

Curriculum Vitae

Benjamin E. Berkman, JD, MPH

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CURRENT POSITION

- 2009 – Present** **Senior Staff Bioethicist**
Section on Ethics and Genetics, Department of Bioethics
Clinical Center, NIH
Bethesda, MD
- 2009 – Present** **Deputy Director**
Bioethics Core, Office of the Clinical Director
National Human Genome Research Institute (NHGRI), NIH
Bethesda, MD
- 2007 – Present** **Adjunct Professor**
Georgetown University Law Center
Washington, DC

EDUCATION

- 2005** **JD**
University of Michigan School of Law
Ann Arbor, MI
- 2005** **MPH**
University of Michigan School of Public Health
Department of Health Policy and Management
Ann Arbor, MI
- 1999** **BA**
Harvard University
Department of History and Science
Cambridge, MA

POSTDOCTORAL TRAINING

- 2005 – 2006** **Fellowship**
Center for Law and the Public's Health
Georgetown University Law Center
Washington, DC

PREVIOUS POSITIONS

- 2010 – 2011 Adjunct Professor**
University of Maryland School of Law
Baltimore, MD
- 2006 – 2009 Deputy Director**
O’Neill Institute for National and Global Health Law
Georgetown University Law Center
Washington, DC
- 2009 Consultant**
National Commission on Children and Disasters
Washington, DC
- 2007 Consultant**
Institute of Medicine
Report on Ethical Considerations for Research Involving Prisoners
Washington, DC

CERTIFICATIONS/LICENSES

Member, New York State Bar (inactive)

ACTIVE BOARDS AND OTHER POSITIONS (including Editorial)

- 2018-Present Member, General Medicine 1 IRB**
- 2016 – 2018 Vice Chair, NHGRI IRB**
- 2009 – Present Member, Responsible Conduct of Research Committee**
Office of the Director of Intramural Research, NIH
- 2009 – Present Attending Bioethicist**
Clinical Research Ethics Consultation Service
Department of Bioethics (Clinical Center), NIH
- 2009 – 2015 IRB Member**
NIAID Institutional Review Board, NIH

PAST BOARDS AND OTHER POSITIONS

- 2007-2010 Advisory Committee**
Georgetown Human Rights Action Group

2006-2008 Community Mitigation During Pandemic Influenza
Centers for Disease Control and Prevention

2006-2007 Committee on the Legal and Ethical Aspects of Public Health
Interventions for Pandemic Influenza
World Health Organization

2006-2007 Access to Controlled Medicines
World Health Organization

2006-2007 HIV Partner Notification and Referral Guidelines
Centers for Disease Control and Prevention

2006 Board on Modeling Community Containment for Pandemic Influenza
Institute of Medicine
Washington, DC

AWARDS AND HONORS

2018 OD Honor Award
Pilot Institutional Review Board

2018 Genome Recognition of Employee Accomplishments and Talents Award
Stepping In GREAT
National Human Genome Research Institute

2016 NIH Director's Award
NIH Clinical Center Genomics Opportunity (CCGO) Program Team

2011 NIH Director's Award
Bioethics Next Generation Sequencing Advisory Group

2011 Genome Recognition of Employee Accomplishments and Talents Award
Scientific/Medical Achievement
National Human Genome Research Institute

2011 Special Act Award
Division of Clinical Research
National Institute of Allergy and Infectious Diseases (NIAID)

2010 Special Act Award
Division of Clinical Research
National Institute of Allergy and Infectious Diseases (NIAID)

2010 Individual Cash Award (Ratings Based)

- 2004** Award for Excellence in the Study of Health Law
American Bar Association Health Law Section
- 1999** John Harvard Scholarship
Harvard University
- 1999** Harvard College Scholarship
Harvard University

COURSES TAUGHT

Research with Human Subjects: Law, Policy and Ethics.
Georgetown Law, 2010-present (annually).

