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 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.
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 wear. 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 “Pain in America.”

Berman Institute faculty member Brendan Salmer, 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, Salmer 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 $100 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,” Salmer says.

In another area of national concern, Cynda Rushton, RN, PhD, FAAN, the Arne 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, 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 Heinz, 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 drafted an open letter to the president signed by two dozen 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 discussions on refugee resettlement.

Meanwhile, doctoral candidate Rachel Fabi has been studying immigrant access to prenatal and other health care services. A piece she and Salmer 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 Salmer 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.”

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Jeffrey Kahn
Director, Berman Institute
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.

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, Genomics, and Society (BRIDGES) designed to ensure that ethical, legal and social implications (ELSI’s) 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.

This award supports the co-author’s work on the Independent Expert Group (IEG) for the annual Global Nutrition Report which they are to oversee and increase the global commitment to reduction by tracking progress and commitments across the globe. The IEG is responsible for producing the report, identifying gaps in knowledge, assessing and ensuring the quality of the data, and monitoring the independence of the report.


This award supports a study to provide new, reliable, and actionable data on agricultural and nutritional impacts of irrigation projects in the Western Sahel and on the pathways through which these impacts are realized. A group of African health workers were trained to provide nutrition information on infant and young child feeding, dietary quality including diversity, food hygiene, and sanitation; and opportunities to improve dietary quality with the household using crop-growing and income being generated by the project. In addition to group based nutrition sessions, 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 small scale messages that remind farmers about timely applications of certain agricultural inputs have substantial impacts on yield.


As part of the global effort to accelerate progress toward elimination of hunger and undernutrition, the World Food Programme is facilitating a series of Zero Hunger Strategic Reviews that look at results achieved and response gaps to identify areas for informed national and international efforts to achieve Zero Hunger worldwide. The award supports the provision of a comprehensive and detailed understanding of the context of food and nutrition security in Afghanistan and Timor Leste, identifies challenges in achieving zero hunger, and provides actionable options for the government, development partners, private sector actors, and others to best support the countries in moving toward zero hunger.


The Fogarty African Bioethics Consortium Post- Doctoral fellowship Program (FABC-PDF) will provide 36-month, advanced bioethics training to early career bioethicists who have already accomplished research and become bioethicists professionals in the African Bioethics Consortium (Mekelle University, Uganda; University of Zimbabwe, University of Addis Ababa). Ten individuals, selected for their demonstrated bioethics commitment and the ability to develop independent scholarship, will complete research-intensive academic settings which will provide one academic year of mixed-methods, late-stage, training that is complemented by a period of public information dissemination. The Fogarty African Bioethics Consortium Post-Doctoral fellowship Program (FABC-PDF) will provide 36-month, advanced bioethics training to early career bioethicists who have already accomplished research and become bioethicists professionals in the African Bioethics Consortium (Mekelle University, Uganda; University of Zimbabwe, University of Addis Ababa). Ten individuals, selected for their demonstrated bioethics commitment and the ability to develop independent scholarship, will complete research-intensive academic settings which will provide one academic year of mixed-methods, late-stage, training that is complemented by a period of public information dissemination.


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Informed Consent remains too long, complex, and legalistic, thwarting patients’ understanding of key study information. Proposed changes to human subjects’ regulations — and significant bioethics literature in support of shorter, simpler, easier, adaptable, evidence-based communication to promote participation have been strongly endorsed, and some elements validated, in a published randomized controlled trial. To test if we can test if we can test whether these changes would increase lay lay lay reader understanding, this study will compare two simple consent strategies: a bulleted fact sheet and a video interview between a study participant and his or her researcher. Proposed changes to human subjects’ regulations — and significant bioethics literature in support of shorter, simpler, easier, adaptable, evidence-based communication to promote participation have been strongly endorsed, and some elements validated, in a published randomized controlled trial. To test if we can test if we can test whether these changes would increase lay reader understanding, this study will compare two simple consent strategies: a bulleted fact sheet and a video interview between a study participant and his or her researcher.


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+ transplants as well as those patients living with HIV+ who are on HIV- organ and urine. In addition, we will survey patients living with HIV+ to assess their perceptions regarding their knowledge, attitude and beliefs about HIV+ organ transplants. The cohort data will be used to help create patient reported outcome measures at as an standardized informed consent process and guidance for independent research projects. These tools will be implemented in a multicenter clinical trial and observed through peer-reviewed publications as well as professional conferences and network.


RESEARCH AND SCHOLARSHIP

JOURNAL ARTICLES (CONT.)


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.

“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.”
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.

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.

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.
HECH-LIEF 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 the Berman Institute. Among the current research projects are studies on end-of-life care and medical errors, as well as work on the impact of healthcare policies on vulnerable populations.

HECH-LIEF FELLOWSHIP PROGRAM IN BIOETHICS

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 the Hecht-Levi Fellowship program by Dr. Berman, who called her about the fellowship. Berman, a Berman Institute faculty member and associate professor of neonatal-perinatal medicine, told her about the Hecht-Levi Fellowship Program in Bioethics. Seltzer is now completing her fellowship program in bioethics and is currently doing her research on medical foster care and burnout among healthcare providers.

