John Mejia, USB No. 13965 Leah Farrell, USB No. 13696 jmejia@acluutah.org lfarrell@acluutah.org ACLU of Utah Foundation 355 North 300 West Salt Lake City, UT 84103 (801) 521-9862

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American Civil Liberties Union Foundation
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Attorneys for Respondents-Intervenors

# IN THE UNITED STATES DISTRICT COURT DISTRICT OF UTAH, CENTRAL DIVISION

UNITED STATES DEPARTMENT OF JUSTICE, DRUG ENFORCEMENT ADMINISTRATION,

Petitioner,

v.

UTAH DEPARTMENT OF COMMERCE and UTAH DIVISION OF OCCUPATIONAL & PROFESSIONAL LICENSING,

Respondents.

Case No. 2:16-cv-611-DN

DECLARATION OF MARK A.
ROTHSTEIN IN SUPPORT OF
RESPONDENTS-INTERVENORS'
OPPOSITION TO PETITION TO
ENFORCE ADMINISTRATIVE
SUBPOENAS ISSUED BY THE DRUG
ENFORCEMENT ADMINISTRATION

Chief Judge David Nuffer

UNITED STATES DEPARTMENT OF JUSTICE, DRUG ENFORCEMENT ADMINISTRATION,

Petitioner,

v.

IAFF LOCAL 1696, et al.,

Respondents-Intervenors.

- I, Mark A. Rothstein, a resident of Kentucky, hereby declare:
- 1. I am the Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine. I am also a Professor of Law at the Brandeis School of Law of the University of Louisville. As indicated on my attached curriculum vitae, many of my scholarship and public service activities have focused on the ethical, legal, and social implications of health privacy. For example, from 1999 to 2008, I served as a member of the National Committee on Vital and Health Statistics (NCVHS), the congressionally chartered federal advisory committee to the Secretary of Health and Human Services (HHS) on health information policy. I served as Chair of the Subcommittee on Privacy and Confidentiality, and I was responsible for chairing public hearings and meetings throughout the country and initiating the process of drafting NCVHS recommendations on health privacy to the Secretary of HHS and Congress dealing with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, the effect on privacy of adopting electronic health records, and other issues.

- 2. I have been furnished with a copy of the filings in this case. My declaration is based on the information contained in these documents and my own personal knowledge and expertise.
- 3. Ever since the time of Hippocrates in the fourth century B.C.E., the confidentiality of patient health information has been a cornerstone of medical practice throughout much of the world. In the United States, the first Code of Medical Ethics of the American Medical Association ("AMA") in 1847 contained a provision explicitly declaring the importance of preserving the confidentiality of patient health information. Every subsequent edition of the AMA Code of Medical Ethics, as well as the codes of ethics of numerous medical specialty colleges and societies, has also recognized the importance of maintaining confidentiality. Comparable provisions on confidentiality also appear in the ethical codes of other health professionals, including the codes of the American Nurses Association and the American Pharmaceutical Association.
- 4. Confidentiality is essential in encouraging patients to provide their physicians with accurate and complete health information, without which medical care would be severely compromised. It is difficult to imagine modern health care without confidentiality protections because of the potential for numerous harms to individual patients as well as to public health and safety in the four categories described below.
- 5. First, without confidentiality protections, some patients would delay medical care or avoid treatment altogether, especially for sensitive health conditions, such as mental illness, sexually transmitted infections, and domestic violence. Survey research indicates that individuals concerned about the confidentiality of their health information already engage in "defensive"

practices," such as providing inaccurate or incomplete information to their physicians, thereby undermining effective treatment.

- 6. Second, a lack of confidentiality protections can lead to a patient's embarrassment and stigma or the economic harms caused by health-based discrimination. Even the possibility of discomforting disclosures can result in a wide range of psychic harms to patients.
- 7. Third, a lack of individual confidentiality protections can lead to severe adverse public health consequences. For example, when individuals forego seeking prompt treatment for tuberculosis, hepatitis, mental illness, substance abuse, or other stigmatizing health conditions, public health and safety is placed at great risk.
- 8. Fourth, a lack of confidentiality protections undermines the physician–patient relationship which, in turn, can lessen societal support for the health care system in various ways. For example, without confidentiality, individuals may be less willing to comply with public health measures such as immunization; enroll as biomedical research subjects; and support health care institutions in the private and public sectors.
- 9. The harm associated with illicit diversion and use of prescription drugs is well known. What is less well known is that for some populations pain control medicines are actually under-prescribed and under-used. Some physicians, concerned about law enforcement and licensing oversight of their prescribing practices, are reluctant to prescribe scheduled analgesics, even where clinically indicated. Similarly, some—especially elder—patients who are unreasonably concerned about addiction to a scheduled pain medicine are loath to take medicine necessary to control their pain. Needlessly expansive law enforcement access to prescription

drug records is likely to exacerbate these concerns of physicians and patients, resulting in more under-treatment of chronic pain.

- 10. Law enforcement access to prescription drug records is only the first of several intrusions on physicians and patients. In some instances, merely knowing the prescription drug being taken will identify an individual's likely medical condition, thereby disclosing information beyond a mere prescription drug record.
- 11. In the absence of a warrant based on probable cause of unlawful activity by a physician, pharmacist, or patient, a series of intrusive inquiries and investigations based on records submitted to the Controlled Substance Database is ethically indefensible.
- 12. Although the prosecution of those involved in illicit drug use is an important public policy, Congress has recognized it is secondary to the public policy supporting the treatment of individuals with substance abuse disorders. Section 527 of the Public Health Service Act provides that a program receiving federal financial assistance for alcohol and drug abuse treatment may not disclose any information about an individual who is in the program. This provision gives substance abuse treatment centers the right to refuse federal and state administrative and judicial orders for disclosure of their treatment records. Without this protection, many individuals would be unwilling to undergo treatment, especially for addiction to illicit drugs, because they would fear law enforcement access to their records and subsequent prosecution. The regulations implementing this statutory provision appear at 42 C.F.R. Part 2.
- 13. The diversion and unlawful use of prescription drugs is an important social problem and an appropriate activity for law enforcement agencies to address. Nevertheless, based on my experience, the legitimate ends of law enforcement do not justify the use of means

violating constitutional guarantees against unreasonable searches and seizures, particularly in the context of sensitive prescription and other medical records whose unwarranted disclosure can impede access to necessary medical care. It is worth recalling the words of Justice Louis Brandeis, who specifically addressed the issue of excessive governmental intrusions by law enforcement in one of his most famous dissenting opinions:

And it is also immaterial that the intrusion was in aid of law enforcement. Experience should teach us to be most on our guard when the Government's purposes are beneficent. Men born to freedom are naturally alert to repel invasion of their liberty by evil-minded rulers. The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding.

Olmstead v. United States, 277 U.S. 438, 479 (1928) (Brandeis, J., dissenting).

Pursuant to 28 U.S.C. § 1746, I hereby declare and state under penalty of perjury that the foregoing is true and correct to the best of my knowledge, information, and belief.

DATED this 21 day of July, 2016.

