology (Undergraduate), Department of Psychology, Duke University, Durham NC
Fall, 2003	Multivariate Statistics (Graduate), Department of Psychology, Duke University, Durham NC
Spring, 2004	Introductory Psychology (Undergraduate), Department of Psychology, Duke University, Durham NC
Fall, 2004	Multivariate Statistics (Graduate), Department of Psychology, Duke University, Durham NC
Spring, 2005	Introductory Psychology (Undergraduate), Department of Psychology, Duke University, Durham NC
Spring, 2006 Duke	Introductory Psychology (Undergraduate), Department of Psychology, University, Durham NC
Fall, 2006 Duke	Introductory Psychology (Undergraduate), Department of Psychology, University, Durham NC
Spring, 2007	Medical Decision Making (Undergraduate) Department of Psychology, Duke University, Durham NC
Spring, 2008	Introductory Psychology (Undergraduate), Department of Psychology, Duke University, Durham NC.
Fall, 2008	Medical Decision Making (Undergraduate), Department of Psychology, Duke University, Durham NC
Spring, 2009	Introductory Psychology (Undergraduate), Department of Psychology, Duke University, Durham NC.
Fall, 2010	Medical Decision Making (Undergraduate), Department of Psychology, Duke University, Durham NC
Spring, 2011	Clinical Research Training (Graduate), Clinical Research Training Program, Duke University, Durham, NC
Spring, 2012	Clinical Research Training (Graduate), Clinical Research Training Program, Duke University, Durham, NC
Spring, 2013	Clinical Research Training (Graduate), Clinical Research Training Program, Duke University, Durham, NC

**Areas of research interest:** Philosophical and psychological perspectives on informed consent; patient-reported outcomes in clinical trials; psychology of medical decision-making; history of

psychology; quantitative methods in behavioral research.

External support (past and present) – gifts, grants, and contracts:

**Past:**

Title: *AR/BC2 Clinical Trial using the Q-Twist Method*  
Role: Co-Investigator  
Source: Novartis Pharmaceuticals Corporation  
Dates: 10/30/97 - 3/30/98  
Total Cost: \$90,000  
Goals: The purpose of this study was to analyze the effects on quality –adjusted survival of letrozole (2.5 and 0.5 mg) relative to megestrol acetate 160 mg in the treatment of advanced breast cancer.

Title: *The Burden of Illness of Irritable Bowel Syndrome in the United States*  
Role: Co-Investigator  
Source: Novartis Pharmaceuticals Corporation  
Dates: 4/30/98 - 6/30/99  
Total Cost: \$262,500  
Goals: This study used a community sample to evaluate the prevalence, healthcare use and costs, and quality of life of patients suffering from Irritable Bowel Syndrome.

Title: *Economic Evaluation of Apligraf*  
Role: Co-Investigator  
Source: Novartis Pharmaceuticals Corporation  
Dates: 12/1/99 - 6/30/00  
Total Cost: \$125,000  
Goals: The purpose of this study was to document the changes in healthcare resource use, cost, and quality of life following application of a new treatment for skin ulcers.

Title: *Economic Analysis of Zoledronate (Protocol 039)*  
Role: Principal Investigator, Quality of Life Substudy  
Source: Novartis Pharmaceuticals Corporation  
Dates: 9/1/00 - 6/30/03  
Total Cost: \$559,022  
Goals: This study compared zoledronic acid (4 and 8/4 mg) to placebo in reducing the occurrence of skeletal-related morbidities in patients with prostate cancer metastatic to bone. The quality of life substudy examined the effect of treatment on pain, health-related quality of life, and patient preferences.

Title: *Economic Evaluation of ValHeft*  
Role: Principal Investigator, Quality of Life Sub-study  
Source: Novartis Pharmaceuticals/Basel  
Dates: 7/1/00 - 4/30/01  
Total Cost: \$238,172  
Goals: The goal of this project was to evaluate the economic and quality of life outcomes

in a trial of Valsartan plus standard treatment versus standard treatment alone in the care of patients with heart failure.

Title: *Evaluating Advanced Methods for Missing Quality of Life Data*  
Role: Principal Investigator  
Source: Novartis Pharmaceuticals/Basel  
Dates: 9/01/00 - 01/01/01  
Total Cost: \$60,146  
Goals: This methodological study used data from clinical trials to simulate the effects of item-level missing data. Multiple methods for treating item-level missingness were compared.

Title: *Literature Review and Critique for the Ruffinamide Trial*  
Role: Principal Investigator  
Source: Novartis Pharmaceuticals Corporation  
Dates: 9/01/00 - 9/28/01  
Total Cost: \$5,978  
Goals: The goal of this work was to critically evaluate prior clinical research similar to research being proposed by Novartis Pharmaceuticals for one of its compounds.

Title: *NIDA Drug Abuse Treatment Network*  
Role: Co-Investigator  
Source: National Institute of Drug Abuse U10 DA13711-01  
Dates: 1/1/01 - 12/31/02  
Total Cost: \$11,000,000  
Goals: The overall goal of this project is to establish a Southeastern research node of the National Institute on Drug Abuse Clinical Trial Network (CTN) to investigate the effectiveness of behavioral and pharmacological treatments for substance abuse.

Title: *LEP*  
Role: Co-Investigator  
Source: Pharmacia  
Dates: 1/22/01 - 6/30/01  
Total Cost: \$22,021  
Goals: Development of a functional assessment CRF module for Metastatic Breast Cancer

Title: *LEP 2*  
Role: Principal Investigator  
Source: Pharmacia  
Dates: 5/1/01 - 7/31/01  
Total Cost: \$32,533  
Goals: Development of a new functional assessment CRF module for peripheral neuropathy induced by chemotherapy

Title: *Economic and QOL Evaluation of Protocol 010*  
Role: Principal Investigator, Quality of Life Substudy  
Source: Novartis Pharmaceuticals  
Dates: 7/17/00 - 8/15/01  
Total Cost: \$250,000

Goals: This study compared zoledronic acid (4 and 8/4 mg) to aredia in reducing the occurrence of skeletal-related morbidities in patients with breast and multiple mylenoma cancer metastatic to bone. The quality of life substudy examined the effect of treatment on pain, health-related quality of life, and patient preferences.

Title: *Patient Decision Making in Phase I Cancer Clinical Trials*  
Role: Co-Investigator - Subcontract to Duke University from Foxchase Cancer Center  
Source: National Cancer Institute R01-CA82085  
Dates: 7/1/98-9/29/03  
Total Cost: \$2,304,187  
Goals: The goal of this project was to understand the factors related to end-stage Cancer patients' decisions to participate in Phase I clinical research.

Title: *Skeletal Related Events*  
Role: Principal Investigator  
Source: Novartis Pharmaceuticals  
Dates: 11/1/02 - 8/15/03  
Total Cost: \$84,569  
Goals: The purpose of this project was to use existing clinical trial data to explore the relationship between skeletal related events and patient-reported outcomes in cancer patients with bone metastases

Title: *Additional Analysis Required for Manuscript Preparation on Protocols 039, 010 and 011*  
Role: Co-Investigator  
Source: Novartis Pharmaceuticals  
Dates: 10/1/01 - 12/31/03  
Total Cost: \$42,403  
Goals: Conduct additional data analyses in preparation of the final deliverable, the manuscript, on Zometa Protocols 039, 010 and 011.

Title: *Landmark Quality of Life Study*  
Role: Principal Investigator  
Source: Novartis Pharmaceuticals  
Dates: 12/1/03 – 5/31/04  
Total Cost: \$30,907  
Goals: The goal of this project is to use data from the Zometa 039 trial to model the long-term effect of having 0, 1, or  $\geq 2$  skeletal-related events on patient-reported outcomes using a landmark analysis.

