

ETHICAL CRISES



A Hands-on Response

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FROM THE DIRECTOR

The 2017 annual report marks my first as the Andreas C. Dracopoulos Director of the Berman Institute. In my first year as director, I've come to appreciate to an even greater extent than I had realized as a member of the Berman Institute faculty the depth and breadth of the excellence that our faculty and staff bring to their work in bioethics. It is a privilege to work with such a dedicated group of colleagues who everyday bring passion and dedication to the most challenging and important issues faced across the many facets of research and practice in biomedicine and public health.

As my predecessor Prof. Ruth Faden noted in her annual report message last year, the Berman Institute has a solid place within Johns Hopkins University, a significant endowment, a physical home, and a strong base of donors and supporters—it is the ideal foundation on which to build for the next 20 years of the Institute and beyond. As this year's report shows, that building effort is already underway, as we continue to grow our educational programs (more students!), increase our outreach efforts (more public face for our work), and deepen and expand the bioethics topics in which we focus our efforts.

In addition to working with the world's best colleagues in bioethics, I have learned the great value of the counsel from our Advisory Board, both as individuals and through their collective commitment to the Institute. It would be impossible to overstate the importance of the role they play in our success, and we are grateful for it.

In the coming months, we hope you'll follow our work as well as stay in touch, and to facilitate that we are increasing our social media presence and are engaged in a process to renew and redesign our website and its content. All in all, it's an incredibly exciting time to be working in bioethics and for the Berman Institute, and we look forward to sharing that excitement in the coming months.



JEFFREY P. KAHN, PhD, MPH
ANDREAS C. DRACOPOULOS DIRECTOR
ROBERT HENRY LEVI AND RYDA HECHT LEVI PROFESSOR
OF BIOETHICS AND PUBLIC POLICY



THE BERMAN INSTITUTE RESPONDS

From the opioid crisis to nursing burnout and travel bans, if there's a national or global health issue occurring, Berman Institute faculty, staff and students are taking a stand.

Take **Travis Rieder**, PhD, who has become a national authority on the ethical issues surrounding the opioid epidemic. In 2015, Rieder celebrated being hired as Director of the Master of Bioethics (MBE) program and Assistant Director of Educational Initiatives at the Berman Institute by buying a new motorcycle. He and a buddy planned to head out for a daylong ride through the West Virginia mountains that Memorial Day weekend. But, just a few blocks from Rieder's home, a van ran a stop sign and T-boned him, crushing his left foot between the two vehicles.

Rieder spent the next five weeks in and out of hospitals undergoing multiple surgeries to save his foot before being sent home with pain medications. Because the drugs create tolerance, he was gradually taking more, until two months later when one of his physicians suggested he should wean. His plastic surgeon gave him an aggressive one-month tapering regimen, which sent Rieder into severe withdrawal and depression. None of his physicians helped, instead suggesting he go back on medication.



Eventually, Rieder recovered. He discussed his experience at a faculty retreat and in a January 2017 article in Health Affairs, arguing that physicians who prescribe medications have a moral obligation to see patients through the use of those treatments. He also co-authored a National Academy of Medicine special publication, "First, Do No Harm," looking at clinicians' roles in addressing opioid misuse and addiction. Rieder is currently working on a book, tentatively titled In "Pain in America."

Berman Institute faculty member **Brendan Saloner**, PhD, also has been tackling opioids, studying how to get more Americans with opioid use disorder into evidence-based treatment programs. He has been working with the Delaware state government on a targeted response to the opioid epidemic, analyzing how resources are being used and could be redirected. In addition, Saloner co-leads a work group on addiction and overdose as part of the Johns Hopkins Bloomberg School of Public Health's new American Health Initiative, a \$300 million effort to reshape the national public health agenda.

"Our systems are failing people by not providing them with adequate resources to get into treatment programs, treatment not being available when people need it or treatment not being consumer-focused," Saloner says.

In another area of national concern, **Cynda Rushton**, PhD, RN, FAAN, the Anne and George L. Bunting Professor of Clinical Ethics at the Berman Institute and the Johns Hopkins University School of Nursing, has been tackling how the ethical challenges regularly faced by nurses can lead to burnout. Rushton developed the Mindful Ethical Practice and Resilience Academy (MEPRA), a series of six workshops designed to help nurses navigate ethical challenges they confront in everyday practice,



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JEFFREY KAHN
DIRECTOR,
BERMAN INSTITUTE

after seeing a high number of her former students leave their nursing jobs after a year. About 100 Johns Hopkins nurses have participated in MEPRA so far; early analyses show the program has led to nurses' improved work engagement and enhanced ethical competence and confidence.

"Our goal is to give nurses the skills and practices they need to address ethical challenges in a way that preserves their integrity, and to work within systems to address the factors that contribute to situations causing their distress," says Rushton. "We are part of the cutting edge looking for solutions."

As part of the work, Hecht-Levi fellows **Heidi Holtz**, PhD, RN, and **Katherine Heinze**, PhD, RN, have been collaborating with Rushton to develop a tool to measure moral resilience based on a qualitative analysis of interprofessional clinicians' definitions. Items crucial to nurses include living with integrity and feeling like they can take moral action.



Rushton also co-led a two-day scientific symposium in August 2016 on transforming nurses' moral distress into moral resiliency. The program was co-sponsored by the Berman Institute, the School of Nursing and the American Journal of Nursing, which published a summary of the proceedings calling for help promoting resilience at the personal and systems level. Rushton is writing a book on the topic and pursuing philanthropic funding to extend MEPRA.

The Berman Institute also has advocated for immigrants and refugees. When U.S. President Donald Trump issued an executive order in January 2017 suspending the refugee admission program and imposing a travel ban, faculty member **Leonard Rubenstein**, JD, LLM, and colleagues sprang into action. Rubenstein drafted an open letter to the president signed by two dozen Bloomberg School of Public Health faculty and former Dean Michael Klag urging against the action, saying refugees who flee violence inflicted by armed groups or their government should not be denied a safe haven.

In February 2017, Rubenstein and **Nancy Kass**, ScD, the Phoebe R. Berman Professor of Bioethics and Public Health, and Deputy Director



for Public Health at the Berman Institute and Vice Provost for Graduate and Professional Education at The Johns Hopkins University, participated in a live-streamed symposium at the Bloomberg School of Public Health covering the immediate aftermath of the executive order, the public health outcomes of the refugee crisis, and the legal and ethical ramifications of enforcing the order. In addition, Rubenstein co-authored a commentary and a letter in The Lancet speaking out against the original order and a later revised one, noting that shrinking the refugee resettlement program "does not bring any security gains and imposes tremendous mental and physical harm on people who have suffered more than most of us can even imagine."

"We have a real crisis in the refugee resettlement program, and the administration's attitude about refugees raises important questions about the exercise of U.S. responsibilities," Rubenstein says. He, Berman Institute Assistant Professor **Govind Persad**, JD, PhD, and others have embarked on a research project to explore ethics and human rights considerations in informing future policy decisions on refugee resettlement.



Meanwhile, doctoral candidate **Rachel Fabi** has been studying immigrant access to prenatal and other health care services. A piece she and Saloner wrote in The New England Journal of Medicine in November 2016 praising legislation in California to allow undocumented adults to purchase insurance through the state health exchange (which ultimately was withdrawn) garnered positive attention and was the subject of a podcast interview with the editor. Another article she co-authored with Saloner and others, published in April 2017 in Health Affairs, highlighted that immigrant-friendly prenatal policies increase access to prenatal care for documented and undocumented pregnant women.

As Berman Institute Director **Jeffrey Kahn**, PhD, MPH, notes, "The Berman Institute continues to take on the most pressing and morally challenging issues of the day, working to effect change when and where it is most needed."



REAL WORLD TRIALS

With funding from the Patient-Centered Outcomes Research Institute (PCORI), **Nancy Kass**, ScD, Deputy Director for Public Health at the Berman Institute and Vice Provost for Graduate and Professional Education at The Johns Hopkins University, and **Ruth Faden**, PhD, MPH, founder of the Berman Institute and the Philip Franklin Wagley Professor of Biomedical Ethics, have

been asking patients what they think are the best ways to get informed consent for so-called “pragmatic trials.” These trials are embedded directly in the health system and compare already approved medicines to each other.

Patients needing a blood pressure medication, for example, may be randomly assigned one of two FDA-approved medicines by their own physicians, with researchers comparing which one is best.

One project published in 2016 found that the majority of 136 patients from Johns Hopkins Community Physicians and Geisinger Health System in rural Pennsylvania, liked either an “opt-in” or “opt out” consent approach, where they were told explicitly about the research by a doctor, more than blanket statements that research was ongoing in the health system.

Kass’ and Faden’s team are now surveying 2,200 patients from Johns Hopkins, Geisinger and nationally for consent preferences for a low-risk study comparing blood pressure medications. This project will test whether respondents like streamlined consent approaches more if certain features are added that promote respect.



Judah Adashi, a composer whose work centers around contemporary classical music and community engagement, took advantage of a novel funding opportunity to explore the role that 21st century musicians play in addressing sociopolitical issues.

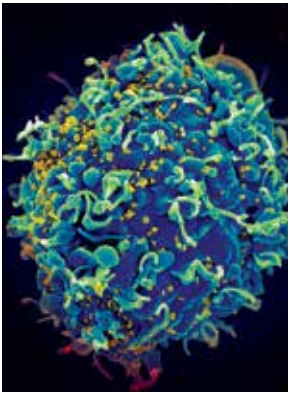
Adashi, a faculty member with Johns Hopkins’ Peabody Institute, directed a grant from the JHU Exploration of Practical Ethics program toward two endeavors: a course for students on the intersection of music and social justice and a novel composition called “Unseen: Kalief Browder and Solitary Confinement in America.” The musical work explores the last hours of Browder, a teenager accused of stealing a backpack and held in prison for three years, two of which were spent in solitary confinement. Browder committed suicide two years after his release.

The project was one of nine interdisciplinary endeavors focused on ethical issues in

research, educational experiences or other activities funded by the offices of the Johns Hopkins University president and provost, the Berman Institute, and six Johns Hopkins divisions, with a matching gift from university trustee Andreas Dracopoulos. Additional projects looked at employers that require a range of moral compromises from their employees, addressed the ethics of paying organ donors and created an ethics course for engineering undergraduates. **Maria Merritt**, PhD, a Berman Institute faculty member, serves as program officer. A second round of grants was awarded to seven additional projects in 2017.



JHU EXPLORATION OF PRACTICAL ETHICS



The Berman Institute has kept pace with numerous events related to infectious diseases. Shortly after Johns Hopkins surgeons performed the nation’s first liver and kidney transplants from an HIV-infected donor to recipients also infected with HIV, **Jeremy Sugarman**, MD, MPH, the Harvey M. Meyerhoff Professor of Bioethics and Medicine, and the

Deputy Director for Medicine at the Berman Institute, co-authored an article in the *Annals of Internal Medicine* outlining the ethical concerns of such operations for potential donors and recipients.

Our previous annual report noted that the Berman Institute received a large National Institutes of Health grant to develop the Johns Hopkins University Center for Bridging

INFECTIOUS DISEASE

Infectious Disease, Genomics, and Society (BRIDGES), designed to ensure that ethical, legal and social implications (ELSI) of advances in human genomics

are understood and considered in clinical and public health decision-making for infectious disease management. In the last year, BRIDGES has broadened its mandate to include the ELSI implications of discoveries related to pathogen/viral genomics alongside human/host genomics. BRIDGES Co-Director **Gail Geller**, ScD, MHS, a professor in the Berman Institute and the School of Medicine, joined an international ethics working group that developed ethical guidance for research involving genetic analysis of the HIV virus.

In other efforts, **Ruth Faden**, PhD, MPH, Philip Franklin Wagley Professor of Biomedical Ethics, is leading a group of colleagues at the Berman Institute, the University of North Carolina Center for Bioethics, and the Kennedy Institute of Ethics at Georgetown University in their ongoing work to advance the interest of pregnant women in vaccine responses to emerging and re-emerging infectious diseases. The group, which also includes colleagues from the Johns Hopkins Bloomberg School of Public Health and School of Medicine, as well as experts from around the world, has developed guidance specific to vaccine development and Zika virus. This year, Faden and her colleagues are expanding their focus to provide guidance on vaccine research and deployment with and for pregnant women in the midst of a broader array of emerging pathogens and outbreaks.