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 Johns Hopkins Berman Institute 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 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 Johns Hopkins Institute for Global Bioethics Training Program hosted a diverse group of scholars in June 2017 for a four-month 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 & Berman Professor of Bioethics and Public Health and the Deputy Director for Public Health, the program combines intensive coursework work with applied, skills-oriented learning, as well as tours to federal agencies in Washington, DC.

This year’s trainees came from Zambia, Botswana, and Uganda and, with a supplemental grant from the NIH Fogarty International Center, three additional trainees attended from Liberia. The trainees enrolled in the Johns Hopkins 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 relevant to educational, career, and research goals. In addition to formal coursework, activities included structured meetings with bioethics personnel at the NIH, the Food and Drug Administration, and the Office for Human Research Protections.

Heidi Holtz, PhD, MD, MPH, Associate Director of Global Programs, and Nancy Kass, ScD, the Phoebe & 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 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.

Silvana Barone, MD

Dr. Barone’s clinical and research interests involve the care of children with complex medical conditions and how to improve the safety and outcomes for these patients. She conducted research on the ways in which healthcare providers ensure good longitudinal care for these children. In fellowship, she will explore the practical and ethical issues that impact the care-making and goal 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, MD

Dr. Boyce serves as the Founding Director of the Johns Hopkins Center for Infectious Disease, Genomics, and Society (BRIDGES), an NIH-funded Center of Excellence (CoE) in Genomics Research. Her research interests include ethical issues in infectious disease (especially related to containment care, outbreak management, and antimicrobial resistance), regulatory policy, inter-agency collaboration, and consumer advocacy; and translating genomics into population health benefit.

Katherine Heitze, PhD, ESN, RN, CN Hom

Dr. Heitze 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 is also interested in investigating the moral distress that healthcare providers experience in ethically challenging contexts. Her long-term research mission is to successfully infuse spirituality in children, their family members, and the healthcare providers who care for them.

Leila Jamal, PhD, MSc

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 underdiagnosed disease research project. She is also interested in developing novel approaches for sharing genetic information within families while respecting individual privacy.

David pensar-Quiniam, PhD

Dr. Pensar-Quiniam’s research addresses key questions in animal ethics, the philosophy of science, and bioethics. He accepts an Assistant Professorship in the School of Humanities and Liberal Studies at San Francisco State University.

Lei Li, PhD

Dr. Li’s research focuses on social inequalities, the role of policies, and interventions to reverse the food system toward the production and consumption of nutritious foods and 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. Li was accepted into the PhD program in the Department of Health Policy & Systems at Rutgers University.

Elizabeth Fox, PhD

Dr. Fox works in the Global Health Equity Unit of the Berman Institute, taking part in weekly seminars, presentations, courses, and events hosted by the Berman Institute and across the University. She also takes advantage of the proximity to policy-making within state and federal governments. Her work centers on the ethical aspects of nutrition interventions to reorient the food system with intended beneficiaries in culturally sensitive ways.

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Marie Nolan, PhD

Dr. Nolan is a former pediatric oncology nurse, who cares for children in medical foster care. She is now longitudinally following 15 children in medical foster care and burnout among healthcare providers. Heidi has a special interest in researching the impact of the Hecht-Levi Fellowship on pediatrics and the regulation of new technologies in healthcare and public health. During her fellowship, Dr. Holtz’s goal is to contribute to federal agencies in Washington, DC.

Clare Heinze, PhD

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Seltzer, MD

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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 DoCarmo, MD, PhD, Gail Geller, MD, SYS, Mark Hughes, MD, MA, Margaret Moon, MD, MPH, Maria Nolan, PhD, MPH, RN, FAAP, Peter Terry, MD, MS, and Yasam Unuvar, 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 Bialous, PhD, RN, FAAN, the Anne and George L. Bunting Professor of Ethics at the Berman Institute and the School of Nursing, developed the Mindful Ethical Practice and Resilience Academy (MERSPA) 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.

Ning Jon Carmine in teaching and mentoring residents are Berman Institute faculty members Zackary Berger, MD, PhD, Mark Hughes, 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 Access 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 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.
Newer genome editing technologies like CRISPR/Cas9 have resulted in an explosion of basic research and enhancements of human traits. 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 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

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, Sc.D., the Prudence B. 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.

The All of Us Research Program is a historic, $1.5 billion 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, and 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.”
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, moral judgments about the past, and the use of historical information to make moral judgments about the past.

“...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.”

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.

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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.

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.
It was the Berman Institute’s unique strengths combining bioethics with a strong public health presence that attracted Govind Persad, JD, PhD, to the Berman Institute. Persad became an assistant professor at the Berman Institute and the Department of Health Policy and Management in 2016, after completing a postdoctoral fellowship in the Department of Health Policy and Management 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 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—instead of 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.”
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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 at the forefront of creating and providing the leaders in 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.

"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."