Title: *Physician's Decisions for the Depressed Medically Ill (1R01 MH60696-01A1)*  
Role: Principal Investigator - Duke Subcontract to Georgetown University  
Source: NIH (Epstein)  
Dates: 7/1/00 - 6/30/04  
Total Cost: \$81,501  
Goals: The diagnosis and treatment of depressed patients can be difficult when patients have another medical illness. The purpose of this study is to describe primary care physicians' decision making for depression care in medically ill patients. The study uses videotaped vignettes

of patient actors who presented with and without a recent myocardial infarction to elicit primary care physicians' diagnostic and treatment judgments.

Title: *Longitudinal Study of Battered Women In the Health Care System ( R49/CCR319780-01)*  
Role: Principal Investigator - Duke Subcontract With Georgetown University  
Source: CDC (Dutton)  
Dates: 10/1/01 - 9/30/04  
Total Cost: \$47,317  
Goals: The overall goal of this study is both to describe and predict longitudinal patterns of battered women's experience over time in order to develop effective prevention strategies for IPV victims, especially those seeking health care.

Title: *Center to Reduce Racial Disparities*  
Role: Co-Investigator  
Source: Duke Endowment  
Dates: 10/1/02 – 3/31/04  
Total Cost: \$379,685  
Goals: Assess the Durham community's readiness to test a comprehensive series of procedures and interventions that can be implemented by our health care delivery system to improve the care of minority patients

Title: *Monitoring QOL and Data Resource Use for VALUE*  
Role: Co- Investigator  
Source: Novartis Pharmaceuticals  
Dates: 10/1/01 – 12/31/03  
Total Cost: \$52,536  
Goals: The purpose of this project is to ensure the quality of data (health-related quality of life and healthcare utilization) as part of the VALUE trial.

Title: *Monitoring QOL and Data Resource Use for VALIANT*  
Role: Co- Investigator  
Source: Novartis Pharmaceuticals  
Dates: 7/1/01 – 12/31/03  
Total Cost: \$59,475  
Goals: The purpose of this project is to ensure the quality of data (health-related quality of life and healthcare utilization) as part of the VALUE trial.

Title: *VALIANT*  
Role: Co- Investigator  
Source: Novartis Pharmaceuticals  
Dates: 8/22/02 – 6/30/04  
Total Cost: \$204,271  
Goals: This is a randomized comparative clinical trial of Valsartan vs. Captopril vs acombination of Valsartan and Captopril for the treatment of post-myocardial infarction patients. The economic and quality of life substudy will evaluate the treatments with respect to their impact on quality of life, as well as healthcare utilization and cost.

Title: *Economic Analysis and QOL of Epoetin Alfa*  
Role: Co- Investigator  
Source: Johnson and Johnson  
Dates: 12/1/03 – 12/31/04  
Total Cost: \$270,512  
Goals: This randomized, controlled trial is designed to compare the hematologic response of epoetin alfa and darbepoetin alfa in anemic cancer patients receiving chemotherapy. The quality of life component of the study will characterize the relationship between the primary clinical outcomes and measures of patient-reported outcomes.

Title: *Economic Analysis and QOL of Epoetin Alfa*  
Role: Co- Investigator  
Source: Johnson and Johnson  
Dates: 12/1/03 – 12/31/04  
Total Cost: \$270,512  
Goals: This randomized, controlled trial is designed to compare the hematologic response of epoetin alfa and darbepoetin alfa in anemic cancer patients receiving chemotherapy. The quality of life component of the study will characterize the relationship between the primary clinical outcomes and measures of patient-reported outcomes.

Title: *BMS 046*  
Role: Co- Investigator  
Source: BMS  
Dates: 11/1/03 – 10/31/06  
Total Cost: \$305,906  
Goals: This phase III randomized, open-label, multicenter trial (Bristol-Meyers-Squibb Protocol Number CA63046) is designed to compare Novel Epothilone plus Capecitabine vs. Capecitabine alone in patients with metastatic breast cancer previously treated with an anthracycline and a taxane. The primary clinical objective is to compare time to progression between the treatment groups. One of the secondary objectives of the trial is to compare symptom experiences of patients in both treatment arms, which is the purpose of our substudy.

Title: *BMS 048*  
Role: Principal Investigator  
Source: BMS  
Dates: 2/1/04 – 6/30/07  
Total Cost: \$196,196  
Goals: Economic and Symptom Assessment of CA163048- A Phase III Trial of Novel Epothilone BMS-247550 Plus Capecitabine versus Capecitabine Alone in Patients with advanced Breast Cancer Previously Treated with an Anthracycline and a Taxane.

Title: *BMS 014*  
Role: Co-Investigator  
Source: BMS  
Dates: 7/1/03 – 10/31/06  
Total Cost: \$222,923  
Goals: Economic Analysis of BMS Protocol CA225014: A Phase III Randomized Multi-center Study of Cetuximab, Oxaliplatin, 5-Fluorouracil, and Leucovorin vs. Oxaliplatin, 5-Fluorouracil, and Leucovorin in Patients with Previously Treated Metastatic BGRF-Positive

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## Colorectal Carcinoma.

Title: *ACTION EQOL Study (1 U01 HL66461)*

Role: Co-Investigator

Source: NIH (Schulman)

Dates: 9/30/02 - 7/31/07

Total Cost: \$2,602,524

Goals: This study is a randomized trial of exercise training versus usual care evaluating all-cause mortality for patients with New York Heart Association Class II-IV congestive heart failure. The Economics and Quality of Life (EQOL) substudy of the ACTION grant is designed to assess the additional costs in terms of money and resources, and the additional benefits in terms of quality and length of life of the exercise training intervention.

Title: *IMDMI*

Role: Principal Investigator

Source: Duke SOM

Dates: 3/1/05 – 4/30/09

Total Cost: \$250,000

Goals: The objective of this internally funded study is to promote better decision making by care givers and patients by (1) facilitating collaborative research and teaching in the area of Medical Decision Making (MDM); (2) developing tools to improve MDM; and (3) to monitor and improve Duke's status in the field of MDM.

Title: *Disclosing Conflict of Interest to Research Participants*

Role: Principal Investigator on Duke Subcontract to Johns Hopkins University

Source: NIH (Sugarman)

Dates: 1/15/04 - 12/31/09

Total Cost: \$3,108,276

Goals: The purpose of this project is to examine the issues and concerns surrounding disclosure of conflict of interest to patients and the effect on patients' understanding, decision-making, trust and participation in research.

Title: *Dynamic Assessment in Multi-Center Trials (1U01-AR-052186-05)*

Role: Principal Investigator

Source: NIH

Dates: 9/1/04 – 9/29/09

Total Cost: \$4,370,015

Goals: The goal of the Patient-Reported Outcomes Measurement Information System (PROMIS) Network is to develop a unified approach for assessing PROs using computerized adaptive testing (CAT). The overall objective is to identify and address challenges to integrating CAT into multi-center clinical trials.

Title: *Clinical and Translational Research Ethics, Law and Policy Core*

Role: Co-Investigator (Califf)

Source: NCRR/NIH

Dates: 9/30/06 – 6/30/11

Total Cost: \$150/696

Goals: This Clinical and Translational Research Ethics, Law and Policy (CTRELP) core's



aim is to identify ethical, legal, and policy issues encountered in carrying out clinical translational science, and in applying that science in practice, and to identify options to address those issues.

Title: *PRoTECT III (1 U01 NS062778-01)*  
Role: Duke Principal Investigator  
Source: Emory University Subcontract Agreement  
Dates: 7/1/09-6/30/11  
Total Cost: \$34,239  
Goals: Our primary objective is to determine the effect of administering intravenous progesterone (initiated within 4 hours of injury and administered for 72 hours, followed by an additional 24 hour taper) versus placebo for treating victims of moderate to severe (GCS 12-4) traumatic brain injury. A maximum of 1,140 patients will be randomized adjusting for age, gender and severity. Patients will be stratified by age and severity. The primary measure of outcome will be Glasgow Outcome Scale – Extended (GOSE) measured 6 months following injury, categorized using a stratified dichotomy scale.