ACCOUNTABLE CARE ORGANIZATIONS

How can accountable care organizations (ACOs) meaningfully bring patients’ voices into their governance and decisions? With over \$500,000 from the Agency for Healthcare Research and Quality, **Matthew DeCamp**, MD, PhD, an assistant professor at the Berman Institute, has been investigating real-world practices and challenges experienced by ACOs nationwide when engaging patients.

Medicare ACOs have a regulatory policy requiring a patient to sit on the board. DeCamp has been interviewing ACO leaders and patient board members to better understand the relationship: “It’s a really unique opportunity to evaluate this particular health policy and use the lens of ethics to shape how that policy is implemented.” DeCamp also is eyeing novel ways of engaging patients, such as patient-family advisory councils or small discussion groups to bring more voices to the board room.

The good news, he says, is ACOs are “definitely interested in finding new, better ways to engage patients,” including those who are vulnerable or marginalized. In addition, ACOs have given him many powerful examples in which patients helped positively shape care programs. While most positive examples come from organizations where the policy requirement is taken seriously, DeCamp notes, “all organizations are free to do more, and that’s again where ethics can shape the how and why of doing more than the bare minimum.”



SELECTED GRANTS

Fanzo, J. Global Nutrition Report. International Food Policy Research Institute. January 2017 – August 2017. \$33,825.

This award supports the co-chair’s work on the Independent Expert Group (IEG) for the annual Global Nutrition Report, which helps sustain and increase the global commitment to malnutrition reduction by tracking progress and commitments across the globe. The IEG is responsible for writing the report, identifying gaps in knowledge, assessing and ensuring the quality of the data/evidence, and maintaining the independence of the report.

Fanzo, J. The Nutritional Impacts of Irrigated Horticulture in the Sahel: Leveraging a Large Scale Randomized Controlled Trial in Senegal. Food and Agriculture Organization of the United Nations. February 2017 – May 2017. \$90,500.

This award supports a study to provide new, experimental evidence on the nutrition and food security impacts of an irrigation expansion initiative in the Western Sahel and on the pathways through which these impacts occur. As part of this study, community health workers were trained to provide nutrition education on: infant and young child feeding; dietary quality including dietary diversity, food hygiene, and sanitation; and opportunities to improve dietary quality within the household using crops being grown and income being generated by the program. In addition to group-based nutrition education, an innovative approach to providing nutrition information using mobile phones was introduced and its feasibility assessed. Emerging evidence from developing countries suggests such approaches can be highly effective in agriculture and even simple automated messages that remind farmers about timely applications of certain inputs have substantial impacts on yield.

Fanzo, J. Strategic Reviews of Food Security and Nutrition Situation (Afghanistan and Timor Leste). United Nations World Food Program. March 2017 – October 2017. \$104,223.

As part of the global effort to accelerate progress toward eliminating food insecurity and malnutrition, the World Food Program is facilitating a series of Zero Hunger Strategic Reviews that look at results achieved and response gaps still to be covered in order to inform national and international efforts to achieve Zero Hunger worldwide. This award supports the provision of a comprehensive and detailed understanding of the contexts of food and nutrition security in Afghanistan and Timor Leste, identifies key challenges in achieving zero hunger, and provides actionable areas for the governments, development partners, private sector actors, and others to best support the countries in making progress toward zero hunger.

Kass, N. Fogarty African Bioethics Consortium Post-Doctoral Fellowship Program. Fogarty International Center. June 2016 – May 2022. \$1,223,755.

The Fogarty African Bioethics Consortium Post-Doctoral Fellowship Program (FABC-PDF) will provide 18-month, advanced bioethics training to 10 accomplished research and bioethics professionals from the African Bioethics Consortium (Makerere University Uganda, University of Zambia, University of Botswana). Ten individuals, selected for their demonstrated bioethics commitments and the ability to develop independent scholarly careers within research intensive academic settings, will spend one academic year (nine months) at Johns Hopkins, taking specialized coursework in bioethics and research methods and engaging in a rich mentored bioethics and research environment; seven months conducting independent research in their home countries; followed by two months in another consortium African country to foster inter-institutional collaboration and allow dedicated writing time such that each trainee generates a publishable manuscript by the end of the 18 months of training. Dedicated mentors from JHU and Africa are built into the program’s core infrastructure to ensure that key substantive concepts are clear, that research and writing are of rigorous quality and are completed in a timely manner, and that fellows are fully supported as they pursue careers in bioethics beyond their training.

Rubenstein, L. Research for Health in Humanitarian Crises. Save the Children Foundation; July 2016-June 2018; \$461,800.

The purpose of the grant is to investigate the nature, scope, and variety of ethical challenges experienced by humanitarian health organizations in Syria, where violence directed at civilians generally, and health care services in particular, is both chronic and extreme; and to develop an ethical framework, tool and guidelines to enable humanitarian health organizations to resolve complex ethical challenges arising in such environments

Saloner, B. Improving Access and Quality of care for Medicaid-Eligible Adults with Opioid Use Disorder. National Institute on Drug Abuse; July 2016 – June 2021, \$917,096.

The project supports research to study factors related to access of evidence-based treatment for Medicaid-eligible adults with opioid use disorder, a major health crisis in many American communities. The analysis will use survey and medical claims data to uncover the interaction between health insurance coverage and geography in determining differences in access to treatment across areas. The study also supports Dr. Saloner to gain training in addiction medicine, causal inference, geospatial analysis, and cost-effectiveness analysis.

Sugarman, J. Addressing the Ethical Issues in HIV+ to HIV+ Organ Transplants. Greenwall Foundation. January 2017 – December 2018. \$199,634.

The HIV Organ Policy Equity Act now permits transplanting organs from HIV+ donors to HIV+ recipients. This project will examine the ethical issues faced by this novel practice in actual clinical settings so that such transplants are responsibly and appropriately performed. First, we will collect in-depth qualitative data from the early recipients of HIV+/HIV+ transplants as well as those patients living with HIV who are offered an HIV+ organ and refuse. In addition, we will survey patients living with HIV who are on an organ waitlist regarding their knowledge, attitudes and beliefs about HIV+ transplants. The aggregate data will be used to help create patient-reported outcome measures of ethics outcomes as well as a standardized informed consent process and guidance for independent recipient advocates. These tools will be implemented in a multicenter clinical trial and disseminated through peer-reviewed publications as well as professional conferences and networks.

Taylor, H. Improving Understanding of Clinical Research studies: an experimental study to compare two simple informed consent strategies to traditional informed consent in the context of ongoing, real clinical studies. July 2017 – June 2019. \$389,479.

Informed Consent remains too long, complex, and legalistic, threatening participants' understanding of key study information. Proposed changes to human subjects’ regulations — and significant bioethics literature — suggest consent forms should be shorter and simpler, yet simple, adaptable, evidence-based approaches to promote participants' understanding are unavailable. In this project, we will test two simplified and easily reproducible consent approaches — a bulleted fact sheet and a video interview between a Principal Investigator and a patient (actor). Both approaches emphasize key information, provide information in discrete chunks, and use lay language. Patients considering enrollment in any of five collaborating, ongoing Johns Hopkins clinical studies will be randomized to one of these two simplified approaches or standard consent (control) to determine which method achieves better participant understanding and/or satisfaction. This work is co-led by bioethics empirical research experts and the JHU vice-dean of clinical investigation, eager and well-positioned to implement findings in future clinical studies.

SELECTED PUBLICATIONS

JOURNAL ARTICLES

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Former fellows of the **Greenwall Fellowship Program** in Bioethics and Health Policy came to Baltimore from as far as Australia and England for the program's final reunion, held in December 2016 at the Inn at Henderson's Wharf.

The Greenwall program, which ran from 1995-2012, was a collaborative effort of Johns Hopkins University and Georgetown University. The two-year postdoctoral fellowships helped launch the bioethics careers of some 50 lawyers, physicians and philosophers.

"The theme was about storytelling, and how we make the work that we do accessible to people," said **Gail Geller**, ScD, MHS, Director of Educational Initiatives at the Berman Institute and reunion organizer.

Participants, joined by current and former fellows in the successor fellowship program, the Hecht-Levi Fellowship in Bioethics, heard career stories from senior bioethicists.

They also pitched stories about their work to documentary filmmakers, who coached them on how to 'sell it' to the general public.

"I can't recall ever having felt so energized at the end of a 14-hour day!" said former Greenwall Fellow Jonathan Marks, current director of the Bioethics Program at Penn State University.

The postdoctoral fellowship program "is really one of the jewels in the crown of the Berman Institute," Geller said.

GREENWALL FELLOWS REUNION

As one of the first three students in the master of bioethics (MBE) program—a collaborative effort between the Berman Institute and the Johns Hopkins Bloomberg School of Public Health—**Farnoosh Faezi-Marian** landed a competitive fellowship working for the federal Office of Management and Budget.

Upon graduation in May 2017, the office hired her as a program examiner. Faezi-Marian now oversees budget and policy issues for health programs within the Department of Health and Human Services, including the Indian Health Service and the National Institutes of Health.

"As a result of my MBE training," she says, "I am able to effectively identify and objectively analyze existing and emerging public health issues and recommend policies that support the Administration's goals."

Her classmates were **Cameron Okeke** (see sidebar), now a research associate with the Justice Policy Center of the Urban Institute in Washington, D.C., and **Diana Mendoza-Cervantes**, a researcher at the Bloomberg School of Public Health. Mendoza-Cervantes spent the summer in Iquitos, Peru, on a project looking to improve cost-effective analysis of cervical cancer diagnostics. She also is applying to medical school. "The MBE training strengthened my skills in conceptual analysis and enabled me to effectively identify and evaluate potentially conflicting value judgments, thus integrating ethics into public health work," she says.

"They're all doing bioethics or health policy work at impressive levels," says **Travis Rieder**, PhD, Director of the MBE program. "I'm just thrilled." Sixteen students are currently enrolled.



FIRST MBE COHORT GRADUATES



Whether it's asking residents how they perceive the police or inquiring about people's gun-carrying habits, Cameron Okeke says he constantly uses skills gained at the Berman Institute to make a difference.

Okeke, who earned an MBE degree in 2017 through the Berman Institute, in partnership with the Johns Hopkins Bloomberg School of Public Health, is a research associate with the Justice Policy Center of the Urban Institute, a Washington, D.C.-based research firm. His work focuses on policing, community healing, and gun violence prevention with an emphasis on public health and social justice approaches to criminal justice issues. Okeke provides support for Community Voices, a project that partners with residents and law enforcement to generate a reliable survey of local perceptions of the police.

MBE Program Profile Cameron Okeke, MBE

"Hopkins gave me the analytical skills to think about issues quickly and succinctly and write about them in ways that are compelling but also follow logical axia," Okeke says. "I really enjoy the work that I do because we generate information about important issues often muddled and mired with reactionary feelings."

While in the MBE program, Okeke received The Marcia G. Pines Award in Bioethics and Public Health for his paper, "An Ethical Response to Female Genital Cutting in Maryland."

EDUCATION AND TRAINING PROGRAMS

Unique interdisciplinary programs and faculty provide a dynamic educational experience that makes the most of the Berman Institute's position within Johns Hopkins.

Bioethics at Homewood: The Undergraduate Minor and HUBS

Berman Institute faculty member **Hilary Bok**, PhD, directs the Bioethics Minor Program, offered in collaboration with the Department of Philosophy of the Krieger School of Arts and Sciences. Students must complete eight courses, including biology and at least two upper-level seminars. To date more than 40 students have graduated with a minor in bioethics.

The Berman Institute also fosters extracurricular interest in bioethics on the Homewood campus through its work with the student-run Hopkins Undergraduate Bioethics Society (HUBS). The group hosts events throughout the school year for the Homewood community, including debates, movie nights, mock institutional review boards, deliberative democracy sessions, and seminars on bioethics topics.

Summer Programs

BERMAN INSTITUTE BIOETHICS INTENSIVE (BI²) COURSES

Now in its fourth year, the BI² Program provides an engaging opportunity for health professionals, students, international scholars, Johns Hopkins faculty and staff, and the general public to enhance their knowledge of bioethics through an interactive short-course format taught by Berman Institute faculty. Courses, held in June during the two-week intersession between spring and summer terms, examine both theoretical and applied aspects of bioethics. In June 2017, the Berman Institute offered the courses *Foundations of Bioethics* and *Introduction to Ethics of Human Subject Research*.

