

BIOGRAPHICAL SKETCH

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NAME: Debra JH Mathews

eRA COMMONS USER NAME (credential, e.g., agency login): DJHMATHEWS

POSITION TITLE: Assistant Director for Science Programs, Berman Institute of Bioethics; Associate Professor, Department of Genetic Medicine

EDUCATION/TRAINING (*Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.*)

INSTITUTION AND LOCATION	DEGREE (if applicable)	Completion Date MM/YYYY	FIELD OF STUDY
Pennsylvania State University	BS	05/1997	Biology
Case Western Reserve University	MA	09/2000	Biomedical ethics
Case Western Reserve University	PhD	01/2003	Genetics
Johns Hopkins University	Fellowship	2002-2004	Genetics
Johns Hopkins & Georgetown Universities	Fellowship	2002-2004	Bioethics/Health Policy

A. Personal Statement

As a human geneticist with training and experience in bioethics and policy, and working as a bioethicist on issues in emerging technologies, I bring a deep knowledge of basic science and discovery as well as a critical understanding of what is required to translate academic research into practical applications in the world. Within ethical, legal, and social implications (ELSI) of genetics and genomics, I conduct research, teach, provide service, and am involved in policy.

I have received both an R03 (#3R03HG004753) and an R01 (#R01HG008045) from NHGRI/ELSI, to study the impact of the ELSI program on federal policy, and the impact of presymptomatic genetic testing for Huntington's disease on at-risk families, respectively. I also served as a Co-Investigator on the Berman Institute Center for Excellence in ELSI Research (CEER), the Center for Bridging Infectious Disease, Genomics, and Society (BRIDGES; # RM1HG009038).

In the Spring of odd-numbered years, I teach a graduate level course on ELSI, genetics and genomics that enrolls graduate students in genetic counseling, genetics, genetic epidemiology, and other disciplines. In the Spring of even-numbered years, I teach a broader graduate-level course on ethics and policy issues raised by emerging biomedical technologies.

I have spent many years in multiple service and policy roles at Johns Hopkins, including on the School of Medicine IRB that reviews genetic research, on the Biospecimen Transfer Committee, and the Institutional Stem Cell Research Oversight Committee. Since 2020, I have served on the ELSI Committee of the Earth BioGenome Project, the goal of which is to sequence all eukaryotes.

I spent almost two years working part-time for the Presidential Commission for the Study of Bioethical Issues, as a Senior Policy and Research Analyst and staff lead on the 2012 genomics report. For the past three years, I have been working with the US National Academy of Medicine towards the development of a cross-sectoral governance framework for emerging technologies in health and medicine that meaningfully integrates equity and other guiding ethical principles.

In sum, I have a tremendous amount of experience relevant to this proposal, including a background in genetics, experience designing and conducting ELSI research, research ethics and ELSI service, and the translation of bioethics research and scholarship into policy.

B. Positions, Scientific Appointments, and Honors

Positions

1995-96 Research Internship in Yeast Genetics, Carlsberg Laboratory, Copenhagen, Denmark
2002-04 Greenwall Fellow in Bioethics and Health Policy, Johns Hopkins and Georgetown Universities
2002-04 Postdoctoral Fellow, Institute of Genetic Medicine, Johns Hopkins University
2003 Visiting Scholar, Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Science and Data Policy, Washington, DC
2004 Instructor, Department of Philosophy, Johns Hopkins University
2005- Assistant Director for Science Programs, Berman Institute of Bioethics, Johns Hopkins University
2005-20 Affiliate Faculty, McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins University
2005- Preceptor, Predoctoral Training Program in Human Genetics, Johns Hopkins University
2006-15 Assistant Professor, Department of Pediatrics, Johns Hopkins School of Medicine, Baltimore, MD
2011-12 Senior Policy and Research Analyst, Presidential Commission for the Study of Bioethical Issues, Washington, DC
2011- Joint Appointment, Department of Health, Behavior and Society, Johns Hopkins School of Public Health
2015-20 Associate Professor, Department of Pediatrics, Johns Hopkins School of Medicine
2019-22 Academic Collaborator, National Academy of Medicine Committee on Emerging Science, Technology, and Innovation
2020- Associate Professor, Department of Genetic Medicine, Johns Hopkins School of Medicine
2020- Secondary Appointment, Department of Pediatrics, Johns Hopkins School of Medicine
2020 Elected Fellow, The Hastings Center
2021- Ethics and Governance Lead, Institute for Assured Autonomy, JHU/APL

