

Ellen Wright Clayton

## CURRICULUM VITAE

February, 2020

**Name:** Ellen Wright Clayton

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**E-mail:** ELLEN.CLAYTON@VANDERBILT.EDU

**Date of Birth:** June 22, 1952

**Place of Birth :** Houston, TX

**Home Address :** 504 Fairfax Avenue  
Nashville, TN 37212  
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### Education:

1970-74: B.S., Duke University, Zoology  
1974-76: M.S., Stanford University, Biology  
1976-79: J.D., Yale Law School  
1981-85: M.D., Harvard Medical School

### Postgraduate Training:

1985-88: Resident, Department of Pediatrics, University of Wisconsin Hospital and Clinics, and Lecturer, Program in Medical Ethics

### Licensure and Certification:

1988- : License to Practice Medicine, Tennessee #MD0000018825  
1989- : Certification, American Board of Pediatrics #211033  
1991- : Fellow, American Academy of Pediatrics #140172001  
1988- : Inactive Member, State Bar of Texas

### Academic Appointments:

## Ellen Wright Clayton

- 1982-83: Research Assistant, Professor Jay Katz, Yale University, worked on his book, The Silent World of Doctor and Patient, Free Press, 1985
- 1985: Visiting Assistant Professor (Spring Semester), Law School and Program in Medical Ethics, University of Wisconsin
- 1988-96: Assistant Professor of Pediatrics, Vanderbilt University Medical School  
Assistant Professor of Law, Vanderbilt University School of Law  
Fellow, Vanderbilt Institute for Public Policy Studies, Center for Health Policy
- 1993: Visiting Professor of Law, University of Houston Law Center, Health Law and Policy Institute
- 1996-99: Associate Professor of Pediatrics with tenure, Vanderbilt University Medical School  
Associate Professor of Law, Vanderbilt University School of Law  
Faculty Member, Vanderbilt Program in Human Genetics  
Senior Fellow, Vanderbilt Institute for Public Policy Studies, Center for Health Policy  
Associate, Center for Clinical and Research Ethics
- 1999-05: Director, Center for Genetics and Health Policy
- 1999-2010: Rosalind E. Franklin Professor of Genetics and Health Policy
- 2005-2011: Director, Center for Biomedical Ethics and Society
- Currently: Craig-Weaver Professor of Pediatrics with tenure, Vanderbilt University Medical School  
Professor of Law, Vanderbilt University School of Law  
Professor of Health Policy, Vanderbilt University Medical School  
Co-Founder, Center for Biomedical Ethics and Society, Vanderbilt University School of Medicine  
Faculty Member, Vanderbilt Program in Human Genetics  
Senior Fellow, Vanderbilt Institute for Public Policy Studies, Center for Health Policy  
Senior Fellow, John F. Kennedy Center for Research on Human Development, Vanderbilt University  
Visiting Professor, Tokai University School of Medicine, Tokyo, JAPAN

## Other Employment:

- 1979-80: Law Clerk, The Honorable John C. Godbold, Judge U.S. Court of Appeals, Fifth Circuit

## Ellen Wright Clayton

1980-81: Attorney, Vinson and Elkins, Houston, TX, and Visiting Fellow, Institute for the Interprofessional Study of Health Law

### Honors:

1970-73: Class Honors, Freshman, Sophomore, and Junior years; Duke University  
National Merit Scholar

1974: Phi Beta Kappa, Duke University  
Summa cum Laude, Duke University

1974-76: National Institute of Health Traineeship, Stanford University

1978-79: Editor, Yale Law Journal, Yale Law School

1985-86: Henry M. Castello Memorial Award for the Outstanding Resident, University of Wisconsin Hospitals and Clinics

1997: Sigma Xi, Vanderbilt University

1999: Jay Healey Award for Outstanding Health Law Teacher

2004: Excellence in Resident Education, Department of Pediatrics, Vanderbilt University School of Medicine

2006: Member, Institute of Medicine/National Academy of Medicine

2007: Founding Member, Vanderbilt Academy for Excellence in Teaching

2008: Member, Alpha Omega Alpha

2010: William G. Bartholome Award for Ethical Excellence, American Academy of Pediatrics

2012: Fellow, American Association for the Advancement of Science

2013: Member, American Pediatric Society

2013: David P. Rall Medal, Institute of Medicine

2015: Frank H. Morriss, Jr. Leadership Award, University of Iowa Department of Pediatrics and University of Iowa Foundation

### Professional Memberships:

1980- : State Bar of Texas and U.S. Court of the Southern District of Texas

1984- : Member, American Society of Law, Medicine, and Ethics

1988- : Member, American Bar Association

1989- : Member, Lawyers Association for Women

1991- : Member, Bioethics Section, American Academy of Pediatrics

1993- : Member, Ambulatory Pediatric Association, now Academic Pediatric Association

1998- : Member, American Society for Bioethics and Humanities

1998- : Member, Health Law Section, American Bar Association

2010- : Member, Public Population Project in Genomics

### Vanderbilt Medical School/Medical Center Service:

1988-2008: Member, Child Abuse Committee, Vanderbilt University

1991: Member, Medicine in Society Committee

1991-93: Consultant, Vanderbilt University Medical Ethics Committee

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- 1993- : Member, Vanderbilt University Medical Ethics Committee
- 1994-96: Chair, Child Abuse Committee, Vanderbilt University
- 1996-2000: Member, Credentials Committee, Vanderbilt University Medical Center
- 1997-2000: Member, Joint Practice Subcommittee, Medical Staff Credentials Committee
- 1997-2000: Member, Internal Review Committee, Graduate Education Review Committee
- 1998: Member, Task Force on Compensation and Incentivization of Faculty (Education)
- 1998-2000: Member, Subcommittee on Protection of and Access to Patient Electronic Records
- 1998- 2001: Member, Software Oversight Committee
- 1998-2002: Member, Promotion Committee for the Class of 2002
- 1999- : Member, Ad Hoc Committee on Center for Fetal Intervention
- 1999-2001: Member, Academic Programs Committee
- 2000: Coordinator, Ecology of Medicine Course, sections on pregnancy and early childhood
- 2000- Member, Working Group on DNA Capture
  - As part of this group, I oversaw the conduct of five focus groups to assess opinions of community members about collection of DNA in conjunction with medical information for use in epidemiologic research and continue to develop a program to develop the optimal approach to collecting DNA and medical records for research
- 2000- : Chair, Education on Research Integrity
- 2000-01: Chair, Conflict of Interest Committee
- 2001: Member, Emphasis Program and Synthesis Course Working Groups for Curriculum Reform
- 2001: Member, Search Committee for the Stahlman Chair in Medical Ethics
- 2001- : Member, Vanderbilt Child Advocacy Council
- 2001- : Faculty, Meharry-Vanderbilt Genetics Training Program
- 2002- : Member, Curriculum Advisory Committee, Meharry Clinical Research Education and Career Development (CRECD)
- 2002- : Member, Emphasis Program Planning Committee
- 2003- : Member, Steering Committee, PhD Program in Human Genetics
- 2003-5: Director, Genetics, second year medical school
- 2003-08: Director, Law and Policy Emphasis Program
- 2005- : Member, DNA Databank Oversight Committee

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- 2008- : Member, Appointments and Promotions Committee, Department of Pediatrics
- 2009- : Member, Academic Advisory Council, Meharry-Vanderbilt Community Engaged Research Program, Vanderbilt Institute for Clinical and Translational Research
- 2009- : Member, Research Enterprise Communications Advisory Council
- 2009-11: Member, Appointments and Promotions Committee, VUMC
- 2011-12: Member, Executive Committee of the Executive Faculty, VUMC
- 2011-14: Mentor, Hazinski Society, Department of Pediatrics
- 2015- : Member, Vanderbilt Institutional Pluripotent Cell Research Committee

### **Vanderbilt Law School Service:**

- 1988-2005: Faculty Advisor, Vanderbilt Bisexual, Gay, and Lesbian Law Students Association
- 1988-2005: Faculty Advisor, Vanderbilt Law Women's Association
- 1989-91: Member, Curriculum Committee, Vanderbilt Law School
- 1991-95: Member, Student-Faculty Relations Committee, Vanderbilt Law School
- 1995-97: Member, Diversity Lectures Committee
- 1997-05: Member, Admissions Committee

### **Vanderbilt University Service:**

- 1989-93: Member, Advisory Board, Margaret Cuninggim Women's Center, Vanderbilt University
- 1998-2001: Member, Advisory Committee, Cal Turner Program in Moral Leadership
- 2000-01: Organizer, Seminar on Genetics and Mental Health, Center for Genetics and Health Policy and Robert Penn Warren Center for the Humanities
- 2001-09: Member, Steering Committee, Medicine, Health, and Society -- an interdisciplinary program that draws from many parts of the university
- 2001- 07: Member, Executive Board, Cal Turner Program in Moral Leadership
- 2002-17: Member, Conflict of Interest Committee
- 2005-09: Member, Technology Review Committee
- 2006-09: Member, Advisory Board, Center for Ethics
- 2006-09: Member, Faculty Advisory Board, Vanderbilt Center for Nashville Studies
- 2009-10: Member, Search Committee, Directors of Center for Medicine, Health, and Society and Program in Health, Environment, and Policy

### **Vanderbilt Health Plan Service:**

- 1996-1997 Member, Pharmacy and Therapeutics Committee
- 1997-99: Member, Medical Resource Management Committee

### **Professional Service on National and International Level:**

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**Institute of Medicine/National Academy of Medicine/National Academies of Sciences, Engineering, and Medicine**

- 1992: Consultant to Institute of Medicine Committee on Assessing Genetic Risks: Issues and Implications for Health, June 28-29, 1992, Irvine, CA
- 1993: Consultant, Institute of Medicine Committee on the Legal and Ethical Issues Relating to the Inclusion of Women in Clinical Studies
- 2002: Invited Speaker, Genomics and Its Implications for Human Health: A New Academies Initiative
- 2002-07: Member, Board on Health Sciences Policy
- 2003-04: Member, Committee on the Use of Third Party Toxicity Research with Human Research Participants, Science, Technology, and Law Program
- 2004-05: Member, Committee on Genomics and the Public's Health in the 21<sup>st</sup> Century
- 2005: Chair, Roundtable on Translating Genomic Information into Improved Health
- 2005-06: Member, Committee on the Disposition of the Air Force Health Study
- 2005-06: Member, Committee on Assessing Interactions Among, Social, Behavioral, and Genetic Factors of Health
- 2007: Member, Panel to Review the National Children's Study (NCS) Research Plan
- 2007-09: Chair, Committee to Evaluate Title X Family Planning
- 2009-11: Chair, Committee to Evaluate Vaccine Safety
- 2010-16: Member, Advisory Council
- 2011-12: Chair, Standing Committee on Family Planning
- 2012-13: Co-Chair, Committee on Commercial Sexual Exploitation and Sex Trafficking of Minors in the United States
- 2012- : Chair, Board on Population Health and Public Health Practice
- 2012: Member, Committee to Revamp "The Role of the Chair" of Consensus Committees
- 2012: Monitor, Reforming Juvenile Justice: A Developmental Approach
- 2012: Reviewer, The Appropriate Future Use of the Department of Defense Joint Pathology Center Tissue Repository
- 2012: Review Coordinator, Review of the California Institute for Regenerative Medicine (CIRM)
- 2013-16: Executive Committee, Council, IOM
- 2013: Member, Report Review Committee, IOM
- 2013: David P. Rall Medal, Institute of Medicine
- 2013-14: Monitor, Integrating Workforce Health Protection at DHS
- 2013-15: Chair, Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
- 2014: Monitor, Treatment for Posttraumatic Stress Disorder in Military and Veteran Populations: Final Assessment
- 2014: Reviewer, Investing in the Health, Safety, and Well-Being of Young Adults
- 2014-15: Chair, Governance Committee