SUMMER INSTITUTE IN BIOETHICS

Launched in June 2017, the Summer Institute offers for-credit courses taught by Berman Institute faculty, exploring today's pressing moral issues. The courses are open to all and applicable to students of broad educational and professional backgrounds. The first two courses offered were: Sex, Drugs, and Bioethics, and The Ethics of Making Babies.

Certificate in Bioethics and Public Health Policy

Berman Institute faculty member **Holly Taylor**, PhD, MPH, directs this program, offered by the Department of Health Policy and Management in the Johns Hopkins Bloomberg School of Public Health. The certificate program is open to any graduate student already enrolled at Johns Hopkins University. Students complete 19 graded course units, with the aim of developing skill at recognizing and analyzing moral problems in public health practice, research, and health policy, and exploring how they apply to public policy debates. To date 20 students have completed the certificate program.



Master of Bioethics

The Berman Institute community was thrilled to welcome the first cohort of MBE students in September 2015. The goal of this innovative, interdisciplinary, cross-divisional program is to prepare students from diverse personal and professional backgrounds for the bioethics challenges of professional and civic life. A collaborative program with the Johns Hopkins Bloomberg School of Public Health, the program courses are taught by Berman Institute faculty in both online and in-person formats.

PhD in Bioethics and Health Policy

A track within the Department of Health Policy and Management in the Johns Hopkins Bloomberg School of Public Health, offered in association with the Berman Institute, the PhD track provides unparalleled training, education, and mentoring to the next generation of bioethics scholars. **Holly Taylor**, PhD, MPH, directs the program, and she is joined by faculty members **Jeffrey Kahn**, PhD, **Nancy Kass**, ScD, **Maria Merritt**, PhD, **Govind Persad**, JD, PhD, MPH, and **Brendan Saloner**, PhD, in advising and mentoring students.

Danielle Edwards, JD, MS

Before coming to Johns Hopkins for a PhD in bioethics and health policy, a program at the Bloomberg School of Public Health led by Berman Institute faculty, Danielle Edwards started reading articles about food sources and the treatment of animals. When it came time to pick a dissertation topic, she kept thinking of ways to get people to eat less meat. Behavioral economics—how social, emotional and other factors affect decision-making—had been used successfully in some studies encouraging people to eat more vegetables and less fat, so Edwards chose to investigate that technique in encouraging meatless eating in restaurants.

"I think people have a gut reaction when you tell them what they should and shouldn't eat," Edwards says. "But if you change their environment, it's fine, as long as it's their choice."

Targeting rural restaurants in the Pocono Mountain area where she grew up—a large hunting community with no vegetarian restaurants—Edwards has interviewed restaurant owners and employees about how they structure their menu items and make suggestions to customers. Next, she'll evaluate a 'nudge' technique to see if restructuring the menu encourages meatless eating, and explore restaurants' ethical responsibilities to offer or encourage meatless options. While most restaurateurs think the clientele would be tough to change, some say they're willing to try Edwards' intervention.



HECHT-LEVI FELLOWSHIP PROGRAM IN BIOETHICS

Designed to support early career development in bioethics, this two-year postdoctoral fellowship program is focused on individual research and publication, with Berman Institute faculty members mentoring fellows one-on-one. Fellows are in residence at the Berman Institute, taking part in weekly seminars, presentations, courses, and events hosted by the Berman Institute and across the University. They also take advantage of the proximity to policy-making within state and federal governments.

The program is funded by a grant from the Hecht-Levi Foundation, a longtime supporter of bioethics, public health, and scholarship at Johns Hopkins University, as well as urban renewal and the arts in Baltimore. The 2016–2017 Hecht-Levi Fellows are listed below.

Silvana Barone, MD Dr. Barone’s clinical and research interests involve the care of children with complex medical conditions and how to improve communication between health care providers to ensure good longitudinal care for these children. In fellowship, she will explore the practical and ethical issues that impact decision-making and goals of care for the families of these children. Her current research employs Photovoice methodology to gain insight on the home lives of families caring for children with complex, chronic medical conditions.

Angie Boyce, PhD Dr. Boyce serves as the Project Director of the JHU Center for Bridging Infectious Disease, Genomics, and Society (BRIDGES), an NIH-funded Center of Excellence in Ethical, Legal, and Social Implications (ELSI) of Genetics Research. Her research interests include: ethical issues in infectious disease (especially related to containment care, outbreak management, and antimicrobial resistance); regulatory politics, inter-agency collaboration, and consumer advocacy; and translating genomics into population health benefit.

Shauna Downs, PhD Dr. Downs’ research focused on two main areas: 1) the role of policies and interventions to reorient the food system towards the production and consumption of nutritious foods and 2) the environmental and health trade-offs of the promotion of healthy diets. She conducts research in India, Senegal, Myanmar and New York City using various methodological approaches (e.g., value chain analysis, policy analysis, impact evaluations, etc.). Dr. Downs accepted an Assistant Professorship in the Department of Health Systems & Policy at Rutgers University.

Elizabeth Fox, PhD Dr. Fox works in the Global Food Ethics and Policy Program (GFEPP). As a nutritionist and a social scientist, her work focuses on improving the design and implementation of nutrition policies such that they effectively reach intended beneficiaries in culturally sensitive ways. Her work centers on the ethical aspects of nutrition policy decisions, and individuals’ nutritional experiences in the context of value tradeoffs.

Katherine Heinze, PhD, BSN, RN, CPHON Dr. Heinze is a former pediatric oncology nurse. Her research involves families with children who have serious illnesses, with an emphasis on palliative care and bioethics. She also is interested in investigating the moral distress that healthcare providers experience in ethically challenging contexts. Her personal research mission is to reduce suffering in seriously ill children, their family members, and the healthcare providers who care for them.

Heidi Holtz, PhD, MSN, RN During her Hecht-Levi Fellowship, Dr. Holtz’s goal is to contribute to the development of interventions and policies to reduce and/or prevent the frequency of moral distress and burnout amongst healthcare providers. Heidi has a special interest in researching the construct of moral resilience and applying that research to develop innovative approaches to foster moral resilience in healthcare environments.

Leila Jamal, PhD, ScM Dr. Jamal’s research interests include rare disease research ethics and the regulation of new technologies in healthcare and public health. During her fellowship, Leila will develop an ethical framework for returning genetic results to patients and their relatives who are enrolled in the Baylor-Johns Hopkins Centers for Mendelian Genomics, an undiagnosed disease research project. She is also interested in developing novel approaches for sharing genetic information within families while respecting individual privacy.

David Pena-Guzman, PhD Dr. Peña-Guzmán’s research addresses key questions in animal ethics, the philosophy of science, and feminist bioethics. He accepted an Assistant Professorship in the School of Humanities and Liberal Studies at San Francisco State University.



Rebecca Seltzer, MD

Following a general pediatrics residency at the Children’s Hospital of Philadelphia, Rebecca Seltzer, MD, was looking for fellowships that could combine her interest in pediatrics with bioethics. She was soon introduced to Renée Boss, MD, a Berman Institute faculty member and associate professor of neonatal-perinatal medicine, who told her about the Hecht-Levi Fellowship Program in Bioethics. Seltzer is now completing dual three-year fellowships in bioethics and in academic pediatrics, with Boss as a primary mentor.

Even before Seltzer came to Johns Hopkins, Boss asked her to coauthor a review paper on medical foster care, which was published in Pediatrics Research. The work ignited Seltzer’s passion in this area: “There’s a significant gap in knowledge about what medical foster care is and what placement options are for medically fragile children who cannot be cared for by their families.”

Seltzer then began a series of projects to better understand the experience of medically fragile children in foster care, their outcomes, and how medical decisions are made for this population. A large secondary data analysis, recently published in Children and Youth Services Review, showed that with increasing medical complexity, children in foster care are more likely to remain longer in care and have more unstable placements. She is now longitudinally following 15 children in medical foster care.

JOHNS HOPKINS-FOGARTY AFRICAN BIOETHICS TRAINING PROGRAM

This international research ethics capacity-building program serves as a coordinating center for the African Bioethics Consortium, which currently includes Johns Hopkins University; the University of Zambia, School of Medicine; Makerere University, College of Health Sciences; and the University of Botswana, Office of Research and Development.

Led by **Adnan Hyder**, MD, PhD, MPH, Associate Director of Global Programs, and **Nancy Kass**, ScD, the Phoebe R. Berman Professor of Bioethics and Public Health and the Deputy Director for Public Health, the Consortium supports graduate-level bioethics training; development of institutional strategic and implementation plans for bioethics; individual and joint-research and evaluation projects; establishment of infrastructure to coordinate bioethics teaching, research, and service; inter-institutional exchanges and benchmarking; and resource sharing. The program is funded by the National Institutes of Health (NIH) Fogarty International Center and has trained 35 scholars to date, many of whom have gone on to teach at their home institutions.

GLOBAL BIOETHICS TRAINING PROGRAM

The Berman Institute Intensive Global Bioethics Training Program hosted a diverse group of scholars in June 2017 for a month-long training in the ethics of research in low- and middle-income countries. Directed by **Adnan Hyder**, MD, PhD, MPH, Associate Director of Global Programs, and **Nancy Kass**, ScD, the Phoebe R. Berman Professor of Bioethics and Public Health and the Deputy Director for Public Health, the program combines intensive course-work with applied, skills-oriented learning, as well as trips to federal agencies in Washington, DC.

This year’s trainees came from Zambia, Botswana, Uganda and, with a supplemental grant from the in the NIH Fogarty International Center, three additional trainees attended from Liberia. The trainees enrolled in Berman Institute Bioethics Intensive Courses and met with key personnel from Johns Hopkins Institutional Review Boards (IRBs). They also participated in special seminars, mock IRB sessions, expert-led case discussions, student-led presentations, and meetings with bioethics faculty to receive mentorship and guidance related to educational, career, and research goals. In addition to formal course-work, activities included structured meetings with bioethics personnel at the NIH, the Food and Drug Administration, and the Office for Human Research Protections.

CLINICAL PROGRAMS

Faculty members from the Berman Institute lead efforts to create substantive educational experiences in clinical ethics for medical students, nursing students, residents, and other clinicians.

MEDICAL STUDENTS: The medical curriculum integrates themes of communication, cultural competence, ethics and professionalism, health disparities and health policy throughout the four-year curriculum. Courses and workshops are led by Berman Institute faculty members **Mary Catherine Beach**, MD, MPH, **Zackary Berger**, MD, PhD, **Renée Boss**, MD, **Joseph Carrese**, MD, MPH, **Matthew DeCamp**, MD, PhD, **Gail Geller**, ScD, MHS, **Mark Hughes**, MD, MA, **Margaret Moon**, MD, MPH, **Marie Nolan**, PhD, MPH, RN, FAAN, **Peter Terry**, MD, MS, and **Yoram Unguru**, MD, MS, MA.

NURSING STUDENTS: Ethics education is integrated throughout the Master of Science in Nursing and the doctoral nursing programs at the Johns Hopkins School of Nursing, including lectures by Berman Institute faculty member **Marie Nolan**, PhD, MS, MPH, also the associate dean for academic affairs in the School of Nursing. **Cynda Rushton**, PhD, RN, FAAN, the Anne and George L. Bunting Professor of Clinical Ethics at the Berman Institute and the School of Nursing, developed the Mindful Ethical Practice and Resilience Academy (MEPRA) to build moral resilience in novice nurses, which hosted its first cohort in spring 2016.

RESIDENTS: Under the leadership of Berman Institute faculty member **Joseph Carrese**, MD, MPH, FACP, the Ethics of Clinical Practice Project enhances ethics education in the Johns Hopkins University School of Medicine residency training programs. In fiscal year 2017, these Berman Institute faculty taught in eight residency programs that together reached approximately 400 residents: Child and Adolescent Psychiatry, Gynecology/Obstetrics, Medicine at both Johns Hopkins Hospital and Johns Hopkins Bayview Medical Center, Ophthalmology, Pediatrics, and Surgery.

Joining Prof. Carrese in teaching and mentoring residents are Berman Institute faculty members **Zackary Berger**, MD, PhD, **Mark Hughes**, MD, MA, FACP, and **Margaret Moon**, MD, MPH. In addition to resident training, they also lead ethics rounds on selected clinical units.

