

Shaping Bioethics Policy and Practice through Leadership and Service

> BERMAN INSTITUTE OF BIOETHICS ANNUAL REPORT 2023-2024

Table Of Contents

FEATURE SECTION

- 2 Shaping Bioethics Policy and Practice through Leadership and Service
 - 3 Addressing Policy
 - 5 Safeguarding the Welfare of Research Participants
 - 5 Protecting Patients' Health
 - 6 Impacting Public Discourse and Sharing Knowledge
 - 7 Contributing Analysis Locally, Nationally, and Around the World
 - 8 Convening to Inform Societal Issues
- 8 Leaders in Service

YEAR IN REVIEW

12 Select Highlights

- 12 Groundbreaking: Honoring the Transformative Legacy of Henrietta Lacks
- 14 In An Enemy of the People, Public Health Discourse Takes Center Stage
- 16 playing god? Podcast Wins National Award, Brings Bioethics Issues to the Public and into Schools
- 16 Overcoming Barriers of Language and Literacy in Neonatal Intensive Care
- 18 Communicating Clinicians' Way to Better Patient Care
- 19 Rushton Honored by American Association of Colleges of Nursing
- 20 Faculty Elected Hastings Center Fellows

- 21 MBE Alumna wins ASBH Student Paper Award
- 22 Faculty Assume New Leadership Roles
- 22 Catastrophe Ethics: How to Choose Well in a World of Tough Choices
- 22 Mathews Appointed President of the International Neuroethics Society
- 24 Multiple Faculty Receive Nexus Awards to Pursue Innovative Interdisciplinary Projects
- 26 Faculty Research Grants
- 26 Faculty Receive Discovery Award for Project Highlighting Children with Medical Complexity
- 28 Scholarship and Research
- 32 In the News

SUPPORT AND LEADERSHIP

- 34 Morain Appointed Inaugural Dracopoulos Rising Professor in Bioethics
- 35 Top Students Receive Faden Scholarship
- 36 In Memory: David Levine and Richard Danziger
- 36 Figiel Named Development Director
- 37 National Advisory Board
- 38 2023-2024 Philanthropic Supporters

COVER PHOTO: HOPKINS BLOOMBERG CENTER, A VITAL NEXUS FOR BERMAN INSTITUTE FACULTY TO CONVENE ACADEMIC AND GOV_ENMENT LEADERS

Director's Letter



T is my great pleasure to share the 2023-24 Johns Hopkins Berman Institute of Bioethics Annual Report. Throughout the year, Berman Institute faculty continued to make outsized contributions in bioethics, not only through their groundbreaking scholarly research and outstanding teaching, but also in their leadership and service to the field and society at large. Our faculty are committed to making a real-world difference, by helping shape laws and policies at the state and national levels, convening gatherings of government and academic leaders to explore solutions to unprecedented challenges, safeguarding the health and welfare of medical patients and research participants, and much more.

Our faculty undertake these challenges not because it is their job, but because it is their purpose. Their tireless work in effecting meaningful societal change is part of our institutional culture. As Berman faculty gain recognition for their achievements in service, they are invited to take on more, higher-profile assignments. In so doing, they capture the attention of other leaders in the field and attract new colleagues who share our commitment to helping make a difference in the world.

The Berman Institute is able to pursue such meaningful work only through the support of our many friends and volunteers. Our faculty's impact — in the traditional areas of scholarship and teaching, as well as in broader areas of societal impact — could not happen without the generosity of our donors. On behalf of the entire Berman Institute community of faculty, staff, trainees and students, thanks for all your support to make our work possible.

Warmly,

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Jeffrey P. Kahn, PhD, MPH Andreas C. Dracopoulos Director Johns Hopkins University Berman Institute of Bioethics

Shaping Bioethics Policy and Practice through Leadership and Service In presenting the Cornerstone Award to the Johns Hopkins Berman Institute of Bioethics last year, the American Society for Bioethics & Humanities said, "the Berman Institute has been one of the truly foundational institutions in the field of bioethics and it is difficult to imagine our field without their influence."

The Berman Institute is renowned, nationally and internationally, for the quality of its academic programs and the outstanding scholarship of its faculty. But what makes its influence so profound is the commitment of its leadership, faculty, and students to transcending the halls of academia to help make the world a more ethical place.

From helping shape state and federal law and policy, to safeguarding the health and welfare of human research participants, to educating the public about important bioethics issues, the leadership efforts of Berman Institute faculty serve society in countless ways.

"The Berman Institute has always had a very real-world orientation. It attracts faculty and students who want to be working on questions about ethics side-by-side with the people working in the health department, or treating patients in the ICU, or conducting stem cell research," said Jeffrey Kahn, Andreas C. Dracopoulos Director of the Institute.

On the following pages, read more about the many ways the Berman Institute is having an impact.

Addressing Policy

WHEN PEOPLE ARE RELEASED from prison or

jail, the weeks and months afterward can be a dangerous time, especially for those addicted to opioids, such as prescription pain pills, heroin or fentanyl. Drug overdose is among the top causes of death when people funnel back into communities with diminished drug tolerance and often little support to help keep them from using again.

That's why Maryland lawmakers passed a bill in 2019 requiring all local correctional facilities to screen people for opioid use disorder and offer three types of medications to stem cravings and prevent debilitating withdrawal symptoms. Lawmakers sought to address an opioid crisis that has worsened with the rise of fentanyl and during the pandemic.

The first-in-the-nation law required all Maryland jails to have opioid treatment programs in place by 2023, but fewer than half of the affected local governments — 11 counties and Baltimore City — were fully compliant as of that deadline. With opioid overdose deaths across Maryland averaging about seven a day, there is a particular urgency to providing treatment to incarcerated individuals, said the Berman Institute's Brendan Saloner, Bloomberg Professor of American Health in Addiction and Overdose in the Hopkins School of Public Health.

"We have one of the most volatile, unpredictable drug supplies on the streets of cities like Baltimore right now, and we have people in crisis and we're not helping them," said Saloner, who serves on a steering committee set up by the state of Maryland last year to discuss challenges in establishing jail treatment programs. "People who have been incarcerated are hugely overrepresented in the overdose death numbers in the state, so if we want to get those



numbers down as a stated public health priority, we need to focus on helping people who are at the greatest risk of overdose," Saloner said. "The people who are cycling in and out of jail or prison are one of the main priorities the state needs to keep their focus on."

Saloner also testified before the U.S. Senate Committee on Finance's Subcommittee on Health Care on April 9, 2024. Speaking at a hearing titled "Closing Gaps in the Care Continuum: Opportunities to Improve Substance Use Disorder Care in the Federal Health Programs," he argued that treatment of substance use disorders should be supported with the same federal resources, oversight and standards as any other chronic disease.

Saloner's efforts this year place him in a longstanding tradition of Berman Institute faculty who strive to shape more ethical laws and practices.

"It is vitally important that those who are making policy and law have the best information and greatest expertise available to them, and our faculty work hard to provide that guidance," said Berman Institute director Jeffrey Kahn.



Saloner appearing at panel about the cost of mental health inequities sponsored by The Hill



YORAM UNGURU, a faculty member at the Institute and pediatric oncologist at Sinai Hospital in Baltimore, has spent years sounding the alarm about the skyrocketing number of drug shortages in the United States. He is a member



of the Children's Oncology Group and leads a multidisciplinary, transnational working group examining the ethical and policy implications of chemotherapy shortages in

childhood cancer. Unguru has testified before Congress about shortages, and currently serves on a U.S. Food and Drug Administration Committee working to resolve pediatric cancer drug shortages.

In a paper published in JAMA Pediatrics, Unguru argued that the U.S. should establish an essential medicines list, like many other countries already have. As defined by the World Health Organization, essential medicines satisfy the priority health care needs of the population. Medicines included in the essential medicines list are both clinically effective and cost effective and are to be available within the context of functioning health systems at all times in adequate amounts and dosage forms, with assured quality and at an affordable price.

"The cynic in me says that people quickly forget about shortages, once they are resolved for the short-term. But I'm hoping that through advocacy



work, the recent federal Mitigating Emergency Drug Shortages Act that Senators Collins and Smith have introduced might make a difference. I don't believe drug shortages will be resolved until the government steps in," said Unguru.

BERMAN INSTITUTE FACULTY MEMBERS

Anne Barnhill and Ruth Faden are engaged in a 3-year project entitled "Enabling Ethical Analysis and Public Justification in State-Level Pandemic Responses in the United States" that will create ethics guidance and tools for state policymakers to use during public health emergencies like

the COVID-19 pandemic. Barnhill and her team are interviewing gubernatorial chiefs of staff and other policymakers involved in state-level policies promulgated during



the pandemic, such as school closing and reopening, vaccine allocation, and support for unemployed workers, to learn how those decisions were reached and to examine their effects. They aim to develop guidance and tools that will assist in the creation of effective, equitable policies for a future pandemic.

"During the COVID-19 pandemic, state governments adopted policies that profoundly affected personal and public life, in some cases imposing costs, curtailing freedom and exacerbating inequities," said Barnhill. "Our work is aimed at ethically assessing such high-stakes policy decisions, accounting for the diverse perspectives and values held by the public, and ensuring they will be clearly explained and justified to the public."



Publicly launched in 2018, All of Us is an effort by the National Institutes of Health to enroll at least one million people from across the U.S. in a research program to advance medical research. By sharing information about their health, habits, and what it's like where they live, participants will help researchers identify patterns that might otherwise be undetectable and use that information to tailor new approaches to medical treatment and care.

TO ENSURE THE RIGHTS AND WELFARE

of people who submit their information are protected in this unprecedented research effort, the NIH turned to Nancy Kass, the Berman Institute's deputy director for public health. Kass has served as Chair of the All of Us Institutional Review Board (IRB) since its inception, over-



seeing the panel of experts responsible for reviewing and approving research on human participants.

"Our work at the outset was making sure the rollout

of the program was ethically appropriate. We are very committed to making sure the explanation of the research is clear and accessible enough for people to make a truly informed decision about participating," said Kass, who is joined on the All of Us IRB by Berman Institute faculty member Kadija Ferryman.

"At this phase of the project, much of our focus is making sure participants are respected and protected in the course of the project, and that the research being conducted is important and beneficial enough to balance out any risks or burdens they are asked to assume."





BERMAN INSTITUTE FACULTY also play a critical role in the Johns Hopkins IRB system, serving as members of all six School of Medicine and both School of Public Health IRBs, with two faculty members in leadership positions on their respective IRBs. The IRBs review all human subjects research projects conducted by Hopkins faculty and staff, and institutional guidelines require that a Berman faculty member serve on each of the IRBs.

"So many of our faculty love to do real world work, and I think they have learned how to talk about ethics in a way that makes sense to specialists in other fields who don't think about ethics exclusively," said Kass. "If we're working side-by-side with researchers in data, or genetics, or some other technical area, we're much more valuable if we can talk about ethics in a way that makes sense to them in their world."

Protecting Patients' Health

Within Hopkins Medicine, Berman faculty Mark Hughes and Cynda Hylton Rushton co-chair the Ethics Committees and Consultation Services at Johns Hopkins Hospital and Joseph Carrese fills the same role at Johns Hopkins Bayview Medical Center. The Ethics Committee provides consultation to care providers and patients concerning ethical questions, educates health care workers on how to resolve ethical dilemmas, and addresses organizational ethical issues, among other functions.