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- 2014: Council Presentations (with Bill Stead), Grand Challenges in Health and Health Care
- 2015: Monitor, Integrating Immigrants Into the United States: Americans All
- 20156: Monitor, Ethical and Social Policy Considerations of Novel Techniques for the Prevention of Maternal Transmission of Mitochondrial DNA Diseases
- 2015-7: Member, Committee on Human Gene Editing: Scientific, Medical, and Ethical Considerations, National Academies
- 2016-7: Member, Health and Medicine Division Committee
- 2016- : Co-Chair, Report Review Committee
- 2020- : Member, Committee on Science, Technology, and Law

### **National Institutes of Health, National Human Genome Research Institute:**

- 1994-1995: Chair, NIH-CDC Workshop on the Role of Informed Consent for Genetic Research on Stored Tissue Samples
- 1995-98: Member, National Advisory Council, National Human Genome Research Institute, National Institutes of Health
- 1997-2000: Member, ELSI Research Program and Evaluation Group, National Human Genome Research Institute
- 2000-01: ELSI Research Advisor
- 2001: Chair, Session on ELSI Issues at Developing a Haplotype Map of the Human Genome for Finding Genes Related to Health and Disease
- 2001-03: Co-Chair, Population/ELSI Group, International Haplotype Mapping Project
- 2003-05: Co-Chair, ELSI Group, International Haplotype Mapping Project
- 2007-11: Co-Chair, Consent and Community Consultation Working Group, eMERGE Network
- 2016: NHGRI Aggregate Genomic Data Workshop

### **National Institutes of Health -- other programs:**

- 1990: Consultant, National Institutes of Health, Review Committee on Legal and Ethical Issues of Human Genome Initiative, Washington, D.C.
- 1991: Working Group on Reproductive Genetic Testing: Impact on Women, National Institutes of Health, Bethesda, MD
- 1996: Member, Workshop on the Inclusion of Children in Clinical Research, National Institute of Child Health and Human Development, American Academy of Pediatrics
- 2000- : Member, Workgroup on Ethical Issues in Pharmacogenomics, Clinical Ethics Section, Bethesda, MD
- 2002-05: Member, Ethics Working Group, National Children's Study, National Institute of Child Health and Human Development
- 2007: Group Leader, Custodianship and Ownership Issues in Biospecimen Research Symposium-Workshop, National Cancer Institute

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- 2009-10: Member, National Children's Study Federal Advisory Committee, Eunice Kennedy Shriver National Institute of Child Health and Human Development
- 2010: Chair, National Cancer Institute, Workshop on Release of Research Results to Participate in Biospecimen Studies
- 2011- : Member, Observational Safety Monitoring Board, NHLBI OSMB for Next Generation Genetic Association Studies
- 2015- : Member, Expert Advisory Panel, NHLBI Trans-Omics for Precision Medicine Whole Genome Sequencing

### **Food and Drug Administration:**

- 1999- : Consultant, Pediatrics Advisory Committee
- 2000: Consultant, Clinical pharmacology during pregnancy: Addressing clinical needs through science

### **Human Genome Organisation:**

- 2010-13: Member, Working Group on Whole Genome Sequencing
- 2010-12: Member, Ethics Committee
- 2012- : Member, Committee on Ethics, Law, and Society

### **Public Population Project in Genomics and Society**

- 2013-16: Chair, Paediatric Platform

### **American Society of Law, Medicine, and Ethics:**

- 1993-98: Member, Board of Directors, American Society of Law, Medicine, and Ethics
- 1994-95: Treasurer, American Society of Law, Medicine, and Ethics
- 1995-96: President-elect, American Society of Law, Medicine, and Ethics
- 1996-7: President, American Society of Law, Medicine, and Ethics
- 1997-2001: Editor-in-Chief, Journal of Law, Medicine, and Ethics
- 2003- : Member, Board of Editors, Journal of Law, Medicine, and Ethics

### **American Bar Association:**

- 1998-2001: Chair, Clinical Ethics Issues Interest Group, Health Law Section

### **Executive Leadership in Academic Medicine:**

- 1999-2000: Participant



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**National and International Committees and Workshops Not Listed Above:**

- 1987-88: Workgroup on Reproductive Issues, MacArthur Foundation Research Group on Health Behavior, Key Biscayne, FL, and Washington, D.C.
- 1987: Workgroup on Genetic Screening, Hastings Center, Briarcliff Manor, NY
- 1989-95: Member, American Academy of Pediatrics Committee on Bioethics
- 1989: Consultant, American Academy of Pediatrics, Provisional Committee on Substance Abuse, Special Meeting on Drug Affected Infants
- 1990: Workgroup on Feminism and Bioethics, Hastings Center, Briarcliff Manor, NY
- 1992- : Member, Technical Advisory Board, National Emergency Medical Services for Children Resource Alliance, Torrance, CA
- 1993-95: Member, Research Group, "Setting Priorities in the Application of Human Genetic Research," Hastings Center, Briarcliff Manor, NY
- 1995: Member, Storage of Genetics Materials Committee, American College of Medical Genetics
- 1995-98: Member, Biological Resources Bank Working Group, National Action Plan on Breast Cancer
- 1996-99: Member, Social Issues Committee, American Society of Human Genetics
- 1997- : Member, National Advisory Committee, Pediatric Palliative Care Committee
- 1997-2000: Member, Advisory Committee, Center for Patients' Rights
- 1998: Consultant, New York State Task Force on Life and the Law, Taskforce on Genetics Research
- 1999-2000: Member, American Academy of Pediatrics Newborn Screening Task Force
- 1998-2001: Member, Expert Advisory Panel on Privacy and Confidentiality, American Medical Association Institute for Ethics
- 1999: Member, Classification-Nomenclature Group, EASL International Consensus Conference on Hemochromatosis, Sorrento, ITALY
- 1999- : Member, External Advisory Board, Public Health Genetics Program, University of Washington
- 2000-02: Member, Ethics and Security Advisory Board, Marshfield Clinic Personalized Medicine Program
- 2000-02: Consultant, Council of International Organizations of Medical Sciences, Geneva, SWITZERLAND
- 2000- : Member, Human Biological Materials Focus Group, Adult AIDS Clinical Trials Group
- 2001-03: Member, Episcopal Task Force on Issues in Human Genetics
- 2002-05: Member, Evaluating Genetic Tests: A Models Process, University of Washington
- 2003: Consultant, ELSI Genetic Variation Consortium, Colliding Categories: Haplotypes, Race, and Ethnicity, University of Minnesota
- 2003: Participant, Newborn Screening for Cystic Fibrosis Meeting, National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) and the Cystic Fibrosis Foundation (CFF)

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- 2003-05: Member, Ethical Decision Making for Newborn Genetic Screening, Hastings Center, New York
- 2004-06: Chair, American Society of Human Genetics Working Group on HIPAA and Genetics Research
- 2004-09: Member, Ethics Review Panel, Shanghai Health Study
- 2005-08: Member, Fellows Council, Hastings Center
- 2005: Chair, Nominating Committee, AAP Section on Bioethics
- 2006-07: Chair, AALS and ASRM Planning Committee for Workshops on Reproductive Medicine and the Law
- 2009-12: Member, External Advisory Board, ESRC Centre for Genomics in Society, University of Exeter, UK
- 2014- : Member, External Advisory Board, CITI Japan

### Professional Service on State Level:

- 1991- : Member, Genetics Advisory Committee, Tennessee Department of Health and Environment
- 1992- : Chair, Committee on Bioethics, Tennessee Chapter American Academy of Pediatrics
- 1993- : Member, Tennessee Lawyers Association for Women Judicial Appointments and Elections Committee
- 1996-2000: Member, Family Law Committee -- Code Revision Committee, Tennessee Bar Association
- 1997-2000: Member, Board of Directors, American Civil Liberties Union of Tennessee
- 2001- : Chair, Ethics/Confidentiality Committee, Statewide Genetics Planning Committee
- 2004- : Chair, Government Relations Committee, Genetics Advisory Committee

### Service at Other Universities:

- 1978-79: Educational Planning Committee, Yale Law School; Treasurer, Yale Law Women's Association, Yale Law School
- 1982-84: Member, Genetics Discussion Group, Harvard Medical School
- 1983-84: Director, Medicine and Society, Harvard Medical School
- 1986-88: Moderator, Ethics Forums, University of Wisconsin Hospital and Clinics
- 1986-88: Member, Ethics Discussion Group, University of Wisconsin
- 1986-88: Human Subjects Committee, University of Wisconsin
- 1987-88: Ethics Committee, VA Hospital, Madison, WI

### Community Service:

- 1989- : Member, Davidson County Child Abuse Team
- 1995- : Member, Board of Directors, Tennessee Health Decision Ethics Guild
- 1996-2002: Member, Nashville Opera Guild

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- 2012-6: Member, Board of Directors, Planned Parenthood of Middle and East Tennessee  
2013-6: Member, Board of Directors, Tennessee Advocates for Planned Parenthood

### **Editorial Board:**

Genomics, Society and Policy  
Journal of Law, Medicine, and Ethics  
JAMA Pediatrics

### **Teaching Interests:**

Ethics and Law; Medical Ethics; Legal and Ethical Issues Raised by Genetics; Genetics and Health Policy; Genetics; Research Ethics; Public Health Law and Ethics; Legal and Ethical Issues in Children's and Women's Health; Family Law; Gender and the Law; Reproductive Rights

### **Teaching Experience:**

- 1973-74: Teaching Assistant, graduate course in cellular physiology, Duke University  
1974-76: Teaching Assistant, Introductory Biochemistry and Human Genetics, Stanford University  
1982-84: Lecturer in Introductory Genetics (Spring), Harvard Medical School  
1984-85: Seminar in Law and Medicine (Spring), University of Wisconsin Law School  
1988- : Bioethics and Law, Reproductive Rights and the Law, Genetics, Medicine, and the Law, Family Law, Gender and the Law, Torts, Health Law and Policy, Seminar on the Health Care Safety Net, Vanderbilt University School of Law  
1988- : Within the medical school, I have taught in various capacities. I have assisted a number of medical students with emphasis projects over the years. I teach in the MSCI and other graduate programs. I directed a Hazinski mentoring group in pediatrics. In 2018, I designed and directed the Public Health, Global Health, and the Research Ethics Course for the MPH program.  
1990- : I have guest lectured in classes in the divinity, business, nursing, and engineering schools, the Kennedy Center, and in the college of arts and sciences on an array of issues in law, medicine, and ethics. I currently do several such presentations every semester.