CLINICAL COMMUNITY: The Berman Institute website hosts the open-access Vision of Hope curriculum on the integration of palliative care in chronic pediatric disease. The curriculum provides evidence-based curricular materials designed in a training sequence of several pediatric palliative care principles relevant to interdisciplinary clinical team members.

The continuing “Ethics for Lunch” seminar series provides the entire hospital community with exposure to critical yet common clinical ethics issues.

For more on Ethics for Lunch, see the Outreach section, page 21.

Whether ethics expertise is needed inside or outside the Johns Hopkins community, Berman Institute faculty are primed to step up to the plate.

Our experts sit on all institutional review boards (IRBs) of the Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins University School of Medicine and participate in a Research Ethics Consulting Service, extending ethics advice to the research setting.

Newer genome editing technologies like CRISPR/Cas9 have resulted in an explosion of basic research and some early clinical trials in humans, prompting the National Academy of Medicine and the National Academy of Sciences to delve into the related scientific, ethical and social issues.

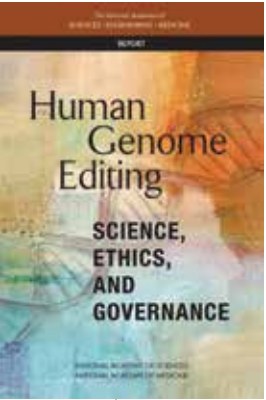
Jeffrey Kahn, PhD, MPH, Andreas C. Dracopoulos Director of the Berman Institute, served on the organization’s International Committee on Human Gene Editing that in February 2017 released its report,

“Human Genome Editing: Science, Ethics and Governance.” The document provided an overview of current capabilities in the rapidly-evolving field, as well as their potential uses and the clinical, ethical, legal and social implications.

The report recommended at least 10 conditions be met before authorizing gene editing that would result in heritable genomic changes. These include the absence of reasonable alternatives; restriction to preventing a serious disease or condition; and ongoing, rigorous oversight during clinical trials of the effects of the procedure on the health and safety of research participants. It also called for more discussion before entertaining the prospect of gene editing for enhancements of human traits.

Follow-up international summits are being planned, Kahn says: “It’s a way of continuing the international dialogue around how to effectively manage the evolution and responsible application of these new technologies.”

To learn more, see <http://nationalacademies.org/gene-editing/consensus-study/index.htm>.



Berman Institute faculty play key roles chairing the multidisciplinary ethics committees at The Johns Hopkins Hospital and Johns Hopkins Bayview Medical Center. Their activities include providing a 24/7 ethics consultation service and creating and reviewing hospital policies with an ethics dimension.

“We address things like end-of-life care when there are disparate goals, decision-making capacity, allocation of scarce resources such as to what extent financial resources ought to determine organ allocation, and who makes decisions when patients and clinicians disagree about treatment options,” says **Cynda Rushton**, PhD, RN, FAAN, the Anne and George L. Bunting Professor of Clinical Ethics in the Berman Institute of Bioethics and the Johns Hopkins University School of Nursing, who co-chairs The Johns Hopkins Hospital’s ethics committee with **Mark Hughes**, MD, MA, a Berman Institute core faculty member. Other Berman Institute faculty who serve on the committee include **Zackary Berger**, MD, PhD; **Renée Boss**, MD;

Megan Collins, MD; **Margaret Moon**, MD, MPH; and **Marie Nolan**, PhD, RN.

At Bayview, the ethics committee tackled a number of issues over 2016-2017, including in-depth discussions about the ethics of denying hip replacement surgery for a cigarette smoker or repeat valve surgery for a patient with a substance use disorder, says committee chair **Joseph Carrese**, MD, MPH, a Berman Institute core faculty member. The group also debated if it is ethically acceptable to give parents of children in a Johns Hopkins pediatric practice information about their due process rights as they relate to immigration status and risk of deportation or if such activity is beyond the accepted boundaries of clinical practice.



HOSPITAL ETHICS COMMITTEES

When the National Institutes of Health went looking for an expert to chair the institutional review board (IRB) for its largest, most ambitious health research study, the agency immediately called on **Nancy Kass**, ScD, the Phoebe R. Berman Professor of Bioethics and Public Health, Deputy Director for

Public Health at the Berman Institute and Vice Provost for Graduate and Professional Education at The Johns Hopkins University.

“ALL OF US” INSTITUTIONAL REVIEW BOARD

The All of Us Research Program is a historic, \$130 million precision medicine effort to gather data from 1 million or more diverse Americans to accelerate research and improve health. Information collected will form the basis of a data set that researchers can analyze to identify better ways to prevent and treat diseases based on individual health, environment and lifestyle.

The 13-member IRB—an ethics committee required to ensure that research is morally acceptable, transparent and fair to participants—encompasses people of diverse backgrounds including three community members, one of whom also serves as a prison representative. The group has approved the study’s main protocol, which outlines all procedures for recruiting and enrolling the study’s participants, with stringent attention to ensuring recruitment materials are understandable to people of different backgrounds. The IRB is also reviewing protocols

from more than 100 sites around the country recruiting study participants, and has pushed for a community voice at each site.

“I really love the committee, because people bring very different expertise and perspective,” Kass says. “It’s a constructive, respectful group.”

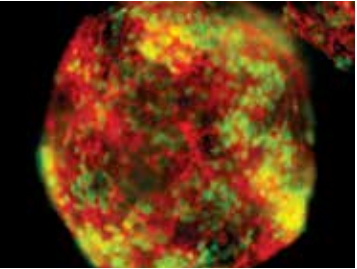


Once a month, **Jeremy Sugarman**, MD, MPH, MA, the Harvey M. Meyerhoff Professor of Bioethics and Medicine and the Deputy Director for Medicine at the Berman Institute, and colleagues meet to review

stem cell research being conducted throughout The Johns Hopkins University to make sure it’s ethically sound. Sugarman co-chairs the Institutional Stem Cell Research Oversight Committee (ISCRO), a multidisciplinary group of 16 members, including scientists, ethicists and some community representatives.

The group reviewed some 89 applications in the 2016-2017 year, including research involving work with human embryonic stem cells and induced human pluripotent stem cells. There are 48 active protocol applications and 18 approved cell lines. The committee also recently helped update the Johns Hopkins Medicine policy governing the use of human biospecimens to derive immortalized or pluripotent stem cell lines, to provide ethical guidance regarding obtaining voluntary and informed consent from donors, when possible.

Others from the Berman Institute who sit on the committee are **Debra Mathews**, PhD, MA, Assistant Director for Science Programs; **Alan Regenberg**, MBE, Director of Outreach and Research Support; and **Andrew Siegel**, JD, PhD, Research Scholar.



INSTITUTIONAL STEM CELL RESEARCH OVERSIGHT COMMITTEE

Additional Institutional Service

Institutional Review Boards

Mary Catherine Beach, MD, MPH
Co-Chair

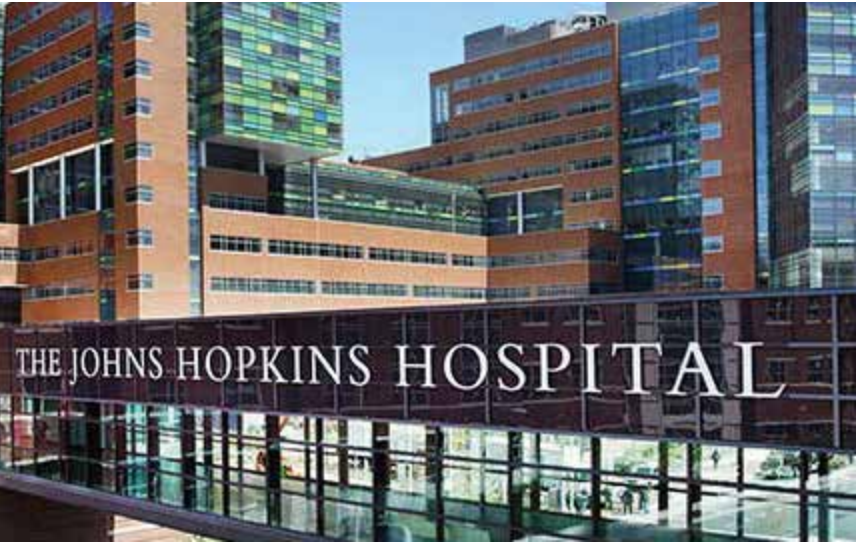
Joseph Carrese, MD, MPH
Chair

Matthew DeCamp, MD, PhD
Maria Merritt, PhD

Margaret Moon, MD, MPH
Peter B. Terry, MD, MA

Research Ethics Consulting Service

Holly Taylor, PhD, MPH



LEVI SYMPOSIA

The Robert H. Levi Leadership symposia have brought important ethical topics at the intersection of public policy to the Berman Institute for in-depth discussion, and this year was no exception.

Human Radiation Experiments

In October 2016, the Berman Institute hosted a daylong symposium looking back at the release of a 1995 report by the White House Advisory Committee on Human Radiation Experiments (ACHRE), which was chaired by **Ruth Faden**, PhD, MPH, Founder of the Berman Institute and the Philip Franklin Wagley Professor of Biomedical Ethics. Former U.S. President Bill Clinton had convened the committee to investigate reports of possibly unethical experiments funded by the government decades prior.

During their investigations, Faden and colleagues heard testimony from more than 200 witnesses and reviewed many thousands of declassified government documents from the mid-1900s as well as contemporaneous documents from the mid-1990s. The committee found that some experiments involved human subjects without their knowledge or consent, and that in some cases, there was active deception of participants or their families. The committee also found serious deficiencies in the research oversight system of the 1990s.

The symposium, called Secrecy, Security and Science, brought together original members of the ACHRE committee and staff to reflect on the report and its impact. They discussed the regulation of human subjects research, informed consent then and now, considerations on remedies for past wrongs and the use of historical information to make moral judgments about the past.

“It was an extraordinary opportunity to see the relevance, 20 years later, of the committee’s work,” Faden says. “It was important to discuss the impact of those of our recommendations that were adopted, but it was also important to see how much of what we had to say then about the relationship between science, national security and the public’s right to know still needs to be addressed.”



Innovative Therapies

In April 2017, the Berman Institute delved into navigating the ethical tensions in patients’ requests for innovative therapies. This included a public session related to innovations in oncology, infectious diseases and obstetrics moderated by **Jeremy Sugarman**, MD, MPH, MA, the Harvey M. Meyerhoff Professor of Bioethics and Medicine and the Deputy Director for Medicine at the Berman Institute.

The following day, an expert multistakeholder group examined the use of amnioinfusions for renal agenesis. The discussion was spurred by the case of Washington state Rep. Jaime Herrera Beutler, whose daughter, Abigail, was born in 2013 with bilateral renal agenesis—the absence of both kidneys. While pregnant, Beutler came to Johns Hopkins for evaluation by perinatologist Jessica Bienstock, who, in order to perform an ultrasound, had to infuse saline solution into the uterus. Beutler underwent five additional infusions over several weeks before going into labor, with the hopes of helping the fetus’ lungs develop more normally.

“People who are faced with a diagnosis of renal agenesis and considering serial amnioinfusions ought to do so in the context of a formal research endeavor,” Sugarman says. “Just because the treatment worked in this one case, we’re not confident it’s going to work in others, and there are enormous ethical and policy implications of doing so. The only way to find out if it’s safe and effective is to do it in a rigorous fashion.”

*An executive summary of the 1995 ACHRE report is available at <https://ehss.energy.gov/ohre/roadmap/achre/summary.html>. A report about the amnioinfusions was published in the journal *Obstetrics and Gynecology*.*



Jeffrey Kahn on WYPR

Tune in to WYPR radio (88.1 FM) in Baltimore during the noon hour and you may hear a familiar voice. Jeffrey Kahn, PhD, MPH, Andreas C. Dracopoulos Director of the Berman Institute, has been a regular guest on the National Public Radio affiliate’s Midday program, discussing ethics topics such as how to ensure that autonomous cars make the “right” decision, physician aid in dying, and the challenges of assuring diverse participation in clinical trials. Each subject easily generates more calls from listeners than they have time to discuss on air, Kahn says.

An archive of previous programs can be found at <http://bioethicsbulletin.org/archive/jeff-kahn-on-wypr-midday>.

