

Curriculum Vitae
Robert Mullan Cook-Deegan, MD
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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

Student thesis supervision

Graduate Student Supervisor (Duke University)
Lisa Warner, Biology PhD Candidate, 2008-Present
Jeremy Block, Biochemistry PhD candidate, MPP project 2008-2009
Matthew DeCamp, Philosophy PhD, July 2002-May 2007 (MD 2008)
Elana Fric-Shamji, MPP (already had her MD), May 2007-May 2008
Deirdre Parsons, MS in Molecular Genetics & Microbiology, May-December 2007
Eric Hoefler, MPP, MBA, Jan-May 2004
Noah Perin, MPP, MBA, Jan-May 2005
Charles Matthews, MPP, Jan-May 2004
Undergraduate Thesis Supervisor (Duke University)
Swathi Padmanabhan, May 2010 (Public Policy Studies, expected)
Matthew Piehl, May 2008 (Biology)
Sarah Wallace, December 2007 (Public Policy Studies)
Catherine Alessandra Colaianni, May 2007 (Biology)
Joe Fore, December 2006 (Public Policy Studies)
Daidree Tofano, May 2006 (Program II)

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, Association of University Technology Managers (AUTM) Public Policy Committee, February 2009-present

Member, AAAS Committee on Council Affairs, 2009-2010

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

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-present

Consultant, Chordoma Foundation, 2007-present

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-Present

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; book forthcoming from Johns Hopkins Press)

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

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, 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-present

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

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

Member, Baldwin Scholars Program Review, 2007-2009

Member, Peter Lange Provost Review Committee, 2007-2008

Member, Truman Scholarship faculty interview panel, 2007-present

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

Member, Fulbright Scholarship faculty interview panel, 2009-present

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

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

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

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

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

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

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

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

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, Ethics Certificate Program, 2006-present

Faculty Member, Health Policy Certificate Program, 2006-present

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

Member, Campus Culture Initiative Steering Committee, 2006-2007

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

Research Ethics Consultation Team Member, Clinical Translational Science Awards, 2006-present

Member, National Breast Cancer Coalition Foundation (NBCCF's) Working Committee, 2006-2008

Member, Duke Translational Medicine Institute Leadership Group, 2006-present

Member, Comprehensive Cancer Center Executive Committee & Institutional Advisory Board, 2005-present

Member, Institute for Genome Sciences & Policy Executive Committee, 2005-2008

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

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

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

Chair, Search Committee, Associate Director, Kenan Institute of Ethics, 2003-2004

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

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)

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

Honors, Fellowships and Specialized Coursework

Faculty Affiliate, Georgetown University, Joseph and Rose Kennedy Institute of Ethics, 2007-2009

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

Fellow, Cecil and Ida Green Center, University of Texas, Dallas, January-April 1996

Fellow, American Association for the Advancement of Science, 1988-present

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 Laboratory (Atomic Energy Commission), University of California at Berkeley, Summer 1974

Special Student, Mathematics, University of Colorado, Denver; 1971, 1973, 1977

Research

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

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

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, 2004-2010 (Overall PI and PI of one core and one research project)

Principal Investigator, Policy, Ethics, and Law Core, Southeast Regional Center of Excellence for Emerging Infections and Biodefense, National Institute of Allergy and Infectious Diseases, 2003-2008 (Fred Sparling, UNC, overall Center PI)

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

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

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

Colaianni CA, **Cook-Deegan R**. "Columbia University's Axel Patents: Technology Transfer and Implications for the Bayh-Dole Act." *Milbank Memorial Quarterly*. Forthcoming.

Green R, Roberts J, Cupples L, Relkin N, Whitehouse P, Brown T, Eckert S, Butson M, Sadvnick A, Quaid K, Chen C, **Cook-Deegan R**, and Farrer L. "A Randomized Trial of APOE Genotype Disclosure for Risk of Alzheimer's Disease: The REVEAL Study." *New England Journal of Medicine*. **361** (July 16):245-254, 2009. NIH MS ID 133885.