Mark A Rothstein

# MARK A. ROTHSTEIN Curriculum Vitae

167 Totem Road Louisville, KY 40207 (502) 895-4688 Institute for Bioethics, Health Policy and Law University of Louisville School of Medicine 501 East Broadway, Suite #310 Louisville, Kentucky 40292 (502) 852-4982, (502) 852-8319 (FAX) mark.rothstein@louisville.edu

# **ACADEMIC APPOINTMENTS**

ADEMIC APPOINTMENTS		
2001 - Present	Herbert F. Boehl Chair of Law and Medicine and Director, Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine	
	Professor of Medicine, Division of General Internal Medicine, Palliative Medicine, and Medical Education, Department of Medicine, University of Louisville School of Medicine	
	Professor of Law, Louis D. Brandeis School of Law, University of Louisville	
	Associate, Division of Medical Humanities and Ethics, Department of Family and Geriatric Medicine, University of Louisville School of Medicine	
	Adjunct Professor of Public Health, University of Louisville School of Public Health and Information Sciences	
	Adjunct Professor of Nursing, University of Louisville School of Nursing	
2003 – 2006	Director, Center for Public Health Law Partnerships, a CDC Collaborating Center, University of Louisville School of Medicine	
1995 - 2000	Hugh Roy and Lillie Cranz Cullen Distinguished Professor of Law, University of Houston	
1986 - 2000	Director, Health Law and Policy Institute, University of Houston	
1988 - 2000	Adjunct Professor of Public Health, The University of Texas	

School of Public Health

1990 - 1995	Law Foundation Professor of Law, University of Houston
1986 - 1990	Professor of Law, University of Houston
1985 - 1986	Visiting Professor of Law, University of Houston
1984 - 1986	Adjunct Professor of Medicine, West Virginia University School of Medicine
1980 - 1986	Professor of Law, West Virginia University
1980 - 1986	Adjunct Professor of Public Health, Graduate School of Public Health, University of Pittsburgh
1979 - 1980	Visiting Associate Professor of Law, University of Pittsburgh
1975 - 1979	Assistant and Associate Professor of Law, Ohio Northern University
Fall 2007	Visiting Professor of Law, University of Maryland
Winter 2005	Sadie Lewis Webb Visiting Professor of Law, University of Virginia (short course)
Summer 1979	Visiting Associate Professor of Law, Georgetown University

# PRACTICE EXPERIENCE

1975 - present	Consultant on biobanks, bioethics, employment law, genetics and the law, health information technology, health policy, health privacy, occupational safety and health law, public health, and research ethics
1973 - 1975	Attorney-advisor to Commissioner Timothy F. Cleary, Occupational Safety and Health Review Commission, Washington, DC

# **EDUCATION**

J.D. Georgetown University, 1973 B.A. University of Pittsburgh, 1970

# PROFESSIONAL ACTIVITIES

2015 – present	Contributing author, "At Law" column, Hastings Center Report
2013 – present	Adviser, Restatement (Third) of Information Privacy Principles, American Law Institute

2011 – present	Department Editor, Public Health Ethics, American Journal of Public Health
2002 – present	Member, Ethics Committee, Jewish Hospital (Louisville, Ky.)
2000 - present	Section Editor and Primary Author of "Currents in Contemporary Bioethics," Journal of Law, Medicine & Ethics
2008 – 2016	Member, Public Stakeholders Committee, National Board of Medical Examiners
2002 – 2014	Adviser, Restatement (Third) of Employment Law, American Law Institute
2014	Member, Special Emphasis Panel on IRBs and Clinical Records, National Institutes of Health
2013	Member, Special Emphasis Panel for the Collaborative Human Tissue Network, National Cancer Institute
2011 – 2013	Member, Research Oversight Committee, Jewish Hospital & Saint Mary's Healthcare (Louisville, Ky.)
2011 – 2013	Member, Carrier Screening Workgroup, Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, Department of Health and Human Services
2009 – 2013	Member, National Advisory Committee, Robert Wood Johnson Foundation Community Health Leaders Award
2012	Member, College of Reviewers, Genome Canada
2011	Member, Lincoln Biohistory Study Group Ethics Board, Chicago History Museum
2011	Member, Working Group on PCAST Report, HIT Policy Committee, Office of the National Coordinator of Health Information Technology, Department of Health and Human Services
2002 – 2010	At-Large Member, National Board of Medical Examiners
2006 – 2008	Member, Personalized Health Care Working Group, American Health Information Community, Department of Health and Human Services
2005 – 2008	Member, Physicians Depression and Suicide Prevention Project, Suicide Prevention International/Milbank Memorial Fund
2003 – 2008	Member, Board of Directors, American Society of Law, Medicine &

	Ethics
2001 – 2008	Chair, Subcommittee on Privacy and Confidentiality (and member, Executive Subcommittee), National Committee on Vital and Health Statistics
1999 - 2008	Member, National Committee on Vital and Health Statistics, Department of Health and Human Services (appointed by Secretary of Health and Human Services Donna Shalala, reappointed by Secretary Tommy G. Thompson)
2007	Member, Special Review Committee, Genome-Wide Studies in Biorepositories with Electronic Medical Records Data, National Human Genome Research Institute, National Institutes of Health
2002 – 2007	Member, Committee on Emerging Issues and Data on Environmental Contaminants (and Chair, Subcommittee on Ethical, Legal, and Social Implications), National Research Council, National Academy of Sciences
2006	President, American Society of Law, Medicine & Ethics
2005 – 2006	Member, Committee on Applications of Toxicogenomic Technologies to Predictive Toxicology, National Research Council, National Academy of Sciences
2003 – 2005	Chair, Government Affairs Committee, Health Enterprises Network, Louisville, Ky.
2001 – 2004	Member, Newborn Screening Expert Group, American College of Medical Genetics
2001 – 2004	Member, Genetics Advisory Committee, Partnership for Prevention
2003	Member, Expert Panel, Canadian Networks of Centers of Excellence
1997 – 2003	Member, Medical Advisory Panel for Nuclear Weapons Workers at the Nevada Test Site, United States Department of Energy
2002	Member, Special Emphasis Panel, Human Genetic Variation, National Human Genome Research Institute, National Institutes of Health
2002	Co-Chair, Working Group on Nonmedical Applications of Genomics, National Human Genome Research Institute, National Institutes of Health
2000 – 2002	Member, Steering Committee on Pharmacogenetic Research,

	National Institute of General Medical Sciences, National Institutes of Health
2000 – 2002	Member, Advisory Board for "Our Genes/Our Choices" PBS Television Series, Fred Friendly Seminars
2000 - 2001	Chair, Section on Post-Graduate Legal Education, Association of American Law Schools
2000 - 2001	Member, Genetics Working Group, Clinical Laboratory Improvement Advisory Committee, Centers for Disease Control and Prevention
1998 – 2001	Member, National Advisory Panel, National Conference of State Legislatures Legislative Task Force on Genetics
1997 - 2001	Member, Social Issues Committee, American Society of Human Genetics (Chair, 1998-2001)
2000	Member, Special Emphasis Panel, Public Health Practice Program Office, Centers for Disease Control and Prevention
1998 - 2000	Chair, Subcommittee on Adoption, Social Issues Committee, American Society of Human Genetics
1997 - 2000	Member, Committee for the Protection of Human Subjects, University of Houston (Chair, 1998)
1998	Member, Subcommittee on Genetic Testing, Clinical Laboratory Improvement Act Advisory Committee, Centers for Disease Control and Prevention
1997 - 1999	Member, Working Group on Hereditary Susceptibility, National Action Plan on Breast Cancer
1997 - 1998	Ethics Consultant, National Aeronautics and Space Administration
1996	Co-Chair, Special Committee to Evaluate the Ethical, Legal, and Social Implications (ELSI) Program, Human Genome Project, National Institutes of Health/U.S. Department of Energy
1996	Member, Working Group to Develop the National Occupational Research Agenda, National Institute for Occupational Safety and Health
1995	Consultant, Therapeutic Chelation Protocols for Nuclear Weapons Workers Exposed to Plutonium and Americium, United States Department of Energy

1994 - 1995	General Reporter, Third American Congress of Labor Law and Social Security, Montreal, Canada
1994 - 1995	Special Legislative Counsel on Genetic Discrimination in Employment, National Center for Human Genome Research, National Institutes of Health
1993, 1995	Reviewer, Ethical, Legal, and Social Issues Grants, Human Genome Program, United States Department of Energy
1994	Consultant, American Bar Association, Special Committee on the Drug Crisis
1993 - 1994	Member, Board of Advisers, Biological Sciences Curriculum Study Genetics Project
1991 - 1993	Member, Committee on Assessing Genetic Risks: Issues and Implications for Health and Social Policy, Institute of Medicine, National Academy of Sciences
1991 - 1993	Member, Committee on Genetics and the Insurance Industry, American Society of Human Genetics
1990	Member, Genome Study Section and Special Review Committee on Ethics Grants, National Center for Human Genome Research, National Institutes of Health
1989 - 1990	Member, Secretarial Panel for the Evaluation of Epidemiologic Research Activities, United States Department of Energy (appointed by Secretary of Energy James D. Watkins)
1988 - 1990	Member, Genetic Testing in the Workplace Advisory Panel, Office of Technology Assessment, United States Congress
1989 - 1990	Chair, Labor and Employment Section, Association of American Law Schools
1988 - 1990	Member, Study Group on Identifying Carriers of Cancer Genes, Environmental Health Institute
1988 - 1990	Member, Advisory Group on Hospital Occupational Health and Safety, American Hospital Association
1987 - 1988	Member, Medical Testing and Health Insurance Advisory Panel, Office of Technology Assessment, United States Congress
1987	Member, Health Monitoring in the Workplace Advisory Panel, National Academy of Sciences