Impacting Public Discourse and Sharing Knowledge

EARLY ON A MONDAY MORNING in November, Berman Institute director Jeffrey Kahn is one of the first people in Deering Hall, arriving even before the heating system has dissipated the weekend chill in the building. But Kahn is warm under the bright lights of a film crew that has traveled from overseas to interview him for a documentary about Henrietta Lacks that will air on Japan's leading news network. While it is sometimes challenging to find time in his busy schedule, accommodating requests from journalists is a priority for Kahn.

"Bioethics is a complex field, regularly producing information that is genuinely important to share. And yet that information is too often inaccessible to the public, even as very important bioethics issues are being discussed in the media and around kitchen tables," he said. "The importance of ethical and policy issues in our everyday lives makes the case for effective, compelling bioethics communication even more urgent, as these discussions will continue whether bioethicists enter the public discourse or not."

Kahn is a regular guest on Baltimore's NPR affiliate, is quoted frequently in The New York Times and other leading media outlets, and encourages his faculty to be similarly receptive to media requests. But fulfilling his vision of making the Berman Institute and Johns Hopkins the world leader in the communication and dissemination of ethics research, scholarship, and commentary to the public requires a programmatic focus on developing new approaches for disseminating faculty research and insight.

The creation of the Dracopoulos-Bloomberg Bioethics iDeas Lab at the Berman Institute is a crucial step in this effort. Dedicated to using storytelling and multimedia in service of promoting engagement and widespread communication with topics in bioethics, the iDeas Lab had a groundbreaking year as its first completed projects emerged.

The work of the iDeas Lab spanned a great array of audiences and purposes, including the production of two podcasts, *Bot Love* and *playing god*?, which reached over 300,000 listeners; the creation of a new tool to assist in NICU patient care through partnerships with the Berman Institute and School of Medicine faculty; and international and local consultive work that brought the lab's skills and connections to bear on the efforts of other talented academics both inside and outside of Johns Hopkins. This work continues to be recognized and amplified through a number of formal speaking invitations as well as prestigious grants.



"Can creative approaches to bioethics communication improve the work of bioethics?" asked Kahn. "We're eager to explore how new approaches might help

address difficult ethical questions. Can immersive storytelling help research participants understand the risks and benefits of research participation? We've done a really good job communicating with people in our field. Our peers and people we're trying to help in the trenches know who we are and what we do. We're never going to exclude those audiences. But we're going to work beyond the traditional boundaries of bioethics. Everyone should know who the Berman Institute is and what we do."

Contributing Analysis Locally, Nationally, and Around The World

ELECTION TO THE NATIONAL ACADEMIES

signifies recognition as a leading expert in a particular field, allowing an individual to contribute to independent, evidence-based advice on critical national issues and provide expertise to inform government policy decisions through rigorous research and analysis.

"It is rare and prestigious for a bioethics program to have even one member of its faculty elected to the National Academies," said Berman Institute director Jeffrey Kahn. "We have four members on our faculty."

In addition, numerous Berman Institute faculty serve on National Academies committees. Kahn serves as the Chair of three such committees, and other Institute faculty include Kadija Ferryman, on the Steering Committee for Responsible AI Code of Conduct, Nancy Kass, on the Learning Health Systems Strategy Group, and Anna Mastroianni on the Standing Committee on Aerospace Medicine and the Medicine of Extreme Environments.

National Academy participation is just one example of the extraordinarily wide range of governing and advisory bodies on which Berman Institute faculty serve, ranging from the state to national and international levels.

"Membership in these groups allows us to provide a vital public service, bring ethical expertise to bear in a wide range of scientific and technological areas, address critical issues, and give unbiased advice to government and the public," said Kahn. "The Berman Institute attracts people who want to do this kind of work, and our reputation ensures that our faculty are in high demand for such positions." JOSEPH ALI, the Berman Institute's associate director for global programs, has worked on a number of World Health Organization (WHO) committees dedicated to ethics oversight of health-related research involving human participants.

"As clinical trial methods get more advanced and complicated, it makes such trials more susceptible to being designed and led by those with more resources. My work helped strengthen the capacity to implement fair partnerships, sharing leadership and all aspects of trials more equitably," said Ali, whose recent work in this regard has taken him to India, Gambia, and South Africa, among other destinations.

Ruth Faden serves the WHO as well, as a member of the Strategic Advisory Group of Experts on Immunization, the principal advisory group to WHO for vaccines and immunization. It is charged with advising WHO on overall global policies and strategies, ranging from vaccines and technology, research and development, to delivery of immunization and its linkages with other health interventions.

Closer to home, Debra Mathews followed a recent term as Chair of the Maryland Stem Cell Commission with an appointment to a two-year term as President of the International Neuroethics Society, where she has hopes to inspire discussion about the responsible use of advances in brain science.

"I stepped forward for consideration for this role, not only out of a sense of duty to this organization that's been such a critical part of my professional life literally from the beginning, and from which I've received so much, but also because I hope that I have something to offer," she said.





Convening to Inform Societal Issues

SINCE THE UNIVERSITY'S Hopkins Bloomberg Center (HBC) opened in the heart of Washington, DC, in October 2023, the Berman Institute has moved quickly to take advantage of the opportunities it creates for convening groups, hosting meetings, engaging in policy-related work, and connecting with policymakers, the National Academies, professional societies, non-governmental organizations, and others.

8

On May 21, 2024, the Institute launched its Center for Ethics, Law, Policy and the Life Science (CELLS), a new program area for Johns Hopkins. More than 100 experts from across the US and abroad gathered for its inaugural conference to discuss emerging areas of life sciences technologies and their applications, the state of approaches to ethics, law, and policy issues raised by these technologies, and identified

gaps and opportunities for addressing the issues. The conference helped shape the initial work of CELLS, which includes issue mapping, policy analysis, and governance recommendations.

The Berman Institute returned to HBC in October 2024 to host the Johns Hopkins AI Ethics and Governance Symposium, bringing together experts from around the world to bridge siloed conversations and literatures, and help build an interdisciplinary community to work toward a future where the development and application of AI is aligned with societal needs, interests, and values. Experts in AI applications, AI ethics, safety, assurance, and algorithmic fairness met to synthesize and map an approach to shared and domain-specific issues in the four key areas of health and medicine, democracy, transportation, and defense and security.

One session brought together scholars and congressional advisors to discuss the impact of President Joe Biden's October 2023 executive order that directed the Department of Commerce to develop guidelines governing the use of AI to promote its "safe, secure, and trustworthy development and use."

"The executive order focuses on two things very early on. It says we must focus on harnessing AI as well as protecting against the perils. And there's a lot, text wise, devoted to the latter point, and I would like to have seen more devoted to the former point of harnessing AI, especially in federal agencies," said Dean Alderucci, a senior congressional fellow and senior advisor for AI with the U.S. House of Representatives' Committee on Science, Space, and Technology.

"It would be really simple to destroy all potential for any risk whatsoever. Don't use AI. The reason we have these conversations

about risks is because we want to use AI, and for good reason. We quite literally could transform our society, could transform people's lives for the better."

In addition to the panel sessions, Berman Institute director Jeffrey Kahn moderated a conversation with Victor Dzau, President of the National Academy of Medicine, and Marcia McNutt, President of the National Academy of Sciences, about the role of the national academies in ensuring ethical governance of AI.

LEADERS

IN SERVICE

In addition to their original research,

scholarship, teaching, mentoring, and

public awareness outreach, Berman

Institute faculty perform significant

University to the broader local,

national and global communities.

service activities in the 2023-2024

academic vear.

service — from within Johns Hopkins

Below is a partial list of our faculty's

Joseph Ali, JD

Steering Committee U.S. National Institutes of Health/U.S. Collaboratory Coordinatina Center

Clinical Study Oversight Committee U.S. National Institutes of Health Ethics Oversight World Health Organization Institutional Review Board

Associate Editor, Human Research Ethics Journal of Empirical Research

Anne Barnhill, PhD

Data Safety and Monitoring Board Nutrition for Precision Health Editorial Board Food Ethics Advisorv Board **Culinary Mind Network**



ROBERT H. LEVI LEADERSHIP SYMPOSIUM

The Berman Institute's longstanding commitment to convening experts is embodied in the annual Robert H. Levi Leadership Symposium, which brings leading experts to Baltimore for a public presentation and two-day working session addressing critical issues in bioethics. Recent topics include:

- the environmental impacts of disposable medical equipment;
- the ethics of virtual humans:
- challenges in supporting children with medical complexity; and
- the ethics of containing infectious disease.

Co-Chair, Ethics and Regulatory Work Group

- Department of Veterans Affairs/U.S. Department of Defense Pain Management
- Data Safety and Monitoring Board (DSMB) and
- Working Group on Measuring Ouality of Research
- Johns Hopkins Bloomberg School of Public Health

Mary Catherine Beach, MD, MPH

Co-Chair Institutional Review Board Chair, Executive Institutional Review Board Co-Director, Initiative for Humanizing Medicine Johns Hopkins Medicine

Juli Bollinger, MS

Institutional Review Board Genetic Counseling Consortium Johns Hopkins Medicine

Renee Boss, MD, MHS

Executive Committee American Academy of Pediatrics' Section of Hospice and Palliative Medicine Chair National Human Genome Research Institute **Data Safety and Monitoring Board**

Organ Donor Council Johns Hopkins Medicine

Lomax Boyd, PhD

Ad hoc Reviewer, ReDDDot Program Panel Reviewer, ENG EFRI Program National Science Foundation

LEADERS IN SERVICE (CONT.)