Heaney C, Carbone J, Gold R, Bubela T, Holman CM, Colaianni A, Lewis T, and **Cook-Deegan R**. "[The Perils of Taking Property Too Far](#)." *Stanford Journal of Law, Science and Policy*. **1**:46-64, 2009. NIH MS ID 111841

Cook-Deegan R, Chandrasekharan S, and Angrist M. "[The Dangers of Diagnostic Monopolies](#)." *Nature* **458**:405-406, 2009. NIH MS ID 105466.

Magnus D, Cho MK, and **Cook-Deegan R**: "[Direct-to-Consumer Genetic Tests: Beyond Medical Regulation?](#)" *Genome Medicine* **1**:17, 2009. PMID: PMC2664950.

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*, ed. B. Andrew Lustig, Baruch A. Brody, and Gerald P. McKenny (Springer) pp. 161-198, 2008.

- Lyerly AD, Steinhauser 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, Tulsy 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* Published online 5 December 2008; doi:10.1016/j.fertnstert.2008.10.015. NIH MS ID 109477.
- Angrist M, Chandrasekharan S, Heaney C, and **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), 2009.
- Chandrasekharan S, Heaney C, James T, Conover C, and **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), 2009.
- Chandrasekharan S, Pitlick E, Heaney C, and **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), 2009.
- Cook-Deegan R**, DeRienzo C, Carbone J, Chandrasekharan S, Heaney C, and 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 Secretary’s Advisory Committee on Genetics, Health, and Society, 2009.
- Colaiani A, Chandrasekharan S, and **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 Secretary’s Advisory Committee on Genetics, Health, and Society, 2009.
- Powell A, Chandrasekharan S, and **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 Secretary’s Advisory Committee on Genetics, Health, and Society, 2009.
- Skeehan K, Heaney C, and **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 Secretary’s Advisory Committee on Genetics, Health, and Society, 2009.
- 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. PMID: 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. PMID: 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*, ed. Huntington F. Willard and Geoffrey S. Ginsburg (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. PMID: 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. PMID: 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. PMID: 17556571.
- 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. PMID: 17023637.
- 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. PMID: [PMC2701726](#).
- Cook-Deegan R** and McGearry 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. PMID: 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. PMID: 16678178.
- Angrist M and **Cook-Deegan R**, “[Who Owns the Genome?](#)” *The New Atlantis*, Winter 2006 **11**: 87-96, 2006. PMID: 16789312.
- Pressman L, Burgess R, **Cook-Deegan R**, McCormack SJ, Nami-Wolk I, Soucy M and Walters L: “[The Licensing of DNA Patents by US Academic Institutions: An Empirical Survey.](#)” *Nature Biotechnology* **24** (January): 31-39, 2006. PMID: PMC2726797.