1986	Consultant, American Medical Association, Study on Drug Testing in the Workplace
1984 - 1985	Principal Legal Contractor, Reproductive Health Hazards in the Workplace, Office of Technology Assessment, United States Congress
1982 - 1985	Founder and Director, West Virginia University Occupational Health Law Program
1982 - 1984	Member, Preventing Illness and Injury in the Workplace Advisory Panel, Office of Technology Assessment, United States Congress
1982 - 1983	Principal Legal Contractor, The Role of Genetic Testing in the Prevention of Occupational Disease, Office of Technology Assessment, United States Congress

# HONORS AND AWARDS

2015	Received American Journal of Public Health Editor's Choice Award for Paper of the Year, "The Moral Challenge of Ebola"
2013	Received Louis D. Brandeis Privacy Award, Patient Privacy Rights
2009	Elected Member, American Law Institute
2001	Named Herbert F. Boehl Chair of Law and Medicine, University of Louisville School of Medicine
1999	Received Esther Farfel Award, University of Houston's highest honor for research, teaching, and service
1999	Received National Public Health Hero Award, University of California-Berkeley School of Public Health
1997	Received Jay Healey Distinguished Health Law Teacher Award, American Society of Law, Medicine and Ethics
1996	Received Ethel M. Baker Faculty Award for Community Service, University of Houston Law Center
1995	Named Hugh Roy and Lillie Cranz Cullen Distinguished Professor of Law, University of Houston Law Center
1995	Received Mayor and City Council of Houston Proclamation for Faculty Excellence
1993	Elected Fellow of the Hastings Center
1990	Named Law Foundation Professor, University of Houston Law Center

1990 Inducted into Abington (Pa.) High School Hall of Fame

1984 Received Hale Posten Award for Legal Scholarship, West Virginia

University College of Law

# **BOARD MEMBER OR GRANT CONSULTANT (current)**

Board of Editors, American Journal of Law and Medicine

Consultant, Baylor College of Medicine Study on Clinical Next Generation Sequencing

Consultant, Duke University Study on Incidental Findings in Pharmacogenomic Testing

Consultant, University of Minnesota and Vanderbilt University Precision Medicine Initiative Coordinating Center

Editorial Board, American Journal of Public Health

Editorial Board, Journal of Law and Biosciences

Editorial Board, Personalized Medicine

Editorial Board, World Journal of Medical Genetics

External Advisory Board, Center for Genetic Privacy and Identity in Community Settings, Vanderbilt University

External Ethics Advisory Board, Vanderbilt University Medical Center DNA Databank

Fellow, Hastings Center

International Editorial Advisory Board, Genetics and Society Book Series

Member, Advisory Board, Patient Privacy Rights

Member, Bioethics Workgroup, International Human Epigenome Consortium

Member, National Workgroup, Genomic Rights Initiative, Mayo Clinic

Member, Regulatory and Ethics Working Group, Global Alliance for Genomics and Health

Member, Scientific Advisory Board, Lifeboat Foundation

Member, Working Group, Law Seq: Building a Sound Legal Foundation for Translating Genomics into Clinical Application, University of Minnesota and Vanderbilt University

## EXTERNAL REVIEWER FOR PROMOTION AND TENURE

Arizona State University College of Law

**Baylor College of Medicine** 

Brooklyn Law School

**Bryant University** 

Case Western Reserve University School of Medicine

Catholic University School of Law

Cleveland State University College of Law

Columbia University School of Law

Drake University Law School

**Duke University** 

Florida A&M University College of Law

Florida State University College of Law

George Washington University Law School

Georgia State University College of Law

Golden Gate University School of Law

Harvard University

IIT-Chicago Kent College of Law

Indiana University School of Law

Johns Hopkins University School of Public Health

Lewis and Clark School of Law

Loyola of Chicago School of Law

Marquette University School of Law

Mayo Clinic College of Medicine

Mercer University School of Law

Northern Illinois University College of Law

Oregon Health & Science University

Seton Hall University School of Law

St. Louis University School of Medicine

St. Thomas University School of Law

South Texas College of Law

Suffolk University School of Law

University of Alberta Faculty of Law

University of Arizona School of Law

University of Arkansas-Fayetteville School of Law

University of California-Berkeley College of Natural Resources

University of California-Berkeley School of Law

University of California-Berkeley School of Public Health

University of California-Davis School of Law

University of California-San Francisco School of Medicine

University of Cincinnati College of Law

University of Cincinnati College of Medicine

University of Houston Law Center

University of Kansas School of Law

University of Maryland School of Law

University of Memphis School of Law

University of Minnesota School of Medicine

University of Missouri School of Law

University of Nevada-Las Vegas School of Law

University of North Carolina School of Law

University of South Carolina School of Law

University of Utah School of Law

University of Washington School of Law

University of Washington School of Medicine

University of Wisconsin School of Law

Vanderbilt University School of Law

Vanderbilt University School of Medicine

# West Virginia University College of Law

#### EDITORAL REVIEWER

**Academic Press** 

ActionBioScience

Agency for Healthcare Research and Quality

American College of Clinical Pharmacy

American Journal of Bioethics

American Journal of Bioethics – Empirical Bioethics

American Journal of Bioethics - Primary Research

American Journal of Epidemiology

American Journal of Human Genetics

American Journal of Law and Medicine

American Journal of Medical Genetics

American Journal of Pharmacogenomics

American Journal of Preventive Medicine

American Journal of Public Health

American Journal of Surgery

**Applied Clinical Informatics** 

Archives of Internal Medicine

Behavioral Sciences and the Law

**Bioethics** 

**BMC Medical Ethics** 

**BMC** Medicine

**BMC** Public Health

**Cambridge University Press** 

Chest

**Community Genetics** 

Comparative Labor Law and Policy Journal

Economic and Social Research Council

Encyclopedia of Bioethics

European Journal of Human Genetics

European Society of Human Genetics

Future Medicine

Genetics in Medicine

Genome Canada

Genomic Medicine

Globalization and Health

Harvard University Press

**Hastings Center Report** 

**Human Genetics** 

Institute of Medicine

International Archives of Occupational and Environmental Health

IRB: Ethics and Human Research

JAMA Internal Medicine

Johns Hopkins University Press

Journal of the American Medical Association

Journal of the American Medical Informatics Association

Journal of Applied and Translational Genomics

Journal of Clinical Ethics

Journal of General Internal Medicine

Journal of Genetic Counseling

Journal of Health Politics, Policy, and Law

Journal of Infection and Public Health

Journal of Law and the Biosciences

Journal of Law, Medicine, and Ethics

Journal of Legal Medicine

Journal of Medical Ethics

Journal of Occupational and Environmental Medicine

Jurimetrics Journal

Kennedy Institute of Ethics Journal

Law and Policy

McGill Journal of Law and Health

Milbank Quarterly

**MIT Press** 

Molecular Genetics and Metabolism

Mount Sinai Journal of Medicine

National Institute for Occupational Safety and Health

National Science Foundation

**Nature Genetics** 

**Nature Reviews Genetics** 

Neuropsychiatric Genetics

New England Journal of Medicine

New Genetics and Society

North American Actuarial Journal

**Nuffield Council on Bioethics** 

Oxford University Press

Personalized Medicine

Pharmacogenomics Journal

Philosophy, Ethics and Humanities in Medicine

**PLOS Medicine** 

**Psychological Services** 

**Public Health Ethics** 

Public Health Law Research Program

**Public Health Reports** 

Robert Wood Johnson Foundation

Science

Science, Technology, and Human Values

Social Studies of Science

Studies in Ethics, Law, and Technology

Theoretical Medicine and Bioethics

Trends in Biotechnology Trial University of California Press Urologic Oncology Wellcome Trust

# SELECTED SPEECHES, LECTURES, AND TESTIMONY

Topics include: Americans with Disabilities Act, behavioral genetics, Big Data, biobanks, bioethics, citizen science, clinical ethics, Ebola, electronic health records and networks, emergency preparedness, employment law, epigenetics, forensics, genetic privacy and discrimination, genome sequencing, health information technology, health insurance, Health Insurance Portability and Accountability Act, health law and policy, infectious diseases, international research, medical privacy and confidentiality, mobile medical devices, occupational health, occupational medicine, pandemic preparedness, pharmacogenomics, privacy, public health, quarantine, research ethics, SARS, synthetic biology, toxicogenomics, unregulated research.