### **Grant and Funding Support:**

Co-Investigator, Birth Outcomes, Satisfaction with Care, and Malpractice, Agency for Health Care Policy and Research (Frank A. Sloan & Gerald B. Hickson, Principal Investigators) HS06499 (\$660,538) (9/30/90-3/31/94)

Co-Investigator, Cystic Fibrosis Screening: An Alternative Paradigm, National Institutes of Health 1R01 HG 00638-02 (John A. Phillips, III, Principal Investigator) (\$386,271) (9/30/91-6/30/95)

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Principal Investigator, Charles E. Culpeper Foundation Scholarship in Medical Humanities (\$90,000) (7/1/92-6/30/95)

Principal Investigator, Shannon Award, National Center for Human Genome Research (\$100,000) (1995-1997)

Consultant, Psychosocial Effects of Neonatal Hearing Screening, National Institutes of Mental Health 1R03 MH53965-01 (Anne Marie Tharpe, Principal Investigator) (\$32,100)(~1995-1997)

Contract, Informed Consent for the Use of Stored Tissue Samples for Genetic Research, National Center for Human Genome Research (Ellen Wright Clayton, Principal Investigator) (\$5,000) (1995)

Contract, Informed Consent for Creation of DNA Libraries for Large Scale Sequencing, Department of Energy (Ellen Wright Clayton, Principal Investigator) (\$2,500) (1996)

Contract, Inclusion of Children in Research, National Institute of Child Health and Human Development (Ellen Wright Clayton, Principal Investigator) (\$2,500) (1996)

Contract, Services Grant for Children with Genetic Conditions, Tennessee Department of Health (~\$2,000/year) (1999)

Principal Investigator, Public Health and Genetics, National Human Genome Research Institute, 1 R01 HG01974-01 (\$103,168) + a supplement for the Public Dialogue on Human Gene Patenting (1999-2002)

Principal Investigator, Japan HapMap Community Engagement, National Human Genome Research Institute (\$68,342) (2002-2003)

Co-Investigator, Primary Pulmonary Hypertension: Mechanisms and Family Registry, National Heart, Lung, and Blood Institute (1998-2008)(Jim Loyd, Principal Investigator) (\$83,000) (08/03-3/09) – 19% effort

Co-Investigator Genetics in Literature, Film, and Popular Culture, National Human Genome Research Institute, R03 HG-03031-01 (Jay Clayton, Principal Investigator) (\$100,000) (2003-2005)

Co-Investigator, Clinical Use of Research Genetic Tests for Arrhythmia, National Human Genome Research Institute, R03 HG-2545-01, (Carol Freund, Principal Investigator) (\$100,000) (2003-2005) – 2% effort

Principal Investigator, Impact of Newborn Screening on Families, March of Dimes, 6-FY05-85 (6/1/05-5/31/08) (\$98,194) – 0% effort

Co-Principal Investigator, Vanderbilt Engaging Nashville Survey (Daniel Cornfield, Principal Investigator) (2007) – 0% effort

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Principal Investigator, Religion and Genomics: Navigating Pathways and Perspectives of Patient Care, National Human Genome Research Institute, 1 R13 HG004689-01 (\$31,900) (03/08- 02/09) – 0% effort

Co- Investigator, Fogarty “Creating Collaborative Research Ethics Education with Costa Rica,” Elizabeth Heitman, PI (09/06-06/11) – 4% effort

Co-Investigator, NHLBI “Treatment of Pulmonary Edema in Organ Donors” Lorraine Ware, PI (04/07-03/11) – 1% effort

Co-Investigator, NHGRI “Vanderbilt Genome-Electronic Records Project” Dan Roden, PI (09/07-07/11) – 15% effort

Co- Investigator, NCR “The Vanderbilt Institute for Clinical and Translational Research (VICTR)” Gordon Bernard, PI (09/07-05/12) – 5% effort

Principal Investigator, NHGRI, “Returning Results of Pediatric Genomic Research to Participants,” (9/30/2011-9/29/2013) -- 8% effort, 20% effort year 2

Co-Investigator, NHGRI “Vanderbilt Genome-Electronic Records Project” Dan Roden, PI (8/12-73/20) – 10% effort

Co-Investigator, NIGMS, “A Risk Management Framework for Identifiability in Genomics Research,” Brad Malin PI (09/30/2012 – 09/29/2016) – 10% effort

Co-Principal Investigator, NHGRI, “Genetic Privacy and Identity in Community Settings” 05/16/2016-06/30/2020 – 20% effort

Co-Principal Investigator, NHGRI, “LawSeq: Building a Sound Legal Foundation for Translating Genomics into Clinical Application,” 06/06/2016-05/31/2019 – 20% effort

Co-Investigator, NCRR, Vanderbilt Institute for Clinical and Translational Research (VICTR) (6/1/2017-2/28/2022) -- 2%

Co-Investigator, NHGRI, Health Care Provider Responses to Receiving Unsolicited Genomic Results (7/1/2018-4/30/2021) – 3%

Principal Investigator, NHGRI, Genetic Privacy and Identity in Sexual and Gender Minorities: GetPriSM – 8%

Co-Investigator, NCI, Improving identification and healthcare for patients with Inherited Cancer Syndromes – 3%

Co-Principal Investigator, NHGRI, “Genetic Privacy and Identity in Community Settings” pending – 20% effort

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Co-Investigator, NHGRI “Vanderbilt Genome-Electronic Records Project” Dan Roden, PI  
pending – 7% effort

**Publications:**

**Articles:**

1. Ellen E. Wright, Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling, Yale Law Journal 1978; 87:1488-515
2. Ellen E. Wright, The Legal Implications of Refusing to Provide Prenatal Diagnosis in Low-Risk Pregnancies or Solely for Sex Selection, American Journal of Medical Genetics 1980; 5:391-97
3. Ellen E. Wright & Margery W. Shaw, Legal Liability in Genetic Screening, Genetic Counseling, and Prenatal Diagnosis, Clinical Obstetrics and Gynecology 1981; 24:1133-49; reprinted in Genetic Disease Diagnosis and Treatment: Proceedings of the Fifth Arnold O. Beckman Conference in Clinical Chemistry 17-40 (A.A. Dietz, ed., 1983)
4. Ellen Wright Clayton, Legal Aspects of Medical Genetics in Wisconsin, Wisconsin Medical Journal 1985; 84:28-33
5. Ellen Wright Clayton, From Rogers to Rivers: The Rights of the Mentally Ill to Refuse Medication, American Journal of Law and Medicine 1987; 13:7-52
6. Ellen Wright Clayton & Jay Clayton, Voices and Violence, Vanderbilt Law Review 1990; 43:1807-1818
7. Ellen Wright Clayton & Gerald B. Hickson. Compensation Under the National Childhood Vaccine Injury Act, Journal of Pediatrics 1990; 116:508-513
8. Gerald B. Hickson, William A. Altemeier & Ellen Wright Clayton, Should Promethazine Be Available Without Prescription? Pediatrics 1990; 86:221-25
9. Ellen Wright Clayton, Screening and Treatment of Newborns, Houston Law Review 1992; 29:85-148
10. Gerald B. Hickson, Ellen Wright Clayton, Penny B. Githens, & Frank A. Sloan, Factors That Prompted Families to File Medical Malpractice Claims Following Perinatal Injuries, Journal of the American Medical Association 1992; 267:1359-1363

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11. Ellen Wright Clayton, Issues in State Newborn Screening Programs, Pediatrics 1992; 90:641-645
12. Ellen Wright Clayton, A Ray of Light About Frozen Embryos, Kennedy Institute Ethics Journal 1992; 2:347-359
13. Ellen Wright Clayton, Reproductive Genetic Testing: Regulatory and Liability Issues, Fetal Diagnosis and Therapy 1993; 8 (Suppl 1):39-59
14. Gerald B. Hickson, Ellen Wright Clayton, Are You and Your Waiting Room's Televised "Expert" Saying the Same Thing? Clinical Pediatrics 1993; 32:172-174
15. Vickie L. Hannig, Ellen Wright Clayton, & Kathryn M. Edwards, Whose DNA Is It Anyway?: Relationships between Families and Researchers. American Journal of Medical Genetics 1993; 47:257-260
16. Ellen Wright Clayton, Newborn Screening for the Pediatrician, Contemporary Pediatrics 1993; 10:34-46
17. Ellen Wright Clayton, Gerald B. Hickson & Cynthia S. Miller, Parents' Responses to Vaccine Information Pamphlets. Pediatrics 1994; 93:369-372
18. Gerald B. Hickson, Ellen Wright Clayton, Stephen S. Entman, Cynthia S. Miller, Penny B. Githens, Kathryn Whetten-Goldstein, Frank A. Sloan, Obstetricians' prior malpractice experience and patients' satisfaction with care, Journal of the American Medical Association 1994; 272: 1583-1587
19. Ellen Wright Clayton, What are the law's priorities about the dispersion of genetic technologies? Special Supplement, Hastings Center Report 1995; 25(3):S13-S15
20. Ellen Wright Clayton, Removing the shadow of the law from the debate about genetic testing of children, American Journal of Medical Genetics 1995; 57: 630-634
21. Ellen Wright Clayton, What is really at stake in Baby K: A Response to Ellen Flannery, Journal of Law, Medicine, and Ethics 1995; 23:13-14
22. Ellen Wright Clayton, Vickie L. Hannig, Jean P. Pfothenauer, Robert A. Parker, Preston W. Campbell, III, John A. Phillips, III. Teaching about cystic fibrosis carrier screening by using written and video information, American Journal of Human Genetics 1995; 57: 171-181
23. Ellen Wright Clayton, Karen K. Steinberg, Muin J. Khoury, Elizabeth Thomson, Lori Andrews, Mary Jo Ellis Kahn, Loretta M. Kopelman, Informed consent for genetic research on stored tissue samples, Journal of the American Medical Association 1995; 274: 1786-1792
24. Ellen Wright Clayton, Panel Comment: Why the use of anonymous samples for research matters, Journal of Law, Medicine, and Ethics 1995; 23: 375-377.

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25. Ellen Wright Clayton, Vickie L. Hannig, Jean P. Pfothauer, Robert A. Parker, Preston W. Campbell, III, John A. Phillips, III, Lack of interest by nonpregnant couples in population based cystic fibrosis carrier screening, American Journal of Human Genetics 1996; 58: 617-627
26. Ellen Wright Clayton, Pediatrics ethics: A view from the United States, Acta Paediatrica Japonica 1996; 38: 299-303
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Vickie L. Hannig, Lisa Wheeler, John A. Phillips III, Cindy L. Vnencak-Jones, John H. Newman, [Ellen Wright Clayton](#), et al., Interest in clinical testing for familial pulmonary arterial hypertension (FPAH), [American Journal of Respiratory and Critical Care Medicine](#) 2008; 177 (Abstracts) A921

Diana L. Jones, Joanne C. Sandberg, Robert C. Saunders, Vickie L. Hannig, [Ellen Wright Clayton](#), What patients and their relatives think about testing for BMPR2, PHA Convention, Houston, TX, June 2008

Kyle B. Brothers, Daniel R. Morrison, Jill Pulley, Dan Masys, [Ellen Wright Clayton](#), Acceptability of an opt-out biobank based on electronic medical record and residual blood samples, HUGO GELS meeting, GENEVA, SWITZERLAND, November, 2009

Brothers KB, [Clayton EW](#), Morrison DR, Pulley J, Masys D: Acceptability of an Opt-Out Pediatric Biobank Based on Electronic Medical Record and Residual Blood Samples. 2010 Pediatric Academic Societies, Denver, CO, October, 2010

Rebecca Zuvich, [Ellen Wright Clayton](#), Melissa Basford, Joshua Denny, Dan Roden, Jonathan Haines, Marylyn Ritchie, Balancing ethics and genetics: classifying individuals by their ancestry groups, American Society of Human Genetics, Washington, DC, November, 2010

Barbara Koenig, Amy Lemke, Catherine McCarty, [Ellen Wright Clayton](#), The eMERGE Consortium: an NIH-supported Model for Integrating Bioethics into Leading-edge Genomic Research, Public Health and Genomics Conference, Washington, DC, December, 2010

[Ellen Wright Clayton](#), MD, JD & Maureen E. Smith, MS, CGC, for the Consent and Community Consultation Working Group, Confronting Real Time Ethical, Legal, and Social Issues in the eMERGE (Electronic Medical Records and Genomics) Consortium, Public Health and Genomics Conference, Washington, DC, December, 2010

Kyle B. Brothers & [Ellen Wright Clayton](#), Peds BioVU: Including Pediatric Samples in a Non-Human Subjects Biobank, Public Health and Genomics Conference, Washington, DC, December, 2010

D.B. Pet; I.A. Holm; J.L. Williams; M.F. Myers; L.L. Novak; K.B. Brothers; G.L. Wiesner; [E.W Clayton](#), Physicians' perspectives on returning unsolicited genomic results to patients and health care providers, Program Number 223, American Society of Human Genetics Annual Meeting, Orlando, FL, October, 2017