Title: *Understanding Patient Expectations of Treatment Outcomes (1R01-CA-100771)*  
Role: Principal Investigator  
Source: NCI  
Dates: 6/8/09 – 11/30/11  
Total Cost: \$261,396  
Goals: The objective of this proposal is to better understand the meaning of patients' reported expectations regarding treatment outcomes in the informed consent process. To accomplish this objective, we will pursue 3 SPECIFIC AIMS: (1) To determine how patients who are offered participation in phase I and II studies understand questions regarding their expectations of treatment outcomes. (2) To determine how patients' estimates of treatment outcomes depend upon how the patients are asked to provide the estimates. (3) To describe patient characteristics that are associated with higher expectations regarding treatment outcomes. Findings from the proposed research will help to determine if and when patients' reports of treatment expectations indicate a failure of the informed consent process. The results will also be applicable to a broad array of patients who are considering treatment options for life-threatening diseases.

Title: *Assessing the Use and Understanding of Certificates of Confidentiality*  
R01-HG005087 (Beskow)  
Role: Co-Investigator  
Source: NIH  
Dates: 5/28/10-2/29/12  
Total Cost: \$275,220  
Goals: The purpose of this study is to examine how research institutions understand and use Certificates in protecting research participants and the role they play in assessments of risk.

Title: *An Open Source Research Permissions Management System for South Carolina*  
(11-1873)  
Role: Consortium Principle Investigator  
Source: NIH/Health Sciences South Carolina  
Dates: 9/30/10 – 9/29/12  
Total Cost: \$164,483  
Goals: The overarching goal of the proposed project will allow USC and its partner

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organizations to accelerate and enhance the Health Sciences South Carolina Integrated Platform for Research thought the development and implementation of processes and technology to manage research permissions. The study team at Duke University will provide leadership and oversight concerning the ethical and legal aspects of the HS-SCIPR by establishing an Ethical, Legal and Social Issues (ELSI) advisory structure. The ELSI advisory structure will provide for activities: (1) convene an Advisory Panel; (2) design a community engagement program; (3) identify training needs for end-users; and (4) develop and implanted protocols for patient interface studies. Enhancing the clinical trials network will allow for growth and investment in biomedical research and development, public health, and healthcare delivery in South Carolina

**Present:**

Title: *Validating and Extending the PROMIS Sexual Function Measure for Clinical Research* (U01-AR052186)  
 Role: Principle Investigator  
 Source: NIH  
 Dates: 9/30/09 – 7/31/13  
 Total Cost: \$323,345  
 Goals: The National Institutes of Health (NIH) established the Patient-Reported Outcomes Measurement Information System (PROMIS) Network with the goal of developing a comprehensive, standardized, and efficient means of measuring patient-reported outcomes in persons with chronic diseases. As one of the 7 original research sites, Duke University led the development of 2 domains of measurement for patients with cancer, including sexual function. Sexual function and satisfaction are strong determinants of overall quality of life and are affected by many chronic diseases and their treatments. Yet little work has been done to measure sexual function across chronic diseases using consistent, high quality measurement approaches. The first phase of PROMIS supported research toward the development of the sexual function domain for cancer populations. Early testing suggests the PROMIS measure is superior to many alternatives in terms of understandability, comprehensiveness, and appropriateness for many types of people. In the next phase of PROMIS, we wish to broaden the applicability of the measure to chronic diseases beyond cancer. The work proposed in this application will ensure that the initial investment by NIH in the PROMIS sexual function domain will result in a measure that is useful across therapeutic areas and meets all of the PROMIS standards.

Title: *PREMIS: Preventive Misconception in HIV Prevention Trials* (R21-MH092253)  
 Role: Principle Investigator  
 Source: NIH  
 Dates: 7/1/10-4/30/13  
 Total Cost: \$128,700  
 Goals: The objective of this study is to understand how risk behavior may be related to participants' false beliefs about the prevention trial and the investigational intervention being tested.

Title: *CTTI U19*  
 U19-FD-003800 (Kramer)  
 Role: Co-Investigator

Source: Food and Drug Administration

Dates: 9/20/09-8/31/14

Total Cost: \$961,538

Goals: The objectives of this project are two-fold. First, we plan to conduct a review of informed consent documents to describe how safety monitoring is currently being conveyed to research participants. Our major analytic goals are to identify how many informed consents contain language about how investigators will monitor and communicate the evolving safety profile of the investigational product to study participants and to document the language with which the consent forms address these issues. Second, we aim to explore via focus groups how patients expect investigators to monitor and communicate safety of the investigational product during the conduct of a clinical trial.

Title: Enhancing the Biobanking Informed Consent Process to Improve Comprehension  
R01 HG006621 (Weinfurt)

Role: Principle Investigator

Source: NIH

Dates: 8/24/12-5/31/16

Total Cost: \$219,478

Goals: The successful completion of the proposed study will lead to significant improvements in the way informed consent is conducted and evaluated for biobanking research.

1U54AT007748 (Califf)

Title: Health Care Systems Research Collaboratory-Coordinating Center

Role: Co-Investigator

Source: NIH

Dates: 9/30/12-8/31/17

Total Cost:

Goals: The objective is to lead the development of model governance policies to guide research collaborations in health system research, along with guidances, best-practice documents, and technical standards for conducting health system research; create the Distributed Research Network that will facilitate collaborative clinical research by allowing organizations to share data with research partners without disclosing PHI or proprietary data; assist Demonstration Projects in implementing health system focused practical and cluster randomized trials, and disseminate Collaboratory products.

1 U01 DK097779 (Weinfurt)

Title: Advancing the Measurement and Classification of Lower Urinary Tract  
Dysfunction (LURN)

Role: PI

Source: NIH

Dates: 9/30/12- 5/31/17

Total Cost:

Goals: The objective is to work as a Research Site within LURN to produce high quality patient-reported measures of LUTD symptoms and use these new measures in exploratory studies to advance our understanding of LUTD and its treatment.

**PENDING**

**Kevin P. Weinfurt, Ph.D.**

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Clinical activity – type of practice and estimate of time commitment:

Participation in academic and administrative activities of the University and Medical Center

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Date

Signature of Chair

## Personal Information

Faculty member's preferred familiar name: Kevin Weinfurt

Local home address: 3817 Chippenham Rd.  
Durham, North Carolina 27707

Local phone number: 919-401-6223

Marital status: Married

Name of spouse: Jean L. Weinfurt

## ***CURRICULUM VITAE***

Huntington Faxon Willard, Ph.D.  
Duke University  
Director, Duke Institute for Genome Sciences & Policy  
Senior Advisor to Vice Provost, Office of Undergraduate Education

### **Academic Information:**

**Academic appointments:** Duke Institute for Genome Sciences & Policy  
School of Medicine  
School of Arts & Sciences

**Academic departments (joint):** Molecular Genetics & Microbiology  
Biology

**Present academic rank and title:** Professor with Tenure  
Nanaline H. Duke Professor of Genome Sciences

**Date of Duke faculty appointment:** January 1, 2003

### **Personal Data:**

**Home Address:** 3710 Northampton Road  
Durham, North Carolina 27707

**Email:** [hunt.willard@duke.edu](mailto:hunt.willard@duke.edu) [work]  
[hfwillard@gmail.com](mailto:hfwillard@gmail.com) [personal]

**Date of Birth:** June 18, 1953  
Boston, Massachusetts

**Citizen of:** United States of America

<b>Education</b>	<b>Institution</b>	<b>Date</b>	<b>Degree</b>
Baccalaureate	Harvard University	1975	A.B.
Doctorate	Yale University	1979	Ph.D.