Ethics for Lunch

Berman Institute faculty continue to offer nourishment for the body and mind during monthly “Ethics for Lunch” seminars at The Johns Hopkins Hospital and Johns Hopkins Bayview Medical Center. During each program, an expert panel presents and discusses a medical ethics case study, then opens the floor to attendees.

Topics over the 2016-2017 year included medical decision-making for parentless children, caring for patients with chronic pain, managing medical mistakes, and asking for and receiving gifts from patients. CME credits are available and lunch is provided; seminars are available on the Berman Institute’s YouTube channel.

For more information or to view previous talks, see <http://www.bioethicsinstitute.org/efl>.

Bioethics Seminar Series

Dealing with racist patients, conflicts over treatments in the intensive care unit, and the legal and ethical issues surrounding medical tourism were among the 17 topics discussed during the Berman Institute’s biweekly seminar series this year. The lunchtime lectures, open to the public, were delivered by leading bioethics scholars from institutions nationwide. Additional topics included physician-assisted death of non-terminally ill psychiatric patients, the ethical challenges of unregulated health research using mobile devices and the role of courage and culture in addressing moral distress in health care.

Seminars are recorded and available for viewing on the Berman Institute’s YouTube channel: <https://www.youtube.com/user/BermanInstitute>.

BERMAN INSTITUTE IN THE NEWS

A selection of the media outlets that quoted, published or mentioned the Berman Institute and its faculty this year:

91.5 KJZZ	Johns Hopkins Nursing magazine	The Daily Beast
ABC News	Kaiser Health News	The Federalist
American Nurse Today	KPCC: AirTalk	The Global Observatory
APA's Medical Mind podcast	KSCB Radio	The Millions
Associated Press	Medical Express	The Nation's Health
Baltimore Sun	Medium (Simpson Center for the Humanities)	The National Review
Bay Journal News	Medscape	The New England Journal of Medicine podcast
Bill Nye Saves the World, Netflix	MPR News	The New Republic
Bioengineer.org	National Geographic Explorer	The New York Times
Bioethics.net	News-Line	The New Yorker
Broadly	NPR	The Philosopher's Eye
Buzzfeed	NPR: Shots	The San Francisco Gate
CNN	Oncology Nursing News	The Wall Street Journal
Conversation Earth podcast	Ozy	The Washington Post
Desert News	PBS Nova Next	The Week
Devox	Pharmaceutical Engineering magazine	The Wire
Digg	Quartz	USA Today
Efecto Naim	Radiology Business	VICE News
Esquire Magazine	Reuters	Vox
Fivethirtyeight	SAIS Perspectives	WBAL-TV
Food Tank	Salon	Wired
Fusion	San Diego Union-Tribune	WTOP
Geo Beats	Science blog	WUBR: On Point
Health Medicine Network	Science magazine	WYPR: Midday
Health Minute podcast	Scientific American	WYPR: On the Record
HealthDay	Slate	
Hopkins Medicine magazine	SparkDialog	
Huffington Post	STAT	
JHU Rising blog	The Boston Globe	
Johns Hopkins Health Review	The Catholic News Agency	
Johns Hopkins HUB	The Chronicle of Higher Education	
Johns Hopkins Medicine podcast	The Climate Changer podcast	
Johns Hopkins Newsletter	The Conversation	

SELECTED PRESENTATIONS

Abraham P, **DeCamp M**. Why Should we Engage Patients in Healthcare Organizational Governance and Decision-Making? American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Ali J, Hyder AA. Consultation on the ethical, legal and societal issues associated with the use of mobile phone surveys for non-communicable disease surveillance in low- and middle-income countries. Baltimore, MD. November 2016.

Ali J. Ethical and Legal Issues: A User's Guide for Integrating Patient-Reported Outcomes in Electronic Health Records. PCORI Meeting, Washington, DC. May 2017.

Ali J. Mobile Phone Surveys for Global Non-Communicable Disease Surveillance: Exploring the Ethical Challenges. Annual ICT4D Conference, Hyderabad, India. May 2017.

Ali J. Mobile Phone Surveys for NCD Risk Factor Surveillance in LMICs (panel). Global Digital Health Forum & Connected Health Conference, National Harbor, MD. December 2016.

Anjum S, Halpern S, Kumar K, Nguyen A, Rasmussen S, Massie A, Tobian A, Segev D, **Sugarman J**, Durand C. Knowledge and attitudes associated with willingness to accept HIV+ organs among persons living with HIV. American Transplant Congress, Chicago, IL. April 2017.

Barone S. Bone marrow transplant in adolescents and young adults - get them talking! Annual Academy of Hospice and Palliative Medicine Annual Assembly, Phoenix, AZ. February 2017.

Barone S. Providers, Parents & Privacy: ethical issues surrounding social media use in pediatrics. Bioethics Interest Group meeting, National Institutes of Health, Bethesda, MD. June 2017.

Beach MC. Assessing the quality of physician communication: How do we know what 'quality' is? University of Massachusetts Medical School, Springfield, MA. October 2016.

Beach MC. How the language used in medical records can stigmatize patients and perpetuate bias. 6th OCHER workshop on Clinical Communication Research, Oslo, Norway. January 2017.

Beach MC. Language used in Medical Records May Reflect Bias. International Conference on Communication in Healthcare, Heidelberg, Germany. September 2016.

Beach MC. Language used in Medical Records May Reflect Bias. COMET 2016, Aalborg, Denmark. July 2016.

Beach MC. Radiologist communication during breast imaging: a systematic review. International Conference on Communication in Healthcare, Heidelberg, Germany. September 2016.

Berger Z, Cahan J. Patient Autonomy in Talmudic Context: The Patient's I Must Eat on Yom Kippur in the Light of Contemporary Bioethics. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Berger Z. 'Everyone is Something of an Expert': Saving a Life on the Sabbath in the Context of Modern Guides of Jewish Law. Association for Jewish Studies 48th Annual Conference, San Diego, CA. December 2016.

Boss R, Dodge R, **Seltzer R**. Who Knows the Best Interests of a Parentless Child? The Challenges of Medical Decision-Making for Children in Foster Care. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Boyce A. Anticipating the ELSIs of Genomics in the Clinical Management of Colonization. NHGRI Training Meeting, St. Louis, MO. April 2017.

Bush L, Grady C, Hardart G, Harrison C, Lantos J, Mitchell C, **Rothenberg K**, **Seltzer R**, Truog R. When the Insider Stands as an Outsider: A Play Explores the Critical Distance Continuum Conundrum. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Caga-anan EC, Dawson L, Edwards K, Hemlers K, **Merritt M**, Starks H. Navigating Federal Funding for Bioethics Research: From Soup to Nuts. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Carrese J, Hughes M. Physician Assisted Death/Suicide. Johns Hopkins School of Medicine Faculty Senate, Baltimore, MD. January 2017.

Carrese J. Institutional Review Boards (IRBs) at the Johns Hopkins University School of Medicine. 2016 Henrietta Lacks Memorial Lecture, Baltimore, MD. October 2016.

Carrese J. Operationalizing Professionalism: A Direct Observation Checklist to Measure Respect and Dignity in the ICU. 5th Annual Academy for Professionalism in Health Care Meeting, Chicago, IL. April 2017.

Carrese J. Curtis R. Holzgang Visiting Scholar Lectures. Providence St. Vincent Medical Center and Providence Portland Medical Center, Portland, OR. November 2016.

Childerhose J. The Disappearance of the Vulnerable Adolescent in Clinical Practice Guidelines for Bariatric Surgery. Adolescent Grand Rounds, Department of Pediatrics, Johns Hopkins Hospital, Baltimore, MD. October 2016.

Childerhose J. It's Not a Quick Fix: How Adolescents Characterize Bariatric Surgery. Bioethics Interest Group meeting, National Institutes of Health, Bethesda, MD. April 2017.

Childerhose J. Challenges of Weight Loss Surgery for Adolescents with Obesity. Twitter chat. May 2017.

Childerhose J. The Disappearance of the Vulnerable Adolescent in Clinical Practice Guidelines for Bariatric Surgery. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Cohen G, **DeCamp M**, Dunn L, Klugman C. My Doctor Knows What I Did Last Night: The Ethics of Ingestible Pill Logging Technology. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

DeCamp M, Berger Z. An Ethics Assessment of Population Health Measures: Considering Multiple Dimensions in the Clinical Context. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

DeCamp M, Johnson V, Miller J, **Unguru Y**. Shortages of Drugs, Surpluses of Perspectives: Finding Ethical Equilibrium Among Key Stakeholders. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Dukhanin, V, Zwerling A, Searle A, **Taylor HA**, Dowdy D, **Merritt M**. Systematic Review: Incorporating Social Justice Considerations into Economic Evaluations in Healthcare and Public Health. International Society for Priorities in Health Annual Meeting, Birmingham, United Kingdom. September 2016.

Eyal N, Faust H, **Saghai Y**. The Ethics of Health Policy Decision-Making for the Proper Balance of Prevention and Treatment Using Marginal Cost-Effectiveness Analyses. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Fabi R. Prenatal Care for Undocumented Immigrants: A Comparative Case Study in Policy and Ethics. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Faden R, Henry LM, Little M, Luna F, Lyerly A, Mastroianni A. Zika and the Ethical Complexities of Pregnancy: Identifying Priorities for the Global Health and Research Communities. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Faden R. Ethical Issues in the Zika Virus Vaccine Trials and Pregnancy. Bioethics Conference of the Center for Bioethics and Nanoethics, University of Aarhus, Aarhus, Denmark. October 2016.

Fanzo J. Panel: The Future of Food: Your Plate. Our Planet. Nobel Week Dialogue conference, Stockholm, Sweden. November 2016.

Fanzo J. Key Parameters for Nutrition and Sustainability. Sackler Institute of Nutrition Sustainability Workshop, London, England. January 2017.

Fanzo J. Keynote Address: Sustainable Diets: Can we feed the world well and protect the planet? Agriculture and Climate Change, Sitges, Spain. March 2017.

Fanzo J. Strengthening accountability, resilience and equity within food systems. International Symposium on Sustainable Food Systems for Healthy Diets and Improved Nutrition, UN FAO, Rome, Italy. December 2016.

Fanzo J. Sustainable Diets: Can we Feed Ourselves and the Planet Well? USDA ERS, Washington, DC. 2017.

Fanzo J. Keynote address. International Life Sciences Institute (ILSI) Annual Meeting, San Diego, CA. January 2017.

Fanzo J. (2016) Framing: Education and training the workforce for nutrition in the future. Session: The critical role of capacity for delivering micronutrient interventions. Micronutrient Forum Global Conference 2016, Cancun, Mexico. October 2016.

PRESENTATIONS (CONT.)

Fanzo J. Climate change and effect on health. Session: Climate Change and Micronutrient Nutrition. Micronutrient Forum Global Conference 2016, Cancun, Mexico. October 2016.

Fanzo J. Environmental impacts of shifting diets. International Food Technology Conference, Las Vegas, NV. June 2017.

Fanzo J. Investing in women's economic resilience and social wellbeing: Rethinking the role of private sector development in Africa. Foreign Policy Centre (FPC). House of Parliaments, London, England. July 2016.

Fanzo J. SMART Commitments for the Decade of Action. UN Committee on Food Security 43. Rome, Italy. December 2016.

Fanzo J. Stories of Change Session. Micronutrient Forum Global Conference 2016, Cancun, Mexico. October 2016.

Fanzo J. Sustainable Diets for Nepal. Nutrition Innovation Lab Scientific Meeting, Kathmandu, Nepal. July 2016.

Fanzo J. Sustainable diets. G20Y Summit, St. Moritz, Switzerland. September 2016.

Geller G, Henderson G, **Kahn J, Henry LM.** ‘Critical Distance’ from Emergent Infectious Diseases: Ethical Challenges in Public Health Containmentment. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Geller G, Kahn J, Boyce A. Ethical issues that genomics introduces for the clinical management of high consequence infections in the hospital setting. National Ebola Training and Education Center (NETEC) site visit, Baltimore, MD. May 2017.

Geller G, Kahn J, Boyce A. Panel: Anticipatory ELSI, Anticipating Disease. ELSI Congress, Farmington, CT. June 2017.