Joseph Carrese, MD, MPH, FACP

Chair, Institutional Review Board Johns Hopkins Medicine Chair Ethics Committee Johns Hopkins Bayview Medical Center

Ruth Faden, PhD, MPH

COVID-19 Ethics & Governance Working Group Working Group on Tuberculosis and Pregnancy Vaccine Strategic Advisory Group of Experts on Immunization, Working Group on COVID-19 Vaccines and Vaccination World Health Organization Evidence Mobilization Action Collaborative

Working Group

Inclusive, Equitable Systems Working Group National Academy of Medicine

Strengthening the Usefulness of Epidemiological Modeling

Lancet Commission

Ethics Advisor, Office of the Commissioner U.S. Food and Drug Administration

HeLa Genome Data Access Working Group, Advisory Committee to the Director U.S. National Institutes of Health

Member

Maryland Judicial Ethics Committee

Editorial Board **Dublic Health Ethics**

International Advisory Board Journal of Medical Ethics

Kadija Ferryman, PhD

Institutional Review Board Member All of Us Research Program, U.S. National Institutes of Health Steering Committee, Responsible AI Code of Conduct National Academy of Medicine

Co-Chair Black Health Informatics Working Group

Responsible AI Task Force Al and Data Trust Council Public Health AI Strategic Effort Validation and Curation Committee Johns Hopkins Medicine

Gail Geller, ScD, MHS

Co-Director, "Culture of Medicine" Core Theme, Undergraduate Medical Curriculum Advisory Board Center for Medical Humanities and Social Medicine Johns Hopkins University

Mark Hughes, MD, MA

Co-Chair, Ethics Committee Medical Board Administrative Committee Johns Hopkins Hospital

Coordinator, Annual Holocaust Remembrance Day Johns Hopkins Schools of Medicine and Nursing

Jeffrey Kahn, PhD, MPH

Chair. Committee on Processes to Evaluate the Safety and Efficacy of Drugs for Rare Diseases or Conditions in the United States and the **European Union** Chair, Standing Committee on Aerospace Medicine and Medicine of Extreme Environments National Academies of Sciences. Engineering. and Medicine

Steering Committee, Epidemic Ethics Working Group

World Health Organization Advisory Board

Center for ELSI Resources and Analysis

Chair, Board on Health Sciences Policy National Academy of Medicine

Science Review Committee

Genome Canada Emeritus President and Director

Association of Bioethics Program Directors

Nancy Kass, ScD

Chair, Institutional Review Board All of Us Research Program, U.S. National Institutes of Health

Ethics Advisor, Office of the Commissioner U.S. Food and Drug Administration

Strategy Group, Learning Health Systems National Academy of Medicine

> National Academies of Sciences, Engineering, and Medicine

> > Novel and Exceptional Technology and Research Advisory Committee

Olivia Kates, MD, MA

Institutional Review Board

Johns Hopkins Medicine

Deceased

Bioethicist

Ethics Committee

Transplantation

Clinical Infectious Diseases

Community of Practice

Bioethics Advisory Panel

Administration

and Medicine

Lactating Persons

President

National Academy of Medicine

Debra Mathews, PhD, MA

International Neuroethics Society

Earth BioGenome Project

Health and Medicine

Section Editor

Associate Director for Ethics and Qualitative

Review Committee for Research in the Recently

National Tuberculosis Controllers Association

Guideline Development Group for TB Isolation

International Society of Heart and Lung

Co-Chair, Conflict of Interest Committee

American Society of Transplantation

U.S. National Aeronautics and Space

the Medicine of Extreme Environments

Standing Committee on Aerospace Medicine and

National Academies of Sciences, Engineering,

Committee on Developing a Framework to

Address Legal, Ethical, Regulatory, and Policy

Issues for Research Specific to Pregnant and

Chair, Ethics, Legal, and Social Issues Committee

Stem Cell-based Embryo Models Working Group

Emerging Science, Technology, and Innovation in

International Society for Stem Cell Research

Committee on Creating a Framework for

Anna Mastroianni, JD, MPH

Executive Committee Psychosocial and Ethics

Research Transplant Research Center

Working Group on Data Science and Emerging Technology

Co-Lead, AI & Society Cluster, Bloomberg Distinguished Professor Search Ethics and Governance Lead, Institute for Assured

Autonomy AI-X Colloquium Committee School of Medicine Biospecimen Transfer Committee

Johns Hopkins University

Advisory Board, Genetic Counseling Training Program Working Group Johns Hopkins/National Human Genome

Research Institute Research Management Committee

Canadian Stem Cell Network

Member (and past Chair) Marvland Stem Cell Research Commission

Maria Merritt. PhD

Maryland Health Professionals for a Healthy Climate

Participant, legislative visits with U.S. Senate and House staff

Society Consortium on Climate and Health

Stephanie Morain, PhD, MPH

Regulatory Core

Institutional Review Board Johns Honkins Medicine

Member, Data and Safety Monitoring Board

Editorial Board American Journal of Bioethics

Clinical Trials Advisory Panel Patient-Centered Outcomes Research Institute

Ethics Advisor. Office of the Commissioner

U.S. Food and Drug Administration

Hanna Pickard, DPhil

Advisory Board F1000Research Gateway for Addiction and **Related Behaviors**

Advisorv Board

Philosophical Gourmet Report

Volunteer "Philosopher-in-residence" Venniro Lab, Department of Anatomy & Neurobiology. University of Maryland School of Medicine

10

Committee Johns Hopkins Medicine Collaborative

Travis Rieder, PhD

Reduction Services

Study for the Treatment of Methamphetamine Use Disorder

Editorial Board

Leonard Rubenstein, JD, LLM

The Lancet

American Luna Association and the Medical

and Medicine

Co-Chair, Pragmatic Trials Collaboratory Ethics &

U.S. National Institutes of Health

U.S. National Institute of Mental Health

America

Brendan Saloner, PhD

Advisorv Board

Nurses

Steering Committee

Guest Editor

Institutional Review Board Institutional Stem Cell Research Oversight

Clinical Research Ethics Consultation

National Advisory Council for Drug Abuse Chair, Data and Safety Monitoring Board SHOUT Study for Evaluating Low-Barrier Harm Data and Safety Monitoring Board

Kennedy Institute of Ethics Journal

Commission on Health and Human Rights

Advisor, Committee on Human Rights National Academies of Sciences, Engineering,

Cynda Hylton Rushton, PhD, RN

Co-Chair, Ethics Committee Johns Hopkins Hospital Chief Synergy Strategist Renewal, Resilience and Retention for Maryland

Shav Center for Moral Injury, Volunteers of

Implementation of Maryland House Bill 116

Rebecca Seltzer, MD, MHS

Monash Bioethics Review (special edition)

Jeremy Sugarman, MD, MPH, MA

Co-Chair, Institutional Stem Cell Oversight Committee Johns Hopkins Medicine Scientific and Research Advisory Committee Canadian Blood Services Ethics and Public Policy Committees International Society for Stem Cell Research Ethics Advisory Panel for Science and Technology Merck KGaA Editorial Board AJOB Empirical Research Editorial Board Narrative Inquiry in Bioethics Special Advisor, Advisory Editorial Board EMBO Reports Editorial Board Journal of Law and Biosciences Editorial Board Ethics & Human Research Clinical Advisory Panel Aspen Neurosciences

Yoram Unguru, MD, MS, MA

Chairman Ethics Committee Vice Chair. Medical Executive Committee Co-Chair, Patient Advisory Committee Sinai Hospital Clinical Guidelines Steering Committee Artificial Intelligence Governance Committee LifeBridae Health Chair Children's Oncology Group Bioethics Committee Steering Committee and Chairman, Working Group Chemotherapy Drug Shortages in Pediatric Oncology Founding Member and Chairman Children's Oncology Group Allocation Task Force Temporary Member and Ethics Expert Participant U.S. Food and Drug Administration Center for

Drug Evaluation and Research, Pediatric Oncology Subcommittee of the Oncologic Drugs Advisory Committee Meeting

GROUNDBREAKING: HONORING THE TRANSFORMATIVE LEGACY OF HENRIETTA LACKS

Leaders gather to launch construction of Berman Institute's new home



From left to right: U.S. Rep. Kweisi Mfume, Jeri Lacks Whye, JaBrea Rodgers, Veronica Robinson, School of Medicine Dean Theodore DeWeese, Maryland House Speaker Adrienne Jones, JHU President Ron Daniels, Victor Vines, Lisa Cooper, Lainie Rutkow, Dan Ford, and Jeffrey Kahn.

In October 2024, Johns Hopkins University, together with descendants of Henrietta Lacks, broke ground on the future site of the building named in honor of Mrs. Lacks, the Baltimore County woman whose HeLa cells have contributed to medical advancements around the world.

The new 34,000-square-foot building will be located on the East Baltimore campus at the corner of Ashland and Rutland avenues and will adjoin Deering Hall, the Berman Institute's historic home.

"Today we make a concrete commitment to ensure that Henrietta Lacks' name will be as immortal as her cells," JHU President Ron Daniels said. "When the Henrietta Lacks Building rises, it will be a vibrant, multidisciplinary site of learning, discovery, and dialogue that will facilitate community-oriented medical research and nurture the next wave of progress in the study and promotion of research ethics. We look forward to a building that will do justice to Henrietta Lacks' transformative legacy, and we offer our heartfelt thanks to the members of the Lacks family for their generosity of spirit in lending this building her name." The building will support multiple programs of the Berman Institute, Johns Hopkins University and the School of Medicine, and will house flexible program and classroom space for educational, research, and community use purposes.

"The success of the Berman Institute is built on opportunities for collaboration within our community and across the university," said Jeffrey Kahn, director of the Berman Institute. "The breadth and depth of our work will expand with this new building, and its dedication to Henrietta Lacks is an important reminder of the need for ethics, equity, responsible science, and communityengaged research."

Daniels and Kahn were among several speakers at the East Baltimore event, held beneath a tent on a crisp, sun-drenched fall morning. They were joined by university and community leaders, federal and local elected officials, and several descendants of Henrietta Lacks.

Lacks was a 31-year-old Black mother of five from Baltimore County who sought treatment at The Johns Hopkins Hospital in the early 1950s. Doctors diagnosed her with cervical cancer and, as medical records show, she received care that included the best medical treatment available at the time. Unfortunately, treatment was unsuccessful, and Lacks died in October 1951.

A sample of Lacks' cancer cells was retrieved during a biopsy and sent to cancer researcher George Gey's nearby tissue lab, where he had been collecting cells from patients who came to Johns Hopkins Hospital with cervical cancer. He discovered these cells were unlike any of the others he had seen. Where other cells would die, Lacks' cells survived, and the number of cells would double every 20 to 24 hours. Soon after that, he began sharing the cells, at no cost, with researchers around the world.

Deemed "HeLa" cells, from the first two letters of her first and last name, the cell line that began from the biopsy from Lacks proved to be remarkably durable and prolific, and while many additional cell lines are in use today, HeLa cells have had a unique contribution to untold medical breakthroughs over the decades since their discovery—from vaccines for polio and COVID-19 to studies of the human genome to treatments for cancer and HIV/AIDS. "Today is not about those immortal cells, as important as they are," said Theodore DeWeese, dean of the medical faculty and CEO of Johns Hopkins Medicine. "Today is about immortalizing the name of the woman from whom those cells came. It is about ensuring that her name and her unknowing role will always be remembered by all of the students, by all the residents, by all the other trainees, by the faculty, the staff who walk into the building that's going to rise on this plot of ground.

"She is without doubt one of the most important contributors to science and medicine, and it really is our hope that this building will serve as an important reflection on the meaning of her life to this world."

In 2013, Johns Hopkins worked with members of the Lacks family and the National Institutes of Health to help craft an agreement that requires scientists to receive permission to use Henrietta Lacks' genetic blueprint in NIH-funded research. The NIH committee tasked with overseeing the use of HeLa cells now includes two members of the Lacks family, including Jeri Lacks Whye, granddaughter of Henrietta Lacks, who was in attendance at the groundbreaking. Other family members in attendance included JaBrea Rodgers and Veronica Robinson, both great granddaughters of Henrietta Lacks.

"I'm excited to break ground for the Henrietta Lacks Building," Lacks Whye said in a statement. "Although this building will bear her name, it will also provide space for continued research, learning, and inspiring future generations. We acknowledge more than the scientific contributions made possible by her cells. We also acknowledge the story of a Black woman who did not live to see the world that her cells helped to create—a story that for too long was hidden. Our hope is that this building will continue to shed light on her legacy."