Albany Law School (1995)

American Academy of Pediatrics (2013)

American Association for the Advancement of Science (2003, 2007, 2009)

American Association of Health Plans (1998)

American Bar Association, Committee on Employee Rights and Responsibilities (1995)

American Bar Association, Section on Business Law (2001)

American Bar Association, Section on Health Law (2003)

American Bar Association, Section on Labor and Employment Law (2003)

American Bar Association, Section on Science and Technology Law (1992, 2003)

American Cancer Society (1990)

American Civil Liberties Union of Delaware (1996)

American College of Legal Medicine (1993)

American College of Medical Genetics and Genomics (2008)

American College of Occupational and Environmental Medicine (2002, 2004,

Patterson Memorial Lecture 2011)

American College of Physicians (2004)

American College of Preventive Medicine (2006)

American Council of Life Insurers (1998)

American Enterprise Institute (1997)

American Health Lawyers Association (1998)

American Heart Association (1992)

American Hospital Association (1987, 1988, 1989)

American Law Institute/American Bar Association (1999)

American Liver Foundation (1999)

American Medical Association (2000)

American Medical Informatics Association (2007)

American Psychiatric Association (2008)

American Public Health Association (2005)

American Society for Bioethics and Humanities (2002, 2003)

American Society for Pharmacology and Experimental Therapeutics (2002)

American Society for Preventive Oncology (1995)

American Society of Clinical Oncology (1999)

American Society of Human Genetics (1993, 2001, 2003, 2005)

American Society of Law, Medicine, and Ethics (1987, 1993, 1995, 2004, 2005, 2006, 2010, 2012, 2013, 2014, 2015, 2016)

Arizona State University College of Law (2005, 2007, 2013, 2014)

Association of American Law Schools (1998, 2000, 2001, 2002)

Baptist Health System (San Antonio) (1999, 2000)

Baylor College of Medicine (1989, 1994, 1999, 2006)

Biotechnology Industry Organization (Toronto) (2002)

Brooklyn Law School (2001)

Canadian Institute of Health Services Research (2015)

Capital University Law School (2009)

Case Western Reserve University School of Law (1996, 2013)

Case Western Reserve University School of Medicine (1988, 2005, 2012)

Center for Democracy and Technology (2008)

Centers for Disease Control and Prevention (1997, 1998, 2001, 2002, 2003, 2006)

Chartered Property Casualty Underwriters Society (1999)

Cleveland Clinic (2005, 2012)

Cleveland-Marshall College of Law (GTE Lecture) (1994)

Cold Spring Harbor Laboratory (1990, 2002)

College of Wooster (2002)

Colorado Springs Osteopathic Foundation (1994)

Columbia University School of Law (2000)

Columbia University School of Public Health (1989)

Columbus State University (2004)

Council of Appellate Staff Attorneys (2003)

Computers, Freedom, and Privacy Annual Conference (1998)

Council of State Governments (1991, 1992)

Dartmouth College (2000)

Duke University School of Law (Siegel Lecture) (2008)

Duquesne University School of Law (2001)

Eighth and Tenth Circuit Judicial Conference (2000)

Environmental Mutagen Society (2012)

Fairleigh Dickinson University (2007)

Federal Judicial Center (1995, 1999)

Federalist Society (1998)

Fifth Circuit Judicial Conference (1996, 1999)

Fifth International DNA Sampling Conference (Banff, 2009)

Forum Club of Houston (1993)

Fourth International DNA Sampling Conference (Montreal, 2006)

Georgetown University (2001)

Gulf States Hemophilia Foundation (1996)

Hartford Hospital (2005)

Harvard Law School (2001)

Hastings Center (1987, 1988, 2002, 2003, 2007, 2012)

Hawaii Bar Association (1998)

Hawaii Judicial Conference (1998)

Hawaii Legislature (1998)

Health Care Compliance Association (2007)

Health Information and Management Systems Society (2007)

Huntington Disease Society of America (1998)

IIT-Chicago-Kent College of Law (Piper Memorial Lecture 1987, 1997)

Indiana University School of Law (2002, 2014)

Institute of Medicine (2007, 2009)

International Council of Chemical Associations (2001)

International Society for Technology Assessment in Health Care (1990)

International Society for the Study of Xenobiotics (2002)

International Society of Labor Law and Social Security (Montreal, 1995)

Japanese Embassy (Washington, D.C.) (2015)

Jewish Hospital (Louisville) (2005, 2006)

Johns Hopkins University School of Public Health (2005, 2007)

Kentucky Bar Association (2003)

Kentucky Cabinet for Health Services (2001)

Kentucky Legislature (2001, 2003)

Kentucky Department for Public Health (2012, 2013, 2015)

Kentucky Medical Association (2010)

Kentucky Office of the Attorney General (2010)

Kentucky Public Health Association (2007)

Keystone Conference on Epigenetics (2011)

Los Alamos National Laboratories (1991)

Louisiana State University (2004)

Louisville Bar Association (2002, 2005, 2014)

Marshall University School of Medicine (2008)

Massachusetts Institute of Technology (1998)

Mayo Clinic (2001)

M.D. Anderson Cancer Center (1991, 1996, 1997, 1999, 2002)

Medical University of South Carolina (1997)

Methodist Hospital (Houston) (2000)

Mexico-U.S. Committee for Occupational and Environmental Health (Cuernavaca, Mexico 1990)

Miami Children's Hospital (2004)

Midwest Center for Occupational Health and Safety (1991)

Milbank Memorial Fund (1999, 2000)

Missouri Judicial Conference (2001, 2002)

Mt. Sinai (N.Y.) School of Medicine (Richman Lecture, 1999)

National Academy of Arbitrators (1991, 1993, 1998)

National Academy of Sciences (1992, 1993, 2002, 2003, 2014)

National Action Plan on Breast Cancer (1996, 1997)

National Association of Science Writers (2001)

National Association of Women Judges (2005)

National Cancer Institute (1994, 2005)

National Committee on Vital and Health Statistics (2010, 2016)

National Conference of State Legislatures (1998, 2001, 2004)

National Health Law Teachers Conference (1995, 1996, 1997, 2003, 2006)

National Heart, Lung and Blood Institute (1997)

National Human Genome Research Institute (1997)

National Institute of General Medical Sciences (2001)

National Institute of Environmental Health Sciences (2001, 2002, 2004)

National Institutes of Health (1991, 1994, 1996, 1997, 2001, 2002, 2003, 2016)

National Institute for Occupational Safety and Health (1991, 2000, 2010, 2013)

National Research Council (2004, 2007)

New York Academy of Medicine (1991, 2002)

New York Academy of Sciences (1988)

New York Law School (2001)

Ninth Circuit Judicial Conference (2000)

North Central Occupational and Environmental Medicine Association (1998)

Norton Healthcare System (Louisville) (2005, 2008, 2011)

Occupational Safety and Health Review Commission (2012)

Ohio State Medical Association (1987)

Open Minds (2008, 2010)

Organization Resources Counselors (1998)

Overlook and Morristown Memorial Hospitals (N.J.) (Wolfe Lecture, 1999)

Parkinson's Disease Foundation (2004)

Patient Privacy Rights, International Summit (2012, 2015)

Pennsylvania Bar Association (1992)

Pharmaceutical Manufacturers Association (1987)