### Reviewer for:

#### Editorial functions:

Board, Journal of Law, Medicine, and Ethics

Board, JAMA Pediatrics

PLOS ONE: Human Research Advisory Board

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Board, American Journal of Bioethics

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French National Cancer Institute

Journals:

American Journal of Bioethics

American Journal of Obstetrics and Gynecology

American Journal of Public Health

Archives of Pediatrics and Adolescent Medicine, formerly American Journal of  
Diseases of Children

BMC Medical Ethics

Clinical Genetics

Clinical Pharmacology and Therapeutics

Community Genetics

European Journal of Human Genetics

Genetic Testing and Molecular Biomarkers

Genetics in Medicine

Genome Medicine

Genome Research

Genome Science and Technology

Hastings Center Report

Health Affairs

Human Genetics

Human Mutation

JAMA Pediatrics

Journal of General Internal Medicine

Journal of Genetic Counseling

Journal of Health Politics, Policy and Law

Journal of Law, Medicine, and Ethics

Journal of Medical Ethics

Journal of Personalized Medicine

Journal of the American Medical Association

Journal of the American Medical Women's Association

Lancet

Milbank Quarterly

Nature Review Genetics



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New England Journal of Medicine  
Norwegian Journal of Epidemiology  
Pediatric Nephrology  
Pediatrics  
Physiological Genomics  
PLOS ONE  
PLOS Genetics  
Social Science and Medicine  
The Pharmacogenomics Journal  
Theoretical Medicine and Bioethics

### **National and International Lectures:**

#### **Genetics:**

"Legal Issues in Sex Selection," Annual Convention, American Society of Human Genetics, Minneapolis, MN, October, 1979

Grand Rounds, Obstetrics and Gynecology, Medical College of Virginia, Richmond, VA, April, 1980

"Genetic Counseling: The Legal Issues," Annual Conference, American Society of Human Genetics, Norfolk, VA, October, 1983

"Feminism, Bioethics, and Genetics," Hastings Center, Briarcliff Manor, NY, November, 1990

"Genetic Screening and Treatment of Newborns," Legal and Ethical Issues Raised by the Human Genome Project, Health Law and Policy Institute of the University of Houston, Houston, TX, March, 1991

"Reproductive Genetic Testing: Regulatory and Liability Issues" Working Group on Reproductive Genetic Testing: Impact on Women, National Institutes of Health, Bethesda, MD, November, 1991

"Legal and Ethical Issues in Screening and Treating Newborns" Workshop on Ethical and Legal Issues, Southeastern Regional Genetics Group, Atlanta, GA, February, 1992

"The Law's Rhetoric About Reproductive Genetic Testing," Health Law Teacher's Conference, Seattle, WA, May, 1992

"Written Education Materials for CF Carrier Testing." Workshop on the Delivery of Carrier Screening Services, Sixth Annual North American Cystic Fibrosis Conference, Washington, DC, October, 1992

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"Neonatal Genetic Screening for Treatable Diseases," Charting the Genome: Implications of Genetic Technologies for Healthcare Practitioners in the 1990s, Second Annual Frontiers of Healthcare Ethics Conference, Pacific Center for Health Policy and Ethics and UniHealth America, Los Angeles, CA, February, 1993

"How Does the Law Affect the Dispersion of Genetic Technologies? Can It Be More Effective?" Priorities in Genetics, The Hastings Center, Briarcliff Manor, NY, September, 1993

"Neonatal Screening: PKU to CF and Beyond." Pediatric Grand Rounds, University of Chicago. October, 1993

"Response: Cystic Fibrosis, Genetic Testing and Women." The Human Genome Project and Women, University of Chicago. October, 1993

"Genetics and the Law," College for New Jersey Judiciary, Teaneck, NJ, November, 1993  
"All in the Family: Special Problems Posed by Genetic Research in Human Subjects."  
National Center for Human Genome Research, Washington, DC, March, 1994

"What You Need to Know About the New Genetics," Medical Ethics for Physicians and Nurses: End of Life Issues, University of Alabama in Huntsville School of Primary Medical Care, Huntsville, AL, July, 1994

"What Will Genetic Testing Mean for Women?" Symposium on Women's Health Care Issues, American Association for Clinical Chemistry, New Orleans, LA, July, 1994

"Ethical, Legal, and Technical Issues Involved in the Collection of Patient Specimens and Data -- Prospective versus Retrospective Collections," Breast Cancer Resources to Facilitate Research, National Institutes of Health, Bethesda, MD, September, 1994

Testimony before the Subcommittee on Energy, Committee on Science, Space, and Technology, United States House of Representatives, Washington, DC, October, 1994

"Ethical, Legal and Social Concerns of Genetic Testing in Women," Women's Hospital Visiting Professor, Pennington Biomedical Research Center, Baton Rouge, LA, October, 1994

"Interest and Demand for Cystic Fibrosis Carrier Screening in Nonpregnant Couples," American Society of Human Genetics Annual Meeting, Montreal, CANADA, October, 1994

"Ethical Issues in Genetic Preselection," American Academy of Pediatrics Annual Meeting, Dallas, TX, October, 1994

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"Ethical/Social Implications," Ethical Issues for the Next Decade and Beyond: Genetics Research and Violence/Abuse, Colorado Springs Osteopathic Foundation and Family Medicine Center, Colorado Springs, CO, November, 1994

Visiting Professor Lecture Series, Department of Pediatrics and Center for Medical Ethics, Ethics for Lunch -- "The Impact of Genetic Testing," Research Colloquium -- "Informed Consent and the Use of Stored Tissue Samples for Genetic Research," University of Pittsburgh Medical Center, Pittsburgh, PA, December, 1994

"Issues of Informed Consent," The Human Genome and Disease Prediction, President's Cancer Panel, Bethesda, MD, March, 1995

"Ethical Issues in Genetics," Genetics in the 90s, Children's Hospital, Columbus, OH, April, 1995

"Ethical Issues in Presymptomatic Genetic Testing for Cancer Risks," Symposium on Clinical Aspects of Genetic Testing with Anil K. Rustgi, MD and Ann-Marie Codori, PhD, Digestive Disease Week, American Gastroenterological Society, Digestive Disease Week, San Diego, CA, May, 1995

"Ethical Issues in Genetic Testing for Cancer Risks," Symposium on Ethical, Legal, and Social in Genetic Testing for Cancer Risks with Elizabeth J. Thomson, MS, RN and Caryn Lerman, PhD, American Society of Clinical Oncology, Los Angeles, CA, May, 1995

"Problems Posed by Genetics for Law and Ethics: American Policies," Biotechnological Challenges for Law and Ethics, Bellagio, ITALY, August, 1995

"Current Legal Issues in Genetics and Medicine: From prenatal diagnosis to predictive testing," Harvard Medical School Law and Medicine Society, Boston, MA September, 1995

"Genetic Research: Welcoming IRBs to this Brave New World," Public Responsibility in Medicine and Research Annual Convention, Boston, MA, October, 1995

"Informed consent and competency," Genetic testing in children and adolescents: Ethical, legal, and social issues, American Society of Human Genetics Annual Convention, Minneapolis, MN, October, 1995

"Genetic testing and children," National Society of Genetic Counselors, Minneapolis, MN, October, 1995

"Genetic testing in children: From newborn screening to predictive testing," East Carolina University, Greenville, NC, November, 1995

"Legal and ethical issues in screening for genetic predisposition to cancer," 1996 Baptist Memorial Health Care Foundation Forum on Cancer Research, Memphis, TN, April, 1996

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"Ethical issues in DNA diagnosis," National Institute of Neuroscience, Tokyo, JAPAN, April, 1996

"A conversation on genetic testing of children: Legal, ethical, and family Issues," Intramural Program, National Center for Human Genome Research, Bethesda, MD, September, 1996

"Managing the genetics revolution," ASLME Annual Meeting, Maintaining Responsive Health Care in the 21st Century: Accountability, Quality, and Change in Traditional Roles and Relationships, Boston, MA, November, 1996

"Ethical issues in genetics and research," Second Annual Institute on Legal Issues Affecting Academic Medical Centers and Other Teaching Institutions, American Academy of Healthcare Attorneys, Arlington, VA, December, 1996

"Pretest education, counseling, and informed consent Issues," Iron Overload, Public Health, and Genetics, CDC/NHGRI Conference, Atlanta, GA, March, 1997

"Genetic discrimination," Risk, Regulation, and Responsibility: Genetic Testing and the Use of Information, American Enterprise Institute for Public Policy Research, Washington, D.C., September, 1997

"What should the law say about family disclosure?" Testing and Telling?: Implications for Genetic Privacy, Family Disclosure, and the Law, University of Maryland School of Law, The Law and Health Care Program, October, 1997

"Implications of recommendations for couples in the prenatal period," Genetic Testing for Cystic Fibrosis Consensus Development Conference Development Workshop, Bethesda, MD, October, 1997

"Whither the law and practice? Is There a Professional Duty to Warn At-Risk Relatives?" Annual Meeting, American Society of Human Genetics, Baltimore, MD, October, 1997

"Genetics, public health, and the law," Centers for Disease Control and Prevention, Atlanta, GA, November, 1997

"Cystic fibrosis," Risky Business: Perils and Payoffs of Genetic Testing, STEP Program, National Institutes of Health, Bethesda, MD, December, 1997

"Challenges raised by genetics for research and clinical practice," Second Caribbean Congress on Bioethics: Ethical Issues in Biomedical Research, Mayagüez, PUERTO RICO, March, 1998

"Privacy and confidentiality: Disclosure of familial genetic information," Ethical, Legal, and Social Implications of Genetic Medicine, Genetic Medicine and the Practicing Physician, New Orleans, LA, March, 1998

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“Balancing individual interests, group interests, and the public health: Addressing the special issues raised by genetics,” First Annual Conference on Genetics and Public Health, Atlanta, GA, May, 1998

“What should you be telling families about genetic testing?” James Grant Thompson Memorial Lecture, Annual Meeting, Mississippi State Medical Association, Biloxi, MI, May, 1998

“Genetic Testing and the Law: From the Labs to the Courts and All the Steps In Between,” Twentieth Annual National Association of Women Judges Conference, Gateway to the Future, St. Louis, MO, October, 1998 (with Sandra Johnson)

“Genetics and Public Health: Legal and Ethical Issues” American College of Legal Medicine 1988 Mid-Year Educational Conference, St. Louis, MO, October, 1998

“Insurance and Confidentiality -- What About Genetic Information?” Practical Issues in Cancer Genetics 1998, University of Tennessee, Knoxville, TN, October, 1998

“Disclosure of Genetic Information in Families,” American Association of Medical Colleges, New Orleans, November, 1998

“The Permissibility of Using Blood Spots for Research,” Hard Cases in Genetics, Sponsored by Deutsches Zentrum für Luft- (DLR) also Projektträger des Bundesministeriums für Bildung, Wissenschaft, Forschung und Technologie (BMBF) im Rahmen des Deutsches Humangenomprojekts (DHPG), Memphis, TN, April, 1999

“Privacy and Confidentiality in the 21<sup>st</sup> Century: Ethical Issues Surrounding the Disclosure of Genetic Information to Family Members,” TexMed - 99, Dallas, TX, May, 1999

“The Ethics of Sharing Genetic Information,” Ethics Grand Rounds, National Institutes of Health, Bethesda, MD, June, 1999

“Genetics and Family Law,” The New Genetics and Reproduction: The Legal Response, The Gruter Institute, Squaw Valley, CA, June, 1999

“Trustees of Patients and Their Families: Ethical Challenges on the Genetics Frontier,” Where No One Has Gone Before: The Ethics of Modern Medical Advances, Jackson, MI, October, 1999

“Policy Challenges: Ethical, Legal, and Social Implications of Genetics,” Genetics and Ethics, St. Louis, MO, October, 1999