Plans for the building were first announced in 2018, with initial designs shared in 2022. Vines Architecture is the design architect; Baltimore-based Design Collective is the architect of record; and local Baltimore construction firm Mahogany—in conjunction with Turner Construction Company—has led pre-construction services and will serve as the construction manager to deliver the building. Construction is expected to be complete in 2026. Victor Vines, president of Vines Architecture, described the building's features, including "a magnificent stair that ascends upward through the building toward the heavens, where I choose to believe Henrietta Lacks is today," and a distinctive exterior that evokes the structure of DNA and is at once "veil-like" and "delicate," yet also "strong, bold, and beautiful, which we believe is who this person was."

U.S. Rep. Kweisi Mfume, a Baltimore native who represents Maryland's seventh congressional district in Congress, spoke about his long friendship with the Lacks family, dating to his childhood. He also noted his ongoing efforts to have Henrietta Lacks posthumously honored with a Congressional Gold Medal, the nation's highest civilian honor.



U.S. Rep. Kweisi Mfume, a childhood friend of the Lacks family, addressed the gathering

"The Henrietta Lacks story is immortal, but for me it's also personal," he said. "Having seen and witnessed the struggle that it took all these many years to get attention on the cells and to bring attention back to Mrs. Lacks is a story in and of itself. ... When I say this is a great and glorious day, I really, really do mean it."

Added Adrienne Jones, speaker of Maryland's House of Delegates: "All too often we see these stories forgotten by our history. The building we are breaking ground on today ensures that Henrietta's story will continue to be told. It will stand as a testament to the spirit with which she lived her life. It will support programs that enhance partnership with the Baltimore community, and it will promote the study of research ethics.

"To Henrietta's family, thank you for carrying her strength in your hearts," she added. "We honor you with this building, and we honor Henrietta's enduring legacy."

IN AN ENEMY OF THE PEOPLE, PUBLIC HEALTH DISCOURSE TAKES CENTER STAGE

A doctor discovers pathogens causing a public health threat and outlines steps the community must take to save lives. He's respected at first, but public sentiment toward the medical leader sours once the cost and inconvenience of his intervention become known. The health emergency ultimately becomes politicized and the doctor discredited—publicly shouted down and branded "an enemy of the people."

That's the plot of Norwegian playwright Henrik Ibsen's 1882 play *An Enemy of the People*. But this fictional tale set in a 19th-century Scandinavian village also calls to mind some place recent and real: the United States during the COVID-19 pandemic. Anthony Fauci, then director of the National Institute of Allergy and Infectious Diseases, faced growing hostility over the U.S. public health response, which included mandates designed to slow the disease's spread. Pushback grew and at least one congressman literally labeled him an enemy of the people.

These parallels were explored at "An Enemy of the People: A Public Health Project," two evenings on which professional actors joined public health leaders and scientists in performing dramatic readings of Ibsen's play, with a moderated, town hall-type discussion that followed. It was a joint production of the Berman Institute, the National Academy of Sciences, and Theater of War Productions, a New York City theatrical company that uses classic plays to explore contemporary issues.

"It's meant to spur some interesting conversations," said Berman Institute director Jeffrey Kahn, who was among the performers. "It's an everything-old-is-newagain story. And it's also turning the tables where the



members of the chorus—the citizens who shout down the doctor—are the very people who were in the other position during the pandemic. So former NIH director Francis Collins and Hopkins public health faculty are all going to be in the chorus shouting down the doctor."

The pair of free and open-to-the-public performances took place February 22 at the Hopkins Bloomberg Center in Washington, D.C., and February 24 at the National Academy of Sciences building. Professional actors participating included David Strathairn (*Nomadland*), Kathryn Erbe (*Law & Order: Criminal Intent*), Frankie Faison (*The Wire*), Peter Francis James (*Oz*), and Jay O. Sanders (*True Detective*).

Kahn first witnessed how historic dramas can emotionally connect with modern issues several years ago at a Theater of War reading of an English translation of Sophocles's tragic war play *Ajax*. Though Sophocles was writing about the Trojan War some three millennia ago, its military themes and messaging proved evergreen.

"An army vet stood up and talked about how a particular part of the play resonated with his experience having led a battalion in Afghanistan," Kahn said. During the pandemic, the Berman Institute, Johns Hopkins School of Nursing, and Johns Hopkins' Program in the Arts, Humanities, and Health worked with Theater of War to develop "Theater of War Frontline", a series of Zoom readings of Sophocles' tragedies *Philoctetes* and *Women of Trachis* focused on themes of injury and caregiving. The aim was to help nurses, doctors, first responders, and other health care providers have constructive discussions around the pandemic's challenges.

Ibsen's play is one of the newer works Theater of War has turned to, though its public health themes are a good fit for both COVID and global warming. The play's would-be hero, Dr. Stockman, discovers that the water used in his town's new bathing spa is polluted by nearby tanneries. Though designed to bring the community much-needed income, he says the spa will have to close for an extended period while its water delivery pipes are reconfigured. The town's mayor, who happens to be Stockman's brother, doesn't want to lose the tourist dollars and suggests keeping mum about the problem while proposing a less obtrusive solution that keeps the spa open—despite a lack of scientific or engineering training. The press turns on Dr.

"It's meant to spur some interesting conversations. "It's an everything-oldis-new-again story."

JEFFREY KAHN

Stockman once it learns that the repair costs will largely come from new taxes on the working class. Dr. Stockman takes his concerns to a rowdy town meeting where he gets branded with the play's title. Theater of War materials say the readings and discussions explore the "corrosive influence of power and money in politics, the distortions of the media, and the many other challenges to public health in our culture today."

While the major roles were performed by the trained actors, public health practitioners played the roles of angry citizens. "I was cast as a drunken man, so I had to polish up on my slurred speech," Kahn said with a laugh. But while there will moments of levity as academics become actors, Kahn said the evenings also provided meaningful food for thought.

"Every one of such performances I've been part of or have seen has surprised me in some way," Kahn said. "People are touched. It's different than somebody giving a lecture or showing slides and giving a talk. It's another way for people to connect with the issues that we've lived with for the last four years, and access some of those themes in a different way."

PLAYING GOD? PODCAST WINS NATIONAL AWARDS. BRINGS **BIOETHICS ISSUES TO THE PUBLIC AND INTO SCHOOLS**



In October 2023, the Berman Institute launched the first major project developed by the Dracopoulos-Bloomberg iDeas Lab with playing god?, a globally distributed 10-part podcast about the complex ethical questions that arise with groundbreaking medical innovations. The podcast has attracted more than

200,000 listeners and in fall of 2024 was recognized by the Signal Awards, a national competition recognizing the most meaningful and potent podcasts being made today, with a gold medal for Best Science Program, and gold and silver medals for Best Individual Episode.

playing god? was created in conjunction with Pushkin Industries and made possible by generous support from the Greenwall Foundation. Berman Institute Director Jeffrey Kahn and faculty member Anna Mastroianni were executive producers, with support from the BI's Amelia Hood, and iDeas Lab director Lauren Arora Hutchinson hosted the first season. The podcast introduced listeners to the stories of people faced with medical challenges that raise bioethics issues, including a burn victim kept alive by a ventilator while family and friends fought over whether to allow her to die, and a mother hoping against hope that a new combination of reproductive technologies might bring her a healthy child who was also a genetic match for her other child suffering from a fatal genetic disease.

To expand the podcast's reach, the Berman Institute has partnered with a group of nationally recognized K-12 educators from across the country to create free educational materials that use episodes of playing god? to introduce bioethics concepts and facilitate discussions of ethics among high school and above students. A second season of the podcast, currently in production, will launch early in 2025.

OVERCOMING BARRIERS OF LANGUAGE AND LITERACY IN **NEONATAL INTENSIVE CARE**

s physicians in the Johns Hopkins Hospital Neonatal Intensive Care Units (NICUs), Renee Boss and Sara Munoz-Blanco know their patients' outcomes following discharge are often directly linked to effective communication with parents. Making the transition from hospital to home can be overwhelming and frightening for any parent, and even more so when the parents can't effectively ask questions or receive information because of a language barrier.

To help address this problem among Latinos, the fastest-growing ethnic group in both Maryland and the United States, Boss and Munoz-Blanco collaborated with the Berman Institute's Dracopoulos-Bloomberg iDeas Lab to develop "Nos Vamos a Casa." (which translates as "We Are Going Home"). This novel webbased interface enables patient families and their doctors to overcome barriers of language and literacy to exchange vital information.

"We care for a substantial number of Latino Spanish-speaking children and their families across our healthcare system who often have medical com-



plexity and ongoing healthcare needs after NICU discharge," said Boss, the Rembrandt Foundation Professor of Pediatric Palliative Care at Johns Hopkins University School of Medicine,

and a Berman Institute faculty member.

"Our tool will increase a family's knowledge about their child's medical big picture, being a NICU parent, and preparedness of anticipated challenges after NICU discharge. We believe it will help improve communication between families and medical teams during their admission, promote family-centered care, as well as better prepare families for life at home."

Available at the patient's bedside, "Nos Vamos a Casa" contains a question prompt list (OPL) that Boss and Munoz-Blanco developed in a pilot study by conducting focus groups with NICU and primary care providers, as well as Spanish-speaking parents of NICU

patients. As parents review the OPL, accessible in Spanish in both print and audio, they can flag the questions they need to have addressed. Members of their care team, including doctors, nurses, case managers and social workers, then access that list of highlighted questions electronically, in either English and Spanish, and use it as a guide for discussion with parents.

"During our pilot study, providers found the OPL helpful. Families reported they would use our tool and would recommend it to other Latino families in the NICU. In addition, they reported the tool would help them to prepare for life at home, make it easier to ask guestions, to think about questions, and even put their concerns into words," said Munoz-Blanco, a School of Medicine faculty member. "But there were still literacy barriers and we wanted to have an interactive, user-friendly web-based audio interface that would make both families and physicians more likely to use the QPL."

Supported by a JHU Innovation Grant and grant from the Thomas Wilson Sanitarium for the Children of Baltimore City, Boss and Munoz-Blanco worked with the Berman Institute's Dracopoulos-Bloomberg iDeas Lab to create the solution they envisioned. "Nos Vamos a Casa" is the first QPL ever to be designed in audio format, and its user-friendliness was intentional and essential to overcome potential literacy barriers.

"This has been a very rewarding project for the iDeas Lab. We collaborated with the researchers from the outset, helping them identify the right communications vehicle then working with them throughout the development process to get the best possible result for families as well as their doctors and other care providers," said Lauren Arora Hutchinson,



RENEE BOSS

director of the Dracopoulos-Bloomberg iDeas Lab.

"While we are really proud of other public-facing projects we have done, such as podcasts with hundreds of thousands of listens, we found it inspiring to work on this tool which had such a specific audience. Renee and Sara's earlier research had demonstrated the need to create a tool for supporting parents at such a crucial period of their life, so using technology and storytelling to find a solution to this communication issue was important to our values as a creative lab."

To provide the Spanish-language audio narration, the team turned to a Spanish-speaking parent. As the tools were being developed, a consultation session was held with members of Baltimore's Latino community through Centro SOL (Salud y Oportunidades for Latinxs) to ensure they were not only useful but also culturally appropriate.

