This annual report catalogues my final year as the Andreas C. Dracopoulos Director of the Berman Institute. As the depth and breadth of this report illustrate, this year was not about my leaving the directorship, but rather about the community of faculty, board members, donors, and staff who make the Berman Institute possible each and every year. As I step aside and focus on my continuing academic work, I take great comfort in knowing that dynamic will not change.

A number of communities come together to make a place like the Berman Institute possible. I cannot begin to describe how critically important our National Advisory Board is to the success of the Berman Institute and to its director. Their impact can be seen everywhere, from the Dracopoulos Directorship to the Meyerhoff Professorship to the Levi Leadership Symposium to Deering Hall. They are transformational leaders in the truest sense, and the work described in this report is only possible with their support, counsel, and encouragement.

The Berman Institute began 20 years ago with 13 faculty members, a remarkable beginning particularly in that it included champions such as Profs. John Freeman, Henry Seidel and Nancy Kass. Incredibly, we are now 38 faculty strong. We have more philosophers and lawyers than we had total faculty when we started, not to mention international leaders in nursing, medicine, and public health. This faculty, their talent, their commitment to the Institute and its mission— that is the core of the Berman Institute’s success. Prof. Jeffrey Kahn now emerges from that faculty to serve as the next Dracopoulos Director, a wonderful selection that sets the Institute on a path of renewed energy and accomplishment.

Being the founding director of a successful institute is an extraordinary honor, but it is also an extraordinary responsibility. I thought about and planned for this moment for a long time. I knew it was essential that the Berman Institute have a solid place within Johns Hopkins University, a significant endowment, a physical home, and a strong base of donors and supporters. I knew that the Institute had to have a stellar faculty, with the right balance of superstars and rising stars to take us into the future. Because all of these things are in place, I know that now is the right time for me to step aside. I leave the directorship, not the Berman Institute, knowing that the future is secure, knowing that the next twenty years are going to be just as remarkable, if not better, than the first twenty have been. To all those who make this possible, I offer my deepest thanks and gratitude.

Sincerely,

Ruth Faden, PhD, MPH
ANDREAS C. DRACOPOULOS DIRECTOR,
PHILIP FRANKLIN WAGLEY PROFESSOR OF BIOMEDICAL ETHICS
Twenty years ago, Ruth Faden, PhD, MPH, transformed an informal bioethics interest group of faculty members dispersed across Johns Hopkins University into the Berman Institute of Bioethics, which now has 38 faculty, 25 staff, and alumni who hold leadership positions across the field.

On June 30, 2016, Prof. Faden stepped aside as the Andreas C. Dracopoulos Director of the Berman Institute, passing the torch to Jeffrey Kahn, PhD, MPH. Prof. Kahn is the Robert Henry Levi and Ryda Hecht Levi Professor of Bioethics and Public Policy. He was selected to succeed Prof. Faden after a global search carried out by the Provost’s office, and becomes the Institute’s second Andreas C. Dracopoulos Director on July 1. Prof. Faden retains her faculty position as the Philip Franklin Wagley Professor of Biomedical Ethics, with a full academic portfolio, including work on streamlined consent in comparative effectiveness research; the inclusion of pregnant women in medical research; global food ethics and policy; and social justice.

During Prof. Faden’s tenure, the Berman Institute has grown into one of the world’s largest bioethics centers, with its interdisciplinary faculty having joint appointments in the Johns Hopkins schools of Medicine, Nursing, Public Health, Arts and Sciences, or Advanced International Studies. The Berman Institute faculty includes some of the most distinguished senior scholars in the field, as well as a deep bench of emerging leaders. The Institute sponsors or co-sponsors an undergraduate minor, a master’s degree, PhD training, postdoctoral training, and certificate programs. Many graduates of these programs, including over 50 post-doctoral fellows, have assumed leadership positions in the public, private, academic, and charitable sectors.