Health and Science Policy Workshop: Regulation of Genomic Research.
Maryland Law, 2011.

Health and Human Rights.
Georgetown Law, 2006-2009 (annually).

SELECTED INVITED LECTURES

“Incidental Findings in Low-Resource Settings”
Global Pandemics and Sovereignty over Biological Resources
Georgetown University Law Center
May 2015

“Incidental Findings and Next-Generation Genomic Research”
Ethical and Regulatory Aspects of Clinical Research
National Institutes of Health, Bethesda, MD
2009-present (annually)

“Ethics of Genetic Testing”
Bioethics Fellow Seminar
National Institutes of Health, Bethesda, MD
2013-present (annually)

“Ethics Issues in Genomic Research”
Clinical Center Nursing Department
Intermediate Genetics and Genomics in Healthcare
National Institutes of Health, Bethesda, MD
2014-present (quarterly)

“Refuting the Right Not to Know”
Genomic Rights Initiative (Mayo Clinic)

Chicago, IL
October 2015

“Challenging the Right Not to Know”
American Society for Bioethics and Humanities
Houston, TX
October 2015

“The Right Not To Know in a Genomic Era: Time to Break from Tradition?”
American Society for Law, Medicine and Ethics
St. Louis, MI
June 2015

“Ethical Issues Raised by the Availability of Whole Genome Sequencing”
Chinese University of Hong Kong
Hong Kong
January 2015

“The Blurring Line Between Research and Clinical Care”
International Collaboration for Clinical Genomics
Bethesda, MD
June 2014

“Debating Return of Results and Incidental Findings in Research and Clinical Care”
American Society for Law, Medicine and Ethics
San Francisco, CA
June 2014

“Incidental Findings in Genomic Research”
National Academy of Science
Washington, DC
February 2014

“IRB Views on the Obligation to Return Genetic Incidental Findings”
American Society for Bioethics and Humanities
Atlanta, GA
October 2013

“Do Researchers Have an Obligation to Look for Incidental Findings?”
American Society of Human Genetics
Boston, MA
October 2013

“Do Researchers Have an Obligation to Actively Look for Incidental Findings?”
American Society for Law, Medicine and Ethics
Newark, NJ

June 2013

“Prenatal Whole Genome Sequencing”
Cold Spring Harbor Biology of Genomes
Long Island, NY
May 2013

“Pediatric Incidental Findings”
National Society of Genetic Counselors
Boston, MA
October 2012

“Prenatal Whole Genome Sequencing: Just Because We Can, Should We?”
American Society for Law, Medicine and Ethics
Tempe, AZ
June 2012

“The Ethics of Community Based Participatory Research”
American Public Health Association
Philadelphia, PA
September 2011

“Teaching a Health and Science Policy Workshop on the Role of Genomic Research”
American Society for Law, Medicine and Ethics
Chicago, IL
June 2011

“Research Ethics Consultation”
American Society for Bioethics and Humanities
San Diego, CA
October 2010

“Ethical Implications of Whole Genome Sequencing”
American Society for Bioethics and Humanities
San Diego, CA
October 2010

PUBLICATIONS

Books

Danis M, Largent E, Wendler D, Hull SC, Shah S, Millum J, **Berkman BE**, Grady C. *Research Ethics Consultation: A Casebook*. Oxford University Press, 2012.

Book Chapters

Berkman BE. Is There a Right Not to Know Genetic Information About Oneself. In *Deliberate Ignorance: Choosing Not to Know* (R. Hertwig and C. Engel, eds.) Strüngmann Forum Reports, vol. 29, J. R. Lupp, series editor. Cambridge, MA: MIT Press, in press.

Schwartz B, Richerson PJ, **Berkman BE** et al. The Deep Structure of Deliberate Ignorance: Mapping the Terrain. In *Deliberate Ignorance: Choosing Not to Know* (R. Hertwig and C. Engel, eds.) Strüngmann Forum Reports, vol. 29, J. R. Lupp, series editor. Cambridge, MA: MIT Press, in press.