Geller G. Social and Cultural Influences on Community Perspectives Regarding HIV Viral Genomics: The U.S. Context. Ethical, Legal and Social Considerations. Ethics Working Group of the PANGEA (Phylogenetics and Networks for Generalised HIV Epidemics in Africa) Consortium, London, England. May 2017.

Geller G. Discussion: ethical issues that arise for infectious disease biobanks. International Society for Biological and Epidemiologic Repositories (ISBER) meeting, Toronto, Ontario. May 2017.

Geller G. Panel: Manifestations and Challenges of Moral Distress for Social Workers. National Social Work Month Celebration, Baltimore, MD. March 2017.

Geller G. The Role of Genomics in the Prevention and Treatment of Infectious Disease: Ethical, Legal and Social Implications (ELSI) for Public Health and Clinical Practice. Centre for Biomedical Ethics, National University of Singapore’s School of Medicine, Singapore. November 2016.

Geller G. Tolerance for Ambiguity in Medical Education: Its Significance for Selection and Training of Future Health Professionals. Uncertainty Tolerance: Nature And Manifestations in Health Care, panel. International Conference on Communication in Healthcare, Heidelberg, Germany. September 2016.

Gluck J, Heitman E, **Kahn J,** Rubbelke T. Some Look Like Us, Others Live in Our Homes: Critical Distance and Animal Research Ethics. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Greene J. Making Old Drugs New Again: Uses of History in Health Policy and Practice. University of Exeter, Exeter, UK. October 2016.

Hahn E. My Patient’s Mom Friended Me: Rethinking Professionalism and Use of Social Media in the Neonatal Intensive Care Unit. American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Halpern S, Kumar K, Nguyen A, Rasmussen S, Anjum S, Massie A, Tobian A, Segev D, **Sugarman J,** Durand C. Willingness to donate organs among persons living with HIV. American Transplant Congress, Chicago, IL. April 2017.

Hughes MT. Determining Preferences for Control in Decision-Making: A Starting Point in the Clinical Relationship. Panel, Culture-Appropriate Care – Challenges, Dilemmas. Emirates Oncology Conference, Abu Dhabi, United Arab Emirates. November 2016.

Hyder AA. Launch Meeting for First World Report on Health Policy and Systems Research. Stockholm, Sweden. April 2017.

Kahn J, Faden R, Mathews DJH. Workshop: Ethical Issues Involved in iPS/Stem Cell and Genetic Research and Therapy. Uehiro Foundation of Japan, the Carnegie Council of New York, and the Centre for Practical Ethics at Oxford University. Tokyo, Japan. May 2017.

Kahn J, moderator. Panel: *Just a Pocketful of Soap... An Open Discussion.* Documentary Filmmaker Retreat, Science & Entertainment Exchange, National Academy of Sciences, Woods Hole, MA. September 2016.

Kahn J, Rieder T. Ethics of Gene Editing. Hopkins MED Panel, AED Premedical Society, Triple Helix, and the Hopkins Undergraduate Bioethics Society, Baltimore, MD. March 2017.

Kahn J. Bioethics and Johns Hopkins: Where We’ve Been and Where We’re Going. 2017 Susruta Lecture. Wilmer Residents Association Annual Meeting Baltimore, MD. May 2017.

Kahn J. Current Oversight Approaches and Research on Big Data. NIH Ethics and Regulation in Clinical Research Conference, Bethesda, MD. October 2016.

Kahn J. Ethics and the risk to human health of long duration spaceflight. 62nd Annual Radiation Research Society Meeting, Kona, HI. October 2016.

Kahn J. Ethics, Technology, and the 21st Century: Taking Stock and Looking Ahead. Intelligent Systems Group (ISC) Seminar Series, Applied Physics Laboratory, Laurel, MD. January 2017.

Kahn J. Mitochondria Replacement: Ethics, First Human Trials, and Treatment for Genetic Disease. Optum Health Medical Directors Forum, Las Vegas, NV. November 2016.

Kahn J. Personalized Public Health? Ethics and Policy Issues in the Application of Genomics to Infectious Disease. University of Pittsburgh Graduate School of Public Health, Pittsburgh PA. February 2017.

Kahn J. Advances in Gene Editing: Balancing Promise and Risk. Congressional Research Service, Washington, DC. April 2017.

Kahn J. Bioethics — The Dilemmas of Modern Medicine. One Day University, New York, NY. April 2017.

Kahn J. Communicating with Legislators and their Staffs: Testimony, Meetings and Briefings. Bloomberg School of Public Health, Baltimore, MD. April 2017.

Kahn J. Ethics and Outbreak Response. University of Zurich, Zurich, Switzerland. May 2017.

Kahn J. History and Henrietta Lacks: Baltimore, Biomedicine and Bioethics. University of Maryland, Baltimore County, Baltimore, MD. March 2017.

Kahn J. Human Genome Editing: Science, Ethics, and Governance. Genetic Alliance, Washington, DC. May 2017.

Kahn J. Learning from Ebola: Ethically Appropriate Response to Pandemics. NYC Medical Reserve Corps 5th Annual Symposium, New York, NY. April 2017.

Kahn J. Medical Automation & Robotics Roundtable. The University of Maryland Francis King Carey School of Law, Baltimore, MD. April 2017.

Kahn J. Panel: Approaches and Impulses for Development and Training Cooperation between Science and Fiction. International MINTEEE=Conference 2016—Science Meets Fiction, Berlin, Germany. November 2016.

Kahn J. Panel: Perspectives on Massive Transfusions: Surgeons, Blood Centers and the Impact on the Community. American Association of Blood Banks Annual Meeting, Orlando, FL. October 2016.

Kahn J. Panel: The Future Is Here: The Peril & Promise of Our Genetic Information. HealthLab, Light City Festival, Baltimore, MD. April 2017.

Kahn J. Scientific Evidence in Development of Human Cells, Tissues, and Cellular and Tissue-Based Products Subject to Premarket Approval. Food and Drug Administration Public Workshop, Silver Spring, MD. September 2016.

Kahn J. The Use of Non-human Primates in Research. NIH Office of Science Policy Workshop, Bethesda, MD. September 2016.

Kahn J. Brocher Conference on Ethics, Policy, and Vascular Composite Allograft Transplants. Geneva, Switzerland. May 2017.

Kahn J. TEDxMidAtlantic 2016: New Rules. Washington, DC. October 2016.

Kahn J. Remedies: Population Risk and Government Wrongdoing. Robert H. Levi Leadership Symposium—Secrecy, Security, and Science, Baltimore, MD. October 2016

Kass N. Development of Global Research Ethics. University of Central Florida College of Nursing, Orlando, FL. November 2016.

Kass N. Panel: Precision Medicine Initiative: What Are the Promises and What Are the Ethical Challenges? PRIM&R’s 2016 Advancing Ethical Research Conference, Anaheim, CA. November 2016.

Kass N. Unveiling of the Portrait of Henrietta Lacks. Baltimore, MD. December 2016.

Kass N. Informed Consent, Then and Now. Robert H. Levi Leadership Symposium—Secrecy, Security, and Science, Baltimore, MD. October 2016.

Krubiner C. Ethics & Equity Considerations for Health Benefits Design. International Seminar on Using Evidence for Decision-Making, Pretoria, South Africa. March 2017.

Krubiner C. Guidance for the Ethical Inclusion of Pregnant Women in Zika Vaccine Research and Development. Global Forum on Bioethics in Research — Ethics of Research in Pregnancy, Buenos Aires, Argentina. November 2016.

Krubiner C. Meeting the Needs of Pregnant Women in the Zika Response: Testing and Using Vaccines in Pregnancy. Global Forum on Bioethics in Research — Ethics of Research in Pregnancy, Buenos Aires, Argentina. November 2016.

Krubiner C. Toward Guidance for Ethically Addressing Pregnant Women in Zika R&D. Wellcome Trust Meeting of Zika research grantees, London, England. September 2017

Krubiner C. Zika infection and pregnancy. International Center for Maternal and Newborn Health, Johns Hopkins University, Baltimore, MD. February 2017.

Krubiner C, Lyerly A, Saenz C. Zika and the Ethical Complexities of Pregnancy: Identifying Priorities for Global Health and Research Communities. American Society of Bioethics and Humanities, Washington, DC. October 2016.

Mathew DJH. Bioethics in our Everyday Lives Part II. Marian Koshland Science Museum, Washington, DC. April 2017.

Mathew DJH. Review of Return of Results Policy, As Reflected in Clinical Trial Informed Consent Documents. Annual Meeting of the American Society of Human Genetics, Vancouver, Canada. October 2016.

Mathews DJH. Change is Coming to a Genome Near You — How Much (If Any) Is Okay? Howard University, Washington, DC.

Mathews DJH. Neurotechnology and Society: Strengthening Responsible Innovation in Brain Science. Organization for Economic Cooperation and Development, Washington, DC. September 2016.

Mathews DJH. Should We Modify Our Genome? Basic Research, Rogue Clinics, and the Role of Scientists. Science Policy Series Lectures, Baltimore, MD. October 2016.

Mathews DJH. Assisted Reproductive Technologies and Gene Transfer. Dunbar High School, Baltimore, MD. February 2017.

Mathews DJH. Bioethics in our Everyday Lives. Marian Koshland Science Museum, Washington, DC. March 2017.

Mathews DJH. Compensating Research Tissue Donors: Henrietta Lacks and the Ethics of Paying for Biological Specimens. ENRICH Forum. National Cancer Institute, Rockville, MD. June 2017.

Mathews DJH. Ethics and Genomics Panel. BioGenomics 2017 Conference at the Smithsonian Museum of Natural History, Washington, DC. February 2017.

Mathews DJH. Findings of the Individual Return of Results Working Group. Multi-Regional Clinical Trials (MRCT) Annual Meeting, Boston, MA. December 2016.

Mathews DJH. Human Genome Editing. JHU’s Project Bridge Baltimore Science Café, Baltimore, MD. November 2016.

Mathews DJH. Workshop: Policy and ethical implications of CRISPR-Cas9. Biophysical Society Annual Meeting, New Orleans, LA. February 2017.

Mathews DJH. 5th Annual Sc2.0 and Synthetic Genomes Conference. Edinburgh, Scotland. July 2016.

Mathews DJH. Council of Neuroethics Program Leaders Meeting. International Neuroethics Society Annual Meeting, San Diego, CA. November 2016.

Mathews DJH. Keynote Address. Annual Forum on Bioethics, St. Vincent College, Latrobe, PA. April 2017.

Osman M, **Saghai Y** (chair). Defensive Thinking: Psychological Barriers to Accepting Food Futures. Food Futures Panel. World Futures Studies Federation Annual Meeting, Jondal, Norway. June 2017.

Peña-Guzmán D. Feminism, Existentialism, and the Philosophy of Science. Annual Meeting of the Society for Phenomenology and Existential Philosophy, Salt Lake City, UT. October 2016.

Peña-Guzmán D. Science and Ethics intensive course. Emory-Tibet Science Initiative. Dharamsala, India. May 2017.

Peña-Guzmán D. Transnational Surrogacy as Capacity-Building: Exploitation, Coercion, and Empowerment. Exploitation and Coercion Workshop. Center for Ethics & Policy at Carnegie Mellon University, Pittsburgh, PA. November 2016.

Persad G. Household Debt, Disadvantage, and Status Maintenance. Finance and Social Justice Conference, University of Bayreuth, Bayreuth, Germany. November 2016.

Persad G. Rethinking Financial Risk Protection In Universal Health Coverage. McDonough School of Business, Georgetown University, Washington, DC. April 2017.

Persad G. Setting Priorities for Genomic Research: Cost-Effectiveness and Distributive Fairness. ELSI Congress, Farmington, CT. June 2017.

Persad G. Why Wide-Scope Benefits Should Count in Public Policy. Symposium on Ethics and What Is Not Seen: The Effects of Remote Consequences on Ethical Analysis, Georgetown University Institute for the Study of Markets and Ethics, Washington, DC. November 2016.

Persad G. Health Care Reform. National Institutes of Health Department of Bioethics First Year Seminar, Bethesda, MD. March 2017.

Persad G. Justice and public health. PCORI Lunch and Learn Session, Washington, DC. January 2017.

Persad G. Panel: Can’t Buy Me Love, but Maybe a Clinical Trial Spot? How IRBs Wrestle With Participant Funding and Influence. PRIM&R’s 2016 Advancing Ethical Research Conference, Anaheim, CA. November 2016.