- Zick CD, Mathews C, Roberts JS, **Cook-Deegan R**, and Pokorski RJ: “[Genetic Testing for Alzheimer’s Disease and Its Impact on Insurance Purchasing Behavior](#).” *Health Affairs* **24** (March/April): 483-490, 2005. PMID: PMC1761120.
- Palmer JG and **Cook-Deegan R**: “[National Policies to Oversee Inheritable Genetic Modifications Research](#).” Chapter in *Designing Our Descendants: The Promises and Perils of Genetic Modifications*. Audrey R. Chapman and Mark S. Frankel, eds. Baltimore, MD: Johns Hopkins University Press, 2003, pp. 275-295.
- Cook-Deegan R**: “[Colossus of Codes](#).” Biographical sketch of James D. Watson in *Inspiring Science: Jim Watson and the Age of DNA*. (This volume celebrates the 50th anniversary of DNA structure, Watson’s 75th birthday and his 35th year at Cold Spring Harbor Laboratory.) John Inglis, Jan Witkowski, and Joseph Sambrook, eds. Cold Spring Harbor Press, 2003, pp. 387-393.
- Bar-Shalom A and **Cook-Deegan R**: “[Patents and Innovation in Cancer Therapeutics: Lessons from CellPro](#).” *Milbank Quarterly* **80** (December): 637-676, 2002.
- Cook-Deegan R** and McCormack S: “[Patents, Secrecy, and DNA](#),” with webnote [supplement](#). *Science* **293**: 217, 2001.
- Cook-Deegan R**: “[Privacy, Families, and Human Subject Protections: Some Lessons from Pedigree Research](#).” *Journal of Continuing Education in the Health Professions* **21** (Fall): 224-237, 2001.
- Cook-Deegan R**, Johnson A and Chan C: “[World Survey of Funding for Genomics Research: Final Report for Health Research and the World Health Organization](#).” *Global Genomics & Health Disparities: Emerging Issues for Nations and Populations*, RJR Blatt and B Kivimae Krimgold, eds. *Journal of BioLaw and Business*, Special Supplement: 22-36, 2001.
- Cook-Deegan R**: “[Protecting the Vulnerable in Brain Research](#).” *Cerebrum*, **2** (Spring): 73-91, 2000.
- Cook-Deegan R**: “[Medical Biotechnology, United States Policy Influencing Its Development](#).” *Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology*, TH Murray and MJ Mehlman, eds. (New York: John Wiley & Sons) pp. 798-809, 2000.
- Cook-Deegan R**: “[Government Policy and the Commercial Value of Academic Information](#).” Chapter 26 in *AAAS Science and Technology Policy Yearbook 2000*. AH Teich, SD Nelson, C McEnaney, and SJ Lita, eds. Washington, DC, American Association for the Advancement of Science. pp. 273-289, 2000.
- Cook-Deegan R**: “[The Genetics of Alzheimer Disease: Some Future Implications](#).” Chapter 15 in *Concepts of Alzheimer Disease Biological, Clinical, and Cultural Perspectives*, SPJ Whitehouse, K Maurer, and JF Ballenger, eds. (Baltimore, MD: Johns Hopkins University Press) pp. 269-290, 2000.
- Cook-Deegan R**: “National Policies Influencing Innovation Based on Human Genetics.” Chapter in *The Commercialization of Genetic Research: Ethical, Legal, and Policy Issues*, T Caulfield and B Williams-Jones, eds. (New York: Plenum) pp. 13-27, 1999.
- Thomas AM, Cohen G, **Cook-Deegan R**, O’Sullivan J, Post SG, Roses AD, Schaffner KF, and Green RM: “[Alzheimer Testing at Silver Years](#).” *Cambridge Quarterly of Healthcare Ethics* **7**: 294-307, 1998.
- Burris J, **Cook-Deegan R**, Alberts B: “[The Genome Project after a Decade: Policy Issues](#).” *Nature Genetics* **20**: 333-335, 1998.

- Cook-Deegan R:** “Some Questions Arising in the Commercial Development of Genetic Tests for Alzheimer’s Disease.” Chapter 6 in *Genetic Testing for Alzheimer's Disease: Ethical and Clinical Issues*, S Post and P Whitehouse, eds. (Baltimore, MD: Johns Hopkins University Press) pp. 84-100, 1998.
- Cook-Deegan R:** “[Confidentiality, Collective Resources, and Commercial Genomics.](#)” Chapter 9 in *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, MA Rothstein, ed. (New Haven, CT: Yale University Press) pp.161-183, 1997.
- Cook-Deegan R:** “[Does NIH Need a DARPA?](#)” *Issues in Science and Technology* **13** (Winter): 25-28, 1996.
- Cook-Deegan R:** “Genome Mapping and Sequencing.” In *Encyclopedia of Bioethics*, WT Reich, Editor-in-Chief; JC Fletcher, Genetics Section Editor; M Solberg, Project Editor. New York: Macmillan. pp. 1011-1019, 1995.
- Cook-Deegan R:** “[Germ-Line Gene Therapy: Keep the Window Open A Crack.](#)” *Politics and the Life Sciences* **13** (August): 217-220, 1994.
- Geiger HJ and **Cook-Deegan R:** “[The Role of Physicians in Conflicts and Humanitarian Crises: Case Studies from the Field Missions of Physicians for Human Rights.](#)” 1988-1993. *Journal of the American Medical Association* **270**: 616-620, 1993.
- Cook-Deegan R:** “[Origins of the Human Genome Project.](#)” *Risk: Health, Science, and Environment* **5** (Spring): 97-118, 1994.
- Hanna KE, **Cook-Deegan R**, and Nishimi RY: “[Finding a Forum for Bioethics in U.S. Public Policy.](#)” *Politics and the Life Sciences* **12** (August): 205-219, 1993.
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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 author.)