### **Scholarly Societies:**

American Academy of Arts & Sciences (Fellow, 2008)  
American Association for the Advancement of Science (Fellow, 2005)  
American Society of Human Genetics  
Human Genome Organization (HUGO)

**Academic Career:**

<b>Institution</b>	<b>Position/Title</b>	<b>Dates</b>
Duke University		
Institute for Genome Sciences & Policy	Director	2003 - present
Department of Molecular Genetics & Microbiology	Nanaline H. Duke Professor	2004 - present
Department of Biology		
Case Western Reserve University		
Department of Genetics	Henry Willson Payne Professor and Chairman	1992 - 2001
	Professor	2001 - 2002
Center for Human Genetics	Director	1992 - 2002
University Hospitals of Cleveland		
Research Institute	Director and President	1999 - 2002
Stanford University		
Department of Genetics	Associate Professor	1989 - 1992
University of Toronto		
Department of Molecular Genetics	Assistant Professor	1982 - 1987
Faculty of Medicine/Arts & Science	Associate Professor	1987 - 1989
Johns Hopkins University School of Medicine		
Division of Medical Genetics	Fellow	1979 - 1981

**Administrative, Executive and Professional Experience:**Academic and Executive Positions

2003 – present	Director, Institute for Genome Sciences & Policy, Duke University
2010 – 2012	Senior Advisor, Office of the Dean and Vice Provost for Undergraduate Education
2009 – 2012	Member, Appointments, Promotion and Tenure Committee, Duke University
2009 – 2010	Member, Undergraduate Education Strategic Planning Committee, Duke University
2003 – 2009	Vice Chancellor for Genome Sciences, Duke University Health System and Duke University
1999 – 2002	Director and President, Research Institute, University Hospitals of Cleveland
1992 – 2002	Director, Center for Human Genetics, University Hospitals of Cleveland
1992 – 2001	Chairman, Department of Genetics, Case Western Reserve University

National Institutes of Health / Department of Health and Human Services

2003 – 2007	Secretary's Advisory Committee on Genetics, Health & Society, Department of Health and Human Services
1999 – 2002	Mammalian Genetics Study Section, National Institutes of Health (Chairman, 2000-2002)
1987 – 1991	NICHD Mental Retardation Research Committee, National Institutes of Health (Chairman, 1990-1991)

#### American Society of Human Genetics

2005 – 2006	Nominating Committee, American Society of Human Genetics (Chair, 2006)
2000 – 2003	Board of Directors, American Society of Human Genetics
2001	President, American Society of Human Genetics
1997 – 2001	Awards Committee, American Society of Human Genetics
1994 – 1996	Board of Directors, American Society of Human Genetics
1990 – 1994	Program Committee, American Society of Human Genetics (Chair, 1994)
1986 – 1987	Nominating Committee, American Society of Human Genetics (Chair, 1987)

#### Other Scientific Review and Advisory Committees

1997 – 2014	Scientific Review Board, Howard Hughes Medical Institute
2012	Academic Program Review Committee, Graduate Programs in Biomedical and Biological Sciences, University of Southern California
2011 – present	Scientific Advisory Board, Simons Foundation Autism Research Initiative
2011 – present	Chair, Scientific Advisory Board, Geisinger Health System
2009 – 2011	Scientific Review Panel, Simons Foundation
2007	External Review Committee, Institute for Systems Medicine Planning Authority, Spokane, WA
2006	External Review Committee, Department of Biology, Boston College
2004 – 2010	Chair, Basil O'Connor Advisory Committee, March of Dimes Birth Defects Foundation
2004, 2006	Review Panel (Chair, 2004), Genome Canada
2002	External Review, Graduate Programs in Human Genetics, University of California, Los Angeles
2001	Chair, Human Genetics External Review Committee, University of California, San Francisco
1992 – 1998	Basil O'Connor Advisory Committee, March of Dimes Birth Defects Foundation

#### Other National and International Organizations

2002 – 2005	Member, Excellence in Science Award Committee, Federation of American Societies for Experimental Biology (FASEB)
2000 – 2001	Member, Committee on Understanding the Biology of Sex and Gender Differences, Institute of Medicine
1997 – 2000	Member, Council of Academic Societies, American Association of Medical Colleges (AAMC)
1996 - 1999	Member, Board of Councilors, Association of Professors of Human/Medical Genetics
1992 - 1995	Co-editor, Genetic Constitution of the Human X Chromosome, Human Gene Mapping Workshops
1993 - 1995	Human Genome Mapping Committee, Human Genome Organization (HUGO)
1988 - 1991	Committee on Genetic Constitution of the Human X Chromosome, International Workshop on Human Gene Mapping
1982 - 1989	Committee on Human Gene Mapping Using Recombinant DNA Techniques, International Workshop on Human Gene Mapping

#### Academic Publications

2011 – 2015	Editorial Committee, <i>Annual Review of Genomics and Human Genetics</i>
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2005 – 2010	Editorial Board, <i>BMC Genomics</i>
2005 – present	Consulting Editor, <i>Human Molecular Genetics</i>
1991 – 2005	Co-Founder and Executive Editor, <i>Human Molecular Genetics</i>
1990 – 1999	Editor, <i>Chromosoma</i>
1987 - 1988	Editorial Board, <i>Genomics</i>
1988 - 1991	Subject Area Editor, <i>Genomics</i>
1989 - 1991	Associate Editor, <i>The American Journal of Human Genetics</i>
1984 - 1989	Editorial Board, <i>Cytogenetics and Cell Genetics</i>

Other Organizations (Academic, Corporate and Community):

2011 – present	Chair, Scientific Advisory Board, Geisinger Health System, Danville, PA
2009	Co-Founder, Athleticcode, Inc., San Francisco, CA
2007 – 2008	Chair, Strategic Advisory Board, Institute for Systems Medicine, Spokane, WA
2004 – 2009	Scientific Advisory Board, LabCorp Inc, Research Triangle Park, NC
2004 – 2008	Advisory Board, McLaughlin Centre for Molecular Medicine, University of Toronto
2004 – 2005	Board of Directors, N. Carolina Biotechnology Center, Research Triangle Park, NC
2002 – 2005	Advisory Board, Genetics Prize, Peter Gruber Foundation
2001 – 2002	Board of Directors, Cleveland BioEnterprise Corporation, Cleveland, OH
2001 – 2002	Board of Trustees, Great Lakes Science Center, Cleveland, OH
2000 – 2003	Strategic Advisory Board, NineSigma, Inc., Cleveland, OH
1999 – 2003	Technology Advisory Council, Biomec, Inc., Cleveland, OH
1999 – 2002	Board of Trustees, Edison Biotechnology Center, Inc.
1995	Co-Founder, Athersys, Inc., Cleveland, OH
1988 – 1998	Consultant, Oncor, Inc. and OncorMed, Inc., Gaithersburg, MD

Professional Awards, Named Lectures and Honors:

2013 (scheduled)	James V. Neel Memorial Lecture, University of Michigan
2011	Wilbur Cross Medal, Yale Graduate School
2009	William Allan Award, American Society of Human Genetics
2008	Elected to American Academy of Arts and Sciences
2007	Elected to Society of Scholars, Johns Hopkins University
2006	Catherine Birch McCormick Distinguished Scholar and Lecture, Genomics Center, George Washington University
2006	David L. Rimo Lecture, UCLA
2005	Elected, Fellow, American Association for the Advancement of Science
2004	Abelson Family Lecture, Washington State University, Pullman, WA
2001	President, American Society of Human Genetics
1999	Pruzansky Lecture, American College of Medical Genetics
1998 – 2003	Franklin Delano Roosevelt Investigator, March of Dimes Birth Defects Foundation
1988 – 1993	Scientist Award, Medical Research Council of Canada (resigned, 1989)
1983 – 1988	Scholar Award, Medical Research Council of Canada
1982 – 1984	Basil O'Connor Award, March of Dimes Birth Defects Foundation

