

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

Roesner N, McGrew S, Connor C, **Berkman BE**. Artificial Womb Technology: Emerging Legal and Bioethical Debates in Ectogestation. *Yale Journal of Health Policy, Law, and Ethics* (forthcoming).

Mumford K, Hendriks S, Miner S, Huelsnitz CO, Wakim P, **Berkman BE**. Factors Affecting Couples’ Decision-Making About Expanded Prenatal Cell-Free DNA Screening. *Genetics in Medicine Open* (forthcoming).

Bonini KE, Smith HS, Bonkowski ES, **Berkman BE**, Jamal L. Modern Family: An Ethical Justification for System-Led Contact of Relatives Eligible for Cascade Screening in the United States. *Public Health Genomics* (forthcoming).

Connor C and **Berkman BE**. Incorporating Research Burden and Utility Considerations as Limiting Factors in a Framework for Returning IRR. *American Journal of Bioethics* 24(2):96-98 (2024).

Grebe TA, Khushf G, Grealley J, Turley P, Foyouzi N, Rabin-Havt S, **Berkman BE**, Pope K, Vatta M, Kaur S; on behalf of the ACMG Social, Ethical and Legal Issues Committee. Clinical utility of polygenic risk scores for embryo selection: A points to consider statement of the American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine* 26(4): pages (2024).

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* 25:67 (2024).

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).