Persad G. Polarization, Distributive Justice, and the Future of the Middle Class. American Philosophical Association Central Division meeting, Kansas City, MO. March 2017.

Persad G. Right to Health and Fair Trade Labeling as a Tool for Access. Cornell University, Ithaca, NY. March 2017.

Persad G. Social Change and Status Quo Maintenance in Applied Ethics. Workshop on Methodology in Applied Ethics, Georgetown University, Washington, DC. February 2017.

Persad G. Taxing Health. Health Law Professors Conference, Boston, MA. June 2017.

Persad G. The Ethics of Cost-Effectiveness: How Organ Transplantation Costs Lives. American Philosophical Association, Eastern Division, Baltimore, MD. January 2017.

Persad G. The Law and Ethics of Paying Patients. Mid-Atlantic Health Law Professors Works in Progress Retreat, Seton Hall University, South Orange, NJ. February 2017.

Persad G. Transparency Trade-Offs: Priority-Setting, Scarcity, and Health Fairness. Petrie-Flom Center for Health Law, Biotechnology, and Bioethics Annual Conference, Harvard Law School, Cambridge, MA. April 2017.

Persad G. Universal Health Coverage. Bioethics Boot Camp. University of Pennsylvania, Philadelphia, PA. June 2017.

Persad G. When Should Employee Health Be Employers’ Business? Normative Business Ethics Workshop, The Wharton School, University of Pennsylvania, Philadelphia, PA. January 2017.

PRESENTATIONS (CONT.)

Rieder T, Jamal L. Panel: Ethical and policy issues related to international pregnancy surrogacy. Single Carrot Theater, Baltimore, MD. February 2017.

Rieder T. Birth Control for the Earth? Being a Parent in the Age of Overpopulation. Brain Bar Budapest, Budapest, Hungary. June 2017.

Rieder T. Panel: Biology and Family: Regulating Reproductive Technologies and Protecting the Rights of the Children. International Social Service's 6th Annual Fall Conference — The Ties That Bind: Exploring the Causes and Consequences of Children Separated From Their Families Across International Borders, Baltimore, MD. October 2016.

Rieder T. A Moral Principle for Prescribers. Mid-Atlantic Society of Anesthesiologists, 2nd Annual Conference, Georgetown University, Washington, DC. April 2017.

Rieder T. A New Perspective on the 'Opioid Epidemic.' American Society for Bioethics and Humanities 18th Annual Meeting, Washington, DC. October 2016.

Rieder T. America's Deadly Opioid Epidemic: Is There a Path Forward? Bioethics Interest Group meeting, National Institutes of Health, Bethesda, MD. February 2017.

Rieder T. Managing Opioids: Becoming a Patient Taught Me about the Opioid Epidemic. Conversations in Ethics. Inova Fair Oaks Hospital, Falls Church, VA. June 2017.

Rieder T. Population, Climate Change, and the Ethics of Making Babies. Fort Lewis College, Durango, CO. March 2017.

Rieder T. The New Rules: Biotechnology and the Future of Humans. JHU Alumni Weekend, Baltimore, MD. April 2017.

Rieder T. Toward a Small Family Size in the Age of Climate Change. NYC Sierra Club's Sustainability Series, New York, NY. April 2017.

Rubenstein L. After Aleppo? Can Health Care be Protected from Attack? 6th Annual National Conference of the Syrian American Medical Society, Los Angeles, CA. February 2017.

Rubenstein L. Human rights and health reconstruction. 3rd Annual Symposium of the Syrian American Medical Society—Beyond Medical Relief: Education, Research and Advocacy in Focus, Boston, MA. October 2016.

Rubenstein L. Human rights, global health and state fragility. Global Health 2030 Symposium, Tysons Corner, VA. October 2016.

Rubenstein L. Reconstruction of Health Systems and the Transition to Peace. Javeriana University Institute of Public Health, Department of Public Health and Epidemiology of Cali, and Institute of Bioethics IV International Conference on Health Systems, Bogotá, Colombia. October 2016.

Rubenstein L. Torture and Dual Loyalty Conflicts. Fordham University Graduate School of Social Service, New York, NY. November 2016.

Rubenstein L. Violence Against Health Care in War and Political Conflict. Annual Meeting of the American Public Health Association, Denver, CO. November 2016.

Rubenstein L. Attacks on Health Care: What We Know, How to Know More, What to Do. Health Care in Danger Annual Meeting of the International Committee of the Red Cross, Geneva, Switzerland. May 2017.

Rubenstein L. Panel: Adding Value through Collaboration: Working with Advocacy and Professional Groups. Bloomberg School of Public Health Policy Engagement Seminar Series, Baltimore, MD. April 2017.

Rubenstein L. Panel: Health Workers in Conflict Zones. Consortium of Universities on Global Health, Washington, DC. April 2017.

Rubenstein L. Panel: Options and Examples on the Provision of Pre- and In-service Training to Support the Syrian Refugee Health Workforce. World Bank/OECD Conference on Strengthening Human Resources for Health—Integration of Refugees into Host Community Health Systems, Marseille, France. March 2017.

Rubenstein L. Protection of health care in conflict — where we are and where we need to go? Royal Society of Medicine, London, England. June 2017.

Rubenstein L. The Lancet Special Issue Release: HIV and Related Infections in Prisons. International AIDS Conference, Durban, South Africa. July 2016.

Rubenstein L. Keynote speech, Being a Nurse in a Conflict Zone. 2017 Biennial Convention of the Canadian Federation of Nurses Unions: Speak Up, Calgary, Alberta. April 2017.

Rubenstein L. Keynote speech, Protection of health care in conflict. Global Nurses United, Dublin, Ireland. September 2016.

Rushton CH, Holtz HK, Rodney P. A Collaborative State of the Science Initiative: Transforming Moral Distress to Moral Resiliency in Nursing. International Nursing Research Congress. Dublin, Ireland. 27-31 July 2017.

Rushton CH. From toxic to thriving: Transforming moral distress in the workplace. European Business Ethics Network Annual Conference, Jyväskylä, Finland. June 2017.

Rushton CH. Intensive training in cultivating compassion-based interactions. Upaya Zen Center, Santa Fe, NM. February 2017.

Rushton CH. Panel: Creating and Supporting Authentic Healing Relationships. Compassion in Action Conference, Boston, MA. June 2017.

Saghai Y, Faust H, Eyal N. The Ethics of Health Policy Decision-Making for the Proper Balance of Prevention and Treatment Using Marginal Cost-Effectiveness Analyses. Annual Meeting of the American Society for Bioethics and Humanities, Washington, DC. October 2016.

Saghai Y, van der Weele C, ven den Belt H. Workshop: Imagining Alternative Futures for Food Systems and the Environment. Wageningen University and Research Department of Social Sciences (Philosophy Group and Public Administration Policy Group). Wageningen University, Netherlands. June 2017.

Saghai Y, Verwekk M, van den Hoven M. Workshop: Changing Social Norms: Bicchieri and Sunstein on Mechanisms and Ethics. Wink: The Nudge Conference, University of Utrecht, Utrecht, Netherlands. June 2017.

Saghai Y. Cones, Spider Webs, and Teddy Bears: Philosophical Reflections on Topologies of the Futures and the Concept of Plausibility. Philosophy of Foresight Panel. World Futures Studies Federation Annual Meeting, Jondal, Norway. June 2017.

Saghai Y. From Research to Action: The Scalability and Generalizability Problem in Evidence-based Behavioral Economics Health Policy. Symposium in Honor of Cass Sunstein. International Conference on Thinking, Brown University, Providence, RI. August 2016.

Saghai Y. Ethics and Global Food Futures: Mapping the Terrain. Stanley N. Gershoff Symposium (Theme: Next Generation Food Production). Friedman School of Nutrition Science and Policy, Tufts University, Medford, MA. March 2017.

Saghai Y. Exploring the Futures of Food Systems: Imagination and the Selection of Plausible Futures. Philosophy Group, Wageningen University, Netherlands. June 2017.

Saloner B. Do Medicaid Lockouts Affect Enrollment and Access to Care? Evidence from Wisconsin. AcademyHealth Annual Research Meeting, New Orleans, LA. June 2017.

Saloner B. Primary Care Access and Affordability for the Uninsured Before and After the ACA. AcademyHealth Annual Research Meeting, New Orleans, LA. June 2017.

Saloner B. The Impact of the Affordable Care Act on Access to Treatment for Substance Use Disorders. Invited seminar. Urban Institute Health Policy Center, Washington, DC. April 2017.

Saloner B. Using Data Science to Identify Individuals at High Risk of Opioid Overdose. Association of Public Policy and Management meeting, Washington, DC. November 2016.

Sandfort T, Fawzy M, Elharrar V, Kanyemba B, Kayange N, Lucas JP, Ogendo A, Panchia R, **Sugarman J**, and the HPTN 075 Protocol Team. Mitigating the risk of social harms in men who have sex with men (MSM) in sub-Saharan Africa participating in cohort research of the HIV Prevention Trials Network (HPTN). 21st International AIDS Conference, Durban, South Africa. July 2016.

Schuh H, Igusa T, Lee B, **Merritt M** (*in absentia*), Peters D. Exploring Feedback and Effects of Immunization Systems Interventions on Afghanistan's Health System Using System Dynamics Modeling. 4th Global Symposium on Health Systems Research, Vancouver, Canada. November 2016.

Sripad P, Jennings L, **Merritt MW** (*in absentia*), Kerrigan D, Ozawa S, Ndwiga C, Abuya TO, Warren CE. Trust-building in maternity care through empowerment and communicative action: a qualitative exploration amidst Kenya's policy transition. 4th Global Symposium on Health Systems Research, Vancouver, Canada. November 2016.

Sugarman J, moderator. Panel: Implications for consent, authorization, and data stewardship. PRIM&R Data Sharing Meeting—The Ethics of Data Access, Use, and Sharing for Human Subjects Research, Boston, MA. March 2017.

Sugarman J, Seils D, Lin L, Weinfurt K. Participants' beliefs about preventive efficacy in the HPTN 069/ACTG 5305 HIV trial: preliminary data using the PREMIS measure. 21st International AIDS Conference, Durban, South Africa. July 2016.

Sugarman J. Ethics and Innovative Treatments. NIH Clinical Center Grand Rounds, Bethesda, MD. February 2017.

Sugarman J. A Tentative Introduction to the Revised Common Rule for the Protection of Human Subjects. NIH Health Care Systems Research Collaboratory Grand Rounds, Bethesda, MD. February 2017.

Sugarman J. Cutting-Edge Challenges in HIV Research Ethics in the Developing World: Lessons from the Ethics Working Group (EWG) of the HIV Prevention Trial Network (HPTN). PRIM&R's 2016 Advancing Ethical Research Conference, Anaheim, CA. November 2016.

Sugarman J. Empirical Research about Attitudes on the Ethics of Research on Medical Practices. PRIM&R's 2016 Advancing Ethical Research Conference, Anaheim, CA. November 2016.

Sugarman J. Ethical and Regulatory Issues in Pragmatic Clinical Trials, Pragmatic Trials Collaborative Project. Westat, Rockville, MD. May 2017.

Sugarman J. Ethical and Regulatory Issues in Pragmatic Clinical Trials. Regional Research Ethics Committee, Western Region, Bergen, Norway. June 2017.

Sugarman J. Ethical Considerations. Panel: Prevention Clinical Trials in an Era of Highly Effective Combination Prevention: Ethical Considerations. HIV Research for Prevention (HIVR4P) Satellite Conference, Chicago, IL. October 2016.

Sugarman J. Ethics and Innovative Treatments. Offering Patients Innovative Therapy: When Is It a Good Idea? Ethics Rounds, National Institutes of Health, Bethesda, MD. February 2017.

Sugarman J. Gene Editing: Ethical Opportunities and Challenges with this Breakthrough Technology. Copernicus IRB, Durham, NC. April 2017.

Sugarman J. Gene Editing: What are the Ethical Opportunities and Challenges with this Breakthrough Technology? 55th Annual Meeting of the American College of Neuropsychopharmacology, Hollywood, FL. December 2016.

Sugarman J. Guidelines and Standards for Ethics in Global Health. Symposium on the Ethics of Help, University of Minnesota, Minneapolis, MN. June 2017.