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“What the Human Genome Project Means for You,” Genetics for the New Millennium: Ethical and Health Care Considerations, 18<sup>th</sup> Missouri Conference on Genetic Disorders, Kansas, City, MO, November, 1999

“Genomics: Will It Help or Hurt Us,” Lafayette College, Easton, PA, February, 2000

“Genetics Research: Toward International Guidelines,” Council for International Organizations of Medical Sciences, Geneva, SWITZERLAND, March, 2000

“Handling Genetics in Academic Internal Medicine: Research, Education, and Clinical Care,” 2000 Association of Professors of Medicine Fall Symposium, Washington, DC, October, 2000

“Regulating Germ-Line Gene Transfer in the United States,” International Guidelines in Genetics, International and Interdisciplinary Symposium. Lutherstadt Wittenberg, GERMANY, October, 2000

“Emerging Ethical Issues in Pharmacogenomics,” Bethesda, MD, November, 2000

“Genetics in Our Lives: Separating the Hope from the Hype,” Public lecture, University of Notre Dame, South Bend, IN, February, 2001

“Genetic Testing in Children,” North Central Indiana Ethics Consortium, University of Notre Dame, South Bend, IN, February, 2001

“So What Has ELSI Done?” Social Implications of Applied Genomics Panel, Beyond the Human Genome Project, Harvey Mudd College, Claremont, CA, March, 2001

“Genomics: What Does It Mean for Clinical Care and Beyond?” Department of Neurology and Rehabilitation, University of Illinois at Chicago, June, 2001

"Genetics for Judges," Tennessee Judicial Conference, Paris Landing State Park, Paris, TN, October, 2001

"Ethical Issues in New Genetics Research Including Haplotyping and Pharmacogenomics," Gheens Bioethics Lecture Series, Institute for Bioethics, Health Policy and Law, Louisville, KY, November, 2001

"Genomic Medicine in the Real World," Duke University, Durham, NC, November, 2001

"How Can You Teach ELSI to PCPs?" NCHPEG Membership Annual Meeting, Bethesda, MD, January, 2002

"Thinking Through the Challenges of Genomic Medicine," Presidential Lecture, Annual Meeting, Endocrine Society, San Francisco, CA, June, 2002

Ellen Wright Clayton

“Ethical Issues in Creating a Haplotype Map,” Tsukuba, JAPAN, August, 2002

“Using Genetic Information in the Employment Context,” Fifth Annual Conference of Tennessee Employment Relations Research Association, Arnold Air Force Base, TN, October, 2002

“Ethical, Legal, and Social Issues in Pediatric Genomics,” Hacia la Pediatria Genomica, Oaxaca, MEXICO, October, 2002

“Ethics and the Haplotype Map,” Annual Meeting, American Society of Bioethics and Humanities, Baltimore, MD, October, 2002

“Overview of Shared Decision-Making in Newborn Screening and Other Public Health Settings,” Challenges for the Future: Newborn Screening State Policies and Procedures, Los Angeles, CA, November, 2002

“Lessons for the New Millenium from the History of Newborn Screening,” Evaluating Genetic Tests: A Model Process,” Washington, DC, January, 2003

“Implications of Genomics for Society,” From Double Helix to Human Sequence – *and Beyond*, Scientific Symposium, National Institutes of Health, April, 2003

“Ethical Issues in Genomics and Cardiovascular Disease,” GlaxoSmithKline Research & Education Foundation for Cardiovascular Disease, Philadelphia, PA, May, 2003

“Legal Issues of HAPMAP: Individual and Community Rights,” Working at the Frontiers of Law and Science: Applications of the Human Genome,” Section of Science and Technology Law, American Bar Association, American Medical Association, American Association for the Advance of Science, Chapel Hill, NC, October, 2003

“Newborn Screening -- Why All This Commotion About an Old Program?” University of Washington Program in Public Health Genetics, Seattle, WA, October, 2003

“How Important is Informed Consent?” Newborn Screening for Cystic Fibrosis, Centers for Disease Control and Prevention and Cystic Fibrosis Foundation, Atlanta, GA, November, 2003

“Ethical Issues in Genetic Testing – The Clinical Context,” La medicina genómica: Una nueva era en el cuidado de la salud, La Facultad de Medicina de la UNAM y el Consorcio Promotor del Instituto de Medicina Genómica, Mexico City, MEXICO, December, 2003

“Genomics and Society,” Academia Nacional de Medicina, Mexico City, MEXICO, December, 2003

“The evolution of newborn screening in Tennessee focusing on MCAD – A view from the Genetics Advisory Committee,” Hastings Center, Garrison, NY, February, 2004

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“Talking with Parents – What are the Issues,” 2004 Newborn Screening and Genetic Testing Symposium, Association of Public Health Laboratories and the Centers for Disease Control and Prevention, Atlanta, GA, May, 2004

“Human Genetics and the Courts: Malpractice, Personal Injury Litigation, and Family Law,” 64<sup>th</sup> Conference of the Sixth Judicial Circuit of the United States, Louisville, KY, May, 2004

“The Ethical and Social Issues Associated with Genetic Testing in Children,” Mayo Clinic, Rochester, MN, October, 2004

“Duty/Desire to Warn: What is at Stake?” Genetics, Pharmacogenetics, and Ethics Faculty Workshop, University of Chicago, Chicago, IL, November, 2004 and Genetics Grand Rounds, University of Michigan, Ann Arbor, MI, January, 2005

“Genomic Medicine in the Real World – Pharmacogenomics in Translation,” Pediatrics Grand Rounds, University of Michigan, Ann Arbor, MI, January, 2005

“The HAPMAP and Genetic Epidemiology: Setting the Stage for Pharmacogenomics,” Pharmacogenomics: Ethical, Social and Regulatory Issues, Annual Meeting, AAAS, Washington, DC, February, 2005

“Over-reading the Human Genome: The Threat to Privacy, Employment, Group Identity, and Responsibility, Deinar Memorial Lecture on Law and Medicine, University of Minnesota, February, 2005

“Publicidad sobre las medicinas y los análisis directo al consumidor,” I Simposio Internacional de Bioética, Hospital Nacional de Niños, Dr. Carlos Sáenz Herrera, San Jose, COSTA RICA, May, 2005

“Recent Evolution of Newborn Screening – A View from a State Advisory Committee,” The Public's Health and the Law in the 21st Century: 4th Annual Partnership Conference, Centers for Disease Control and Prevention and the American Society of Law, Medicine, and Ethics, Atlanta, GA, June, 2005

“Ethical Issues That Must be Addressed in an Expanded Newborn Screening Program,” State of the Art Plenary Session, Society for Pediatrics Research, San Francisco, CA, May, 2006

“Newborn Screening for HIV,” Section on Bioethics, American Academy of Pediatrics, San Francisco, CA, May, 2006

“Use of Residual Blood Spots for Research,” Genomics and Public Health, 4<sup>th</sup> International DNA Sampling Conference, Montreal CANADA, June, 2006



Ellen Wright Clayton

“Ethical Implications of Transformative Technologies in Newborn Screening,” 6<sup>th</sup> Meeting of the International Society for Neonatal Screening, Awaji, Hyogo & Tokushima, JAPAN, September, 2006

“Patients or Subjects or Both? What Biobanks Will Mean for You,” UCLA Healthcare Ethics Lecture, Los Angeles, CA, October, 2006

“Ethical Challenges in Implementing Genetic Medicine – What We Expected, What Actually Happened, and What We Should Do About It,” 1<sup>st</sup> Annual Lecture on Ethical Issues in Genetics, Cedar-Sinai Medical Center, Los Angeles, October, 2006

“Bioética en Público” Comisión Nacional de Bioética, Distrito Federal, MÉXICO, October, 2006

“Genomic Medicine: Emerging Trends in Ethics,” Second Annual Congress of Genomic Medicine, Mexico City, MEXICO, October, 2006

“Defining Benefit and Treatment – Implications for Newborn Screening,” Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, Department of Health and Human Services, Washington, DC, December, 2006

“Systems Biology: Ethical, Legal, and Social Implications,” Systems Biology and Information Medicine in a Global Society, Princeton University, January, 2007

“Genética y los derechos humanos,” XIX Simposium Internacional de Derecho, Monterrey, MÉXICO, October, 2007

“Ethical, Legal, and Societal Issues Raised by Neurogenomics of Childhood Disorders,” Emerging Problems in Neurogenomics: Ethical, Legal & Policy Issues at the Intersection of Genomics & Neuroscience, Minneapolis, MN, February, 2008

“Regulaciones de marcadores genéticos en la investigación,” II Simposio Internacional de Bioética, Hospital Nacional de Niños, San José, COSTA RICA, March, 2008

“Ten Fingers, Ten Toes,” Newborn Screening Conference, Case Western Reserve University Law-Medicine Center, Cleveland, OHIO, April, 2008

“Where Should We Go with Newborn Screening?” Harvey and Bernice Jones Lecture, Arkansas Children’s Hospital, Little Rock, AK, December, 2008

“Pros and Cons of Screening for Untreatable Disorders,” American College of Medical Genetics annual meeting, Tampa, FL, March 2009

“Why Parents Should Not Have the Authority to Consent on Behalf of Their Children, but Adolescents May Consent for Themselves,” American College of Medical Genetics annual meeting, Tampa, FL, March 2009

Ellen Wright Clayton

“Return of Results in Genet(om)ics Research,” David Green Memorial Lecture, University of Utah, April, 2009

“Regulating Clinical Genomics,” Yale Law School Reunion, New Haven, CT, October, 2009

“Ethical Issues in Moving Clinical Genomics from the Bench to the Bedside,” Medical Genome Science in the Personal Genome Era, International Symposium on Applied Genomics 2009, TOKYO, JAPAN, December, 2009

“Clinical Genetics and Identity,” Genomics, Medicine and the Humanities Workshop, University of Exeter, EXETER, UK, March, 2010

“Governance Issues in Whole Genome Diagnostics,” Changing Landscape of Genetic Testing and Its Impact on Clinical and Laboratory Services and Research in Europe, GOTEBOG, SWEDEN, June, 2010

“Ethical Issues in Expanded Newborn Screening,” European Society of Human Genetics, GOTEBOG, SWEDEN, June, 2010

“Newborn Screening: Informed Consent Through the Back Door,” Is Medical Ethics Really in the Best Interest of the Patient?” UPPSALA, SWEDEN, June, 2010

“Newborn Screening: The Canary in the Genomics Mine” and “Dealing with Genomics in the Clinic,” Hagop S. Mekjian Lectures in Medical Ethics and Professionalism, Ohio State University, Columbus, OH, September, 2010

“What are Advances in Genomics Really Going to Mean for Patients? Issues in Translation,” Hartnell College, Salinas, CA, October, 2010

“Surfing the Tsunami of Whole Genome Sequencing,” Pacific Symposium on Biocomputing, Kona, HI, January, 2011

“Surfing the Tsunami of Whole Genome Sequencing,” Advances in Genome Biology and Technology, Marco Island, FL, February, 2011

“Challenges Posed by New Technologies for the Standard of Care,” Personalized Medicine Symposium, Birmingham, AL, February, 2011

“Challenges Posed by Translating Whole Genomes to the Clinic,” Presidential Commission for the Study of Bioethical Issues, Washington, DC, February, 2011 and HUGO 15<sup>th</sup> Human Genome Meeting: Genomics of Human Diversity and Heritable Disorders, DUBAI, UAE, March, 2011

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“Imagined Futures: Capturing the Benefits of Genome Sequencing for Society,” HUGO 15<sup>th</sup> Human Genome Meeting: Genomics of Human Diversity and Heritable Disorders, DUBAI, UAE, March, 2011

“What should we do with whole genomic sequences in the clinic and in research?” Personal Genomes, Cold Spring Harbor, NY, October, 2011

