

Curriculum Vitae

Benjamin E. Berkman, JD, MPH

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CURRENT POSITION

- 2009 – Present** **Faculty**
NIH Department of Bioethics
Head, Section on Ethics of Genetics and Emerging Technologies
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

AWARDS AND HONORS

- 2022 NIH Clinical Center CEO Award**
Making an Impact: Bioethics Consultation Service Team

- 2021** NIH Clinical Center CEO Award
Advanced Directive Policy Working Group
- 2019** NHGRI Group Recognition Award for the Bioethics Core
- 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).

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

Jamal L, Schupmann W, **Berkman BE**. An Ethical Framework for Genetic Counseling in the Genomic Era. In *Consuming Genomics* (I. G. Cohen, H. T. Greeley, N. A. Farahany, eds.) (2021).

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, 2020).

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, 2020).

Berkman BE. Unresolved Ethical Questions Raised By Genomic Sequencing Research. In *Total Exposure Health: An Introduction* (P.R. Yamamoto, ed.). (Boca Raton; CRC Press, 2020).

Sullivan HK and **Berkman BE**. Researcher Management of Unanticipated and Incidental Findings in Low Resource Settings. In *Viral Sovereignty, Technology Transfer, and the Global System for Sharing Pathogens for Public Health Research* (S. Halabi and R. Katz, eds.) (Cambridge: Cambridge University Press, 2020).

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).

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

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

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).

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

Hendriks S, Althaus J, Atkinson MA, Baschat AA, Berkman BE, Grady C, Wasserman W, Wendler D, Miller JL. Precarious Hope: Ethical Considerations for Offering Experimental Fetal Therapies Outside of Research After Initial Studies in Human. *Prenatal Diagnosis* (forthcoming).

Musvipwa F, Wonkam A, **Berkman BE**, De Vries J. Perspectives of Researchers, Science Policy Makers and Research Ethics Committee Members on the Feedback of Individual Genetic Research Findings in African Genomics Research. *BMC Medical Ethics* (forthcoming).

Astrachan I and **Berkman BE**. Distinguishing “Reasonable Accommodation” From Physical Assistance in Aid-in-Dying. *American Journal of Bioethics* 23(9): 28-30 (2023).

Jamal L, May M, Setzer MR, Yu M, **Berkman BE**, and Similuk M. Research participants’ perspectives about the return of uninformative genomic test results in a clinical research setting. *Journal of Genetic Counseling* (forthcoming 2023).

Mumford K, Roesner N, **Berkman BE**. The Potential Role of Nudging in Expanded Non-Invasive Prenatal Testing. *American Journal of Bioethics* (forthcoming 2023)

Roesner N, Jamal L, Wasserman D, **Berkman BE**. Reason-Based Abortion Bans, Disability Rights, and the Future of Prenatal Genetic Testing. *American Journal of Law and Medicine* 48(2-3): 187-199 (2022).

Miner SA, Similuk M, Jamal L, Sapp J, **Berkman BE**. Genomic tools for health: Secondary findings as *findings* to be shared. *Genetics in Medicine* 24(1): 2220-2227 (2022).

Euwoso C, **Berkman BE**, Wonkam A., De Vries J. Should Institutions Fund Feedback of Individual Findings in Genomic Research. *Journal of Medical Ethics* <http://dx.doi.org/10.1136/medethics-2021-107992> (2022).

McGrew S and **Berkman BE**. When to Disclose a Borderline Incidental Finding. *American Journal of Bioethics* 22(10):91-93 (2022).

Berkman BE, Miner SA, Wendler D, Grady C. The Ethics of Encouraging Employees to Get the COVID-19 Vaccination. *Journal of Public Health Policy* 43(2): 311-319 (2022).

Miner SA, **Berkman BE**, Jamal L, Altieri De Jesus V, Grady C. Navigating pandemic moral distress at home and at work: Frontline workers' experiences. *AJOB Empirical Bioethics* 13(4): 215-225 (2022).

Strassle CL, Schwann B, **Berkman BE**. Autonomy Concerns with Using Contracts to Enhance Patient Adherence. *Bioethics* 36(6): 666-672 (2022).