Even before she established the Berman Institute, Prof. Faden was a thought leader in the young field of bioethics. She authored the now-landmark text, A History and Theory of Informed Consent, with her husband, philosopher Tom L. Beauchamp, in 1986. She has served on numerous national committees and advisory panels, including chairing the White House Advisory Committee on Human Radiation Experiments.

Prof. Faden has continued to exert influence on both the theory and practice of bioethics. Her book Social Justice, co-authored with Madison Powers, JD, DPhil, is considered another landmark in the field. Prof. Faden is also a leading voice in revising society’s understanding of the moral relationship between medical research and medical practice, to help bring about higher quality and more just healthcare systems, and in focusing attention on issues of justice in global food security. She is an elected member of the Institute of Medicine and was awarded lifetime achievement honors by the American Society for Bioethics and Humanities and by Public Responsibility in Medicine and Research.

In their announcement to University faculty and staff, the JHU President and Provost noted Prof. Faden’s work, along with the Berman Institute National Advisory Board, to establish a physical home for the Institute in Deering Hall, a historical landmark in East Baltimore. A dedicated building for a university bioethics center is rare, and supports the community environment Prof. Faden has sought to foster. In addition to providing a home for faculty and staff, Deering Hall also hosts monthly faculty meetings, quarterly research retreats, and “community lunches” for all faculty, staff, and students.

In 2014, the Berman Institute became the first bioethics center to have an endowed directorship, made possible by a gift from the long-time Institute supporter, advisory board member, and University trustee for whom it is named, Andreas C. Dracopoulos. The endowed directorship further secured the future of the Berman Institute beyond Prof. Faden’s tenure as Director. “Dr. Faden has spent her entire career passionately committed to dealing with ethical challenges in the biomedical science field and in women’s health,” Mr. Dracopoulos said in his speech at a ceremony installing Prof. Faden as the first Andreas C. Dracopoulos Director. “I am honored to have been a member of the National Advisory Board of the Berman Institute for almost 15 years now, honored to count everyone at the Institute as a friend, very grateful to have been blessed in my own personal life to be able to express my gratitude with this personal contribution, which is nothing more than a simple acknowledgment of how far Ruth has taken the Institute and how promising its future is both within the Hopkins family and within society at large.”

“I have been incredibly fortunate in my professional life at Johns Hopkins to be able to form a community with so many insightful, passionate colleagues committed to building a more ethical world,” Prof. Faden said. “I am incredibly fortunate, yet again, to be able to move on to the next stage of my career with the certain knowledge that the Berman Institute’s future is secure and in exactly the right place for the second Dracopoulos Director to lead it successfully into a third decade.”

“Without Dr. Faden’s vision, scholarship, determination, and leadership, what we know today as the Berman Institute of Bioethics would not exist. She is the Institute’s founding director, and her international reputation as a scholar and leader in bioethics has added great luster to the reputation of both the institute and the University.”

PRESIDENT RONALD J. DANIELS AND PROVOST ROBERT C. LIEBERMAN, IN AN EMAIL TO JOHNS HOPKINS UNIVERSITY FACULTY AND STAFF

JEFFREY KAHN, PHD, MPH,
officially takes on the position of Andreas C. Dracopoulos Director of the Johns Hopkins Berman Institute of Bioethics on July 1, 2016. He came to Johns Hopkins and the Berman Institute in 2011 as the inaugural Robert Henry Levi and Ryda Hecht Levi Professor of Bioethics and Public Policy. He is also a Professor in the Department of Health Policy and Management of the Johns Hopkins Bloomberg School of Public Health. Prior to joining the faculty at Johns Hopkins, Prof. Kahn was Director of the Center for Bioethics at the University of Minnesota and held an endowed chair in bioethics.

Prof. Kahn is chair of the National Academies Board on Health Sciences Policy, and has previously chaired its committee on the Use of Chimpanzees in Biomedical and Behavioral Research (2011) and the committee on Ethics Principles and Guidelines for Health Standards for Long Duration and Exploration Spaceflights (2014).