Berkman BE, Shapiro ZE, Eckstein L, Pike ER. The Ethics of Large-Scale Genomic Research. In *The Ethics of Big Data: Reasoning about Ethical Implications of Conducting Research with Big Data* (New York: Springer, 2016).

Berkman BE and Hull S. Ethical Issues in Genomic Databases. In *Encyclopedia of Ethics, 2nd ed.* (London: Elsevier, 2012).

Gostin LO and **Berkman BE.** Preparing for Pandemic Influenza: Legal and Ethical Challenges. In *Ethical and Legal Considerations in Mitigating Pandemic Disease* (Washington, DC: National Academies Press, 2007).

Journal Articles

Strassle CL and **Berkman BE.** Workplace Wellness Programs: Empirical Doubt, Legal Ambiguity, and Conceptual Confusion. *William and Mary Law Review* (forthcoming)

Chung ET and **Berkman BE.** Should Patient Groups Have the Power to Redirect How Their Samples Are Used? *American Journal of Bioethics* 19(8):26-28 (2019).

Sullivan HK, Bayefsky M, Wakim P, Huddleston, K, Biesecker BB, Hull SC, **Berkman BE.** Noninvasive Prenatal Whole Genome Sequencing: Pregnant Women's Views and Preferences. *Obstetrics and Gynecology* 133:525-532 (2019).

Miller WK and **Berkman BE.** The Future of Physicians' First Amendment Freedom: Professional Speech in an Era of Radically Expanded Genetic Testing. *Washington and Lee Law Review* 76(2): 577-654 (2019).

Prince AE and **Berkman BE.** Reconceptualizing Harms and Benefits in the Genomic Age. *Personalized Medicine* 15(5):419-428 (2018).

Lockhart NC, Weil CJ, Carithers LJ, Koester SE, Little AR, Volpi S, Moore HM, **Berkman BE.** Development of a Consensus Approach for Return of Pathology Incidental Findings in the Genotype-Tissue Expression (GTEx) Project. *Journal of Medical Ethics* 44(9): 643-645 (2018).

Bayefsky M and **Berkman BE.** Toward the Ethical Allocation of Uterine Transplants. *American Journal of Bioethics* 18(7): 16-17 (2018).

Berkman BE, Miller WK, Grady C. Is it Ethical to Use Genealogy Data to Solve Crimes? *Annals of Internal Medicine* 169(5): 333-334 (2018)

Berkman BE, Wendler D, Howard D. Reconsidering the Need for Reconsent at 18. *Pediatrics* 142(2) (2018).

Sullivan HK and **Berkman BE**. Incidental Findings in Low-Resource Settings. *Hastings Center Report* 48(3): 1-9 (2018).

Berkman BE, Wendler D, Sullivan HK, Grady C. A Proposed Process for Reliably Updating the Common Rule. *American Journal of Bioethics* 17(7): 8-14 (2017)

Odwazny LM, **Berkman BE**. The “Reasonable Person” Standard for Research Informed Consent. *American Journal of Bioethics* 17(7): 49-51 (2017).

Berkman BE and Bayefsky MJ. Prenatal Whole Genome Sequencing: An Argument for Professional Self-regulation. *American Journal of Bioethics* 17(1): 26-28 (2017).

Berkman BE. Refuting the Right Not to Know. *Journal of Healthcare Law and Policy* 19(1): 1-75 (2017).

Chen SC, **Berkman BE**, Hull SC. Recontacting Participants for Expanded Uses of Existing Samples and Data: A Case Study. *Genetics in Medicine* 19(8): 883-889 (2017).

Bayefsky MJ, White A, Wakim P, Hull SC, Wasserman D, Chen, S, and **Berkman BE**. Views of American OB/GYNs on the ethics of prenatal whole-genome sequencing. *Prenatal Diagnosis* 36: 1250–1256 (2016).