[*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 author.)

[*Background paper on Tobacco Control*](#), July 1997. (Staff author. 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-author 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 Wypiejewska.)

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/>).

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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 author.)

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Short Communications and Letters

- Cook-Deegan R**, and Rai A: 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.
- 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, 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)

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

“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.

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

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

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

- “Gene-Environment Interactions Research: Lessons from Eugenics,” Gene-Environment Interactions research conference, Sanford Institute of Public Policy and Center for Child and Family Policy, Duke University, May 18, 2009.
- Invited Lecture, Duke University Responsible Conduct of Research Class, April 13, 2009.
- Invited Lecture, Duke University Biology Class, April 7, 2009.
- “Personal Genomics” and “The Political Economy of Biomedical Research,” University of Texas Southwestern Medical Center, Ethics Grand Rounds and occasional lecture, May 12, 2009.
- Invited Lecture, *The Genome*, Duke University Science Policy Class, March 25, 2009
- “International Clinical Research and Genetics and Stem Cell Research,” Invited Lecture, Responsible Conduct of Research in Humans Course, Duke University, March 24, 2009.
- Panel Moderator, “ELSI Research Challenges Associated with Influencing Policy at Various Levels,” CEER Investigators Meeting, 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.
- Invited Commentary, *Commercialisation of Genomic Research Workshop*, University of Montreal, Montreal, Canada, January 30, 2009.
- “The Changing Face of Genomic Patents: The Future is Complexity, Not Pharma,” Bloomberg School of Public Health at Johns Hopkins, January 27, 2009.
- “Public Genomics: Do we need doctors anymore?” Invited Lecture, Berman Institute of Bioethics Seminar Series, Johns Hopkins University, January 26, 2009.
- “Policy issues entwined in the triple helix: government, academe, and pharma/biotech,” Lecture, School of Medicine at East Carolina University, January 17, 2009.
- “Personal Genomics: Do We Need Doctors Anymore?” Lecture, Humanities in Medicine Lecture Series, Trent Center for Bioethics, Humanities and History of Medicine, Duke University, January 14, 2009.
- “Unique Concerns in Sharing Merged Social Environment and Genetics Data,” Lecture, Crossroads: Sharing Social Environment and Genetic 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.
- “Do Patents and Licensing Affect Clinical Access to DNA Diagnostics: Can We Tell,” Genome Medicine Forum, Duke University, October 25, 2008.

- “Sharing Data, Materials and Intellectual Property in Genomics: Some Implications for Public Policy” Speaker at *2020 Vision: The Impact of Science on Society*, Genome Canada International Conference, British Columbia, Canada, October 22, 2008.
- “Four Decades of Bioethics and Genetics: How Have We Done?” The Sixteenth Annual Joseph B. Brennan Lecture, Kennedy Institute of Ethics, Georgetown University, October 16, 2008.
- “Personal Genomes: Technology, Interpretation & Challenges,” Poster presentation at Personal Genomes Conference, Cold Spring Harbor Laboratory, New York, October 9-12, 2008.
- “Race, Ancestry, Geography, Ethnicity, Disparity, and Population Genetics: Can We Reduce Confusion and the Propensity to Misinterpret Results?” Speaker at *Who Are We?: Kinship, Ancestry and Social Identity*, Cold Spring Harbor Laboratory, New York, October 8, 2008.
- Presentation at *Advancing Global Health, Making University Innovations Available in Developing Countries*, Universities Allied for Essential Medicine, Duke University, September 29, 2008.
- “The Bioethics of Biobanking,” Speaker at the *Law and Ethics of Biobanking*, Annual Symposium of the Stanford Journal of Law, Science, and Policy, Palo Alto California, September 26, 2008.
- “Do Patents and Licensing Affect Clinical Access to DNA Diagnostics: Can We Tell?” Speaker, Duke University Genomic Medicine Forum, September 25, 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 *20th 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, technologies, and patents: What role in global health?” *Universities Allied for Essential Medicines, 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.
- “Digging your own grave: Pharma, biotech and academia in intricate mutualism,” *Davidson University Spring Ethics Symposium*, April 4 – 5, 2008.