Earlier this year, families and medical teams at Johns Hopkins Children's Center began using "Nos Vamos a Casa." Preliminary data is very promising. For example, almost 60% of families reported discussing website questions with their baby's medical team and reported initiating those conversations. All families reported the website content helped them cope with being a NICU parent, thinking of and asking questions to the medical team, and preparing for life at home.

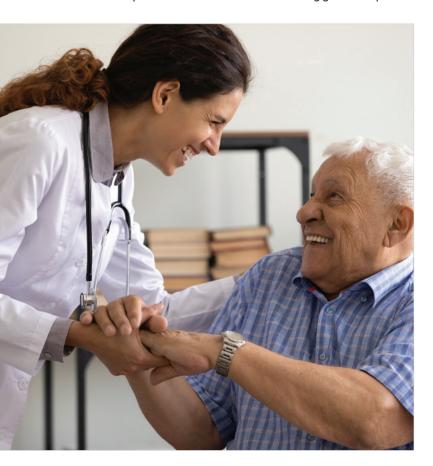
Research is ongoing. Boss and Munoz-Blanco hope to share it with families and NICUs across the country, at first in Spanish and then in other languages as well.

"We're doing implementation science," said Boss. "It's not just studying patients and families, it's doing medical research that will benefit those patients and families and then making sure it's available to them."

"Our tool will increase a family's knowledge about their child's medical big picture."

COMMUNICATING CLINICIANS' WAY TO BETTER PATIENT CARE

After more than a quarter-century as a physician, the Berman Institute's Mary Catherine Beach knows that simply asking a patient about how they're doing is likely to produce a reflexive and unilluminating general response.



But asking a slightly different question — "Is there anything in particular you want to discuss today?" — is much more likely to produce a detailed answer highlighting specific areas of patient concern.

That's among the key findings of a recent study Beach and her team conducted to pinpoint the most effective communication for conducting patient exams. It's an increasingly important issue, given the time constraints facing today's doctors and the growing volume of topics they must cover in a visit.

"When it comes to 'agenda setting,' we found that doctors should elicit patient agendas by using direct

language and solicit additional concerns using 'what else?' vs. 'anything else?' because patients are more likely to raise concerns to direct questions," said Beach. Unfortunately, she says, her study found "the most effective agenda-soliciting questions are used least frequently by clinicians." As a result, patients leave their visit without getting important concerns addressed.

Beach has been on a careerlong mission to improve the way clinicians communicate with patients. Her research, conducted in collaboration with dozens of researchers across Johns Hopkins, is probing issues such as: How can physicians best find out whether patients are taking their medications? What is the most effective way to achieve shared decision-making with patients? How should doctors demonstrate empathy?

"Not only is good communication the most important part of humanizing health care — it is one of the most important ways we can deliver high-quality clinical care," said Beach, a professor of medicine at the Johns Hopkins School of Medicine. "If we can't communicate accurately and make sure we've conveyed information in a way that is understandable, our patients won't be able to be healed because they won't take their medication correctly or we will get their diagnosis wrong."

Much of Beach's clinical work has focused on care for patients with HIV. Medication adherence is crucial for keeping the virus tamped down, but studies have shown that one-quarter to one-half of patients don't take their antiretroviral medication consistently. Moreover, physicians often fail to detect the non-adherence, "which means lost opportunities for them to counsel their patients," Beach said.

In a study that involved analysis of dozens of audio recordings of physician encounters with non-adherent patients, she and her team found that the best type of question to elicit truthful responses is one that is negatively framed — that is, asking when (rather than if) doses had been missed ("When was the last time you missed a dose? Do you remember?") "The goal for doctors is not to make the patient feel worse by admitting they haven't taken their medication or to put them on the defensive — but to open the conversation further," said Beach. "With this and other ongoing studies, we've found that negatively framed questions do that best, allowing doctors to follow up



with neutral questions, such as: 'What happened then?' Or, 'Tell me more about that.' Or, 'Let's unpack that.'" Beach has shared these findings with

colleagues in the HIV ambulatory care practice at Johns Hopkins whose communications were analyzed for the study — and at a national conference. "I've found that clinicians are excited to learn about

In the medication adherence studies and in the many other communication studies Beach has led or collaborated on, the science is rigorous and the analysis methods are complex, involving case control studies, surveys, and audio and statistical analysis.

findings they can put into practice," she said.

In the past, said Beach, "we tended to think of this general idea of 'bedside manner' as a vague, subjective concept that was 'nice' but not definable. That it couldn't be evaluated in any kind of objective way."

In fact, she emphasized, effective doctor/patient communication can be measured and analyzed, resulting in definitive conclusions and actionable results information valuable to clinicians at every stage of their careers.

"Teaching effective communication can't just happen with a single course during the first year of medical school. We need to reinforce a culture where it's a constant source of learning throughout medical school and residency training, and it should be revisited in continuing medical education," said Beach.

"It's my life's mission to conduct research to inform these efforts to forge more meaningful human connections — and better outcomes for patients."

CYNDA RUSHTON HONORED BY AMERICAN ASSOCIATION OF COLLEGES OF NURSING

ynda Rushton, Anne and George L. Bunting Professor of Clinical Ethics at the Berman Institute,was selected by the Board of Directors of the American Association of Colleges of Nursing (AACN) to receive the Dr. Geraldine "Polly" Bednash Lectureship Award at the 2024 AACN Deans Annual Meeting.

The Bednash Lectureship Award was established in 2014 to honor AACN's previous CEO, who led the association for 28 years. The award recognizes leadership and/or scholarly contributions to interprofessional education, and support of AACN as the collective voice for academic nursing and the catalyst for excellence and innovation in nursing education, research, and practice. Rushton delivered a lecture, "Cultivating Relational Integrity: Being Whole Amid Chaos," at the AACN meeting.

Rushton is an internationally recognized researcher



in the areas of bioethics, ethics education, and the moral suffering of clinicians. In her most recent work, she is serving as the chief synergy strategist for Maryland's R3 Resilient Nurses

Initiative. The initiative seeks to renew, retain, and amplify the integrity and resilience of nurses, students, and nursing educators across Maryland, in all specialties and roles, through a culture of ethical practice. Rushton is editor and author of the book *Moral Resilience: Transforming Moral Suffering in Healthcare* (Oxford University Press) which had a second edition published in August.

JOE ALI, ANNE BARNHILL, ANNA MASTROIANNI, AND TRAVIS RIEDER ELECTED HASTINGS CENTER FELLOWS

Four members of the Berman Institute faculty — Joe Ali, Anne Barnhill, Anna Mastroianni, and Travis Rieder — were elected as Fellows by The Hastings Center in 2024.Hastings Center Fellows are a group of more than 200 individuals of outstanding accomplishment whose work has informed scholarship and public understanding of complex ethical issues in health, health care, science, and technology. Their common distinguishing feature is uncommon insight and impact in areas of critical concern to the Center—how best to understand and manage the inevitable values questions, moral uncertainties, and societal effects that arise as a consequence of advances in the life sciences, the need to improve health and health care for people of all ages, and mitigation of human impact on the natural world.

Joseph Ali is associate director for global programs



and core faculty at the Berman Institute. Ali's research and teaching engage a range of challenges in domestic and global health ethics. This includes empirical and normative work in U.S. and international

research ethics, and projects that address the implications of emerging global mobile and digital technologies as applied in the context of health research, public health programs, and disease surveillance. Ali is committed to collaboratively supporting the capacity of scholars from resource-constrained countries and settings to lead bioethics research, teaching, and practice on issues of local importance. He has been involved in establishing and operating NIH Fogarty-funded nondegree, master's, doctoral and post-doctoral programs in bioethics at Johns Hopkins and with partners in Uganda, Ethiopia, Zambia, Botswana, and Malaysia. He also co-leads the Wellcome-funded Oxford University-Johns Hopkins University Global Infectious Disease Ethics Collaborative, which supports research and training to address emerging issues involving ethics and infectious disease. He is associate editor for the Journal of Empirical Research on Human Research Ethics.

Anne Barnhill is an associate research professor at the

Berman Institute. She is a philosopher and bioethicist whose research centers on the ethics of food and agriculture, and the ethics of public health. Her food ethics research explores the ethics of healthy

eating policy, the ethical dimensions of efforts to promote plant-based diets, ethnically and racially targeted food marketing, and human rights violations within food systems. Her most recent book, co-authored with Matteo Bonotti is *Healthy Eating Policy and Political Philosophy: A Public Reason Approach* (Oxford University Press), explores the ethics and legitimacy of healthy eating policy in high-income countries. During the Covid-19 pandemic, she and colleagues at Johns Hopkins explored the ethical challenges of the pandemic, including the ethics and legitimacy of lockdown and reopening, the ethics of digital contact tracing, and ethical issues related to vaccination.

Anna Mastroianni is a research professor in bioethics



and law at the Berman Institute. Her scholarly work examines complex issues at the intersection of law, bioethics, public health, and health policy, with special emphasis on the legal and ethical challenges

arising in research in pregnancy, the use of genetic technologies in public health, reproductive rights, and family building through assisted reproductive technologies. She is Charles I. Stone Emeritus Professor of Law at the University of Washington School of Law and served as associate director of the university's Institute for Public Health Genetics and held additional faculty appointments in the School of Public Health and School of Medicine. Before joining the full-time faculty at the University of Washington, she was a practicing attorney and served in several legal and governmental policy positions in Washington, D.C. including as staff director of the White House Advisory Committee on Human Radiation Experiments and study director for the National Academy of Medicine. She is an elected fellow of the American Association for the Advancement of Science, recognized for her contributions to health policy, law, and bioethics. She serves on consensus, advisory, and oversight committees, both nationally and internationally.

Travis Rieder is the director for education initiatives



and an associate research professor at the Berman Institute, where he directs the Master of Bioethics degree program. He also has secondary appointments in the departments of philosophy and of

health policy & management, as well as in the Center for Public Health Advocacy. Most of his scholarship, speaking, and writing for the public falls into one of two research programs. The first involves the ethical and policy issues raised by pain, pain medicine, drugs, addiction, and North America's drug overdose crisis. On this subject, he has published in the bioethics, medical, and public health literature, as well as for the popular press, including a TED Talk and his first book, *In Pain* (HarperCollins).

MBE ALUMNA MARIAM KHAN WINS ASBH STUDENT PAPER AWARD COMPETITION

Mariam Khan, who recently completed the Berman Institute's



Master of Bioethics program, has been named winner of the 2024 American Society for Bioethics and Humanities (ASBH) Student Paper Award competition for her paper, "Weigh Over the

Anti-Blackness': How the Harms of Medicalizing Obesity 'Outweigh' Potential Benefits."

Khan is passionate about decolonial research, disability justice advocacy in public policy, and exploring global health issues from a social justice framework. She has remained a dedicated Participatory Action Researcher in her undergraduate research team, SiSTEM ("Sisters Interrogating STEM"), leading many initiatives of the project — including designing Halagah as a decolonial and decolonizing methodology. She The second research program involves the overarching theme of "catastrophe." In particular, Rieder is concerned with how to engage in ethical reasoning about our own, individual lives in a time dominated by massive, structural threats that are too big and too complex for any one of us to meaningfully address on our own. This has led to publications on climate change, pandemics, food ethics, and overpopulation—and is the subject of his second book, *Catastrophe Ethics*, published by Penguin Random House (see more on page 22).