Prof. Kahn’s publications include the books Contemporary Issues in Bioethics; Beyond Consent: Seeking Justice in Research; and Ethics of Research With Human Subjects: Selected Policies and Resources, as well as over 115 articles in the bioethics and medical literature. He also speaks widely across the U.S. and around the world on a range of bioethics topics, in addition to frequent media outreach. From 1998-2002 he wrote the bi-weekly column Ethics Matters on CNN.com.
EDITING THE HUMAN GERMLINE

In the future, 2015 may be remembered as a turning point in science, as new techniques reignited scientific and public debate over genetic modification in humans. The Berman Institute played an important role in these global discussions.

First, a new gene editing tool appeared to be a game-changer, with its unprecedented precision and accessibility. Named CRISPR, this method was expected to put the long-anticipated promise — and peril — of effective gene editing in human hands. Also in 2015, the United Kingdom and the United States considered the legal and ethical aspects of permitting unprecedented assisted reproductive procedures that would incorporate the genes of a mother and father with additional genetic material from a female donor. Dubbed “three-parent babies” by the news media, these procedures, called mitochondrial replacement techniques (MRT), rely on a donor to provide healthy cellular material known as mitochondria when the mother’s mitochondria are likely to pass a debilitating disease on to her child. Mitochondria have their own relatively small complement of genes, which are separate from the trait-determining DNA in a cell’s nucleus.

Both CRISPR and MRT were quickly recognized as having the potential to permanently alter the human “germline” — the set of genes that are passed from parents to children through future generations. Previously, when technological hurdles made the idea seem like science fiction, editing the germline was widely regarded as an ethical bright line too unsafe and uncertain to be crossed. But with the development of the CRISPR gene editing tool and MRT, altering the human germline, and thereby affecting human evolution, became a real possibility and sparked fresh debate.

Berman Institute Assistant Director for Science Programs Debra Mathews, PhD, MA, and Alan Regenberg, MBE, Director of Outreach and Research Support, took lead roles in convening the meeting of the influential Hinxton Group in Manchester, England. This interdisciplinary, multinational group of experts — including Berman Institute Deputy Director for Medicine Jeremy Sugarman, MD, MPH, MA, and other leaders in bioethics, science, policy, as well as research funders and journal editors — has previously tackled challenging issues in stem cell science and international scientific collaboration.

In Manchester the Hinxton Group reached consensus and published a statement endorsing basic science research that involves editing the human genome, while drawing a sharp distinction between research and clinical applications. “We believe that while this technology has tremendous value to basic research and enormous potential for somatic [the cells of the body, in contrast to germ — sperm and egg cells] clinical use, it is not sufficiently developed to consider human genome editing for clinical reproductive purposes at this time,” the consensus statement reads.

Prof. Mathews and Mr. Regenberg also co-authored a commentary with other members of the Hinxton Group Steering Committee, laying out key ethical issues for consideration as the human genome editing debate continues. The commentary, “CRISPR: A Path through the Thicket,” was published in the November 12, 2015, issue of Nature.

The debate also prompted the US National Academies of Sciences, Engineering, and Medicine to co-host an International Summit on Human Gene Editing in Washington, DC, with the Chinese Academy of Sciences and the British Royal Society. At the summit’s conclusion, participants declared a goal of creating an ongoing forum where the international community can strive to establish norms for gene editing and harmonize regulations, while discouraging ethically unacceptable activities. The summit was followed by the first meeting of a multidisciplinary group of experts, convened by the National Academies of Science and Medicine, to conduct a consensus study of these issues. The group includes Jeffrey Kahn, PhD, MPH, the Levi Professor of Bioethics and Public Policy at the Berman Institute.

A separate National Academy of Medicine committee analyzed the issue of MRT, with Prof. Kahn serving as chair. After a year-long process, the multi-disciplinary expert committee concluded that clinical investigations of MRT in humans are ethically permissible, as long as particular conditions and principles are met. These include limiting clinical investigations to women who are at risk of passing on a serious mitochondrial disease to their children that is predicted to cause early death or substantial impairment.