Educational Program Leadership, Awards and Honors:

2009, 2010, 2011	Arts & Sciences Faculty “Dean’s List” (top 5% of student evaluations), Duke University
2008 – present	Director, Certificate Program in Genome Sciences & Policy, Duke University
2006 – 2010	Appointed HHMI Professor, Howard Hughes Medical Institute

2005 – 2008	Interim Director, Graduate Program in Computational Biology & Bioinformatics, Duke University
2001	Outstanding Faculty Award, Biomedical Sciences Doctoral Training Programs, Case Western Reserve University
1992 – 2001	Director, Graduate Program in Genetics, Case Western Reserve University

## Publications

### Books:

- Thompson MW, McInnes RR, **Willard HF** (1991). *Genetics in Medicine*, Fifth Edition. Philadelphia: WB Saunders Co., 500 pp.
- Nussbaum RL, McInnes RR, **Willard HF** (2001). *Genetics in Medicine*, Sixth Edition. Philadelphia: WB Saunders Co., 444 pp.
- Nussbaum RL, McInnes RR, **Willard HF** (2007). *Genetics in Medicine*, Seventh Edition. Philadelphia: WB Saunders Co., 585 pp.
- Willard HF**, Ginsburg G (eds) (2008). *Genomic and Personalized Medicine* (2 vols). New York: Elsevier, 1558 pp.
- Ginsburg G, **Willard HF** (eds) (2009). *Essentials of Genomic and Personalized Medicine*. New York: Elsevier, 785 pp.
- Ginsburg G, **Willard HF** (eds) (2012). *Genomic and Personalized Medicine, 2<sup>nd</sup> edition* (2 vols). New York: Elsevier (in press).
- Willard HF**, Angrist M (20xx). *The Genome Revolution* (in final preparation).

### Original Contributions in Refereed Journals:

1. Latt SA, Stetten G, Juergens LA, **Willard HF**, Scher CD (1975). Recent developments in the detection of DNA synthesis by 33258 Hoechst fluorescence. *J. Histochem. Cytochem.* 23:493-505.
2. **Willard HF**, Latt SA (1976). Analysis of DNA replication in human X chromosomes by fluorescence microscopy. *Am. J. Hum. Genet.* 28:213-227.
3. Latt SA, **Willard HF**, Gerald PS (1976). BrdU-33258 Hoechst analysis of DNA replication in human lymphocytes with supernumerary or structurally abnormal X chromosomes. *Chromosoma* 57:135-153.
4. **Willard HF**, Ambani LM, Hart AC, Mahoney MJ, Rosenberg LE (1976). Rapid prenatal and postnatal detection of inborn errors of propionate, methylmalonate and cobalamin metabolism: a sensitive assay using cultured cells. *Hum. Genet.* 34:277-283.
5. **Willard HF** (1977). Tissue-specific heterogeneity in DNA replication patterns of human X chromosomes. *Chromosoma* 61:61-73.
6. Mellman IS, Youngdahl-Turner P, **Willard HF**, Rosenberg LE (1977). Intracellular binding of radioactive hydroxycobalamin to cobalamin-dependant apoenzymes in rat liver. *Proc. Natl. Acad. Sci. USA* 74:916-920.
7. **Willard HF**, Rosenberg LE (1977). Inherited deficiencies of human methylmalonyl CoA mutase activity: reduced affinity of mutant apoenzyme for adenosylcobalamin. *Biochem. Biophys. Res. Comm.* 78:927-934.
8. **Willard HF**, Mellman IS, Rosenberg LE (1978). Genetic complementation among inherited deficiencies of methylmalonyl CoA activity: evidence for a new class of human cobalamin mutant. *Am. J. Hum. Genet.* 30:1-13.
9. Mellman IS, **Willard HF**, Rosenberg LE (1978). Cobalamin binding and cobalamin-dependent enzyme activity in normal and mutant human fibroblasts. *J. Clin. Invest.* 62:952-960.

10. **Willard HF**, Rosenberg LE (1979). Inborn errors of cobalamin metabolism: effect of cobalamin supplementation in culture on methylmalonyl CoA mutase activity in normal and mutant human fibroblasts. *Biochem. Genet.* 17:57-75.
11. Mellman IS, **Willard HF**, Youngdahl-Turner P, Rosenberg LE (1979). Cobalamin coenzyme synthesis in normal and mutant human fibroblasts: evidence for a processing enzyme activity deficient in cbl C cells. *J. Biol. Chem.* 254:11847-11853.
12. Wolf B, **Willard HF**, Rosenberg LE (1980). Kinetic analysis of genetic complementation in heterokaryons of propionyl CoA carboxylase-deficient human fibroblasts. *Am. J. Hum. Genet.* 32:16-25.
13. **Willard HF**, Rosenberg LE (1980). Interactions of methylmalonyl CoA mutase from human fibroblasts with adenosylcobalamin and methylmalonyl CoA: evidence for non-equivalent active sites. *Arch. Biochem. Biophys.* 200:130-139.
14. **Willard HF**, Breg WR (1980). Human X chromosomes: synchrony of DNA replication in diploid and triploid fibroblasts with multiple active or inactive X chromosomes. *Somat. Cell Genet.* 6:187-198.
15. **Willard HF**, Rosenberg LE (1980). Inherited methylmalonyl CoA mutase apoenzyme deficiency in human fibroblasts: evidence of allelic heterogeneity, genetic compounds, and codominant expression. *J. Clin. Invest.* 65:690-698.
16. Schmeckpeper BJ, **Willard HF**, Smith KD (1981). Isolation and characterization of cloned human DNA fragments carrying reiterated sequences common to both autosomes and the X chromosome. *Nucl. Acids Res.* 9:1853-1872.
17. Fenton WA, Hack A, **Willard HF**, Gertler A, Rosenberg LE (1982). Purification and properties of methylmalonyl CoA mutase from normal human liver. *Arch. Biochem. Biophys.* 214:815-823.
18. **Willard HF**, Smith KD, Sutherland J (1983). Isolation and characterization of a major tandem repeat family from the human X chromosome. *Nucl. Acids Res.* 11:2017-2033.
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271. **Willard HF** (1995). Sex chromosomes and X chromosome inactivation, *In: The Metabolic and Molecular Bases of Inherited Disease*, 7th ed., Scriver CR, Beaudet AL, Sly WS, Valle D (eds). New York: McGraw-Hill Publishing Co., pp. 719-737.
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273. Tilghman SM, **Willard HF** (1995). Epigenetic regulation in mammals. *In: Chromatin Structure and Gene Expression* (Elgin S, ed.). Oxford: Oxford Univ. Press, pp. 197-222.
274. Warburton PE, **Willard HF** (1996). Evolution of centromeric alpha satellite DNA: molecular organization within and between human and primate chromosomes. *In: Human Genome Evolution*, Jackson M, Strachan T, Dover G, eds. Oxford: BIOS Scientific Publishers, pp. 121-145.
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278. **Willard HF**, Rudd MK (2006). Genomic organization and function of human centromeres. In: *Genomic Disorders: The Genomic Basis of Disease*. Edited by Stankiewicz P, Lupski J., pp. 115-129.
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#### **Other Reviews and Commentaries:**

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286. **Willard HF** (1991). Evolution of alpha satellite. *Curr. Opin. Genet. Dev.* 1:509-514.
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288. Brown CJ, **Willard HF** (1993). Molecular and genetic studies of human X chromosome inactivation. *Adv. Dev. Biol.* 2: 37-72.
289. Tyler-Smith C, **Willard HF** (1993). Mammalian chromosome structure. *Curr. Opin. Genet. Dev.* 3: 390-397.
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293. **Willard HF** (1996). X chromosome inactivation, *XIST*, and pursuit of the X inactivation center. *Cell* 86: 5-7.