Presidential Commission for the Study of Bioethical Issues (2012)

Princeton University (2000)

Public Responsibility in Medicine and Research (2014, 2015)

Rice University (1994)

Risk and Insurance Management Society (1992)

St. Jude Children's Research Hospital (1999)

St. Louis University School of Law (1989)

Secretary's Advisory Committee on Human Research Protections (2004, 2008)

Seton Hall Law School (Merck Distinguished Scholar 2002)

Seventh and Eighth Circuit Judicial Conference (1998)

Sixth Circuit Judicial Conference (2004)

Society for Occupational and Environmental Health (1993)

Society of General Internal Medicine (2001)

Society of Toxicology (2010, 2014)

South Carolina State Bar, Employment Law Section (2009)

Southern Illinois University School of Law (John & Marsha Ryan Bioethicist in Residence, 2007)

Southern Illinois University School of Medicine (2007)

Southern University Law Center (2000)

Stanford University School of Medicine (2003)

Substance Abuse and Mental Health Services Administration (2005)

Suffolk University Law School (2001)

Swiss Institute of Comparative Law (Lausanne, Switzerland 1994)

Temple University School of Law (2004)

Tenth Circuit Judicial Conference (1996)

Texas Cancer Council (1998)

Texas Center for the Judiciary (1990)

Texas Legislature (numerous)

Texas Lutheran University (1996)

Texas Medical Association (1994)

Texas Medical Center/Medical World Americas (2015)

Texas State Bar, Health Law Section (2008)

The Institute for Rehabilitation and Research (1992)

Transylvania University (2002)

United States Commission on Civil Rights (1998)

United States Department of Energy (1991, 1993, 1994, 1997, 1998)

United States House of Representatives, Committee on Government Reform (2006)

United States House of Representatives, Committee on Energy and Commerce,

Subcommittee on Investigations and Oversight (2013)

United States House of Representatives, Committee on Science and Technology,

Subcommittee on Investigations and Oversight (1982)

United States Senate, Committee on Homeland Security and Governmental Affairs (2007)

Universidad Nacional Autónoma de México (Mexico City, 1995)

University of Alberta Faculty of Law (2003)

University of Calgary Faculty of Medicine (O'Byrne Lecture, 2003)

University of California-Berkeley School of Public Health (1999, 2010)

University of California-Hastings College of the Law (2013)

University of California-Los Angeles School of Law (2004)

University of California-Los Angeles School of Medicine (2003, 2004)

University of California-Los Angeles School of Public Health (2005)

University of Chicago School of Law (1987)

University of Cincinnati College of Law (2007)

University of Cincinnati College of Medicine (annual 1984-1998, 2003, 2012)

University of Georgia School of Law (2000)

University of Houston Law Center (2015)

University of Kentucky College of Law (2002)

University of Kentucky College of Medicine (2013, 2014, 2016)

University of Maryland School of Law (2008)

University of Memphis School of Law (1996)

University of Michigan School of Public Health (1987, 1988, 1991)

University of Minnesota School of Law (2002, 2003, 2007, 2012, 2013, 2014)

University of Minnesota School of Medicine (2002, 2003)

University of Missouri School of Law (2000)

University of Nevada-Las Vegas College of Law (2015)

University of North Carolina (2011)

University of North Carolina School of Law (2015)

University of North Carolina School of Medicine (2003, 2015)

University of Ottawa (2009)

University of Pittsburgh Medical Center (2006)

University of Pittsburgh School of Law (1988)

University of Pittsburgh School of Medicine (2000)

University of Pittsburgh School of Public Health (2000)

University of South Carolina School of Law (Johnson & Johnson Lecture, 2005)

University of Tennessee Health Sciences Center (2002)

University of Texas Graduate School of Biomedical Sciences (1993, 1994, 1995)

University of Texas – Houston School of Medicine (2010)

University of Texas Medical Branch-Galveston (1994, 1996)

University of Texas School of Law (1999)

University of Texas School of Public Health (annual, 1985-2000)

University of Toronto School of Law (2011)

University of Utah School of Law (2010)

University of Utah School of Medicine (1999, 2004, 2007)

University of Virginia (2008)

University of Virginia Medical Center (2005)

University of Virginia School of Law (2009, 2011, 2013)

University of Washington School of Medicine (2003)

Utah Legislature (1998)

Vanderbilt University School of Medicine (2003, 2013)

Washington State Department of Health (1999)

Workshop on International Cooperation for the Human Genome Project (Valencia, Spain 1990), (Bilbao, Spain 1993)

World Conference on Diabetes Research (Monaco, 1992)

World Healthcare Innovation & Technology Congress (2008)

World Research Group (2004)

Wyoming Medical Association/Wyoming Bar Association (1987)

Xavier (La.) University (1999)

Yale School of Medicine (2015)

Yale University (2004)

Zeta Phi Beta Educational Foundation (2003)

## **BAR MEMBERSHIPS**

Supreme Court of the United States District of Columbia Court of Appeals

Supreme Court of Pennsylvania

## PROFESSIONAL MEMBERSHIPS

American Public Health Association

American Society for Bioethics and Humanities

American Society of Human Genetics

American Society of Law, Medicine & Ethics

# **SPONSORED RESEARCH** (all as principal investigator unless otherwise noted)

2016	"Addressing Ethical Challenges in Networked Biorepositories," National Human Genome Research Institute, National Institutes of Health, \$37,000 (co-investigator)
2014	"Harmonizing Privacy Laws to Enable International Biobank Research," National Institute of General Medical Sciences and National Human Genome Research Institute, National Institutes of Health, \$642,690
2013	"Crisis Standards of Care," Kentucky Department of Public Health and Health Resources and Services Administration, HHS, \$30,356 (coinvestigator)
2013	"Genomic Diagnosis in Children with Developmental Delay," Hudson/Alpha Institute for Biotechnology, National Human Genome Research Institute, National Institutes of Health, \$17,415 (consultant)
2007	"Center for Environmental Genomics and Integrative Biology," National Institutes of Health, \$50,552 (co-investigator)
2003	"Center for Public Health Law Partnerships," Centers for Disease Control and Prevention, \$989,000
2003	"Quarantine and Isolation: Lessons Learned from SARS," Centers for Disease Control and Prevention, \$99,868
2002	"Education in Genetics Ethics," National Human Genome Research Institute, National Institutes of Health, \$1,460,592
2002	"Research Agenda for Maternal Fatality Review Laws," Centers for Disease Control and Prevention/American College of Obstetricians and Gynecologists, \$10,868
2001	"Analysis of State Child Fatality Review Laws," Centers for Disease Control and Prevention, \$171,202
2001	"Regulation of Biobanks: Banking Without Checks or Insured Deposits?," United States Department of Energy, \$600,000
2001	"Genetic Ties and the Future of the Family," National Human Genome Research Institute, National Institutes of Health, \$814,471
2000	"Pharmacogenomics and Minority Populations," National Institute of General Medical Sciences, National Institute of Environmental Health Sciences, and National Human Genome Research Institute of

	the National Institutes of Health, \$903,748
2000	"Genetic Information and Life Insurance Underwriting," National Human Genome Research Institute, National Institutes of Health, \$784,227
2000	"Texas Genetics Legislation," Texas Department of Health, \$7,500 (co-investigator)
2000	"Legal Issues in the Regulation of Tuberculosis," Centers for Disease Control and Prevention, \$7,500
2000	"Evaluating the Effectiveness of Laws Regulating Tobacco in Texas," Centers for Disease Control and Prevention/Texas Department of Health, \$50,000 (co-investigator)
1999	"Texas Health Legislation Research Center," Texas Legislature, \$700,000
1998	"Texas Partnership to Improve End-of-Life Care," Robert Wood Johnson Foundation, \$75,000 (co-investigator)
1998	"Policy Development on Managed Care and Cancer in Texas," Texas Cancer Council, \$105,000
1997	"Legal Protections for People with Disabilities," National Institute on Disability and Rehabilitation Research, United States Department of Education, \$60,000 (co-investigator)
1997	"Texas Health Legislation Research Center," Texas Legislature, \$700,000
1997	"Education on Legal Issues Involving Managed Care and Cancer," Texas Cancer Council, \$104,000
1996	"Measuring the Effects of a Unique Law Limiting Employee Medical Examinations to Job-Related Matters," United States Department of Energy, \$126,000
1996	"Impact of Managed Care on Cancer Services in Texas," Texas Cancer Council, \$99,000
1995	"Privacy, Confidentiality, and New Genetic Technology," United States Department of Energy, \$30,000
1995	"Family Violence and the Health Care System in Texas," Texas Legislature, \$518,200