The committee also recommended that only male embryos be transferred to a woman for a possible pregnancy during initial clinical investigations. Mitochondrial DNA is inherited from the mother, so using only male embryos would avoid the germline modifications via mitochondrial replacement to be passed from females to their daughter’s offspring. “Although MRT would not treat a person with a mitochondrial disease, its pursuit could satisfy prospective parents’ desire to bear genetically related offspring with a significantly reduced risk of passing on mitochondrial disease,” Prof. Kahn said. “The limitations on MRT that we propose focus on protecting the health and well-being of children born as a result of the techniques.”

The discussion of human germline editing continues. Looking forward, Prof. Mathews said, “While there is controversy and deep moral disagreement about human germline genetic modification, what is needed is not to stop all discussion, debate and research, but rather to engage with the public, policymakers, and the broader scientific community, and to weigh together the potential benefits and harms of human genome editing for research and human health.”
Infectious diseases account for a significant proportion of illness worldwide. Recent research suggests that a person’s genes can play a significant role in susceptibility to infection, its severity and transmissibility, and response to treatment.

For example, the IL28B genetic variant predisposes a person to spontaneously clear the Hepatitis C virus (HCV) and thus avoid chronic disease. “People with these genotypes may benefit from less expensive or onerous treatments,” said Gail Geller, ScD, MHS, the Berman Institute Director of Education Initiatives. “However, these variants are much rarer among people with African ancestry;” she added, “which raises ethical concerns about whether treatment decisions should be influenced by race.”

The Berman Institute’s affiliations with the Johns Hopkins Bloomberg School of Public Health and School of Medicine, as well as faculty members’ established leadership on ethical issues related to genetics and genomics, position the Institute well to explore the ethical, legal, and social implications (ELSI) of genomics as applied to infectious disease.

The Berman Institute began work on these issues three years ago as an exploratory Center of Excellence in ELSI Research (CEER), the first such project to focus attention on genomic ELSI issues in the context of infectious disease. In spring 2016, the National Human Genome Research Institute of the National Institutes of Health (NIH) awarded the Berman Institute $4 million over four years to establish a specialized CEER to continue this important effort: The Center for Bridging Infectious Disease, Genomics, and Society (BRIDGES).

Only seven other such centers have been established across the country. The CEER brings together a multidisciplinary team from across Johns Hopkins University and Johns Hopkins Medicine, led by Berman Institute Co-Principal Investigators Prof. Geller and Jeffrey Kahn, PhD, MPH, the Levi Professor of Bioethics and Public Policy at the Berman Institute.

The Johns Hopkins CEER team members include experts in bioethics, epidemiology, genomics, health policy, immunology and infectious disease, public health preparedness and education, in keeping with the NIH’s intention that CEERs create opportunities for transdisciplinary research.

The CEER research plan has three specific program areas, each with a unique pilot project. The program on “Implications for Research” will address the impact of discoveries related to genetic variation in HIV and HCV transmission on cohorts of at-risk urban populations. The program on “Implications for Public Health Policy” will analyze the role and impact of advances in vaccinomics for informing population-based prevention in the context of a pandemic. The program on “Implications for Clinical Practice” will assess the application of genomics in the clinical management of acute, high-consequence infectious diseases like Ebola.

“While there are important benefits to be realized in the application of the tools of genomics, and so-called precision medicine to infectious disease, there are also unique ethical, legal, and policy issues that must be addressed,” Prof. Kahn said. “We are pleased that the NIH recognizes the importance of this area of research.”

When the beginning of life is spent in the neonatal intensive care unit (NICU), the ethical issues inherent in critical care are compounded by the vulnerability of the young patients and the raw emotions of their families.

The Berman Institute is home to a growing team working to address these issues on several fronts, including faculty member and neonatologist Renee Boss, MD; Hecht-Levi Fellows Emily Hahn, MD, Miriam Shapirn, MD, and Rebecca Seltzer, MD, and staff member Erin Williams, MBE; with generous support from National Advisory Board Member Judy Starkey.