Other Experience and Professional Memberships

1999- Member, American Society for Bioethics and Humanities
2000- Member, American Association for the Advancement of Science
2001- Member, American Society of Human Genetics
2001- Member, Association for Practical and Professional Ethics
2005- Member, International Society for Stem Cell Research
2006- Member, International Neuroethics Society
2006-16 Student Pugwash USA, Board of Directors
2006-08 *Ad hoc* Reviewer, NIH/NIMH
2006-08 Member, MD Science Center, Cellular Universe, Advisory Board
2006-08 Member, Human Genome Hispanic Outreach Initiative Campaign
2008-09 *Ad hoc* Reviewer, NSF Peer Review Committee: Science, Technology, & Society Program
2009 Site Visit Team Member, NSF Peer Review Committee: Science, Technology, & Society Program
2009 American Society for Bioethics and Humanities, Membership Taskforce & Mentorship Subgroup
2009 Site Review Team Member, National Science Foundation
2009-10 Member, University of Maryland Biotechnology Institute
2009-10 Member, Embryonic Stem Cell Research Oversight Committee
2009-13 Canadian Stem Cell Network, Scientific Advisory Board
2012 International Neuroethics Society, Member, Industry Sponsorship Subgroup
2012-19 Co-Chair, Centers for Mendelian Genomics, IRB Committee
2013-14 Member, International Expert Panel for the Canadian Stem Cell Strategy, Canadian Stem Cell Fdn.
2013-16 Member, National Human Genome Research Institute Data and Safety Monitoring Board
2014-20 Member, Coriell NIGMS Human Genetic Cell Repository Scientific Advisory Committee (Chair, 2016-19)
2014 *Ad hoc* Reviewer, NIH/NIDCR
2015, 19 *Ad hoc* Reviewer, Netherlands Organisation for Scientific Research, Vidi grant programme
2016 Reviewer, Division on Earth and Life Studies, National Academy of Sciences
2016 *Ad hoc* Reviewer, Societal and Ethical Issues in Research Study Section, NIH
2017-21 Member, Policy Review Committee, Canadian Stem Cell Network

- 2018-19 Member, International Neuroethics Society, Nominating Committee
- 2018-19 *Ad hoc* Reviewer, NIH/NCI
- 2019- Member, International Neuroethics Society, Executive Committee
- 2019 *Ad hoc* Member, NHGRI Council
- 2019- Member, NIDDK RADIANT Observational Safety and Monitoring Board (OSMB)
- 2019-21 Member, International Society for Stem Cell Research (ISSCR), Guideline Revision Committee
- 2020- Member, Ethics, Legal, and Social Issues sub-committee, Earth BioGenome Project Working Group
- 2020- Member, Johns Hopkins/National Human Genome Research Institute Genetic Counseling Training Program Working Group (Advisory Board)
- 2020- Member, Johns Hopkins University School of Medicine Biospecimen Transfer Committee
- 2021 Member, Johns Hopkins University AI-X Research and Scholarship Task Group
- 2021- Member, Johns Hopkins University AI-X Colloquium Committee
- 2021- Member, Research Management Committee, Canadian Stem Cell Network
- 2021- Member, Novel and Exceptional Technology and Research Advisory Committee (NExTRAC) Working Group on Data Science and Emerging Technology
- 2022- Member, Committee on Creating a Framework for Emerging Science, Technology, and Innovation in Health and Medicine (ESTI), National Academies of Sciences, Engineering, and Medicine
- 2022- President-Elect, International Neuroethics Society

C. Contributions to Science

I have contributed to policy development through the development and execution of a number interdisciplinary, international expert consensus conferences. The methods used and developed through the Stem Cell Policy and Ethics (SCOPE) program and the Hinxton Group, which I run, have served as a model for technology assessment in themselves and have produced influential products that have informed policy in both the US and the UK. I have also been deeply involved in work on emerging technology governance at the National Academy of Medicine since 2019.