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301. **Willard HF** (2000). Artificial chromosomes coming to life [Perspectives]. *Science* 290: 1308-1309.
302. **Willard HF**, Carrel L (2001). Making sense (and antisense) of the X inactivation center [Commentary]. *Proc. Natl. Acad. Sci. USA* 98: 10025-10027.
303. **Willard HF** (2001). Neocentromeres and human artificial chromosomes: an unnatural act [Commentary]. *Proc. Natl. Acad. Sci. USA* 98: 5374-5376.
304. **Willard HF** (2001). You say tomato and I say tomahto: human genetics and gene therapy. *Mol. Therapy* 4: 514
305. **Willard HF** (2002). ASHG Presidential Address – On black boxes and storytellers: lessons learned in human genetics. *Am. J. Hum. Genet.* 70: 285-296.
306. Chadwick BP, **Willard HF** (2003). SETting the stage: Eed-Enx1 leaves an epigenetic signature on the inactive X chromosome. *Dev. Cell* 4: 445-447.
307. **Willard HF** (2003). Genome biology: Tales of the Y chromosome [News & Views]. *Nature* 423: 810-812.
308. Shianna KV, **Willard HF** (2006). Human genomics: in search of normality [News & Views]. *Nature* 444: 428-429.
309. **Willard HF** (2007). Honest Jim talks manners [review of *Avoid Boring People* by James D. Watson]. *Nature* 449: 787.
310. Haga SB, **Willard HF** (2008). Letting the genome out of the bottle. *New Engl. J. Med.* 358: 2184-2185.
311. **Willard HF** (2010). Allan Award Address – Life in the Sandbox: unfinished business. *Am. J. Hum. Genet.* 86: 318-327.
312. Anderson WA et al. (including **Willard HF**) (2011). Competencies: A cure for the pre-med curriculum. *Science* 334: 760-761.

### **Public Opinion / Editorials (Op-Eds):**

**Willard HF.** "Hollywood Gives Real Scientists a Bad Rep"

*The Herald Sun* (Durham, NC), May 24, 2004

**Willard HF.** "The Way to Double Our Bet"

*News & Observer* (Raleigh, NC), June 4, 2004

**Willard HF.** "Evolution Sticker Shock"

*The Seattle Times* and *News & Observer*, December 16, 2004

Goldstein D, **Willard HF.** "Dr. King's Legacy in Our Genomic Future"

*The Boston Globe* and *The Contra Costa Times*, January 17, 2005

**Willard HF.** "The Race Against Gene Doping"

*The Orlando Sentinel* and *The Newark Star-Ledger*, July 13, 2005

*The Boston Globe* and *News & Observer*, July 14, 2005

Haga S, **Willard HF.** "Act Now to Prevent Genetic Discrimination"

*The Washington Post*, December 28, 2005

Goldstein DB, **Willard HF.** "Is she just what Japan needs?"

*News & Observer*, April 21, 2006

**Willard HF.** "What a pig! – after a new genome"

*News & Observer*, May 26, 2006

**Willard HF.** "Genes and a Sporting Chance"

*News & Observer*, July 11, 2010

### **Patents:**

U.S Patent No. 5,695,967

December 9, 1997

Method for stably cloning large repeating units of DNA

Van Bokkelen G, Harrington JJ, Willard HF

U.S Patent No. 5,869,294

February 9, 1999

Method for stably cloning large repeating DNA sequences

Harrington JJ, Van Bokkelen G, Willard HF

U.S. Patent No. 6,348,353

February 19, 2002

Artificial mammalian chromosome

Harrington JJ, Van Bokkelen G, Willard HF

## **Invited Editorial Review**

Cell  
Molecular Cell  
Developmental Cell  
Science  
Nature  
Nature Genetics  
Nature Neuroscience  
Nature Structural Biology  
Nature Cell Biology  
Nature Methods  
Proceedings of the National Academy  
of Sciences, USA  
EMBO Journal  
American Journal of Human Genetics  
Human Molecular Genetics  
Human Genetics  
American Journal of Medical Genetics  
Trends in Genetics  
Trends in Cell Biology  
European Journal of Human Genetics  
Clinical Genetics  
Journal of Medical Genetics  
BMC Genomics  
BMC Biology

Nucleic Acids Research  
Journal of Cell Biology  
Molecular and Cellular Biology  
Journal of Molecular Biology  
Molecular and Biological Evolution  
Journal of Molecular Evolution  
Molecular Therapy  
PLoS Biology  
PLoS Genetics  
PLoS Computational Biology  
Cytogenetics and Cell Genetics  
Genome Biology  
Genome Research  
Genomics  
Mammalian Genome  
Chromosoma  
Chromosome Research  
EMBO Reports  
Gene  
Genes and Development  
Somatic Cell and Molecular Genetics  
Developmental Dynamics  
Development

## **Invited Seminars and Lectures (since 2000 only)**

### **2000**

Seminar, Department of Human Genetics, University of California, Los Angeles, CA, February.  
Invited Speaker, Tenovus Symposium, Glasgow, Scotland, April.  
Invited Speaker, Rett Syndrome Conference, Washington, DC, June.  
Keynote Speaker, Genetics in the 21<sup>st</sup> Century Conference, Columbus, OH, June.  
Invited Speaker, Gene Therapy Research Symposium, March of Dimes Conference, Matsue, Japan, July.  
Visiting Faculty, 41st Annual Short Course in Medical and Experimental Mammalian Genetics, Bar Harbor, ME, July.  
Invited Speaker, Department of Pediatrics, University of Illinois at Chicago Medical Center, Chicago, IL, July.  
Invited Speaker, NIH Conference on Klinefelter Syndrome, Washington, DC, August.  
Seminar, Department of Medical and Molecular Genetics, Indiana University, Indianapolis, IN, September.  
Invited Speaker, Molecular Genetics Update for the Endocrinologist, Genes 2000 Pediatric Endocrinology International Congress, Sydney, Australia, October.  
Seminar, Division of Human Genetics, Washington University School of Medicine, St. Louis, MO, November.  
Seminar, Department of Genetics, Duke University School of Medicine, Durham, NC, December.

### **2001**

Seminar, Division of Medical Genetics and Markey Molecular Medicine Program, University of Washington, Seattle, WA, January.  
Invited Speaker, AAAS Genome Symposium, San Francisco, CA, February.  
Plenary Speaker, 2<sup>nd</sup> Annual Conference on Sex and Gene Expression, Winston-Salem, NC, March.  
Seminar, Edinburgh Chromatin Group, Edinburgh, Scotland, April.  
Invited Speaker, Symposium on Gene Regulation, HGM2001 Conference, Edinburgh Scotland, April.  
Invited Speaker, Gordon Conference, Human Molecular Genetics, Newport, RI, August.  
Seminar, Division of Human Genetics, University of Cincinnati, Cincinnati, OH, September.  
Invited Speaker, Nordic Association for Andrology Annual Meeting, Symposium on Klinefelter Syndrome, Copenhagen, Denmark, October.

### **2002**

Invited Speaker, Society for Women's Health Annual Conference, Stanford, CA, February.  
Invited Speaker, International Society of Barristers, Kona, Hawaii, March.  
Keynote Speaker, Annual Scientific Retreat, Children's Hospital Research Institute, Columbus, OH, April.  
Invited Speaker, 3<sup>rd</sup> Annual Rett Syndrome Symposium, Rett Syndrome Research Foundation, Baltimore, MD, June.  
Panelist, Summit for a Cure, MSNBC special broadcast (hosted by Brian Williams), Cleveland, OH, June.