“Returning Results of Genome Wide Tests in Research and the Clinic – Addressing the Issues” Sanger Center and HeLEX, Oxford, UNITED KINGDOM, November, 2011

“Consent,” Human Microbiome Project, Houston, TX, March, 2012

“Whole Genome Sequencing in the Clinic,” Law Gene Centre, University of Tasmania Law School, Hobart, AUSTRALIA, March, 2012

“Imagined Futures: Capturing the Benefits of Genome Sequencing for Society,” HUGO Annual Meeting, Sydney, AUSTRALIA, March, 2012

“How Not to Drown in the Whole Genome in the Clinic,” Pediatric Academic Societies Meeting, Boston, MA, April, 2012

“Ethical Issues in Non-Invasive Prenatal Diagnosis,” IOM Annual Meeting, Interest Group, Washington, DC, October, 2012

“Pediatricians Beware! Direct to Consumer Marketing of Genetic Testing for Children,” AAP Annual Meeting, New Orleans, LA, October, 2012

“The Role of Genomics in Primary Prevention,” University of Michigan, Ann Arbor, MI, March, 2013

“Genomics in Primary Prevention,” Greenwall Fellows Program, Chicago, IL, May, 2013

“Transdisciplinarity – Why it matter for the Future, Exeter University, UNITED KINGDOM, June, 2013

“Who Should Decide About Genetic Testing in Kids? A Response to the ACMG,” Bioethics Seminar, Seattle Children’s Hospital, October, 2013

“Major Policy Questions in Genomic Medicine,” University of Washington Center for Genomics and Health Care Equality, 2013 CGHE All-Investigators’ Meeting, Seattle, WA, October, 2013

“Return of results in research and the clinic – Getting back on the right track,” University of Pittsburgh Law School, Pittsburgh, PA, October 2013

“Challenging the Duty to Hunt,” ASHG Annual Meeting, Boston, MA, October, 2013

Ellen Wright Clayton

“Newborn Screening: From Guthrie to the Uniform Panel and Beyond,” AAP Annual Meeting, Orlando, FL, October, 2013

“From Peapods to Whole Genome Sequencing: Old and New Ethical Challenges,” AAP Annual Meeting, Orlando, FL, October, 2013

“Challenges Posed by the ACMG Recommendations on Incidental Findings in Clinical Genomic Sequencing,” Eighth Annual Cynthia Jean Stolman Lecture in Medical Ethics, Rutgers New Jersey Medical School, Newark, NJ, November, 2013

“What findings, if any, from archival data and samples should be offered to research participants? Some reflections and practical issues in the US,” Returning Genetic Results in Biobanks: Opening an International Dialogue,” Brocher Foundation, Hermance, SWITZERLAND, November, 2013

“Return of Results? No, Unless,” HandsOn Biobank Annual Meeting, The Hague, NETHERLANDS, November, 2013

“What to Ask Your Doctor About Genetic (and Other Complex) Tests,” Policy Forum: Policy implications of genomic sequencing for individual and population health, Brown School, Washington University, St. Louis, MO, February, 2014

“Whole Genome Sequencing in Newborn Screening?,” Human Genome Meeting 2014, Geneva, SWITZERLAND, April, 2014

“What Should You Know and Be Doing About Genome Privacy?” Workshop on Genome Privacy held in conjunction with the 14th Privacy Enhancing Technologies Symposium (PETS 2014), Amsterdam, NETHERLANDS, July, 2014

“On the Cusp of Adulthood: Ethical and Legal Issues Raised by Genomics Research and Care Involving Adolescents,” Grand Rounds, St. Jude Research Hospital, Memphis, TN, January, 2015

“Current Controversies in Whole Genome Sequencing,” Challenging the Norm: Fostering Ethics, University of Wisconsin, March, 2015

“When Participants in Genomic Research Grow Up: Contact and Consent at the Age of Majority,” Annual Meeting, Paediatric Platform, P3G, May, 2015, Montreal, CANADA

“Genomics Over the Pediatric Life Course: Addressing the Issues,” Center for Research on Ethical/Legal/Social Implications of Psychiatric, Neurologic & Behavioral Genetics, Columbia University, September, 2015

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“Modeling Risk to Privacy in Genomics Research Shows How the NPRM Misses the Mark,” Specimen Science, Petrie-Flom Center, Harvard Law School, November, 2015

“Genetic Privacy and Identity in Community Settings (GetPreCiSe) and LawSeq – Explorations in Privacy in the US,” Global Alliance for Genomics and Health, Vancouver, CANADA, October, 2016

“Context is Crucial for the Genome Privacy Debate,” 3rd International Workshop on Genome Privacy and Security, Chicago, IL. November 12, 2016

“Shaping Future Generations – Promise or Problem, A View From the USA,” Stemcell Knowledge Information Center, Keio University, Tokyo, JAPAN, January, 2017

“Liability Issues in Clinical Translation,” Legal Challenges in Precision Medicine, Case Western Law School, Cleveland, OH, April, 2017

“Privacy in Our Genomic Future – A View from the US,” School of Law, University of Paris- 2, Paris, FRANCE, May, 2017

“Reflections on Human Gene Editing and Implications for Disabilities,” Bioderecho y Derechos Humanos, International Network of BioLaw, Mexico City, MEXICO, August, 2017

“Human Genome Editing: Science, Ethics, and Governance” International Seminar of Biolaw, Mexico City, MEXICO, August, 2017

“Ethical and Practical Implications of Using Genetics in Medicine,” From Genes to Medicine: Building a Translational Path from Genetic Discoveries to Clinical Practice, Vanderbilt Genetics Institute, Nashville, TN, November, 2017

“Lessons (Not) to be Learned from the Debate about Genetic Privacy,” BioGen, Cambridge, MA, February, 2018

“Lessons (Not) to be Learned from the Debate about Genetic Privacy,” CPCP Privacy/Fairness Seminar, University of Wisconsin, Madison, February, 2018

“Privacy and Informed Consent in an Era of Big Data,” Committee on Science, Technology, and Law, National Academies of Sciences, Engineering, and Medicine, California Institute of Technology, Pasadena, CA, March, 2018

“Genomics and Privacy,” Genomic Medicine Conference, Hudson Alpha, Huntsville, AL, March, 2018

“Understanding Genomics in Context – Why a Public Health Perspective is Crucial,” 4<sup>th</sup> Annual Public Health Day, University of California at San Diego, April, 2018

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“The Ethical Duties Underlying Return of Results,” Addressing ELSI Issues in Unregulated Health Research Using Mobile Devices,” Chicago, IL, April, 2018

“Enhancement and Human Rights,” National Academy of Medicine Annual Meeting, Washington, DC, October, 2018

“Genetic Privacy in a Big Data World – A View from the USA” University of Granada, Granada, SPAIN, November, 2018

“Dealing with Discordant Results,” UT Southwestern Medical Center, Dallas, TX, March, 2019

“How can law and policy advance quality in genomic analysis and interpretation for clinical care?,” Health Law Teachers Conference, Chicago, IL, June, 2019

“Drowning in a sea of genomic data: Challenges of DTC tests and patient requests,” PLUGS 5<sup>th</sup> annual conference, Seattle, WA, June, 2019

“Privacy and Access Through a Genomics Lens: Lessons from the United States,” Canadian GE3LS and Health Services and Research Policy Conference, Institute of Genetics, Canadian Institute for Health Research, Montebello, CANADA, June, 2019

“Data Sharing and the Individual: The Tension between Privacy and Open Source Data in Science,” Annual Meeting, National Academy of Medicine, Washington, DC, October, 2019

“Is it Time for a Universal Genetic Forensic Database?” American Society of Bioethics and Humanities, Pittsburgh, PA, October, 2019

“The Changing Ecology of Genetic Privacy,” Department of Genome Sciences, University of Washington, Seattle, WA, February, 2020

## **Ethical and Legal Issues in Research and Patient Care (often includes genetics):**

"Informed Consent for Genetic Research Using Stored Tissue Samples," The Responsibility of Oversight in Genetic Research and Technology Assessment, Public Responsibility in Medicine and Research Annual Convention, Boston, MA, May, 1996

"Genetic Screening and Research," First International Conference on DNA Sampling -- Human Genetic Research: Ethical, Legal and Policy Aspects, Montreal, Quebec, CANADA, September, 1996

“Underlying Ethical Principles in Research Using Repository Material,” Science to Practice: The Role of Research in Public Health, Emory University, Atlanta, GA, April, 1997

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“Issues Related to the Re-Analysis of Stored Samples,” Biomarkers: The Genome and the Individual: Workplace and Medical Implications of a Rapidly Evolving Technology, Medical University of South Carolina, Environmental Hazards Assessment Program, Charleston, SC, May, 1997

“Protection of Privacy vs. Promotion of Research,” Privacy and Confidentiality: Is It a Privilege of the Past? Massachusetts Medical Society, 1997 Annual Education Program, Boston, MA, May, 1997

“Human Research: A Step Forward for Newly Included Populations?” 18th Annual Health Law Teachers Conference, Seton Hall Law School, Seton Hall, NJ, June, 1997

“Whose Tissue is It? The Patient as Product” Military Research Symposium: Protection of Human Subjects, Uniformed Services University of the Health Sciences, Bethesda, MD, June, 1997

“Using Stored Tissues for Genetics Research,” Interagency Human Subjects Conference, Genetics Research and Human Subjects: The Changing Landscape, Department of Energy, Bethesda, MD, June, 1997

“Impact of Regulation on Medical Research,” Regulation of Health Care: Latest Developments, ABA Society of Administrative Law and Regulatory Practice, ABA Midyear Meeting, Nashville, TN, January, 1998

“Research Ethics,” Health Law Teachers Meeting, Houston, TX, June, 1998

“Who Needs Informed Consent in Human Subjects Research,” Tennessee Technological University, Cookeville, TN, October, 1998

“DNA Banks and Human Research on Cancer Genetics,” Ethical Boundaries in Cancer Genetics, St. Jude’s Children’s Research Hospital, Memphis, TN, May, 1999

“Ethical Issues in Research in Pediatrics,” Pediatric Subcommittee, Anti-Infective Drug Committee, Food and Drug Administration, Chevy Chase, MD, November, 1999

“Genetics Research,” Ethical and Regulatory Aspects of Human Subjects Research Protocol, National Institutes of Health, Bethesda, MD, December, 1999

“Genetics,” Privacy and Confidentiality in Clinical and Social Science Research: Myth or Reality?, University of Texas Health Science Center at Houston, February, 2000

“Children as Research Subjects,” Research Ethics: Institutional Review Board Responsibilities and Related Competencies, Georgetown University Center for Clinical Bioethics, March, 2000

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“Ethical Issues in Human Subjects Research: Staying Oriented in a Shifting Landscape,” Ethical Issues in Health Care: The Nancy Tatum O’Neal Series, University of Mississippi Medical Center, Jackson, MS, April, 2000

“Legal Aspects of Studying Pregnant Women,” Clinical Pharmacology During Pregnancy: Addressing Clinical Needs Through Science, FDA/NICHHD Conference, Washington, DC, December, 2000

“Creating a Process to Collect Human Biological Materials and Medical Records for Research from Patients in Teaching Hospitals,” A Decade of ELSI Research, Bethesda, MD, January, 2001

“Genetics Research in the International Context – The CIOMS Experience,” A Decade of ELSI Research, Bethesda, MD, January, 2001

“The Academic Medical Center Perspective,” Conflicts of Interest in Clinical Research: Legal and Ethical Issues, Widener University School of Law, Wilmington, DE, March, 2001

"So What Should We Do About Genetics Research?", Bringing Ethics to Life in Human Subjects Research: A Case Approach, Meharry Medical College, Program in Clinical and Research Ethics, Nashville, TN, September, 2001