- “Genomics and Intellectual Property: Life in the Information Jungle,” *Clarke Forum* at Dickinson College, Carlisle, Pennsylvania, March 18, 2008.
- “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 Southeast Regional Center of Excellence for Emerging Infections and Biodefense annual meeting, February 28, 2008.
- “The Misuse of Genomic Human Variation Data by Scientists and Society,” for *Genome Revolution Focus IDC*, Julianne O'Daniel, Nov 5, 2007.
- “From the Farm to the Capital: Stanford Faculty in Government,” *20th Anniversary Celebration, Stanford in Washington*, Washington, DC, 26 – 28 Oct 2007.
- Presentation on dual-use review, *Center for Arms Control and Non-Proliferation, Transparency in Current and Emerging Approaches to Biosecurity*, October 19, 2007.
- Convenor, “‘Na 'Oia'i'o': Multiple Truths—An Indigenous Perspective on Genomics, Intellectual Property and Community Consent,” *Faculty Colloquium*, Maile Taulii, 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.
- “Who Owns Your Genes? Intellectual Property and the Human Genome,” presentation at National Press Club, 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).
- “Technology-Intensive Biology: A Succession of Controversies,” *Director's Distinguished Lecturer Series*, Lawrence Livermore National Laboratory, Livermore, CA, May 22, 2007.
- “Democracy, Justice and Genomics: Promises, Perils and Paradoxes,” *University of California, Santa Cruz, Genomics and Justice Conference*, Santa Cruz, California, May 18, 2007.
- “Intellectual Property and Genomic Innovation: DNA Science, Patents and Money,” *Genome Sciences Seminar*, University of Washington, Seattle, Washington, May 15, 2007.
- “Topsy Turvy: Science, Money, & the Human Genome,” presentation for *GE³LS Genome Canada Project*, “Dissecting Gene Expression Networks in Mammalian Organogenesis,” Celebration Research Week, Centre for Applied Ethics, University of British Columbia, Vancouver, B.C., March 8, 2007.
- “Ethical Implications of Prospective Health Care,” *Second Annual Prospective Health Care Conference*, Duke University, Keynote speaker, March 30, 2007.
- “A Primer on DNA Patenting and Its Relevance to Access to Genetic Tests,” presentation to *Secretary's Advisory Committee on Genetics, Health, and Society* (SACGHS), 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.

"Challenges of Collaboration" *Data Sharing and the Bioethics of Collaborative Genetic Research Conference*, Southwestern Medical Center and NIAID, Dallas, Texas, January 17-18, 2007.

"The Future of Biotechnology in International Relations," presentation for *Berkeley-Duke Center for America's Global Strategic Challenges*, Council on Foreign Relations, 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.

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

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

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

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

"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 *American Society for Microbiology (ASM), 106th Annual General Meeting*, Orlando, Florida, May 22-23, 2006.

Intellectual Property in Biotechnology. Liberty Fund Colloquium, 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.

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

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

"Under Attack: Maintaining the Integrity and Independence of the FDA," talk for plenary panel, *National Breast Cancer Coalition Foundation 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.