### **2003**

Invited Speaker, Symposium on Sex and the Pediatrician, Pediatric Endocrine Society, Seattle, WA, May.  
Invited Speaker, Tanenbaum Molecular Medicine Symposium, University of Toronto, Toronto, May.  
Invited Speaker, Cold Spring Harbor Symposium on Quantitative Biology, The Sequence of the Human Genome, Cold Spring Harbor, NY, June.  
Invited Speaker, Gordon Conference, Human Genetics and Genomics, Waterville, ME, August.  
Seminar, Department of Human Genetics, Emory University, Atlanta, GA, October.  
Invited Speaker, Taiwan-America Biotechnology Conference, Taipei, Taiwan, November.



Invited Speaker, Joint Meeting of Chinese Society of Genetics and Taiwan Human Genetics Association, Taipei, Taiwan, November.

Invited Speaker, Exploring the Genomic Frontier, Pfizer Distinguished Lecture Series, Smithsonian Institution, Washington, DC, November.

## **2004**

Invited Speaker, CSBi Annual Symposium on Systems Biology, Massachusetts Institute of Technology, Cambridge, MA, January.

Invited Speaker, Keystone Symposium on Epigenetics, Tahoe, CA, January.

Seminar, Department of Genome Science, Lawrence Berkeley National Laboratory, Berkeley, CA, February.

Seminar, Department of Genetics and Genomics, Boston University, Boston, MA, March.

Seminar, Department of Genetics, University of North Carolina, Chapel Hill, NC, March.

Seminar, School of Molecular Biosciences, Washington State University, Pullman, WA, April.

Invited Speaker, Genomics Symposium, University of Arizona, Tucson, AZ, April.

Keynote Speaker, 11<sup>th</sup> Annual Science Symposium, Belmont Hill School, Belmont, MA, April.

Invited Speaker, Genomic Medicine, Association of Clinical Endocrinology, Boston, MA, May.

Invited Speaker, Special Symposium for March of Dimes Birth Defects Foundation Prize, Pediatric Research Society, San Francisco, CA, May.

Invited Plenary Speaker, 15<sup>th</sup> Annual International Chromosome Conference, London, UK, September.

Invited Speaker, Epigenetics Symposium, American Society of Human Genetics annual meeting, Toronto, October.

Seminar, Molecular Biology Institute, University of California, Los Angeles, CA, December.

## **2005**

Invited Speaker, Conference on Genetic Variation and Human Health, Royal Society, London, UK, January.

Seminar, Genetics Colloquium, University of Wisconsin, Madison, WI, April.

Invited Speaker, Gordon Conference, Human Genetics and Genomics, Newport, RI, July.

Keynote Speaker, 12<sup>th</sup> International Conference on Fragile X Syndrome and X-linked Mental Retardation, Williamsburg, VA, August.

Invited Discussant, Affymetrix Partners Conference, Cape Cod, MA, October.

Invited Discussant, National Academies-Keck Futures Initiative Conference, Orange, CA, November.

## **2006**

Seminar, McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins University School of Medicine, Baltimore, MD, January.

Invited Panelist and Program Committee, Genomics Revolution and Infectious Disease, U.S. National Academies of Sciences and Chinese Ministry of Science and Technology, Beijing, China, March.

Seminar, Department of Genetics, University of Alabama at Birmingham, School of Medicine, Birmingham, AL, April.

Seminar, Center for Human Genetics and Genomics, University of California, San Diego, La Jolla, CA, May.

Seminar, Program in Genetics and Genomics, University of Maryland, Baltimore, MD, May.

David L. Rimo Lecture in Genetics Education, Medical Genetics Training Program, University of California, Los Angeles, CA, June.

Keynote Speaker, Second International Cytogenetics and Genome Society Congress, Canterbury, U.K., June.

Invited Speaker, 11<sup>th</sup> International Congress of Human Genetics, Brisbane, Australia, August.

Invited Speaker and Panelist, Genetic Testing, CAP '06 (College of American Pathologists Annual Meeting), San Diego, CA, September.  
Invited Speaker, 2<sup>nd</sup> International Conference on X Inactivation, Paris, France, September.  
Seminar, McCormick Genomics Lecture, George Washington University, Washington, DC, November.

## **2007**

Seminar, Department of Genome Sciences, University of Washington, Seattle, WA, January.  
Seminar, Department of Genetics, Massachusetts General Hospital, Boston, MA, January.  
Seminar, Institute for Systems Biology, Seattle, WA, March.  
Invited Speaker, Genetics Annual Symposium, "Neglected Parts of the Genome", University of Chicago, IL, April.  
Invited Speaker, Symposium, "Centromeres and Kinetochores", American Society for Biochemistry and Molecular Biology, Annual Meeting, Washington, DC, April.  
Invited Speaker, Gordon Research Conference on Human Genetics and Genomics, Newport, RI, July.  
Seminar, Duke-NUS Graduate Medical School, Singapore, July.  
Seminar, Whitehead Institute, Cambridge, MA, December.

## **2008**

Seminar, Michael Katz Symposium, Department of Pediatrics, Columbia University, New York, NY, March.  
Seminar, Genome Center, University of California, Davis, Sacramento, CA, April.  
Keynote Speaker, Organization for the Study of Sex Differences, Annual Meeting, New Orleans, LA, June.  
Keynote Speaker, Genomic Medicine, Southeast Regional Genetics Group Annual Meeting, Charleston, SC, July.  
Seminar, Genetics Group, Geisinger Health System, Geisinger, PA, October.

## **2009**

Keynote Address, Keystone Symposium on Epigenetics, Development and Human Disease, Breckenridge, CO, January.  
Seminar, Biomedical Sciences Series, University of California, San Francisco, CA, March.  
Invited Speaker, Gordon Research Conference on Human Genetics and Genomics, Biddeford, ME, July.  
Invited Speaker, Symposium on Centromeres, American Society of Human Genetics, Annual Meeting, Honolulu, HI, October.  
Invited Speaker, Mid-Atlantic Centromere Workshop, National Institutes of Health, Bethesda, MD, November.  
Seminar, HudsonAlpha Institute, Huntsville, AL, December.

## **2010**

Invited Speaker, Pinkel Symposium on Transformational Genomics, University of California, San Francisco Cancer Center, San Francisco, CA, February.  
Invited Speaker, President's Symposium, Annual Meeting of the Society for the Study of Reproduction, Milwaukee, WI, August.  
Co-organizer, Sixth Annual Burrill Personalized Medicine Meeting, San Francisco, CA, September.

## **2011**

Keynote Address, Systems Biology & P4 Medicine Symposium, Institute for Systems Biology, Seattle, WA, May.  
Invited Speaker, 50<sup>th</sup> Anniversary International Conference on X Inactivation, Oxford, UK, July.  
Invited Seminar, Wilbur Cross Lecture, Yale School of Medicine, New Haven, CT, October.