"Fusing/Confusing Ethics and Regulation," "President's Advisory Committee on Stem Cell Research," "Third Party Human Subjects, Including Genetic Privacy," IRBs and New Approaches: Assessing, Evaluating, Discarding, and Moving Forward, PRIM&R's 2001 IRB Conference, Boston, MA, December, 2001

"Protecting the Privacy of Research Specimens," Inaugural Symposium, Genetic Privacy and Discrimination, University of Rochester, Rochester, NY, June, 2002

“Ethics, Politics, and the Haplotype Map,” Genetics Symposium 2002, Nashville, TN, September, 2002

“Race and Genetics,” “Race and Law,” Research Ethics, Meharry CRECD Program, Nashville, TN, October, 2002

“Ethical Issues in Research Design,” Research Ethics, Meharry CRECD Program, Nashville, TN, December, 2002

“Ethical Issues in Genetic Epidemiology – International Perspectives,” US-Japan Symposium: Advances in Genetic Research in Cardiovascular Disease, Osaka, JAPAN, and Ethical Concerns in Molecular Epidemiology, Tokyo, JAPAN, February, 2003

“Collecting Human Biological Materials – The CPCRA Protocol,” Terry Beirn Community Programs for Clinical Research on AIDS, Reston, VA, May, 2003



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“Genetic Research in the Global Community,” Globalization and Human Rights: Bioethics, Mexico City, MEXICO, June, 2003

“Ethics and Policy,” 44<sup>th</sup> Annual Short Course in Medical and Experimental Mammalian Genetics, Jackson Laboratories, Bar Harbor, ME, July, 2003

“Legal Issues of HAPMAP: Individual and Community Rights,” Working at the Frontiers of Law and Science: Applications of the Human Genome, The American Bar Association, American Medical Association and the American Association for the Advancement of Science, Chapel Hill, NC, October, 2003

“Ethical, Legal, and Social Issues in the International Haplotype Map Project,” Colliding Categories: Haplotypes, Race, and Ethnicity, Minneapolis, MD, October, 2003

“Ethical Issues in Genomic Research,” International Ethical Guidelines for Research Involving Human Beings, SANTIAGO, CHILE, October, 2003

“Legal and Policy Issues in the HapMap,” The Genomics Revolution: Science, Law, and Policy, Louisiana State University, Baton Rouge, LA, February, 2004

“Privacy’ in Research,” American Society of Experimental NeuroTherapeutics, Bethesda, MD, March, 2004

“The Web of Relations: Thinking About Physicians and Patients,” A World Less Silent: Celebrating Jay Katz’s Contributions to Law, Medicine, and Ethics, Yale Law School, New Haven, CT, October, 2004

“Ethical Issues in International Genetics Research,” Distinguished Lecture Series, University of Texas at Houston Health Science Center – IRB, February, 2005

“Investigaciones genéticas con los niños,” I Simposio Internacional de Bioética, Hospital Nacional de Niños, Dr. Carlos Sáenz Herrera, San Jose, Costa Rica, May, 2005

“Sheathing the Sword of Conscience,” Legal Issues Affecting Academic Medical Centers and Other Teaching Institutions, American Health Lawyers Association, Washington, DC, January, 2006

“The Future of Ethics in Genetic Research: Informed Consent, Oversight, and Engagement, Tufts New England Medical Center, Boston, MA, January, 2006

“The HapMap Experience: Lessons for the Future,” Wellcome Trust Advanced Course, Sanger Centre, Hinxton, UNITED KINGDOM, August, 2006

“Incidental Findings in Genetics Research Using Archived DNA,” Managing Incidental Findings in Human Subjects Research, Minneapolis, MN, May, 2007

“Data Sharing in the Genomic Era,” Egenis, Exeter, UNITED KINGDOM, May, 2007

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“Ethical Challenges in Exploring Genomic Diversity,” HGM2007, Montreal, CANADA, May, 2007

“Data Sharing and Its Implications,” Second Circuit Judicial Conference, Bolton Landing, NY, June, 2007

“Genome-Wide Association Studies: What are the Issues?,” Translating ELSI, Cleveland, OH, May, 2008

“Biobanking in the 21<sup>st</sup> Century: Lessons Learned About Navigating in Turbulent Waters from the HapMap and Other Projects, Instituto Superiore de Sanità, Rome, ITALY, June, 2008

“Returning Individual Results,” SACHRP, Arlington, VA, July, 2008

“BioVU: Vanderbilt’s Approach to Biobanking,” Biobanking, Bioethics, and the Law, Stanford Law School, Stanford, CA, September, 2008

“Data Access v. Confidentiality: Balancing Risks and Benefits,” American Society of Bioethics and Humanities, Cleveland, OH, October, 2008

“Data Access versus Confidentiality,” Committee on Population and Committee on Collecting, Storing, Protecting and Accessing Biological Data Collected in Social Surveys, National Academies, Washington, DC, November, 2008

“Looking at the Ends of the Spectrum: What That Can Tell Us about the Big Question,” Genetics Results Reporting Workshop, National Heart, Lung, and Blood Institute, Bethesda, MD, January, 2009

“What’s Next in Genomic Research,” What’s Next in Law, Health and the Life Sciences? Debating Openness, Access, and Accountability, University of Minnesota, March, 2009

“Research on Residual Bloodspots: When Should We Report Back Results?,” American College of Medical Genetics annual meeting, Tampa, FL, March 2009

“Informed Consent and What Else in Genomics?” Northwestern University, Chicago, IL, September, 2009

“What Data Do We Owe Back to Participants in Genetics & Genomics Research? Everything? Nothing?” American Society of Bioethics and Humanities, Washington, DC, October, 2009

“Biobanking at Vanderbilt University: Lessons Learned and Future Opportunities and Challenges,” Medical Genome Science in the Personal Genome Era, ISAG2009, Tokai University, TOKYO, JAPAN, and Kyoto University, KYOTO, JAPAN, December, 2009

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“What is the policy landscape for addressing IFs and IRRs in research using biobanks & archives?,” University of Minnesota, January, 2010

“Biobanking of Residual Samples: Opt-Out?” Public Population Project in Genomics, MONTREAL, CANADA, April, 2010

“What Data Do We Owe Back to Participants?” OHRP Research Community Forum, Regulatory Responsibility and Innovative Research: An Opportunity for Partnership, Chicago, IL, May, 2010

“Legal Issues Related to the Usage of Newborn Screening Samples,” Challenges and Opportunities in Using Newborn Screening Samples for Translational Research: A Workshop, Roundtable on Translating Genomic-Based Research for Health, Institute of Medicine, Washington, DC, May, 2010

“Legal Issues Related to the Use of Newborn Blood Spots for Research,” Health Law Professors, Austin, TX, June, 2010

“What Role Should Research Participants’ Preferences About Data Sharing Play?,” International Data Sharing Conference, Oxford, UNITED KINGDOM, September, 2010

“What Data Do We Owe Back to Participants in Genetics & Genomics Research? Everything? Nothing?,” Human Subjects Protection: A Time to Remember, Covington, KY, October, 2010

“Retos éticos para las aplicaciones clínicas de la medicina genómica” 10th Anniversary, INMEGEN, Mexico City, MEXICO, October, 2010

“National policy statements on the retention and use of residual samples for research,” Methods for Promoting Public Dialogue on the Use of Residual Newborn Screening Samples for Research, Salt Lake City, UT, January, 2011

“Challenges in Genetic Research” and “Panel on Genetic Research,” 6<sup>th</sup> Annual Columbia University IRB Conference, New York NY, March, 2011

“Hot Topics in Genomics Research,” 6<sup>th</sup> annual Columbia University IRB conference, New York, NY, March, 2011

“Workshop on Return of Results,” Exploring the ELSI Universe, University of North Carolina, Chapel Hill, NC, April, 2011

“Reservations about Return of Results,” ISBER Conference, Arlington, VA, May, 2011

“The Misguided Debate about Return of Research Results,” Should We Return Individual Research Results and Incidental Findings from Genomic Biobanks and Archives? University

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of Minnesota, Consortium on Law and Values in Health, Environment, and the Life Sciences, Bethesda, MD, May, 2011

“Panel on Joint Consideration of Special Complexities in Genotype-Driven Recruitment,” Ethical Approaches to Genotype-Driven Research Recruitment,” Durham, NC, May, 2011

“Using Newborn Blood Spots for Research and the Common Rule,” American College of Medical Genetics, Salt Lake City, UT, September, 2011

“Biospecimen Exceptionalism,” The Future of Human Research Regulation, Harvard Law School, Boston, MA, May, 2012

“Should Results of Genomics Research Be Returned to Study Participants?” Personalized Medicine for the Care of the Child with Heart Disease: Discovery to Application, Toronto, CANADA, October 2012

“How Should We Use Genomic Information for Primary Prevention?” 2013 Research Education Symposium: Life at the Interface of Genomics & Clinical Care, University of Michigan, Ann Arbor, MI, March, 2013

“The Role of Bioethicists in Policy Formation,” Greenwall Fellows Meeting, Chicago, IL, May, 2013

“Ethical and Community Perspectives: The need for community consultation in biospecimen collection”, 2013 Biospecimen Science and Cancer Health Disparities Conference, Johns Hopkins Center to Reduce Cancer Disparities and Meharry Medical College, Nashville, TN, July, 2013

“Lessons Learned from Biobanking,” Treuman Katz Lecture, Seattle Children’s Hospital, Seattle, WA, October, 2013

“A Review of the SUPPORT Study and Ethical Challenges in Assessing and Disclosing Research Risk,” CTSA Clinical Research Ethics Key Function Working Group Workshop on Medical Practice Research, Atlanta, GA, October, 2013

“Ethical Issues in Anticipate and Communicate,” eMERGE Consortium Steering Committee Meeting, Bethesda, MD, January, 2014

“Ethical Perspectives on Big Data,” Ethical Issues in Data Science and Digital Medicine, Icahn School of Medicine, New York, NY, February, 2014

“Ethical Challenges in Genome-Based Cancer Research: Liability and Other Challenges,” IOM Workshop on Contemporary Issues in Human Subjects Protections in Cancer Research, Washington, DC, February, 2014

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“Return of Results – From the Clinic to Research,” Sophia University and 164<sup>th</sup> Committee on Genome Technology, TOKYO, JAPAN, March, 2014

“Ethical Issues in Anticipate and Communicate,” CSER Consortium meeting, Bolger Center, Potomac, MD, May, 2014

“Ethical Issues in Human Genetics Research,” Statistical Genetics and Genomics Short Course, University of Alabama at Birmingham, Birmingham, AL, July, 2014

“How Much Individual Choice?” Institute for Public Health 7<sup>th</sup> Annual Conference: Public Good and Individual Choice, Washington University, St. Louis, MO, October, 2014

“Finding Your Way on Shifting Sands: Reflecting on the Changing Ethical, Regulatory, and Policy Landscape of Genomics Research,” Novartis, Boston, MA, November, 2014

“How much control do adolescents have over parental access to and sharing of their genomic test results? How much should they?” Should We Offer Genomic Research Results to a Participant's Family, Including After Death? University of Minnesota, Minneapolis, MN, November, 2014

“Balancing autonomy with social benefit: From broad or tiered consent to notification?” International Biobanking Summit, Phoenix, AZ, May, 2015

“When Participants in Genomic Research Grow Up: Contact and Consent at the Age of Majority,” 3<sup>rd</sup> P3G International Paediatric Platform Conference, Montreal, CANADA, May, 2015

“Requiring Informed Consent for Biospecimens in the Proposed Changes to the Common Rule,” CTSA-sponsored National Webinar, Nashville, TN, October, 2015

“Where are genomics research and biobanks headed in this changing regulatory and funding landscape?” ASBH Annual Meeting, Houston, TX, October, 2015