- a. **Mathews DJH**, Sugarman J, Bok H, Blass DM, Coyle JT, Duggan PS, Finkel J, Greely HT, Hillis A, Hoke A, Johnson R, Johnston M, Kahn J, Kerr D, Kurtzberg J, Liao SM, McDonald JW, McKhann G, Nelson KB, Rao M, Regenber A, Siegel AW, Smith K, Solter D, Song H, Vescovi A, Young W, Gearhart JD, R Faden. (2008) *Cell-based Interventions for Neurological Conditions: Ethical Challenges For Early Human Trials*. *Neurology* 71(4):288-93. 7 May 2008.
 - b. **Mathews DJH**, Graff GD, Saha K, Winickoff D. (2011) Access To Stem Cells And Data: Persons, Property Rights, And Scientific Progress. *Science*. 331(6018):725-7.
 - c. **Mathews DJ**, Chan S, Donovan PJ, Douglas T, Gyngell C, Harris J, Regenber A, Lovell-Badge R. CRISPR: A Path Through the Thicket. *Nature*. 2015 Nov 12;527(7577):159-61.
 - d. **Mathews DJH**, Balatbat CA, Dzau VJ. Governance of Emerging Technologies in Health and Medicine - Creating a New Framework. *NEJM*. Epub 2022 Apr 13. doi: 10.1056/NEJMms2200907.
2. Another focus of my work has been the evolving role of individuals in research, from being merely subject to research, to being participants in research. This thread of my work runs across several technologies. This work has informed consensus and policy development involving staff of the California Institute of Regenerative Medicine and the National Institutes of Health.
- a. Rabins PV, Appleby BS, Brandt J, DeLong MR, Dunn LB, Gabriëls L, Greenberg BD, Haber SN, Holtzheimer III PE, Mari Z, Mayberg HS, McCann E, Mink SP, Rasmussen S, Schlaepfer TE, Vawter DE, Vitek JL, Walkup J, **Mathews DJH**. Scientific and Ethical Issues Related to Deep Brain Stimulation for Disorders of Mood, Behavior and Thought. *Arch Gen Psychiatry*. 2009; 66(9):931-7.
 - b. **Mathews DJ** & Jamal L. Revisiting Respect for Persons in Genomic Research. *Genes*. 2014. 5(1):1-12.
 - c. Ishan Dasgupta, Juli Bollinger, **Mathews DJH**, Neumann NM, Rattani A, Sugarman J. Patients' Attitudes toward the Donation of Biological Materials for the Derivation of Induced Pluripotent Stem Cells. *Cell Stem Cell*. 2014; 14(1):9-12.
 - d. **Mathews DJH** and Ram N. Get Law Enforcement Out of Biospecimen Authentication. *Science*. 2022 Jun;376(6599): 1274-1276.

3. My dual training and experience in science and ethics enabled me to join the staff of the Presidential Commission for the Study of Bioethical Issues as a part-time Intergovernmental Personnel Act appointment from 2011-2012. While not published under my name or solely my work, I designed and helped execute a massive document analysis project for the 2011 Guatemala report and was a Staff Lead on the 2012

Genomics report. The Guatemala report was produced alongside a phenomenal archive for historians and others interested in studying the events from 1946-1948. In addition, this work earned the project team an award from the Office of the Assistant Secretary for Health in the U.S. Department of Health and Human Services. Both the Guatemala and the Genomics reports continue to be used and cited.

- a. Presidential Commission for the Study of Bioethical Issues. "Ethically Impossible": STD Research in Guatemala from 1946 to 1948. Sep 2011. Washington, DC. (Role: Senior Policy & Research Analyst)
- b. Presidential Commission for the Study of Bioethical Issues. Privacy and Progress in Whole Genome Sequencing. Oct 2012. Washington, DC. (Role: Staff Lead)

Complete List of Published Work in MyBibliography:

<https://www.ncbi.nlm.nih.gov/myncbi/browse/collection/48023870/?sort=date&direction=ascending>