1993	"Nonfinancial Barriers to Health Care in Texas," Texas Legislature, \$283,600
1992	"The Human Genome Project and the Future of Health Care," National Center for Human Genome Research, National Institutes of Health, \$70,000 (co-investigator)
1991	"Occupational Injury and Illness in Texas," Texas Legislature, \$290,400
1990	"Legal and Ethical Issues Raised by the Human Genome Project," National Center for Human Genome Research, National Institutes of Health, \$90,000

#### **PUBLICATIONS**

## **Books**

- Mark A. Rothstein, <u>Occupational Safety and Health Law</u> (Thomson Reuters) (1978), (2d ed. 1983), (3d ed. 1990), (4th ed. 1998), and annual editions: 2006, 2007, 2008, 2009, 2010, 2011, 2012, 2013, 2014, 2015, 2016
- 2. Lori B. Andrews, Maxwell J. Mehlman, & Mark A. Rothstein, <u>Genetics:</u> <u>Ethics, Law and Policy</u> (West Academic) (2002), (2d ed. 2006), (3d ed. 2010), (4th ed. 2015)
- 3. Mark A. Rothstein, Lance Liebman, & Kimberly A. Yuracko, <u>Cases and Materials on Employment Law</u> (Foundation Press) (1987), (2d ed. 1991), (3d ed. 1994), (4th ed. 1998), (5<sup>th</sup> ed. 2003), (6<sup>th</sup> ed. 2007), (7<sup>th</sup> ed. 2011), (8th ed. 2015), and 2016-2017 supplement
- 4. Mark A. Rothstein, Charles B. Craver, Elinor P. Schroeder, Elaine W. Shoben, & L. Camille Hebert, <u>Employment Law Treatise</u> (2 vols.) (Thomson Reuters) (1994), (2d ed. 1999), (3d ed. 2004), (4th ed. 2009), (5th ed. 2014), and 2017 supplement
- 5. Mark A. Rothstein, Charles B. Craver, Elinor P. Schroeder, Elaine W. Shoben, & L. Camille Hebert, Employment Law Hornbook (West Academic) (1994), (2d ed. 1999), (3d ed. 2004), (4th ed. 2009), (5th ed. 2015)
- 6. Daniel Oberdorfer & Mark A. Rothstein, <u>West's Legal Forms</u> (<u>Employment Law</u>) (Vol. 24A) (Thomson/West) (3d ed. 2003), and supplements
- 7. Baruch A. Brody, Mark A. Rothstein, Laurence B. McCullough, & Mary Anne Bobinski, Medical Ethics: Analysis of the Issues Raised by the Codes, Opinions and Statements (BNA Books) (2001)
- 8. Mark A. Rothstein, Charles B. Craver, Elinor P. Schroeder, Elaine W.

- Shoben & Lea VanderVelde, <u>Human Resources and the Law</u> (BNA Books) (1994)
- 9. Mark A. Rothstein, <u>Medical Screening and the Employee Health Cost Crisis</u> (BNA Books) (1989)
- 10. Mark A. Rothstein, Medical Screening of Workers (BNA Books) (1984)

## **Books Edited**

- 11. Mark A. Rothstein, Thomas H. Murray, Mary Anderlik Majumder, & Gregory E. Kaebnick, eds., <u>Genetic Ties and the Family: The Impact of Paternity Testing on Parents and Children</u> (Johns Hopkins University Press) (2005)
- 12. Mark A. Rothstein, ed., <u>Genetics and Life Insurance: Medical Underwriting and Social Policy</u> (MIT Press) (2004), paperback (2009)
- 13. Mark A. Rothstein, ed., <u>Pharmacogenomics: Social, Ethical, and Clinical</u> Dimensions (Wiley-Liss) (2003)
- 14. Richard A. Goodman, Mark A. Rothstein, Richard E. Hoffman, Wilfredo Lopez, & Gene W. Matthews, eds., <u>Law in Public Health Practice</u> (Oxford University Press) (2002), (2d ed. 2007)
- 15. Baruch A. Brody, Mark A. Rothstein, Laurence B. McCullough, & Mary Anne Bobinski, eds., <u>Medical Ethics: Codes, Opinions, and Statements</u> (BNA Books) (2000)
- 16. Ronald A. Carson & Mark A. Rothstein, eds., <u>Behavioral Genetics: The Clash of Culture and Biology</u> (Johns Hopkins University Press) (1999), paperback (2002)
- 17. Mark A. Rothstein, ed., <u>Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era</u> (Yale University Press) (1997), paperback (1999)
- 18. Thomas H. Murray, Mark A. Rothstein, & Robert F. Murray, Jr., eds., <u>The Human Genome Project and the Future of Health Care</u> (Indiana University Press) (1996)
- 19. Mark A. Rothstein, ed., <u>Legal and Ethical Issues Raised by the Human</u>

  <u>Genome Project: Proceedings of the Conference in Houston, Texas, March</u>

  <u>7-9, 1991</u> (Health Law and Policy Institute) (1991)

## **Book Chapters**

- 20. Mark A. Rothstein, <u>Health Information and Privacy Law</u>, Population Health: Management, Policy, Technology, and Innovation, 2d ed. (Robert Esterhay et al., eds.) (Convurgent Publishing 2016)
- 21. Mark A. Rothstein, <u>Privacy and Confidentiality</u>, Handbook of Medical Law and Ethics (Bartha Maria Knoppers & Yann Joly, eds.) (Routledge 2015)
- 22. Heather L. Harrell & Mark A. Rothstein, <u>Genetic Privacy</u>, Clinical Genomics: Practical Applications in Adult Patient Care (Michael F. Murray et al., eds.) (McGraw-Hill 2013)
- 23. Mark A. Rothstein, <u>Legal and Ethical Implications of Epigenetics</u>, Environmental Epigenomics in Health and Disease (Randy L. Jirtle & Frederick L. Tyson, eds.) (Springer-Verlag 2013)
- 24. Mark A. Rothstein, <u>Occupational Health Law</u>, Occupational Health Services: A Practical Approach, 2d ed. (Tee L. Guidotti et al., eds.) (Routledge 2012)
- 25. Mark A. Rothstein, <u>Protecting Privacy in Genetic Research on Alcohol</u>
  <u>Dependence and Other Addictions</u>, Genetic Research on Addiction: Ethics, the Law and Public Health (Audrey Chapman, ed.) (Cambridge University Press 2012)
- 26. Mark A. Rothstein, <u>Informed Consent in Pharmacogenomic Research and Treatment</u>, Principles of Pharmacogenetics and Pharmacogenomics (Russ Altman, David Flockhart, & David Goldstein, eds.) (Cambridge University Press 2012)
- 27. Mark A. Rothstein & Yann Joly, <u>Genetic Information and Insurance</u>

  <u>Underwriting: Contemporary Issues and Approaches in the Global</u>

  <u>Economy</u>, Handbook of Genetics and Society: Mapping the New Genomic

  Era (Paul Atkinson, Peter Glasner, & Margaret Lock, eds.) (Routledge 2009)
- 28. Mark A. Rothstein, <u>Occupational Health and Discrimination Issues Raised by Toxicogenomics in the Workplace</u>, Genomics and Environmental Regulation (Richard R. Sharp, Gary E. Marchant, & Jamie Grodsky, eds.) (Johns Hopkins University Press 2008)
- 29. Mark A. Rothstein, <u>Privacy Issues in Public Health Genomics</u>, Genomics and Public Health: Legal and Socio-Ethical Perspectives (Bartha Maria Knoppers, ed.) (Martinus Nijhoff Publishers 2007)
- 30. Mark A. Rothstein, <u>Privacy and Confidentiality in the Nationwide Health Information Network</u>, Paper Kills: Transforming Health and Health Care with Information Technology (David Merritt, ed.) (CHT Press 2007)
- 31. Mark A. Rothstein & Heather L. Hinds, Ethical Criteria for Evaluating Hand