Prof. Boss is the author of a chapter titled “Death at the Beginning: The Neonatal Intensive Care Unit,” in The Oxford Handbook of Ethics at the End of Life. She lays out the unique ethical difficulties and distress faced by clinicians in the NICU, including legal and policy restrictions that can limit parent and clinician decision-making for infants in critical condition.

“Over the past two decades, increasing numbers of children are surviving once-fatal conditions but go on to have chronic medical conditions and often tenuous quality of life. They commonly remain in hospitals for months or even years, missing out on hallmarks of childhood,” said Prof. Boss.

A current study addresses care for children with chronic critical illnesses that keep them in the ICU long term, often fraying family bonds and endangering mental welfare. Prof. Boss and the research team are interviewing inpatient and outpatient clinicians, families, and policy professionals in five metropolitan areas to learn more about the barriers that impede children with chronic critical illnesses from spending more time at home.

“Uneasiness and burnout associated with providing care to such fragile children are barriers to recruiting and maintaining qualified medical foster parents, resulting in delays in home placement and hospital discharge. Medical foster parents need better access to care coordination, home nursing, and respite supports, which are often lacking due to poor reimbursement and availability,” said Dr. Seltzer.

For more information on National Advisory Board member Judy Starkey’s continued personal commitment to these issues, please see the inside back cover.
EQUITY IN RESEARCH FOR PREGNANT WOMEN

The spread of the Zika virus that began in 2015 shed light on a longstanding problem: how little we know about appropriately preventing and treating disease during pregnancy, due to the widespread exclusion of pregnant women from medical research.

Berman Institute scholars are currently examining the ethical dimensions of this important issue from two angles: the prevention, treatment, and management of HIV/AIDS, and research in response to emerging public health crises like Zika. “While there are complex legal and ethical issues involved in testing new vaccines and drugs in women who are pregnant or of reproductive age, that is not a justification for failing to generate evidence that is badly needed to meet the distinctive health needs of pregnant women, who are often at heightened risk during a public health crisis,” said Prof. Faden, PhD, MPH, Director of the Berman Institute and a Co-Principal Investigator on both projects.

With a £1.2 million ($1.7 million) grant from the Wellcome Trust, Prof. Faden and Berman Institute faculty members Leslie Meltzer Henry, JD, PhD, MSc, and Carleigh Krubiner, PhD, will collaborate with bioethics colleagues from the University of North Carolina at Chapel Hill Center for Bioethics, the Kennedy Institute of Ethics at Georgetown University, and the University of Washington School of Law to develop guidance for conducting research with pregnant women during a public health emergency.

The research team includes expert advisors in vaccinology and infectious disease, maternal-fetal medicine, and bioethics from both the United States and Latin America. The guidance will be further informed by consultations with scientists, physicians, and public health practitioners working on various aspects of the Zika response. The team will convene a series of expert working groups to help develop and refine guidance for addressing the health interests of pregnant women in research agendas for public health emergencies — focusing initially on Zika then producing broader guidance for other emerging health crises.

A related, ongoing study is known as PHASES: Pregnancy and HIV/AIDS: Seeking Equitable Study. Funded by the National Institutes of Health (NIH), PHASES aims to develop an action-guiding ethical framework to navigate the complexities of including pregnant women in HIV research in the US and in southern Africa, with a dedicated emphasis on South Africa, Malawi, and Botswana.

“Unlike the emerging threat of Zika, with HIV we have over three decades of experience learning about effective prevention and treatment options. Yet, despite tremendous scientific advancements, we still know comparatively little about how to best meet the health needs of pregnant women in the AIDS response,” said Prof. Krubiner, a PHASES Co-Investigator. “This is due to the dramatic underrepresentation of pregnant women’s needs in the HIV research agenda over the past 35 years — despite the fact that 17.8 million women are living with HIV worldwide with about 1.5 million giving birth each year and millions more at risk of becoming infected.”