Koretsky M, Bonham VL, **Berkman BE**, Kruszka P, Adeyemo A, Muenke M, Hull SC. Towards a More Representative Morphology: Clinical and Ethical Considerations for Including Diverse Populations in Diagnostic Genetic Atlases. *Genetics in Medicine* 18: 1069-1074 (2016).

Bayefsky M and **Berkman BE**. The Ethics of Allocating Uterine Transplants. *Cambridge Quarterly of Healthcare Ethics* 25(3): 350-365 (2016).

Bayefsky MJ, DeCherney AH, **Berkman BE**. Compensation for Egg Donation: A Zero-Sum Game. *Fertility and Sterility* 105(5): 1153-1154 (2016).

Gliwa C, Yurkiewicz I, Lehmann LS, Hull SC, Jones N, **Berkman BE**. IRB Perspectives on Obligations to Disclose Genetic Incidental Findings to Research Participants. *Genetics in Medicine* 18(7): 705-711 (2016).

Botkin JR, Belmont JW, Berg JS, **Berkman BE**, et al. Points to Consider: Ethical, Legal and Psychosocial Implications of Genetic Testing in Children and Adolescents. *American Journal of Human Genetics* 97(1): 6-21 (2015).

Bayefsky MJ, Saylor KW, **Berkman BE**. Parental Consent for the Use of Residual Newborn Screening Bloodspots: Respecting Individual Liberty vs. Ensuring Public Health. *JAMA* 314(1):21-22 (2015).

Grady CG, Eckstein L, **Berkman BE**, et al. Broad Consent for Research With Biological Samples: Workshop Conclusions. *The American Journal of Bioethics* 15(9): 34-42 (2015).

Berkman BE, Hull SC, Biesecker LG. Scrutinizing the Right Not To Know. *American Journal of Bioethics* 15(7): 17-19 (2015).

Bayefsky MJ, **Berkman BE**. FDA's Proposed Guidance for Laboratory Developed Tests: How Should Regulators Balance the Risks and Promise of Innovation in Clinical Genetics? *Food and Drug Law Policy Forum* 5(2): 1-16 (2015).

Gostin LO, **Berkman BE**, Kraemer J. Foundations in Public Health Law. In *International Encyclopedia of Public Health* (London: Elsevier 2015)

Kim SK, Karlawish J, **Berkman BE**. Ethics of Genetic and Biomarker Test Disclosures in Neurodegenerative Disease Prevention Trials. *Neurology* 84: 1-7 (2015).

Mandava A, Millum J, **Berkman BE**. Incidental Findings of Misattributed Parentage. *Hastings Center Report* 45: 1-9 (2015).

Pike ER, Rothenberg K, **Berkman BE**. Finding Fault?: Exploring Legal Duties to Return Incidental Findings in Genomic Research. *Georgetown Law Journal* 102: 795-843 (2014).

Eckstein L, Garrett JR, **Berkman BE**. A Framework for Analyzing the Ethics of Disclosing Genetic Research Findings. *Journal of Law, Medicine and Ethics* 42(2): 190-207 (2014).

Berkman BE, Hull SC, Eckstein L. The Unintended Implication of Blurring the Line between Research and Clinical Care in a Genomic Age. *Personalized Medicine* 11(3): 285-295 (2014).

Hull SC and **Berkman BE**. Grappling with Genomic Incidental Findings in the Clinical Realm. *Chest* 145(2): 226-30 (2014).

Berkman BE and Hull SC. The "Right Not to Know" in the Genomic Era: Time to Break from Tradition? *American Journal of Bioethics* 14(3): 28-31 (2014).

Shah SK, Hull SC, Spinner MA, **Berkman BE**, Sanchez LA, Abdul-Karim R, Hsu AP, Claypool R, Holland SM. What Does the Duty to Warn Require? *American Journal of Bioethics* 13(10): 62-63 (2013).