- <u>Transplantation</u>, Hand Transplantation (Vijay S. Gorantla, ed.) (Landes Bioscience 2006)
- 32. Ellen Wright Clayton & Mark A. Rothstein, <u>Integrating Genetics Into Public Health Policy and Practice</u>, Law in Public Health Practice, 2d ed. (Richard A. Goodman et al. eds.) (Oxford University Press 2007)
- 33. Mary Anderlik Majumder & Mark A. Rothstein, <u>Pharmacogenomics and Cancer: Ethical, Legal and Social Issues</u>, Cancer Bioinformatics: From Cancer Biology to Therapy Design and Treatment (Sylvia Nagl, ed.) (John Wiley & Sons 2006)
- 34. M. Gabriela Alcalde & Mark A. Rothstein, <u>Ethical Considerations in Pharmacogenomic Research</u>, Pharmacogenomics and Proteomics: Enabling the Practice of Personalized Medicine (Steven H. Wong, Mark W. Linder & Roland Valdes, Jr., eds.) (AACC Press 2006)
- 35. Mark A. Rothstein, <u>Translating Values and Interests Into the Law of Parentage Determination</u>, Genetic Ties and the Family: The Impact of Paternity Testing on Parents and Children (Mark A. Rothstein et al., eds.) (Johns Hopkins University Press 2005)
- Mark A. Rothstein, <u>Government Agencies/Statutes/Legislation</u>, Textbook of Clinical Occupational and Environmental Medicine, 2d ed. (Linda Rosenstock et al., eds.) (Elsevier Saunders 2005)
- 37. Mark A. Rothstein & Carlton A. Hornung, <u>Public Attitudes About Genetics</u> and <u>Life Insurance</u>, Genetics and Life Insurance: Medical Underwriting and Social Policy (Mark A. Rothstein, ed.) (MIT Press 2004)
- 38. Mark A. Rothstein, <u>Policy Recommendations</u>, Genetics and Life Insurance: Medical Underwriting and Social Policy (Mark A. Rothstein, ed.) (MIT Press 2004)
- 39. Mark A. Rothstein & Carlton A. Hornung, <u>Public Attitudes About Pharmacogenomics</u>, Pharmacogenomics: Social, Ethical, and Clinical Dimensions (Mark A. Rothstein, ed.) (Wiley-Liss 2003)
- 40. Mark A. Rothstein, <u>Epilogue: Policy Prescriptions</u>, Pharmacogenomics: Social, Ethical, and Clinical Dimensions (Mark A. Rothstein, ed.) (Wiley-Liss 2003)
- 41. Laura Beskow, Marta Gwinn, & Mark A. Rothstein, <u>Integrating Genomics Into Public Health Policy and Practice</u>, Law in Public Health Practice (Richard Goodman et al., eds.) (Oxford University Press 2002)
- 42. Phyllis Griffin Epps & Mark A. Rothstein, <u>Pharmacogenomics: Ensuring Equality in Drugs Based on Difference</u>, Pharmacogenomics: The Search for

- Individualized Therapeutics (Julio Licinio & Ma-Li Wong, eds.) (Wiley-VCH 2002)
- 43. Mark A. Rothstein, <u>OSHA Law and Practice</u>, West's Federal Administrative Practice, 4<sup>th</sup> ed. (vol. 3, chs. 34-38) (West Group 2001), and 2010 Supp.
- 44. Mark A. Rothstein, <u>Bias and Discrimination</u>, <u>Confidentiality</u>, <u>Genetics</u>, <u>Public Health</u>, and <u>Health Care Policy</u>, Medical Ethics: Analysis of The Issues Raised by the Codes, Opinions and Statements (Baruch A. Brody, Mark A. Rothstein, Laurence B. McCullough, and Mary Anne Bobinski, eds.) (BNA Books 2001)
- 45. Mark A. Rothstein, <u>Genetic Determinism: Its Effects on Culture and Law</u>, Behavioral Genetics: The Clash of Culture and Biology (Ronald A. Carson & Mark A. Rothstein, eds.) (Johns Hopkins University Press 1999)
- 46. Mark A. Rothstein, <u>The Law of Medical and Genetic Privacy in the Workplace</u> and <u>Genetic Secrets: A Policy Framework</u>, Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era (Mark A. Rothstein, ed.) (Yale University Press 1997)
- 47. Mark A. Rothstein, <u>The Genetic Factor in Health Care Reform: Framing the Policy Debate</u>, The Human Genome Project and the Future of Health Care (Thomas H. Murray, Mark A. Rothstein, Robert F. Murray, Jr., eds.) (Indiana University Press 1996)
- 48. Mark A. Rothstein, <u>Ethical Issues Surrounding the New Technology as Applied to Health Care</u>, Biotechnology: Science, Engineering, and Ethical Challenges for the Twenty-first Century (Frederick B. Rudolph & Larry V. McIntire, eds.) (Joseph Henry Press 1996)
- 49. Mark A. Rothstein, <u>The Challenge of New Genetic Information for the Law of Health and Life Insurance</u>, The Human Genome Project: Legal Aspects, vol. 3 (Fundación BBV, Madrid 1996)
- 50. Mark A. Rothstein, <u>Medical Record Confidentiality in the Workplace</u>, Healthcare, Privacy @ CYBERSPACE (SUNY at Albany 1995)
- 51. Mark A. Rothstein, <u>Genetic Discrimination in Employment: Ethics, Policy, and Comparative Law</u>, Human Genetic Analysis and the Protection of Personality and Privacy (Schulthess Polygraphischer Verlag, Zurich 1995)
- 52. Mark A. Rothstein, <u>The Americans with Disabilities Act, Workers'</u> <u>Compensation, and Related Issues of Occupational Medicine Practice,</u> Textbook of Clinical Occupational and Environmental Medicine (Linda S. Rosenstock & Mark Cullen, eds.) (W.B. Saunders Co. 1994)
- 53. Mark A. Rothstein, Legal Concerns in Worker Notification and the Use of

- <u>Biomarkers in Medical Surveillance</u>, Biomarkers and Occupational Health: Progress and Perspectives (Mortimer L. Mendelsohn, John P. Peeters, & Mary Janet Normandy, eds.) (Joseph Henry Press 1994)
- 54. Mark A. Rothstein, <u>Genetics</u>, <u>Insurance</u>, <u>and the Ethics of Genetic</u>
  <u>Counseling</u>, Molecular Genetic Medicine, vol. 3 (Theodore Friedmann, ed.)
  (Academic Press 1993)
- 55. Mark A. Rothstein, <u>Arbitration in the Employer Welfare State</u>, Arbitration 1991: The Changing Face of Arbitration in Theory and Practice, Proceedings of the Forty-Fourth Annual Meeting of the National Academy of Arbitrators (BNA Books 1992)
- Mark A. Rothstein, <u>The Genome Project and Employment Law</u>, Legal and Ethical Issues Raised by the Human Genome Project (Mark A. Rothstein, ed.) (Health Law and Policy Institute 1991)
- 57. Mark A. Rothstein, <u>The Law/Medicine Interface in Assessing Vocational</u>
  <u>Capacity</u>, Vocational Assessment of Impaired Workers (Steven Scheer, ed.)
  (Aspen Press 1990)
- 58. Mark A. Rothstein, <u>Legal and Ethical Issues in the Laboratory Assessment of Genetic Susceptibility to Cancer</u>, Genetic Susceptibility to Cancer: Laboratory Approaches (Lawrence Spatz, Arthur D. Bloom, & Natalie W. Paul, eds.) (Environmental Health Institute/March of Dimes 1990)
- Mark A. Rothstein, <u>Employee Testing</u>: <u>Drug and AIDS Testing</u>,
   Occupational Health Services (William L. Newkirk & Lynn D. Jones, eds.)
   (American Hospital Publishing 1989)
- 60. Mark A. Rothstein, <u>Screening Workers for AIDS</u>, AIDS and the Law (Harlon L. Dalton & Scott Burris, eds.) (Yale University Press 1987)