- “Does open science matter? Genomics as a case study,” talk for Carolina Center for Genome Sciences, University of North Carolina, Chapel Hill, April 21, 2006.
- Moderator/Speaker, Global Health Symposium. Duke University, April 18, 2006.
- Poster Presentation on Policy Ethics, and Law Core. *2006 National Institute of Allergy and Infectious Diseases, Regional Centers of Excellence National Annual Meeting*, New York City, NY, March 26-28, 2006.
- Picard Lecture in Health Law*, “Tales of the Genome: Can we tell when patents foster or impede innovation,” University of Alberta School of Law, Edmonton, Alberta, Canada, March 22-24, 2006.
- “Who Owns the Genome?” Radio interview with *Kresta In The Afternoon*, Catholic Radio Network, February 27, 2006.
- “Social Dynamics of Public Engagement in Medical Genetics and Genetic Services,” lecture for Duke Medicine in Singapore; 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.
- “The History of the Human Genome Project,” lecture for the *Department of Genetics and Biochemistry, Kuzey Park, Seminer Odas, Bogazici University*, Istanbul, Turkey, December 20, 2005.
- “Emerging Biotechnology Applications: EU, US and Global Regulatory Perspectives” presentation for a meeting in Lille, France, organized by *US delegation to the European Union*, December 3-6, 2005.
- “The Genomic Revolution: Implications for Science and Health,” presentation as part of *Ethical, Legal and Social Issues IOM/NAE/NAS/NRC Project*, 3rd Annual National Academies Keck Futures Initiative (NAKFI) Conference, Beckman, University of California, Irvine, November 10-13, 2005.
- Global Health* panel discussion for Rubenstein Hall Dedication ceremonies, Duke University, November 4, 2005.
- “Bioethics, policy analysis, and policy engagement: How does it work? How can it work better?” *Greenwall Fellows Seminar Series*, Johns Hopkins University School of Medicine, October 24, 2005.
- Cracking the Code of Life* Discussion - BrainPlay 5th-6th grade – requested by Scott Mitchell, President, Durham PAGE, Director of Admissions, Camelot Academy, October 22, 2005.
- “Legal Models of Biotechnological Intellectual Property Protections: A Transdisciplinary Approach,” *Biotechnology & Intellectual Property: Restructuring for the Public Benefit*, McGill, Montreal, Quebec, Canada, September 25-27, 2005.
- “Education and Raising Awareness: Challenges for Responsible Stewardship of Dual Use Research in the Life Sciences,” presentation for the *National Research Council and Institute of Medicine Meeting on Dual Use Research*, Washington, DC, Sept 8, 2005.
- “Stem Cell Research,” WUNC Live Broadcast 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.
- Race and Genetics*. Moderator of panel, meeting with staff of the Robert Wood Johnson Foundation, Princeton, New Jersey, July 26, 2005.
- “Genomics and World Health: Surviving in the Information Jungle,” talk at University of Leuven *Conference on Microbiological Commons*, University Foundation, 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.
- “Intellectual Property Rights: Why They Matter to Breast Cancer Advocates,” *National Breast Cancer Coalition Foundation Annual Conference*, Washington, DC, May 22, 2005.
- Altering Natures Policy Group Meeting*. Genetics Enhancement Project, Committee Chair, Rice University, Houston, Texas, May 19, 2005.
- “Ethics and Policy Considerations in Genetics,” panel dealing with aspects of Genetics and Genomics, *Nemours Annual Symposium on Children’s Health 2005*, Jacksonville, FL., May 10, 2005.
- “Future of the Field of Bioethics,” *Bioethics and Consortium on Law and Values in Health, Environment & the Life Sciences*, University of Minnesota, May 5, 2005.
- “The Science Commons in Health Research: Structure, Function, and Value,” talk at Rotman School of Business, University of Toronto conference *Bringing Science to Life*, April 29, 2005.
- “Genomics and World Health: Navigating the Information Jungle,” Center for the Study of Medical Ethics and Humanities, *Humanities in Medicine Lecture Series*, Duke University, September 15, 2004.
- “Science as Expertise, Morality, and Politics II: ELSI-So What?” *Gordon Research Conference on Science & Technology Policy*, Big Sky, Montana, August 15-20, 2004.
- “Genomics and World Health: Navigating the Information Jungle,” *Genetics, Ethics, and Health Law lunchtime seminar*, World Health Organization, Geneva, July 21, 2004.
- “Genomics: The Information Jungle,” keynote speaker for conference on *Genetics in Literature, Film and Popular Culture*, Vanderbilt University, 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.
- “The Jewel in the Federal Crown? History, Politics and the NIH,” paper presented to the Robert Wood Johnson Foundation, Investigator Awards in Health Policy Research, *History and Social Policy Research Group*, October 11, 2003.