Gliwa C, **Berkman BE**. Response to Open Peer Commentaries on "Do researchers have an obligation to actively look for genetic incidental findings?" *American Journal of Bioethics* 13(5): W10-W11 (2013).

Gliwa C, **Berkman BE**. Do researchers have an obligation to actively look for genetic incidental findings? *American Journal of Bioethics* 13(2): 32-42 (2013).

Abdul-Karim R, **Berkman BE**, Wendler D, Rid A, Khan J, Badgett T, Hull SC. Disclosure of incidental findings from next-generation sequencing in pediatric genomic research. *Pediatrics*; 31(3): 564-71 (2013).

Donley G, Hull SC, **Berkman BE**. Prenatal Whole Genome Sequencing: Just Because We Can, Should We? *Hastings Center Report*; 42(4): 28-40 (2012).

Prince A, **Berkman BE**. When Does Illness Begin: Genetic Discrimination and Disease Manifestation. *Journal of Law, Medicine and Ethics*; 40(3): 655-664 (2012).

Hull SC, Chan B, Biesecker LG, **Berkman BE**. Response to Open Peer Commentaries on “Genomic Inheritances: Disclosing Individual Research Results From Whole-Exome Sequencing to Deceased Participants’ Relatives.” *The American Journal of Bioethics*, 12(12): W9-W10 (2012).

Chan B, Facio F, Eidem H, Biesecker L, Hull SC, **Berkman BE**. Genomic inheritances: Disclosing individual research results from whole exome sequencing to deceased participants' relatives. *American Journal of Bioethics*; 12(10): 1-8 (2012).

Berkman BE, Rothenberg KH. Teaching Law Students to Be Policy-Makers: The Health and Science Policy Workshop on Genomic Research. *Journal of Law, Medicine, and Ethics*; 40(1): 147-153 (2012).

Solomon B, Hadley D, Pineda-Alvarez D, Kamat A, Teer J, Cherukuri P, Hansen N, Cruz P, Young A, **Berkman BE**, Chandrasekharappa S, Mullikin J. Incidental Medical Information in Whole-Exome Sequencing. *Pediatrics*;129:e1605 (2012); originally published online May 14, 2012; DOI: 10.1542/peds.2011-0080

Tabor HK, **Berkman BE**, Hull SC, and Bamshad MJ. Genomics Really Gets Personal: How Exome and Whole Genome Sequencing Challenge the Ethical Framework of Human Genetics Research. *American Journal of Medical Genetics Part A*, Epub ahead of print. 155(12): 2916-2924 (2011).

Berkman BE, Kim S and Wiley L. Assessing the Impact of Federal Law on Public Health Emergency Preparedness. *St. Louis University Journal of Health Law and Policy*, 4(1): 155-186 (2010).

Berkman BE. Incorporating Explicit Ethical Reasoning into Pandemic Influenza Policies. *Journal of Contemporary Health Law and Policy*, 26(1): 1-19 (2009).

Berkman BE. Mitigating Pandemic Influenza: The Ethics of Implementing a School Closure Policy. *Journal of Public Health Management and Practice*, 14(4): 372-8 (2008).

Gostin LO and **Berkman BE**. Pandemic Influenza: Ethics, Law, and the Public's Health. *Administrative Law Review*, 59: 121-175 (2007).

Gostin LO and **Berkman BE**. Ethics of Public Health Measures in Response to Pandemic Influenza," World Health Organization Working Group Paper (Project on Addressing Ethical Issues in Pandemic Influenza Planning) (2007).

Srabstein JC, **Berkman BE** and Pyntikova E. Anti-Bullying Legislation: A Public Health Perspective. *Journal of Adolescent Health* 42(1): 11-20 (2008).

Weiss RD, Griffin ML, Mazurick C, **Berkman BE**, et al. The Relationship Between Cocaine Craving, Psychosocial Treatment, and Subsequent Cocaine Use. *American Journal of Psychiatry*, 160: 1320-5 (2003).