ALI, BARNHILL, MASTROIANNI, AND RIEDER JOIN NINE OF THEIR BERMAN INSTITUTE FACULTY COLLEAGUES AS HASTINGS CENTER FELLOWS. THEY ARE:

Mary Catherine Beach Joseph Carrese Ruth Faden Gail Geller Jeffrey Kahn Nancy Kass Debra Mathews Maria Merritt Cynda Hylton Rushton

received a B.A. in Spanish Language, Literatures, and Culture from the University of Maryland in College Park, with a Humanities, Health, and Medicine minor in 2023.

Khan joins 2021 PhD Berman Institute graduate Michael DiStefano as a winner of the ASBH Student Paper Award. DiStefano, who won the award in 2018 for his paper "Characterizing 'civil unrest' as a public health determinant: Implications for public health research and practice," is now an assistant professor at the University of Colorado.

The ASBH Student Paper Award recognizes one paper nationwide for writing clarity and quality, development of the argument, integration of the literature, and novelty/ insight of the contribution. As part of her award, Khan presented her paper at ASBH's Annual Meeting.

THREE FACULTY ASSUME NEW LEADERSHIP ROLES WITH THE INSTITUTE

A trio of outstanding faculty assumed new leadership roles within the Berman Institute this year.

As the newly appointed Associate Director for Research



and Programs in the Berman Institute, Debra Mathews is responsible for leadership of BI programs, such as the Haywood Memorial Symposium and the Charm City Colloquium (in collabo-

ration with colleagues in the University of Maryland Carey School of Law). She also leads Institute-level research efforts, such as growing programmatic efforts in AI ethics, and acts as BI point of contact for research and service requests.

Maria Merritt was named to the new role of Associate



Director for Faculty Affairs. The responsibilities of this new position include chairing the newly formed BI Faculty Development Committee, which will also become the BI's

Appointments and Promotion Committee, and managing the application process for the newly established Dracopoulos Rising Professorship (see page 34 for more information).

Travis Rieder succeeded Gail Geller as Director for



Education Initiatives. In this role, he runs the day-to-day operations of the Berman Institute's Master of Bioethics degree program and the graduate certificate in bioethics and works with

the directors for other education initiatives across the university to promote bioethics education at the undergraduate, graduate, and postgraduate level.

CATASTROPHE ETHICS: HOW TO CHOOSE WELL IN A WORLD OF TOUGH CHOICES

Modern life can be full of tough and unsatisfying choices. On one hand, everything we do seems to matter and have great importance. But on the other hand, it can sometimes seem it's all for nothing. To BI faculty member Travis Rieder, this realization led to an obsession in recent years with answering the question: How do each of us live a morally decent life in an era defined by problems that are too big and too complex for any one of us to solve by ourselves?

Rieder's attempt to wrestle with this question led to his new book, *Catastrophe Ethics: How to Choose Well in a World of Tough Choices* (Dutton), a warm and personal guide that provides the tools to build a strong moral compass in today's world.

From seemingly mundane issues like whether to use a disposable plastic water bottle, to booking a flight for a vacation, to bigger questions like investing in an electric vehicle or having children, Rieder shows how to navigate the issues that often seem to have no good

BERMAN INSTITUTE'S DEBRA MATHEWS APPOINTED PRESIDENT OF THE INTERNATIONAL NEUROETHICS SOCIETY

he Board of Directors of the International Neuroethics Society (INS) appointed the Berman



Institute's Debra Mathews, to serve as president for a 2-year term beginning in October 2023. The president serves as chair of the 15-member Board and quides efforts to achieve the mission of

the Society to encourage and inspire research and dialogue on the responsible use of advances in brain science. Mathews has been an active member of the INS since 2006, a Board member since 2015, and is now the seventh president since its incorporation in 2008. or easy answers. The decisions people make daily all contribute to massive, structural, collective problems.

Catastrophe Ethics includes a tour of the contributions of philosophers like Plato and Kant, as well as old fashioned ethics exercises like trolley problems that involve sacrificing one person on a track for several people. But as Rieder points out, people need to expand their understanding of ethical concepts for modern society.

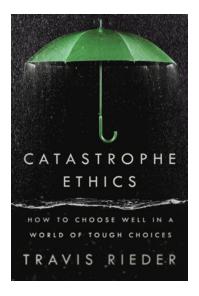
"I don't think an ethic of purity is realistic, because we cannot excise ourselves from the massive problems of today," Rieder said. "But I also want to resist the slide into nihilism. Just because you can't save the world by yourself doesn't mean that what you do doesn't matter."

"In a world where nearly everything we do implicates us in various systems and structures, there are a lot of opportunities to participate in good and bad, and so a lot of careful reasoning to do," said Rieder. "The bad news is that this can feel overwhelming: everything we do seems to matter. But the good news is that we get to matter. The moral work is constant and creative, as we need to (get to!) decide constantly how to structure our lives so as to respond to the threats around us."

"I stepped forward for consideration for this role, not only out of a sense of duty to this organization that's been such a critical part of my professional life literally from the beginning, and from which I've received so much, but also because I hope that I have something to offer," said Mathews, who outlined several priorities she intends to champion during her presidency. Her focus includes:

- Undertaking important inward facing and outward facing work on inclusion, diversity, anti-racism and equity;
- Growing and supporting a pipeline of diverse junior scholars who want to grow from membership, to engaged involvement, and into leadership positions;
- Strengthening and creating robust connections between the INS and institutions and organizations representing allied fields and scholars.

How do each of us live a morally decent life in an era defined by problems that are too big and too complex for any one of us to solve by ourselves?



"I'd like to see the field, and INS — having grown and matured over the last 15 years plus — reach out more, not only to neuroscientists, but also to other areas of science and technology, including genetics, stem cell science, AI, and other subspecialties within bioethics and beyond," said Mathews.

The International Neuroethics Society is a professional association of scientists, scholars, students, and practicing legal and health professionals leading the discussion on the complex ethical issues arising from brain research and an expanding understanding of the mind. Experts in the ethical, legal, and societal impacts of advances in neuroscience, Society members are uniquely equipped to communicate the value and implications that new knowledge, technologies, and potential applications bring to human health and wellbeing.



MULTIPLE BERMAN FACULTY RECEIVE NEXUS AWARDS TO PURSUE INNOVATIVE INTERDISCIPLINARY PROJECTS

ultiple projects led by or supported by faculty at the Johns Hopkins Berman Institute of Bioethics have been selected to receive funding from the Johns Hopkins University's Nexus Awards Program.

The selected projects led by Berman Institute faculty are:

- Neuro-Theater: How Neurotechnology and Artificial Intelligence Can Transform Immersive Media, Interactive Storytelling, and Live Performance (including Berman Institute faculty Lauren Arora Hutchinson and Debra Mathews, and postdoctoral Fellow Graham Sack);
- Centering Equity in Global Partnerships: A Convening of Partners, Donors, Governance Leaders, and Policymakers at the Johns Hopkins Bloomberg Center (including Bl faculty Joseph Ali and Jeffrey Kahn).

In addition, BI faculty are members of teams receiving grants to formulate a policy agenda addressing mental health and addiction in the U.S., creating a dashboard tracking drug supply chain data across the country, and utilizing AI to address inequities in deaths of despair.

"Projects selected for Nexus Awards come from every academic division of the university, so it is fitting that multiple faculty from the Berman Institute — whose work is predicated on interdisciplinary innovation that draws from across Johns Hopkins — have been chosen for grants," said Jeffrey Kahn, director of the Berman Institute. A total of 40 projects designed to support research, teaching, and event programming at the new Hopkins Bloomberg Center in Washington, D.C., were selected to receive funding over the next year. This is the second round of funding distributed via the Nexus Awards, a \$15 million program.

The project "Neuro-Theater: How Neurotechnology and Artificial Intelligence Can Transform Immersive Media, Interactive Storytelling, and Live Performance" will culminate in a performance at the Hopkins Bloomberg Center of sol_AI_rs, a live immersive theater and new media experience, inspired by Stanislaw Lem's *Solaris*, that uses brain-computer interface technology to explore ethics and the relationships between human, artificial, and natural intelligence.



"sol_AI_rs will use an artificial neural network connected to a set of EEG caps worn by both performers and spectators to embody a sentient planet capable of reading the thoughts of mankind," said

Graham Sack, the Inaugural Fellow in the Institute's Dracopolos-Bloomberg iDeas Lab and the project's creative lead.

"The sol_AI_rs character will control a visual, auditory and textual environment consisting of multi-wall video projections, a generative music score, and a responsive dialogue system. The system will be trained to respond in "sol_AI_rs will use an artificial neural network connected to a set of EEG caps worn by both performers and spectators to embody a sentient planet capable of reading the thoughts of mankind."

GRAHAM SACK

real time to brainwave data, thereby creating a feedback loop or ecosystem amongst performers, audience, technology and environment."

The project "Centering Equity in Global Partnerships: A Convening of Partners, Donors, Governance Leaders, and Policymakers at the Johns Hopkins Bloomberg Center" aims to bring together stakeholders from around the world for a two-day gathering to interactively engage with the challenging but important topic of advancing equitable, respectful and sustainable international partnerships. Focal entry points will be global health, development and diplomacy, with the intention to expand to other key areas relevant to JHU's international engagements.

"Global challenges demand collaborative solutions, and Johns Hopkins is a leader in partnering across institutions and sectors to innovatively advance knowledge and the well-being of individuals and populations. At the same time, our understanding of what it means to be a 'good partner' is evolving, especially in the context of



international partnerships where there is likely to be significant power imbalances between institutions and individuals. We are delighted to have the opportunity to gather together a diverse array of inter-

national research and training partners, funding agencies, global governance organizations, and others for multi-stakeholder dialogue on this important topic. Our goal is to collectively chart new pathways for facilitating more equitable and impactful partnerships," said Joseph Ali, the Berman Institute's Associate Director for Global Programs, who will take the lead in organizing the conference.

Other Nexus Award recipients involving Berman Institute faculty are:

- AI-Powered Strategies to Address Inequities in Deaths of Despair: A Series of Translational Workshops (with BI faculty member Kadija Ferryman);
- A New Policy Agenda to Address Mental Health and Addiction in the U.S. (with BI faculty member Brendan Saloner);
- The Johns Hopkins Drug Supply Chain Data Dashboard: Improving Data Transparency and Increasing Resiliency in the U.S. Pharmaceutical Supply Chain (with BI faculty member Jeremy Greene).

"Since last fall, our first class of Nexus winners and their bold ideas have animated our new home in Washington," said JHU President Ron Daniels in announcing the recipients. "With this second cohort of Nexus Award winners, we are building on the momentum underway at the Hopkins Bloomberg Center, as faculty from across Johns Hopkins convene policymakers and the public, embark on innovative research, and inspire our students to engage society's greatest challenges."