“From Genome Sequence to Making Life Better,” *Howard Hughes Precollege Program in the Biological Sciences*, Duke University, June 25, 2003.

“Patents and Innovation in Cancer Therapeutics: The Story of CellPro,” talk at Science and Intellectual Property in the Public Interest meeting *Implications of Gene Patents for Biomedical Research and Clinical Medicine*, American Association for the Advancement of Science in collaboration with Resources for the Future, June 5, 2003.

“Licensing Issues in DNA Based Patents,” panel presentation at Science and Intellectual Property in the Public Interest meeting *Implications of Gene Patents for Biomedical Research and Clinical Medicine*, American Association for the Advancement of Science in collaboration with Resources for the Future, June 5, 2003.

Presenter, Duke in Napa Valley Seminar, Napa Valley, CA, May 22, 2003.

“Genomics, Genotype, and Policy Issues Confronting the Future of Genetics,” guest lecture for the class *Integrity in Research/Responsible Conduct of Research* at Harvard University, Cambridge, MA, May 7, 2003.

“Interactions between Public and Private R&D,” *PhRMA Biologics and Biotechnology Section Meeting*, Boston, Massachusetts, April 9, 2003.

“Ethical, Legal, and Social Implications of the Human Genome Project” talk at Wake Forest University School of Medicine, April 2, 2003.

“The Genome Business: Science, Health, Wealth, and Fairness,” talk at Sigma Xi Scientific Research Society, April 1, 2003.

Keynote for meeting *The Power of the Market in Shaping a New Genomic Order*, Goodenough College, London, UK, March 27, 2003.

“Ethical Challenges Facing Tomorrow’s Leaders,” talk at North Carolina School of Science and Math, March 4, 2003.

“Public and Private Genomics: What’s Going On? What’s Fair?” talk for the Center for the Study of Medical Ethics and Humanities, Duke University, February 5, 2003.

“History of US Bioethics Commissions and The Role of ‘Public’ Bioethics,” German-American Institute, Heidelberg, Germany, December 11, 2002.

“DNA Patenting and Technology Transfer,” talk for the Max Planck Institute on Intellectual Property, Competition, and Tax Law, Munich, Germany, December 10, 2002.

“DNA Patenting and Commercialization of Genomics,” talk for the Max Planck Institute on Biology, Biological Cybernetics, and Developmental Biology, Tübingen, Germany, December 9, 2002.

“History of U.S. Bioethics Commissions and ELSI Research Programs: The Role of ‘Public’ Bioethics,” talk at the Interdepartmental Center for Ethics in Sciences, University of Tübingen, Germany, December 9, 2002.

“The Role of Public Bioethics” (with Daniel Wikler, Harvard School of Public Health), talk for *Genes and Cells Boot Camp*, Knight Science Journalism Fellowship Program, 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.
- “Genome Ethics, Law, and Policy: Building a Program at Duke,” talk at the Kennedy Institute of Ethics, *Tuesday Seminar Series*, Georgetown University, October 22, 2002.
- “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*, The Hastings Center, Garrison, NY, October 17, 2002.
- “From Double Helix to Genomic Sequence: Some Policy Lessons,” plenary lecture for *Institute of Medicine 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.
- “The Urge to Commercialize: Interactions between Public and Private R&D,” presentation at the National Academies of Science and Engineering and the Institute of Medicine *Symposium on the Role of Scientific and Technical Data and Information in the Public Domain*, September 5, 2002.