At the Berman Institute, the PHASES team is led by Profs. Faden and Krubiner, along with Johns Hopkins PHASES Project Director Sappho Gilbert, MPH. Like the Zika-focused project, PHASES is also a collaborative effort with scholars from other research universities; several members of both research teams have worked for more than a decade on these issues. In 2008, Prof. Faden, Anne Lyerly, MD, MA, Associate Director of the Center for Bioethics at the University of North Carolina, Chapel Hill, and Margaret Little, BPhil, PhD, Director of the Kennedy Institute of Ethics at Georgetown University, launched the Second Wave Initiative, referencing the “first wave” of efforts in the early 1990s to include women in the biomedical research agenda. Second Wave grew into a consortium of physicians, scientists, and bioethicists advocating for advancing the evidence base for the treatment of pregnant women facing serious illness.

Profs. Faden, Lyerly, and Little authored multiple opinion articles on the issue of pregnant women receiving the H1N1 “swine flu” vaccine in 2009, noting the high fatality rate, the four-fold risk of hospitalization for pregnant women with H1N1, and the shortage of research specifically informing prevention and treatment of influenza in pregnant women. They also submitted a commentary to the US Department of Health and Human Services, with many co-signers, regarding proposed changes to the “Common Rule” governing research with human subjects, objecting to language labeling pregnant women as “a vulnerable population, at high risk of coercion and undue influence,” and calling for a working group to craft more appropriate and just language to address pregnant women’s needs and interests.
The major goal of this project is to conduct case studies of how program women and research were approached in four previous infectious disease therapies, analysis, Ethics, and HIV, and to develop guidance in understanding the ethics of research with pregnant women.

The major goal of this project is to guide decision-makers in effective, equitable, and efficient healthcare resource allocation strategies for improving the health of individuals.

This grant provides core support for the Global Food Ethics and Policy Program, as also two projects within the program. The first project will lead to specific, concrete work to produce a comprehensive action plan for different public health approaches for different types of infectious diseases, which pose an urgent global health threat and in the US and globally.

The major goal of this project is to develop an ethical framework and specific, possible best practices, around different public health approaches for different types of infectious diseases, which pose an urgent global health threat and in the US and globally.

This project works to strengthen the capacity of the research ethics committee (REC) at the University of Zimbabwe School of Medicine through a series of training, mentoring, and technical assistance designed to improve the knowledge of REC members and the administrative efficacy of REC operations.

This project works to develop a series of ethics questions, considerations, and, where possible, data practices, around different public health approaches for different types of infectious disease national to low- and middle-income countries (LMICs). Using the types of data practices and community members involved in the Ethics national to and in other infectious disease national to LMICs, key reasons will be identified for why public health measures fail, are met with resistance or distrust, and also identify ethics consideration that surround these concerns.

A comprehensive blueprint project will provide critical data on the views and recommendations of cancer research participants on the real-world dilemmas of whether or not to proceed with research using archived biospecimens when the scientific techniques and ethical standards have evolved and the adequacy of prior informed consent is unclear and re-consent is not feasible.

This project works to identify and analyze the ethical and regulatory issues in pharmacogenomics in low- and middle-income countries. The national patient-centered clinical research network. Accountability in Research. 2015, 76—91.

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knowledge, attitudes, and practices in the developing world? A systematic review

Patient Education and Counseling, 22(9), 746-754.


Improving clinician attitudes of respect and trust for persons with sickle cell disease: Results from interviews with leaders from 25 health systems. Global Public Health, 90(Sep), 114-120.


SELECTED PUBLICATIONS


SELECTED PUBLICATIONS


NEW EDUCATION INITIATIVES

In the past five years the Berman Institute has greatly expanded its educational offerings, including a Master of Bioethics (MBE) degree and the Berman Institute Bioethics Intensives (BI²) program of short courses for certification. Plans are also underway for an executive education program.