# **Symposia**

- 61. Mark A. Rothstein & Bartha Maria Knoppers, eds, <u>Symposium:</u>

  <u>Harmonizing Privacy Laws to Enable International Biobank Research</u>, 43(4)

  J.L. Med. & Ethics 673-826 (2015) and 44(1) J.L. Med. & Ethics 7-172

  (2016)
- 62. Melissa M. Goldstein & Mark A. Rothstein, eds., <u>Symposium: The Effects of Health Information Technology on the Practice of Medicine</u>, 38(1) J. L. Med. & Ethics 1-84 (2010)
- 63. Mark A. Rothstein & Bartha Maria Knoppers, eds., <u>Symposium: Regulation of Biobanks</u>, 33(1) J.L. Med. & Ethics 1-101 (2005)
- Articles [\* indicates article may be viewed and downloaded from: http://ssrn.com/author=139038]

- 64. Kyle Brothers, ... Mark A. Rothstein, & Ellen Wright Clayton, <u>Eliciting Preferences on Secondary Findings: The Preferences Instrument for Genomic Secondary Results (PIGSR)</u>, 18 Genomics in Medicine \_\_\_\_ (2016)
- 65. Mark A. Rothstein, <u>For Whom the Doc Toils: Preventing Conflicts of Interest of NFL Team Physicians</u>, 46(6) Hastings Center Report \_\_\_\_ (2016)
- 66. \* Mark A. Rothstein, <u>Some Lingering Concerns About the Precision Medicine Initiative</u>, 44(3) J.L. Med. & Ethics \_\_\_\_ (2016)
- 67. \* Mark A. Rothstein, <u>The End of the HIPAA Privacy Rule?</u>, 44(2) J.L. Med. & Ethics 352-358 (2016)
- 68. \* Mark A. Rothstein & Laura Rothstein, <u>How Genetics Might Affect Real</u> Property Rights, 44(1) J.L. Med. & Ethics 216-221 (2016)
- 69. \* Mark A. Rothstein, <u>International Health Research after Schrems v. Data Protection Commissioner</u>, 46(2) Hastings Center Report 5-6 (2016)
- 70. \* Mark A. Rothstein, Bartha Maria Knoppers, & Heather L. Harrell, Comparative Approaches to Biobanks and Privacy, 44(1) J.L. Med. & Ethics 161-172 (2016)
- 71. \* Heather L. Harrell & Mark A. Rothstein, <u>Biobanking Research and Privacy Laws in the United States</u>, 44(1) J.L. Med. & Ethics 106-127 (2016)
- 72. \* Mark A. Rothstein, John T. Wilbanks, & Kyle B. Brothers, <u>Citizen Science</u> on Your Smartphone: An ELSI Research Agenda, 43(4) J.L. Med. & Ethics 897-903 (2015)
- 73. \* Mark A. Rothstein, Jessica Roberts, & Tee L. Guidotti, <u>Limiting</u>
  Occupational Medical Evaluations Under the Americans with Disabilities
  Act and the Genetic Information Nondiscrimination Act, 41(4) Am. J.L. &
  Med. 523-567 (2015)
- 74. Stephanie O.M. Dyke, . . . Mark A. Rothstein et al., <u>Epigenome Data Release</u>: A <u>Participant-Centered Approach to Privacy Protection</u>, 16 Genome Biology 142, doi 10.1186/s13059-015-0723-0 (2015)
- 75. Yann Joly, . . . Mark A. Rothstein, et al., <u>Risk of Re-identification of Epigenetic Methylation Data: A More Nuanced Response Is Needed</u>, 7 Clinical Epigenetics 45, doi: 10.1186/s13148-015-0079-2 (2015) PMCID: PMC4405848
- 76. Susan M. Wolf, . . . Mark A. Rothstein, et al., <u>Returning a Research</u>

  <u>Participant's Genomic Results to Relatives: Analysis and Recommendations</u>,
  43(3) J.L. Med & Ethics 440-463 (2015)

- 77. Mark A. Rothstein, <u>Innovations of the Americans with Disabilities Act:</u>
  <u>Confronting Disability Discrimination in Employment</u>, 313 (22) JAMA 2221-2222 (2015) PMID: 26057278
- 78. \* Mark A. Rothstein, <u>Ethical Issues in Big Data Health Research</u>, 43(2) J. L. Med. & Ethics 425-429 (2015)
- 79. \* Mark A. Rothstein, <u>From SARS to Ebola: Legal and Ethical Considerations for Modern Quarantine</u>, 12(1) Indiana Health L. Rev. 227-280 (2015)
- 80. \* Mark A. Rothstein, <u>Ebola, Quarantine, and the Law</u>, 45(1) Hastings Center Report 5-6 (2015) PMID: 25600380
- 81. \* Kyle B. Brothers & Mark A. Rothstein, Ethical, Legal, and Social Implications of Incorporating Personalized Medicine into Healthcare, 11(1) Personalized Med. 43-51 (2015) PMID: 25601880
- 82. \* Mark A. Rothstein, <u>The Moral Challenge of Ebola</u>, 105(1) Am. J. Pub. Health 6-8 (2015) PMID: 25354202
- 83. \* Mark A. Rothstein, <u>Autonomy and Paternalism in Health Policy</u>, 42(4) J.L. Med. & Ethics 590-594 (2014) PMID: 25565623
- 84. \* Mark A. Rothstein, <u>Promoting Public Health in Health Care Facilities</u>, 104(6) Am. J. Pub. Health 965-967 (2014) PMID: 24825191
- 85. \* Mark A. Rothstein, <u>Privacy and Technology in the Twenty-first Century</u>, 52 U. Louisville L. Rev. 333-344 (2014)
- 86. \* Mark A. Rothstein, *Tarasoff* Duties After Newtown, 42(1) J.L. Med. & Ethics 104-109 (2014)
- 87. \* Mark A. Rothstein, <u>Epigenetic Exceptionalism</u>, 41(3) J.L. Med. & Ethics 733-736 (2013) PMID: 24134349
- 88. Ribhi Hazin, . . . Mark A. Rothstein, et al., <u>Ethical, Legal and Social Implications of Incorporating Genomic Information into Electronic Health Records</u>, 15 Genetics in Med. 810-816 (2013) PMCID: PMC3926430; PMID: 24030434
- 89. \* Lainie Friedman Ross, Mark A. Rothstein, & Ellen Wright Clayton,

  Mandatory Extended Searches in All Genome Sequencing: "Incidental

  Findings," Patient Autonomy, and Shared Decision Making, 310(4) JAMA
  367-368 (2013) PMID: 23917281
- 90. \* Wylie Burke, . . . Mark A. Rothstein, et al., <u>Recommendations for Returning Genomic Incidental Findings? We Need to Talk!</u>, 15(7) Genetics in Med. 854-859 (2013) PMCID: PMC3832423; PMID: 23907645

- 91. \* Lainie Friedman Ross, Mark A. Rothstein, & Ellen Wright Clayton,

  <u>Premature Guidance About Whole Genome Sequencing</u>, 10(6) Personalized

  Med. 523-526 (2013) PMID: 24348686
- 92. \* Mark A. Rothstein, <u>HIPAA Privacy Rule 2.0</u>, 41(2) J.L. Med. & Ethics 525-528 (2013) PMID: 23802902
- 93. \* Mark A. Rothstein & Abigail B. Shoben, <u>An Unbiased Response to the Open Peer Commentaries on Consent Bias</u>, 13(4) Am. J. Bioethics W1-W4 (2013) PMID: 23514403
- 94. \* Mark A. Rothstein & Abigail B. Shoben, <u>Does Consent Bias Research?</u>, 13(4) Am. J. Bioethics 27-37 (2013) PMID: 23514393
- 95. \* Mark A. Rothstein & Gil Siegal, <u>Health Information Technology and Physicians' Duty to Notify Patients of New Medical Developments</u>, 12(1) Hous. J. Health L. & Pol'y 93-136 (2012)
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July 2016