Hendriks S, Grady C, Wasserman D, Wendler D, Bianchi DW, **Berkman BE**. A new ethical framework for assessing the unique challenges of fetal therapy trials: Response to Commentaries. *American Journal of Bioethics* 22(3): W1-W3 (2022).

Bayefsky MJ and **Berkman BE**. Access to Expanded Prenatal Genetic Testing: Response to Open Peer Commentaries. *American Journal of Bioethics* 22(5): W1-W3 (2022).

Bayefsky MJ and **Berkman BE**. Implementing Expanded Prenatal Genetic Testing: Should Parents Have Access to Any and All Fetal Genetic Information? *American Journal of Bioethics* 22(2): 4-22 (2022).

McGrew S, Raskoff, S, **Berkman BE**. When Not to Even Ask: A Defense of Choice-Masking Nudges in Medical Research. *Journal of Health Care Law and Policy* 25(1):1-48 (2022).

Berkman BE, Schupmann W. Response to Clayton et al. *Genetics in Medicine* 24(2):501-502 (2021).

Schupmann W, Miner SA, Sullivan HK, Glover JR, Hall JE, Schurman SH, and **Berkman BE**. Exploring the Motivations of Research Participants Who Choose Not to Learn Medically Actionable Secondary Genetic Findings about Themselves. *Genetics in Medicine* 23(12): 2281-2288 (2021).

Hendriks S, Grady C, Wasserman D, Wendler D, Bianchi DW, **Berkman BE**. A new ethical framework for assessing the unique challenges of fetal therapy trials. *American Journal of Bioethics* 22(3): 45-61 (2021).

Berkman BE, Mastroianni A, Jamal L, Solis C, Taylor H, Hull SC. The Ethics of Repurposing Previously Collected Research Biospecimens in an Infectious Disease Pandemic. *Ethics and Human Research* 43:1-17 (2021).

Pierson L, Gibert S., **Berkman BE**, Danis M, Millum J. Allocating Scarce Biospecimens for Use in Research. *Journal of Medical Ethics* 47:740-743 (2021).

Miner S, Miller W, Grady CG, **Berkman BE**. It's just another added benefit": Women's experiences with employment-based egg freezing programs. *AJOB Empirical Bioethics* 12(1):41-52 (2021).

Strassle CL and **Berkman BE**. Prisons and Pandemics. *San Diego Law Review* 57(4): 1083-1125 (2020).

Strassle CL, Jardis E, Ochoa J, **Berkman BE**, Danis M, Rid A, Taylor HA. Should Incarcerated Populations be Enrolled in COVID-19 Vaccine Trials? *NEJM* 383:1897-1899 (2020).

Wendler D, **Berkman BE**. Maximizing the Value of Human Biospecimens: Lessons from the Coronavirus and the Seattle Flu Study. *American Journal of Medical Genetics Part A* 182(12):2826-2828 (2020).

Van Dikje I, **Berkman BE**, Bredenoord A, Henneman L, Vliegenthart R, Repping S, Hendriks S. Should germline genome editing be allowed? The effect of treatment characteristics on public acceptability. *Human Reproduction* 36(2):465-478 (2020).

Berkman BE. Commentary on the Right Not to Know and the Obligation Not to Know. *Journal of Medical Ethics* 46(5):304-305 (2020).

Schupmann W, Jamal L, **Berkman BE**. Re-Examining the Ethics of Genetic Counseling in the Genomic Era. *Journal of Bioethical Inquiry* 17:325-335 (2020).

Jamal L, Schupmann W, **Berkman BE**. An Ethical Framework for Genetic Counseling in the Genomic Era. *Journal of Genetic Counseling* 29:718-727 (2020).

Berkman BE, Brody LC, Collins FS and Green ED. Karen Rothenberg's (Not So) Secret Roles and Contributions at the U.S. National Institutes of Health. *Journal of Health Care Law and Policy* 22:167-171 (2020).

Strassle CL and **Berkman BE**. Workplace Wellness Programs: Empirical Doubt, Legal Ambiguity, and Conceptual Confusion. *William and Mary Law Review* 61:1663-1717 (2020).

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):e20171202 (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).

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**. When Should Genome Researchers Disclose 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(6):e1605-11 (2012).

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).

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).