## Teaching

### Undergraduate

1985 - 1987	MGB 470H - "Cellular and Molecular Mammalian Genetics", Faculty of Arts and Science, University of Toronto (6-10 hrs)
1987 - 1989	MGB 470H - "Molecular Genetics of Complex Genomes", Faculty of Arts and Science, University of Toronto (26 hrs)
1993 - 1996	BIO 214 - "Genetics", School of Arts and Sciences, Case Western Reserve University (2 hrs)
2004 – present	BIO 195S / 194S – “Genomes, Biology and Medicine”, Duke University (40 hrs)
2007	HOUSECS 79-06 – “Prospective Medicine”, Duke University (Faculty Sponsor)
2007 – 2009	BIO 289S – “Advanced Topics in Genome Sciences Research,” Duke University (40 hrs)
2009, 2010	GENOME 148 – “Genetics, Genomics and Society”, Duke University (40 hrs)
2009 - present	GENOME 198S – “Genome Sciences & Policy Capstone Course”, Duke University (40 hrs)
2010	HOUSECS 79-09 – “From Science to Society: Decoding Your Genome”, Duke University (Faculty Sponsor)

### Graduate

1982	MBP 1012-1014L - 'Molecular Organization of the Human Genome', Department of Molecular Genetics, University of Toronto (12 hrs)
1987	MBP 1014L - 'Human Molecular Genetics', Department of Molecular Genetics, University of Toronto (6 hrs of 24 hr course, with Drs. R. Worton, L. Tsui and D. Cox)
1991	GEN 210 - 'Advanced Human Genetics', Department of Genetics, Stanford University (with Dr. D. Botstein)
1992 – 2002	GENE 500/504 - 'Advanced Eukaryotic Genetics', Department of Genetics, Case Western Reserve University (with other faculty)
1995, 1997	GENE 515 - 'Chromosome Structure and Function', Department of Genetics, Case Western Reserve University
1996, 1998, 2000	GENE 510 - 'Advanced Human Genetics', Department of Genetics, Case Western Reserve University
1997, 1998	C3MB - 'Cell and Molecular Biology', Human Genetics Section, Case Western Reserve University (with Dr. M. Warman)
2002	GENE 512 – ‘Analysis of Complex Genomes’, Department of Genetics, Case Western Reserve University
2005 - 2006	MGM 300 – ‘Biological Regulatory Mechanisms’, Department of Molecular Genetics & Microbiology, Duke University (6 hrs of 30 hr course)
2006 - 2007	UPGEN 301 – ‘Advanced Topics in Genetics/Genomics’, University Program in Genetics and Genomics, Duke University (15 hrs)

### Medical Students

1983 - 1988	Course Director, Genetics for Second Year Medical Students (30 hrs), Faculty of Medicine, University of Toronto
1982 - 1988	Lecturing in Genetics for Second Year Medical Students, University of Toronto (10-18 hrs)
1989 - 1992	Lecturing in Genetics 201, Stanford University (4 - 10 hrs)
1990 - 1992	Course Director, Genetics 201 (36 hrs), Stanford University
1992 - 1996	Lecturing in First Year Committee course for medical students, Case Western Reserve University School of Medicine (~5 hrs)

2004 - 2007                      Lecturing in First Year “Molecules and Cells” segment, Duke University School of Medicine (4 hrs)

### **Graduate Students Supervised**

#### University of Toronto

1982 - 1985                      Leslie A. Creeper, M.Sc.  
    Thesis: *Functional analysis of a mammalian chromosomal origin in yeast*

1984 - 1987                      John S. Waye, Ph.D.  
    Thesis: *Organization and evolution of chromosome-specific human alpha satellite DNA*

1984 - 1990                      Sharon J. Durfy, Ph.D.  
    Thesis: *Nucleotide sequence variation, homogenization, and evolution of X chromosome alpha satellite DNA*

1987 - 1990                      Carolyn J. Brown, Ph.D.  
    Thesis: *Studies of human X chromosome inactivation*

1987 - 1992                      Rachel Wevrick, Ph.D.  
    Thesis: *Organization and behavior of alpha satellite DNA at the centromeres of human chromosomes*

1986 - 1993                      Peter E. Warburton, Ph.D.  
    Thesis: *Evolution of tandemly repeated DNA: repeat unit variation of human alpha satellite DNA*

#### Stanford University

1988 - 1993                      Melanie M. Mahtani, Ph. D.  
    Thesis: *Physical and genetic mapping studies of the human X chromosome: repression of recombination at the centromere*

1990 - 1995                      Laura Carrel, Ph.D.  
    Thesis: *Developmental and chromosomal basis of gene regulation on the mammalian X chromosome*

1991 - 1995                      Brian Hendrich, Ph.D.  
    Thesis: *Characterization of the human XIST gene and its promoter: implications for mammalian X chromosome inactivation*

1991 - 1995                      Andrew Miller, Ph.D.  
    Thesis: *Physical mapping studies and X inactivation analysis on the short arm of the human X chromosome*

#### Case Western Reserve University

1994 – 1998                      Robert M. Plenge, M.D., Ph.D.  
    Thesis: *Genetic control of skewed X chromosome inactivation*

1995 – 2000                      Anne W. Higgins, Ph.D.  
    Thesis: *Centromere structure and behavior: insight from engineered dicentric chromosomes*

1996 – 2001                      Mary G. Schueler, Ph.D.  
    Thesis: *Structure and evolution of the pericentromeric region of the human X chromosome*

1998 – 2002                      Ivona Percec, M.D., Ph.D. [jointly with University of Pennsylvania; Marisa Bartolomei, advisor]  
    Thesis: *Genetic dissection reveals multiple autosomal elements involved in X chromosome inactivation in the mouse*

1997 – 2004	James Amos-Landgraf, Ph.D. Thesis: <i>A human population study of the genetic control of X inactivation</i>
1999 – 2004	M. Katharine Rudd, Ph.D. Thesis: <i>Organization, evolution and function of alpha satellite DNA at human centromeres</i>
1999 – 2005	Lisa Helbling Chadwick, Ph.D. Thesis: <i>Genetic control of X chromosome choice in X inactivation</i>

#### Duke University

2000 – 2007	Cory Valley, Ph.D. Thesis: <i>Genomic analysis of chromatin organization on mammalian X chromosomes</i>
2005 – 2010	Bayly Wheeler, Ph.D. Thesis: <i>Role of genomic sequence in the spatial and temporal propagation of heterochromatin in fission yeast</i>
2006 – 2011	Katerina S. Kucera, Ph.D. Thesis: <i>States of allelic imbalance on the X chromosomes in human females</i>
2005 – 2011	Karen Hayden, Ph.D. Thesis: <i>A genomic definition of centromeres in complex genomes</i>
2006 – 2012	Christina Sheedy, Ph.D. Thesis: <i>Genomic characterization and comparative analysis of the Xce candidate region in mouse</i>

#### **Postdoctoral Fellows / Research Associates / Senior Research Associates**

1988 - 1991	Cecil B. Sharp, D.M.D., Ph.D.
1990 - 1992	Thomas Haaf, M.D., Ph.D.
1991 - 1994	Tiina Alitalo, Ph.D.
1991 - 1994	Carolyn J. Brown, Ph.D.
1991 - 1992	Cordula Kirchgessner, Ph.D.
1992 - 1994	Daynna Wolff, Ph.D.
1994 - 1997	John Harrington, Ph.D.
1994 - 1996	Gil van Bokkelen, Ph.D.
1994 - 1998	Kosuke Sakai, Ph.D.
1995 - 1996	Beth Sullivan, Ph.D.
1995 - 1999	Laura Carrel, Ph.D.
1996 - 1998	R. Willie Mays, Ph.D.
1996 – 2000	Karen Tsuchiya, M.D.
1998 – 2001	Christie Gunter, Ph.D.
1999 – 2003	Brian P. Chadwick, Ph.D.
1999 – 2003	Brenda Grimes, Ph.D.
2000 – 2005	Satkunanathan (Bala) Balakumaran, Ph.D.
2004 – 2007	Zhong Wang, Ph.D.
2000 – 2008	Kristin C. Scott, Ph.D.
2004 – 2008	Joydeep Basu, Ph.D.
2004 – 2008	Julie Horvath, Ph.D.
2008 – 2010	Kira Bulazel, Ph.D.
2008 – 2011	Erin Strome, Ph.D.
2008 – 2011	Hye-Ran Lee, Ph.D.

**Areas of research interests:**

Genetics  
Chromosome Structure and Function  
Genomic Medicine

Genome Biology  
Epigenetics  
Genetics, Genomics and Society