“Why Precision Medicine Needs Public Health, and why Public Health Needs to Worry about the Notice of Proposed Rulemaking,” Public Health Forum, Boston University School of Public Health, October, 2015

“Human Subjects Research and the Common Rule,” Committee on Federal Research Regulations and Reporting Requirements: A New Framework for Research University in the 21<sup>st</sup> Centuries, National Academy of Sciences, Houston, TX, October, 2015

“Modeling Risk to Privacy in Genomics Research Shows How the NPRM Misses the Mark,” Specimen Science, Petrie-Flom Center, Harvard Law School, November, 2015

“Research Issues for Public Health,” Tennessee Department of Health, Nashville, TN, April, 2016

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“What *Should* We Be Doing With Biobanks?” Berman Institute, Johns Hopkins University, Baltimore, MD, April, 2016

“What the NPMR Will (Should) Mean for Academic Medical Centers,” Bioethics Interest Group, Pediatric Academic Society, Baltimore, MD, May, 2016

“Optimizing risk-utility for rational actors,” NHGRI Aggregate Data Workshop, Bethesda, MD, May, 2016 (Work with Bradley “Addressing Public Concern about Transgenic Mice, Jackson Labs Ethicist-in-Residence, Jackson Laboratory, Bar Harbor, ME, June, 2016

“Ethical Issues in Translation,” Jackson Labs Ethicist-in-Residence, Jackson Laboratory for Genomic Medicine, Farmington, CT, June, 2016

“What the NPRM would (will) mean for health care institutions? OHRP regional conference, Nashville, TN, June, 2016

“Ethical Issues in Biomedical Research Using Big Data,” Third Conference for Institutional Research Ethics Education Directors in CITI Japan Project,” Tokyo, JAPAN, January, 2017

“Return of Results: The Intersection of HIPAA, CLIA, Federal Regulations included the new Common Rule, and Institutional Liability, 15th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Atlanta, GA, June, 2017

“Privacy and Informed Consent in an Era of Big Data,” Committee on Science, Technology, and Law, National Academies of Sciences, Engineering, and Medicine, Pasadena, CA, March, 2018

### **Pediatrics:**

"Compensation for Vaccine-Related Injuries: Developments on the National and State Level," Annual Meeting, American Society of Hospital Pharmacists, Nashville, TN, June, 1989

"Infant Care Review Committees," Huntsville Hospital, Huntsville, AL, January, 1990

"Drug Testing in Teenagers," PRIDE International Convention, Orlando, FL, April, 1990

"Decision-Making for Children: Key Legal Cases, Statutes, Regulations, and Policy Issues in Pediatric Cases," Ethics Committees and the Young: Families, Hospitals and the Courts Trying to Do the Right Thing, St. Louis University Schools of Law, Medicine, and Nursing in conjunction with American Society of Law, Medicine and Ethics, St. Louis, MO, May, 1994

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"Legal vs. Religious Exemptions: A View From the American Academy of Pediatrics," National Council of Juvenile and Family Court Judges, Nashville, TN, July, 1994

"Health Care Decision-Making and the Law," Medical Ethics for Physicians and Nurses: End of Life Issues, University of Alabama in Huntsville School of Primary Medical Care, Huntsville, AL, July, 1994

"Protection and Justice in the Care of Maltreated Children," "Legal Ethics in Child Protection," Cross Training: Knowing Your Way Around the Court, Case Western Reserve Child Protection Resource Center, Cleveland, OH, April, 1995

"Pediatric Ethics -- A View from the United States," Japanese Pediatric Society Annual Meeting, Kumamoto, JAPAN, April, 1996

"Inclusion of Children in Clinical Research," National Institute of Child Health and Human Development, American Academy of Pediatrics, Bethesda, June, 1996

"Legal and Ethical Issues Associated with Newborn Hearing Screening," Fourth International Symposium on Childhood Deafness, Kiawah Island, SC, October, 1996

"Families and Health," Family Re-Union 7, Nashville, TN, June, 1998

"Who Speaks for the Child: Ethical Issues in Pediatric Autonomy," Section on Bioethics, Annual Meeting, American Academy of Pediatrics, San Francisco, CA, October, 2001

"Medical Ethics and Developmental Disabilities," The Young Child with Special Needs, 13<sup>th</sup> Annual Conference, Nashville, TN, March, 2004

"Legal and Ethical Issues in Child Abuse Reporting," Annual Review of Pediatrics, University of Wisconsin, Madison, WI, September, 2007

"How Lawyers Can Help Patients (and Their Pediatricians), Arkansas Children's Hospital, Little Rock, AK, December, 2008

"Legal and Ethical Issues in Reporting Child Abuse and Neglect," Arkansas Children's Hospital, Little Rock, AK, December, 2008

"Pediatric Ethics: What Has Law Got to Do with It?" William G. Bartholome Award for Ethical Excellence Lecture, Section on Bioethics, AAP Annual Meeting, San Francisco, CA, October, 2010

"Vaccines: From Science to Policy," Western Conference of the Bench and Bar, United States Court of Federal Claims, Berkeley, CA, October, 2011

"Do Adolescents Have Rights to Make Decisions About Their Health Care," Buhl Lecture, University School of Nashville, TN, April, 2012

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“Confronting Commercial Sexual Exploitation and Sex Trafficking of Minors in the United States,” Eighth Annual Cynthia Jean Stolman Lecture in Medical Ethics, Rutgers New Jersey Medical School, Newark, NJ, November, 2013

“Lessons Learned on my Path to Child Advocacy,” Frank H. Morriss, Jr. Leadership Award Lecture, University of Iowa, Iowa City, IA, February, 2015

“What Results Should Parents Be Able to Get in Newborn Sequencing,” Hastings Center, New York, November, 2015

“The Ethical Limits of Directive Counseling in the Pediatric Clinic,” ASBH, Kansas City, KS, October, 2017

## Women's Health:

"Women and Advances in Medical Technology: The Legal Issues," The Effects of Pharmacology, Technology, and Other Modern Interventions on Women's Health, MacArthur Foundation Network on Health Behavior, Key Biscayne, FL, June, 1987

"The Law and Advances in Technology: Who Decides How Women and Their Unborn Children Should Live?," Reproductive Technology and Ethics for the Year 2000, Spokane, WA, April, 1988

"The Legal Status of the Fetus: Reflections on the Duties of Pregnant Women and of Society," Birth Defects Symposium XIX, Albany, NY, September, 1988

"Maternal-Fetal Conflicts," Hillsborough and Pinellas County Associations of Women Lawyers and for Women Physicians, Tampa, FL, February, 1989

Grand Rounds, Department of Obstetrics & Gynecology, Staten Island Hospital, Staten Island, NY, June, 1989

"Reproductive Technology and Human Values: A Health Care Professional and Woman's Perspective," Reproductive Technology: Ethical Issues, Ethical Alternatives, Maryville College, Maryville, TN, October, 1990

"Legal Issues and Reproductive Care," Legal, Medical and Ethical Issues in Women's Reproductive Health and Neonatology, American Society of Law, Medicine and Ethics, Naples, FL, January, 1995



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“Legal Aspects of Studying Pregnant Women,” FDA.NICHD Conference, Clinical Pharmacology during Pregnancy: Addressing Clinical Needs Through Science, Washington, DC, December, 2000

“Legal and Ethical Issues in Embryo Mix-Ups,” AALS/ASRM Workshop on Reproductive Medicine and Law, Vancouver, CANADA, June, 2007 and ASRM Annual Meeting, Washington, DC, October, 2007

“Predictive Genetic Testing of Fetuses and Newborns: Mapping the Ethical and Legal Landscape,” Obstetrics and Gynecology Grand Rounds, Pittsburgh, PA, October, 2013

“A Call to Action: Child exploitation and sex trafficking in the US,” AAP Annual Meeting, San Diego, CA, October, 2014

### **Medical Malpractice and Health Care Reform:**

"Conversations with Patients: How Patients See Their Physicians and Why They Say They Sue," Patient Grievances in Health Care: A Research Seminar, Ohio State University Center for Sociolegal Studies and Office for Health Services Research, Columbus, Ohio, November, 1992

"Health Care Reform: Ethics and the Practicing Pediatrician," American Academy of Pediatrics Annual Meeting, Dallas, TX, October, 1994

Visiting Professor Lecture Series, Department of Pediatrics and Center for Medical Ethics, Pediatric Grand Rounds -- "Why People Sue Their Doctors," University of Pittsburgh Medical Center, Pittsburgh, PA, December, 1994

"The Manifestations of Women's Dissatisfaction: Why Women Sue Their Physicians and How the Health Care System Has Responded," Legal, Medical and Ethical Issues in Women's Reproductive Health and Neonatology, American Society of Law, Medicine and Ethics, Naples, FL, January, 1995

"Medicaid, Managed Care, and the New Health Services Markets," Managed Care, Integrated Delivery Systems, and Consolidation -- Law, Medicine, and Ethics, American Society of Law, Medicine, and Ethics, Boston, MA, September, 1995

"Restructuring Healthcare: Jeopardizing Patient Care," Annual Meeting, Oncology Nursing Society, Nashville, TN, November, 1995

“Lawsuits--Why Do They Happen and What Can We Do About It?” Annual Conference, Pediatric Nursing, Integrating Mind, Body, and Spirit to Enhance Pediatrics Outcomes: New Challenges, Nashville, TN, September, 2000

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**Other:**

"Teaching Across Professional Boundaries," 17th Annual Health Law Teachers Conference, Wilmington, DL, June, 1996

"The Confidential Medical Record in the New Millennium - Who Has Access and Where Does It Go?" 26<sup>th</sup> Annual Course, Society for Gastroenterology Nurses and Associates, Nashville, TN, May, 1999

"The Ethics Quagmire – Lifelines for Health Care Practitioners and Lawyers," Tennessee Bar Association, Brentwood, TN, October, 2008

**Conferences Organized:**

Law, Literature, and Social Change, Vanderbilt Law School and Robert Penn Warren Center for the Humanities, Nashville, TN, March, 1990 (with Jay Clayton)

Informed Consent for Genetic Studies on Stored Tissue Samples, Ethical, Legal, and Social Implications Branch/NCHGR/NIH and U.S. Centers for Disease Control and Prevention, Bethesda, MD, July, 1994 (with Elizabeth Thomson)

Legal, Medical and Ethical Issues in Women's Reproductive Health and Neonatology, American Society of Law, Medicine and Ethics, Naples, FL, January, 1995 (with Cindy Hylton Rushton)

The Changing Health Care Environment: Issues for the Future, American Society of Law, Medicine and Ethics and Vanderbilt University School of Medicine, Nashville, TN, March, 1997 (with H. Lee Barfield)

Children, Parents, Professionals, and the State: Ethical, Clinical, and Legal Issues in Health Care for Children, American Society of Law, Medicine and Ethics, Cambridge, MA, September, 1997 (with John Lantos)

A Public Dialogue about Gene Patenting, Vanderbilt University Center for Genetics and Health Policy and the American College of Medical Genetics, Washington, DC, March, 2000 (with R. Rodney Howell)

First Annual Meharry/Vanderbilt Genetics Symposium, Nashville, TN, November, 2000 (with Al George, Jonathan Haines, John Phillips, Shirley Russell, Scott Williams)

Second Annual Meharry/Vanderbilt Genetics Symposium, Nashville, TN, September, 2001 (with Al George, Jonathan Haines, John Phillips, Shirley Russell, Scott Williams)

Third Annual Meharry/Vanderbilt Genetics Symposium, Nashville, TN, September, 2002 (with Jonathan Haines, John Phillips, Shirley Russell, Scott Williams)

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Law, Genomic Medicine & Health Equity: How Can Law Support Genomics and Precision Medicine to Advance the Health of Underserved Populations?, Meharry Medical College, Nashville, TN, November, 2018 (with Susan Wolf, Frances Lawrenz, and Consuelo Wilkins)