GRANTS SECURED BY BERMAN INSTITUTE FACULTY FROM 9/01/2023-8/31/2024

Joe Ali, JD

Centering Equity in Global Partnerships: A Convening of Partners, Donors, Governance Leaders, and Policymakers at the Johns Hopkins Bloomberg Center Johns Hopkins University Nexus Award

Johns Hopkins University-Addis Ababa University Research Ethics Training Program in Ethiopia (JHU-AAU RETP)

National Institutes of Health

Fogarty African Bioethics Post-Doctoral Training Program

National Institutes of Health

Makerere University International Bioethics Research Training Program Makerere University/National Institutes of Health

Pain Management Collaboratory Coordinating Center Grant National Institutes of Health

Anne Barnhill, PhD

Enabling Ethical Analysis and Public Justification in State-Level Pandemic Responses in the United States **National Science Foundation and Greenwall** Foundation

Juli Bollinger, MS

Comparing Direct and indirect Methods for Cascade Screening National Heart, Lung, and Blood Institute

Lomax Boyd, PhD

26

Survey of Unmet Desire Amona Early Career Reseachers to Engage with Neuroscience and Society Dana Foundation

Justice in Basic Research Agendas (JuBRA): An equity-centered protocol for assessing basic research Kavli Foundation

Survey of Unmet Desire Among Policymakers to Engage with Neuroscience and Society **Dana Foundation**

Organoid intelligence: Synthetic Biological Al Johns Hopkins University SURPASS Award

Kadija Ferryman, PhD

AI-Powered Strategies to Address Inequities in Deaths of Despair Johns Hopkins University Nexus Award

Advancing Health Equity in AI/ML in Health Regulation and Policy **Pew Charitable Trusts**

Data and Society Data and Society Research Institute

Jeremy Greene, MD, PhD

The Johns Hopkins Drug Supply Chain Data Dashboard: Improving Data Transparency and Increasing Resiliency in the U.S. Pharmaceutical Supply Chain Johns Hopkins University Nexus Award

Lauren Arora Hutchinson, PhD, MPH

Neuro-Theater: How Neurotechnology and Artificial Intelligence Can Transform Immersive Media. Interactive Storytelling, and Live Performance Johns Hopkins University Nexus Award 'Feels Like Home': Lived Experiences of Children with Medical Complexity and Their Families

Johns Hopkins University Discovery Award

Jeffrey Kahn, PhD, MPH

Centering Equity in Global Partnerships: A Convening of Partners, Donors, Governance Leaders, and Policymakers at the Johns Hopkins Bloomberg Center

Johns Hopkins University, Nexus Convening Award

Oxford-Johns Hopkins Global Infectious Disease Ethics Collaborative (GLIDE) Wellcome Trust

playing god? Podcast Project Greenwall Foundation

Stavros Niarchos Foundation Bioethics Academy Stavros Niarchos Foundation

Non-Fungible Tokens (NFTs) for Ethical, Efficient Biospecimen Use National Philanthropic Trust

Nancy Kass, ScD Fogarty African Bioethics Post-Doctoral Training Program

Fogarty International Center Developing Stakeholder-Engaged Ethical Guidance

for Public Health Wastewater Surveillance Alaska Native Tribal Health Consortium

Debra Mathews, PhD, MA

Guiding Principles for Human Data Sharing and Use: Balancina Public and Scientific Values The Greenwall Foundation

Enhancing Diversity Among Future ELSI Researchers National Institutes of Health / National Human Genome Research Institute

Ethical, Legal, Social, and Policy Implications of Workplace Genomic Testing The Jackson Laboratory

Neuro-Theater: How Neurotechnology and Artificial Intelligence Can Transform Immersive Media, Interactive Storytelling, and Live Performance Johns Hopkins University Nexus Award

Life with an RNA Genome National Science Foundation

NeuroTech Harbor — The Nations' first Equitech Ecosystem for Neuromedical Solutions National Institutes of Health/National Institute of **Biomedical Imaging and Bioengineering**

Fully Implantable Wireless Bidirectional Cortical System for Neuroprosthetics

National Institutes of Health/BRAIN Initiative Survey of Unmet Desire Among Farly Career

Researchers to Engage with Neuroscience and Society Dana Foundation

Survey of Unmet Desire Among Policymakers to Engage with Neuroscience and Society Dana Foundation

Promoting Genetic Counselors in Independent Research Through Advanced Training and Education (PROMTE-GC) National Institutes of Health/ National Human Genome Research Institute

Stephanie Morain, PhD, MPH Institutional Obligations for Pragmatic Clinical Trials

Greenwall Foundation

HEAL Collaboratory Resource Coordinating Center National Institutes of Health

FACULTY RECEIVE DISCOVERY AWARD FOR PROJECT HIGHLIGHTING CHILDREN WITH MEDICAL COMPLEXITY

"'Feels Like Home': Lived Experiences of Children with Medical Complexity and Their Families," an interactive audiovisual experience that will bring multiple audiences into the homes of children with medical complexity (CMC) and their families, has been named the recipient of a 2024 Discovery Award given to interdisciplinary faculty teams across Johns Hopkins University.

Led by the Berman Institute's Rebecca Seltzer and Lauren Arora Hutchinson, the project will result in three distinct outputs:

An audio documentary intended for broad public audiences that explores how families with CMC experience their home environment, a unique blend of a hospital and traditional home setting;

- A short film to immerse the viewers in how families with CMC adapt their home environment to meet their child and family's needs, capturing both challenges and ingenuity;
- An interactive website to house the multimedia created and collected through this project.



"We envision the audio documentary and short film to be used on broader scales as teaching and advocacy tools. This could include incorporating them in medical provider training programs; using

them as central discussion elements at conferences, panels, and live events; sharing short snippets in policy-making

spaces," said Seltzer.

The interactive website created during the initial phase will begin as a dynamic hosting platform for the audio and video deliverables and grow over time into a hub where audiences come to get resources and share their own stories.

The Discovery Awards encourage faculty from various disciplines to collaborate in addressing multifaceted challenges and pushing the boundaries of understanding. Altogether, the winning project teams - chosen from 286 proposals — include 148 individuals representing 11 Johns Hopkins entities.

"This project is an example of how the iDeas Lab can work with faculty from the outset of a project to envision and create outputs that will reach and immerse audiences beyond academia, getting them to think deeply and

Travis Rieder, PhD Multilevel Interventions to Reduce Harm and Improve Ouality of Life for Patients on Long Term Opioid Therapy

National Institute on Drug Abuse MIRHIOL National Institutes of Health

Developing a framework to address the needs of persons with cancer pain and opioid guidelines in the age of the opioid epidemic Johns Hopkins University Discovery Award

Cynda Rushton, PhD, RN MERPA Nurse Cohort Training

Johns Hopkins Hospital

Graham Sack, PhD Neuro-Theater: How Neurotechnology and Artificial Intelligence Can Transform Immersive Media. Interactive Storvtelling, and Live Performance

Brendan Saloner, PhD Addiction in the U.S.

Johns Hopkins University Nexus Award Rebecca Seltzer, MD, MHS

Johns Hopkins University Nexus Award

A New Policy Agenda to Address Mental Health and

'Feels Like Home'. Lived Experiences of Children with Medical Complexity and Their Families Johns Hopkins University Discovery Award

Jeremy Sugarman, MD, MPH, MA

HEAL Collaboratory Resource Coordinating Center National Institutes of Health

Investigating Psychosocial Experiences of HIV Cure Trial Participants National Institutes of Health

Risks, Benefits and Stakeholder Perspective of Molecular Epidemiology for HIV Prevention National Institutes of Health

Strengthening the Master of Health Research Ethics Training Program University of Malava

Immune Tolerance Network National Institutes of Health

Health Care Systems Research Collaboratory Coordinating Center National Institutes of Health



differently about topics," said Arora Hutchinson. "The Lab has a team of creative producers - specialists in audio, video, and digital media who produce podcasts, videos, screenplays, films, and interactive

projects - who look forward to creatively engaging with families with lived experiences on this important matter and making sure their unique perspectives are heard and shared."

"This project's deliverables are both public-facing and family-centered, which we hope will foster feelings of community amongst similarly-situated families and promote a shared sense of humanity amongst audiences who perhaps were previously unaware," said Seltzer.

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📄 erman Institute faculty レ play a vitally important role in informing the public about bioethics issues and helping shape policy by sharing their insight and expertise through media interviews. The following is a partial list, arranged chronologically, of faculty media appearances during the 2023-2024 academic year.

DISCOVER > AUGUST 4, 2023

Experts Examine Use of Effective Altruism in Medicine with Jeffrey Kahn

THE NEW YORK TIMES >

AUGUST 10. 2023 U.S. Watchdog Halts Studies at

N.Y. Psychiatric Center After a Subject's Suicide with Jeffrey Kahn

GLOBAL HEALTH MATTERS > JULY/AUGUST 2023

A Seat at the Table: Diversifying Voices in Bioethics with Nancy Kass

THE ATLANTIC > AUGUST 29, 2023

Hypodermics on the Shore with Jeremy Greene

THE NEW YORK TIMES > AUGUST 30. 2023

Narcan Is Headed to Stores: What You Need to Know with Brendan Saloner

WASHINGTON POST > AUGUST 31. 2023

Woman Gives Birth Alone in Jail Cell an Hour after Seeking Medical Help with Carolyn Sufrin

THE NEW YORK TIMES > SEPTEMBER 3, 2023

Woman Gives Birth Alone in a Tennessee Jail Cell with Carolyn Sufrin

NPR WEEKEND EDITION > **NOVEMBER 11, 2023**

Many Generic Drugs are in Short Supply with Yoram Unguru

CBS NEWS > NOVEMBER 14, 2023

Most States Ban Shackling Pregnant Women in Custody — Yet Many **Report Being Restrained** with Carolyn Sufrin

THE NEW YORK TIMES > DECEMBER 20. 2023

We Know How to Put People on Ozempic. Do We Know How to Get Them Off It? with Travis Rieder

THE ATLANTIC >

JANUARY 10, 2024 Trump Is Coming for Obamacare Again with Brendan Saloner

WYPR MIDDAY>

JANUARY 23, 2024

On the Challenges of Doctors "Playing God" with Jeffrey Kahn

CLINICAL ADVISOR > **FEBRUARY 6. 2024**

Nurses Voted Most Trusted Profession Again But Ratings Are Lower with Cynda Hylton Rushton

THE 19TH> **FEBRUARY 16. 2024**

Pregnancy Care Was Always Lacking in Jails. Could it Get Worse? with Carolyn Sufrin

TIME > MARCH 6, 2024

How to Make Tough Choices in a Morally Exhausting World by Travis Rieder

LOS ANGELES TIMES > MARCH 12. 2024

'Enemy of the People' is the 19th Century Drama that Still Resonates With Our Pandemic-Scarred Society the Berman Institute is mentioned

WALL STREET JOURNAL >

'Catastrophe Ethics' Review:

It Isn't Easy to Do the Right Thing

MARCH 10, 2024

with Travis Rieder

ASSOCIATED PRESS > APRIL 24, 2024

More Doctors Can Prescribe a Leading Addiction Treatment. Why Aren't More People Getting Help? with Brendan Saloner