Sugarman J. Informed consent and clinical trials. NIH International Clinical Studies Support Center (ICSSC) Research Ethics and IRB Operations Training, Buenos Aires, Argentina. December 2016.

Sugarman J. Meeting the Ethical Challenges of Obtaining Informed Consent. Ethical & Legal Dilemmas in the Practice of Medicine and Research: A Middle East Perspective. Weil Cornell Medicine-Qatar, Doha, Qatar. November 2016.

Sugarman J. Navigating the Ethical Issues in HIV Prevention Research. Global Health Research Center of Central Asia, Almaty, Kazakhstan. April 2017.

Sugarman J. Panel: Public Ethics and Public Space. 6th Annual Stavros Niarchos Foundation International Conference on Philanthropy, Athens, Greece. June 2017.

Sugarman J. Preventive Misconception in HIV Prevention: What it Is and How to (Try to) Measure it. PRIM&R's 2016 Advancing Ethical Research Conference, Anaheim, CA. November 2016.

Sugarman J. Responsible and Irresponsible Medical Innovation with Stem Cells. Using Innovative Treatments and Modes of Health Service Delivery. 13th Annual International Conference on Clinical Ethics Consultation, Singapore. May 2017.

Sugarman J. Studying Effectiveness: Ethical and Regulatory Considerations in Pragmatic Clinical Trials. PRIM&R Webinar: Pragmatic Clinical Trials. April 2017.

Sugarman J. Updated International Guidelines for Stem Cell Research: Implications for IRBs, Stem Cell Research Oversight Committees (SCROs), and Institutions. PRIM&R's 2016 Advancing Ethical Research Conference, Anaheim, CA. November 2016.

Sugarman J. Ethics and IRB Operations Training. NIH International Clinical Sciences Support Center, Zhengzhou, China. October 2016.

Sugarman J. Presidential Keynote Address, Exploring Ethical Issues in Medical Toxicology Research. Annual Scientific Meeting of the American College of Medical Toxicology, San Juan, PR. April 2017.

Sugarman J. Bioethics Seminar. University of Malaysia. Kuala Lumpur, Malaysia. August 2016.

Sugarman J. Emerging Data Regarding Informed Consent for Research. Robert H. Levi Leadership Symposium—Secrecy, Security, and Science, Baltimore, MD. October 2016.

Sugarman J. Ethics and Global Health Service and Training Initiatives. York Hospital, York, PA. April 2017.

Sugarman J. Gene Editing: Ethical Opportunities and Challenges with this Breakthrough Technology. Harvard Club, New York, NY. September 2016.

Taylor H. Panel: Vaccine Development. Annual Health Law Conference, Northeastern University, Boston, MA. April 2017.

Taylor HA. Ferguson A, Smith BD. Patient Perspectives on Enrollment in Adjuvant Immunotherapy Trial (Poster). 18th John Goldman Conference on Chronic Myeloid Leukemia: Biology and Therapy, Houston, TX. September 2016.

Taylor HA, Rutkow L, Barnett D. Local Preparedness for Infectious Disease Outbreak: Supporting Willingness/Balancing Commitments. American Society for Bioethics and Humanities 18th Annual Meeting, Washington DC. October 2016.

Taylor HA. Informed Consent for Clinical Trials. 2017 PCOR Symposium. PCORI, Washington University, St. Louis, MO. April 2017.

Unguru Y. Panel: On the Frontline of an Outbreak. Eleventh Annual Allen Schwartz Lectureship—Providers as Global Citizens: When Diseases Go Viral, Baltimore, MD. April 2017.

Unguru Y. Allocating Scarce Lifesaving Chemotherapy for Children with Cancer: An Ethical Approach to an Untenable Situation. Grand Rounds, Hackensack University Medical Center, Hackensack, NJ. March 2017.

Unguru Y. Devils' Choice: Selecting Children for Life-Saving Chemotherapy: An Ethical Prioritization and Allocation Framework. Ninth Annual Pediatric Bioethics Conference, Jacksonville, FL. November 2016.

Unguru Y. Pediatric Ethics: A Grand Rounds Discussion. Pediatric Grand Rounds, Sinai Hospital, Baltimore, MD. February 2017.

Unguru Y. Responding to Parental Request Not to Tell an Adolescent that She has Cancer. Sconyers/Godfrey Ethics Lecture. Treuman Katz Center for Pediatrics, Seattle, WA. May 2017.

Unguru Y. Unenviable challenges, untenable choices. Caring for children with cancer in the era of scarce lifesaving chemotherapy. Treuman Katz Center, Seattle WA. May 2017.

Unguru Y. Allocation, Prioritization, Rationing, Oh My! The Ethics of Treating Children with Cancer in the Era of Scarce Lifesaving Chemotherapy. Medicine Grand Rounds, Sinai Hospital, Baltimore, MD. March 2017.



FACULTY PROFILE Govind Persad, PhD

It was the Berman Institute’s unique strengths combining bioethics with a strong public health presence that attracted Govind Persad, JD, PhD, to the

faculty. Persad became an assistant professor at the Berman Institute and the Bloomberg School of Public Health’s Department of Health Policy and Management in 2016, after completing a

postdoctoral fellowship in the Department of Strategy, Economics, Ethics and Public Policy at Georgetown University, where he taught an undergraduate course on ethics and markets.

Persad’s research interests include the ethical and legal dimensions of health insurance, health care financing, and health care services markets. He also thinks about the ethics of providing medical interventions that are less expensive, but also less effective, than the most costly ones. A piece he coauthored in The Lancet argued that in

resource-limited settings, it makes sense to expand access to care by offering less expensive treatments or medications—even if they are less effective—instead of providing a limited number of “gold standard” interventions.

“I like that I get to read a lot of interesting documents and discussions, not only by people in philosophy and bioethics, but also by people like physicians and policymakers in various settings,” Persad says. “I also have really enjoyed advising and working with PhD students.”

HONORS, AWARDS AND PROMOTIONS

Jean Anderson, MD, was appointed to Affiliate Faculty at the Berman Institute.

Zackary Berger, MD, PhD, was promoted to Core Faculty of the Johns Hopkins Berman Institute of Bioethics.

Matthew DeCamp, MD, PhD, assumed the role of Chair of the Society of General Internal Medicine’s (SGIM) Ethics Committee, a position he will hold for two years.

Michael Erdek, MD, was appointed to Affiliate Faculty.

Rachel Fabi, PhD candidate, was awarded the Gordis Teaching Fellowship to teach “Beyond Borders: Migration, Ethics, and Public Health” during the spring semester of the 2016-2017 academic year.

Rachel Fabi, PhD candidate, was awarded the Barbara Starfield Scholarship by the JHSPH Department of Health Policy and Management.

Farnoosh Faezi-Marian, MBE Student, was inducted into the Alpha Chapter of the Delta Omega Public Health Honor Society

Jessica Fanzo, PhD, was announced as a member of the Sustainability Advisory Board member for Royal DSM.

Jessica Fanzo, PhD, was among the recipients of the 2016 Discovery Award. She joined colleagues in exploring “A Systems Framework for the Societal Costs of Antimicrobial Resistance & Use in Global Food Animal Production.”

Gail Geller, ScD, MHS, was appointed to the Fellows’ Council at the Hastings Center.

Jeremy Greene, MD, PhD, was appointed to Associate Faculty at the Berman Institute.

Heidi Holtz, PhD, has been selected as an American Nurses Association Center for Ethics and Human Rights Moral Resilience Professional Issue Panel Intern.

Adnan Hyder, MD, PhD, MPH, was recognized for teaching excellence by the Bloomberg School of Public Health.

Leila Jamal, PhD, ScM, CGC, has been appointed to the Social Issues Committee of the American Society of Human Genetics for a three-year term.

Jeffrey Kahn, PhD, MPH, was elected to the National Academy of Medicine.

Jeffrey Kahn, PhD, MPH, was named a National Associate by the National Academies of Science, Engineering, and Medicine. The purpose of the National Associate designation is to formally recognize individuals for outstanding contributions to the Academies’ work.

Debra Mathews, PhD, MA, completed the Johns Hopkins Office of Women in Science and Medicine’s Leadership Program as a member of its 7th cohort.

Maria Merritt, PhD, was named Associate Chair for Student Matters in the Department of International Health.

Dr. Merritt also received the 2017 Student Assembly Special Recognition Award for Outstanding Commitment to Student Success. Dr. Merritt was named Associate Chair for Student Matters in the Department of International Health in 2016.

Jacek Mostwin, MD, D. Phil, a professor of urology in Johns Hopkins School of Medicine, appointed Affiliate Faculty at the Berman Institute of Bioethics.

Cameron Okeke, MBE Student, was inducted into the Alpha Chapter of the Delta Omega Public Health Honor Society.

David M. Peña-Guzmán, PhD, Hecht-Levi Fellow, accepted a position as Assistant Professor in Humanities and Liberal Studies at San Francisco State University (SFSU) in San Francisco, CA. The position, which began Fall 2017, is in “Science, Technology and Culture.”

Dimpho Ralefala (née Njadingwe), former Fogarty African Bioethics Training Program fellow (2010), at the University of Botswana, won a “Professional Excellence in Research Management” Award from the South African Research and Innovation Management Association.

Leonard Rubenstein, JD, was appointed to the University College of London–The Lancet Commission on Migration and Health.

Leonard Rubenstein, JD, was recognized for teaching excellence by the Bloomberg School of Public Health.

Yashar Saghai, PhD, MA, published a paper, “Salvaging the Concept of Nudge” which is the Journal of Medical Ethics’ highest-cited paper.

Rebecca Seltzer, MD, won the American Academy of Pediatrics Council on Foster Care, Adoption, and Kinship Care award for best abstract at the October 2016 annual meeting.

Yoram Unguru, MD, MS, MA, was appointed Chair of the Ethics Committee at Sinai Hospital in Baltimore, MD.

Yoram Unguru, MD, MS, MA, was honored as a Birdland Community Hero by the Baltimore Orioles on Friday, September 2. The Orioles Birdland Community Heroes program honors and recognizes community heroes who inspire us through their spirited commitment to extend a hand in charity, service, hope, and harmony.



Yoram Unguru, MD, MS, MA, was awarded a 2016 Baltimore Top Doctor by Baltimore Magazine.

The team-taught “Foundations of Bioethics” course, Term 1 of the 2016-2017 academic year was recognized by students of the Bloomberg School of Public Health for excellence in teaching. Co-instructors, Rachel Fabi and David Peña-Guzmán, were joined by a different faculty member for each weekly session. Participating faculty were: Jeffrey Kahn, PhD, MPH, Jeremy Sugarman, MD, MPH, MA, Mary Catherine Beach, MD, MPH, Gail Geller, ScD, MHS, Nancy Kass, ScD, Joe Ali, JD, and Travis Rieder, PhD.

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“Every action has a reaction, and for nearly twenty-five years, the Berman Institute has played a leading role in identifying and deciphering the thorny ethical dilemmas that are nearly always inherent in medical discovery. Its work touches the lives of everyone in health care, from doctors to nurses to patients and their families, who face issues that present a new world without a compass or map. As new technologies and treatments become available, now more than ever, the Berman Institute will be called upon to address the complex questions that we will face and will, I am confident, provide us with a path forward. I feel privileged to support such a critical endeavor.”

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MICHAEL KNEELAND
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For 22 years, the Johns Hopkins Berman Institute of Bioethics has tackled moral challenges that have no easy resolutions. As an independent, interdisciplinary center of scholarship and research, the Institute stands as one of the world’s leading centers for ethical dilemmas in science, patient care, and public health, impacting policy in areas of tremendous humanitarian importance.

With support from committed partners like Michael Kneeland, the Berman Institute is poised to continue its mission of training, research, and scholarship — ultimately serving patients and the public through improved protocols that respect the rights and safety of all persons.

So much of the Berman Institute’s vital mission is dependent on philanthropic support. Through annual and campaign gifts, the Institute is able to support faculty, students, and facilities. Please join Michael and others who understand the critical need for bioethics scholarship and research. The work generated at the Berman Institute will continue to impact policies and practices that make the world a more ethical, safe, and respectful place. And that is important to all of us.

If you would like to learn more about supporting the Berman Institute of Bioethics, please contact Andrew Rentschler at andrew.rentschler@jhu.edu or 410-614-5651.



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