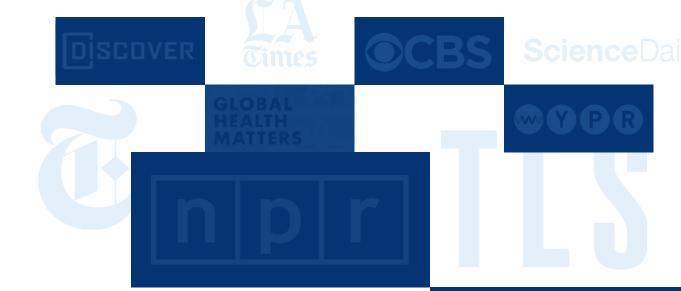
SCIENCE DAILY > MAY 2. 2024

Companies May Buy Consumer Genetic Information Despite Its Modest Predictive Power with Jeremy Sugarman and Alan Regenberg

TIMES LITERARY SUPPLEMENT > MAY 10. 2024

Ethics Man: Moral Reasoning for Modern Times with Travis Rieder





Hospitals in Gaza are Near Collapse Despite Protections Under International law with Len Rubenstein

THE GUARDIAN >

MAY 22, 2024 Attacks on Health Workers in

JUNE 7, 2024

NPR'S "ALL THINGS CONSIDERED" > MAY 14, 2024

Conflict Zones at Highest Level Ever with Len Rubenstein

PBS NEWS HOUR >

Theater Adapts 'An Enemy of the People' to Address Public Health After the Pandemic with Jeffrey Kahn

FORBES > JUNE 26, 2024

Making A Moral Choice That Matters with Travis Rieder

NPR SCIENCE FRIDAY >

JULY 12. 2024

Why Are There So Many Drug Shortages In The U.S.? with Yoram Unguru

CBS NEWS > JULY 18, 2024

Maternal Deaths Found to be Highest in States With Abortion Restrictions with Carolyn Sufrin

THE BALTIMORE SUN > **AUGUST 4, 2024**

Commentary: We Can't Permit Child Gun Deaths to be the Status Quo by Rebecca Seltzer





"The establishment of this professorship is an important investment in the support and development of our outstanding younger faculty." JEFFREY KAHN

STEPHANIE MORAIN NAMED INAUGURAL RECIPIENT OF DRACOPOULOS RISING PROFESSORSHIP IN BIOETHICS

Stephanie Morain, faculty at the Johns Hopkins Berman Institute of Bioethics and a national leader in ethical and regulatory issues in pragmatic clinical trials, is the inaugural recipient of the Dracopoulos Rising Professorship in Bioethics.

The new professorship has been created by an



endowment established by a gift from Andreas Dracopoulos, a trustee of Johns Hopkins University and member of the Berman Institute's National Advisory Board. The professorship is a three-year appointment and includes

financial support for a junior or mid-career member of the Berman Institute's faculty to advance their bioethics research and scholarship.

"Thanks to the support of the Dracopoulos Rising Professorship, I will be able to launch a series of projects that integrate my current work in research ethics with my longstanding interest in and commitment to gender equity and reproductive health," said Morain, whose research focuses on ethical challenges in emerging clinical research designs, particularly learning health systems and pragmatic clinical trials. "Being selected for this professorship is a tremendous honor and opportunity." Specific areas of research envisioned by Morain, who

also holds an appointment as an associate professor in the Department of Health Policy and Management at the Bloomberg School of Public Health, include:

- Addressing exclusion of women of childbearing age from clinical research in emergency and acute care contexts due to the inability to confirm pregnancy status and unknown fetal risk;
- Evaluating policy options to reduce exclusion of lactating individuals from clinical trials:
- Evaluating, managing, and disclosing potential harms related to the collection of pregnancy-related data in research, in light of increasing state efforts to criminalize pregnant persons, clinicians, and other actors for the delivery or receipt of reproductive health services.

Jeffrey Kahn, director of the Berman Institute, said all faculty in the Institute who have not yet reached senior status in their faculty track are eligible to apply. The selection process included evaluation of the applications by an external review committee, who unanimously recommended Morain for the Professorship as well as noting the high quality of all the applications submitted.

"The establishment of this professorship is an important investment in the support and development of our outstanding younger faculty," said Kahn. "The Dracopoulos Rising Professorship will help ensure that the Berman Institute continues to attract and retain the best and brightest scholars in our field."

FADEN FUND IMPACT

PROVIDING SCHOLARSHIP SUPPORT FOR OUTSTANDING STUDENTS

large and vibrant Master of Bioethics Program is essential to the future of the Berman Institute of Bioethics. In each of the past three years, the program has welcomed more than a dozen new students annually and continues to surpass enrollment targets. Donor support of the Faden Fund for Education in Bioethics helped make such growth possible. It is our pleasure to introduce the outstanding students who received scholarships from the Faden Fund this year.



Jannine Balakid graduated with a California, Santa Barbara in 2019. During the COVID-19 pandemic, she worked with University of California — San

Francisco (UCSF) Fresno's COVID-19 Equity Project. Most overseeing clinical trials relating to Deep Brain Stimulation in patients with Parkinson's Disease and Essential Tremor.



Sophie Cleland recently graduated from Michigan State University with a Bachelor's of Science in Human Biology, and minors in Japanese and Bioethics. She hopes to participate in research regarding women's

health and reproductive health, with focuses on underincarcerated groups.



Jeffrey Gao earned a degree in Human Biology from University of California, Merced and intends to pursue a career in for more than a year before spending

interest is clinical ethics, particularly surgical ethics.



Marc LeVan graduated from the University of South Carolina in 2022 and is now pursuing a joint MBE/JD in conjunction with the University of Maryland Francis King Carey School of Law, where he was first



exposed to bioethics research. He is broadly interested in the intersections between law and human rights, specifically access to healthcare in such fragile settings as carceral environments, conflict zones, and places affected by natural disaster.



Naomi Mann graduated in 2024 from the College of Wooster where she completed an undergraduate thesis paper assessing whether it is ethical for hospitals to deny transplant patients an organ if they are

unvaccinated from COVID-19. She hopes to continue this focus on transplant ethics as an MBE student.



Ryan Philips graduated with a BA in 2023. He previously worked as a public health intern at the AIDS Healthcare Foundation in Los Angeles, and as a bio-

ethics intern at the National Institute of Environmental Health Sciences. He plans to attend medical school after



Brian Ricker obtained a B.A. from Johns Hopkins University in medicine, science, and the humanities. After loving an elective introductory class, bioethics became integral within his undergraduate education.

He is interested in exploring the ethical and legal landscapes of diminished decision-making capacity instances, specifically in psychiatric and palliative care. He is also interested in the ethics of health policies.

In 2018, Berman Institute National Advisory Board Chair and Johns Hopkins Trustee Emeritus Alex Levi and his wife Vicki made a landmark \$15 million bequest commitment to establish the Ruth R. Faden Fund for Education in Bioethics, which supports education and training programs at the Institute. Since that bequest was committed, additional donors have provided significant support the fund which has allowed us to offer scholarships to current students. Donors to this effort include Chris Angell, the Bunting Family Foundation, Caroline Bagley Burnett, Dick and Peggy Danziger, and Bud and Phyllis Meyerhoff.

IN MEMORY OF DAVID LEVINE AND RICHARD DANZIGER

Berman Institute pays tribute to two leading figures in its history

With profound sadness, the Berman Institute shares news of the passing of two leading figures in its history, David M. Levine, MD, ScD, MPH, Professor Emeritus of Medicine at Johns Hopkins University, and Richard Danziger, a member of the Institute's National Advisory Board and former Trustee of the university.



Dr. Levine, the former Samsung Professor of Medicine at the Johns Hopkins School of Medicine and a founding core faculty member of the Berman Institute who played a key role in establishing its world-renowned postdoctoral

training programs, passed away on Nov. 5, 2024, at the age of 86. His pioneering work in community-based participatory research helped address health disparities, particularly in cardiovascular disease, and left a legacy in academic medicine and public health. He was a dedicated physician, researcher, mentor and leader who profoundly impacted the field of medicine over the course of his 50-year career.

Dr. Levine received his bachelor's degree from Brandeis University in 1959, his medical degree from the University of Vermont in 1964 and completed his residency at Montefiore Hospital and Waltham Hospital. He earned his Master of Public Health and Doctor of Science at Johns Hopkins and joined the faculty in 1972 at the School of Hygiene and Public Health in the Department of Behavioral Sciences; and became acting chairman in 1981. In 1985, Dr. Levine transitioned to the General Internal Medicine Division in the School of Medicine, serving as Division Director from 1986 to 1996 and again as interim director from 2002 to 2004.

DEANNA FIGIEL NAMED SENIOR DIRECTOR OF DEVELOPMENT

Deanna Figiel joined the Berman Institute as Senior Director of Development in October 2024 to lead the Institute's development efforts and oversee event planning. Figiel joins Berman from the Johns Hopkins Departments of Surgery, Plastic and Reconstructive Surgery, and Anesthesiology and Critical Care Medicine, where she held roles of increasing responsibility since 2016 and was



promoted to Director of Development in 2022. She brings more than two decades of fostering philanthropic support, building development programs and managing community relations efforts.

Figiel is also a Johns Hopkins alumna, having received an MS in Marketing from the Carey School of Business. She received a BA in Marketing and Communications from St. John Fisher University in Rochester, NY.

Figiel joins the Berman Institute as Andrew Rentschler assumes the newly

created role of Executive Director of Development and Alumni Relations. In this new role, Rentschler oversees the fundraising teams at the BI, Center for Talented Youth, and the new School of Government and Policy. He will also lead the Alumni Relations International Programs team.



Richard Danziger died on Nov. 9, 2024, at the age of 86. He was a trustee of Johns Hopkins University before joining the National Advisory Board of the Berman Institute where he played a key role in providing support to its doctoral students. A

graduate of Yale Law School, he practiced law in New York City for decades. After a trip to Japan in 1974, his love for Japanese art was sparked, with his passion for learning translating into teaching at Yale, Princeton and elsewhere. Danziger served as Chair of the Urasenke Tea Ceremony Society of New York, and of the Freer Gallery of Art. He was a member of the Governing Board of the Yale University Art Gallery, served on the Asian Art Visiting Committee of The Metropolitan Museum of Art and on the Visiting Committee of the Japan Society Gallery.

At the Berman Institute, he created the Richard M. Danziger Dissertation Fund to provide PhD students grants of up to \$5,000 to support their doctoral research. Fourth-year PhD student Odia Kane has used the fund for an original survey vignette experiment examining the attitudes of primary care providers towards digital therapeutics for patients of varying demographics.

"This fund has been especially valuable to me as a bioethics student. As part of a small and unique group in a larger doctoral health policy and management program, it can be difficult to compete with our colleagues for certain grants. Sometimes it's because internal awards are directed to other concentrations, other times, our research objectives don't always align perfectly with what the award committee may be looking for," said Kane. "However, many of us go on to have project aims that incorporate primary data collection because we have access to this fund. It gave me the financial support necessary to develop a dynamic multi-method dissertation that will jumpstart my career as an independent researcher. For that, I'm eternally grateful to have benefited from this fund and deeply appreciate how much Mr. Danziger valued our work as emerging bioethicists."

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Helping Shape a **Bright Future**



or retirement plan will help ensure that the Berman Institute can continue to prepare the next generation of leaders in bioethics. Retirement assets can also be used to fund a gift that will pay you income for life.

To learn more, contact the Berman Institute's Deanna Figiel, Senior Director of Development, at 443-801-3725 or dfigiel1@jhu.edu.



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