In addition to bringing new students into the Berman Institute community, these education programs have brought changes for faculty and staff. Faculty member Gail Geller, ScD, MHS, has been named Director of Education Initiatives, while former Hecht-Levi Fellow Travis Rieder, PhD, has joined the faculty as Assistant Director for Education Initiatives. They work closely with Senior Academic Program Coordinator Elice García-Baca to address current student and faculty needs and plan for the program’s future.

“We have an opportunity now to coordinate and create synergies among the full spectrum of educational offerings, both in person and online,” Prof. Geller said. “Through the Hecht-Levi Postdoctoral Fellowship Program, the doctoral track, the Master of Bioethics, the certificate programs, and the undergraduate minor in bioethics, we are committed to building a large and diverse community of learners at the Berman Institute.”

ELICE GARCÍA-BACA

GAIL GELLER

“I became interested in bioethics as I completed my undergraduate thesis on cross-cultural medicine and cross-cultural medical morality at the University of Chicago. I really liked medicine, I really liked science, I really liked health, but I really didn’t want to practice any of them. Ethical issues, however, I loved figuring out. Here at Hopkins, not only do I get exposure to some great public health classes with people doing great poverty, gun and social justice policy work, but I also get a strong background in world philosophy and ethical analysis. It’s a perfect marriage.”

CAMERON OKEKE REFLECTS ON HIS DECISION TO ENTER THE BERMAN INSTITUTE’S MBE PROGRAM

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.

**BIOTECHS 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.

**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, the program courses are taught by Berman Institute faculty in both online and in-person formats.

**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.

**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 2016, the Berman Institute offered the courses Foundations of Bioethics and Introduction to Ethics of Human Subject Research.

**THE BERMANS INSTITUTE’S FIRST MASTER OF BIOETHICS COHORT FROM LEFT TO RIGHT: CAMERON OKEKE, DIANA MENDOZA-CERVANTES, FARDI MOOH PAAZI-MADIAN**
EDUCATION AND TRAINING PROGRAMS

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, Bruce Bos, 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. Moon, MD, MPH, Marie Nolan, PhD, MA, and Zackary Berger, MD, PhD, Mark Hughes, MD, MA, FAAP, 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 newly expanded “Ethics for Lunch” seminar series provides the entire hospital community with exposure to critical yet common clinical ethics issues.

RESIDENTS: Under the leadership of Berman Institute faculty member Joseph Carrese, MD, MPH, FAAP, the Ethics of Clinical Practice Project enhances ethics education in the Johns Hopkins University School of Medicine residency training programs. In fiscal year 2016, 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, FAAP, and Margaret Moon, MD, MPH. In addition to resident training, they also lead ethics rounds on selected clinical units.

GLOBAL BIOETHICS TRAINING PROGRAM

In June 2016 the Intensive Global Bioethics Training Program hosted three scholars from Liberia, thanks to a supplemental grant from the NIH Fogarty International Center. They joined trainees from the Johns Hopkins-Fogarty African Bioethics Training Program 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, Deputy Director for Public Health, the program combines intensive coursework with applied, skills-oriented learning, as well as trips to federal agencies in Washington, DC.

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 coursework, activities included structured meetings with bioethics personnel at the National Institutes of Health (NIH), the Food and Drug Administration (FDA), and the Office for Human Research Protections (OHRP).

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, 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 20 scholars in an intensive program, and 45 in an extended program, including a practicum at their home institution.

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.

Below are the 2015-2016 Hecht-Levi Fellows and their diverse areas of research:

JANET CHILDERSHOE, PhD The challenges that adolescents experience following treatment with adult medical interventions, specifically bariatric surgery.

EMILY HAHN, MD Decision-making and palliative care for infants in the neonatal intensive care unit, perceptions of disability, and the quality of life of medically complex children and their caregivers.

STEPHANIE MORAIRIN, PhD Political and ethical issues concerning the scope of government authority in public health.

AMY PAUL, PhD The moral foundations of responsibility to aid, and the challenges of allocating responsibility in a global context.

YASHAR SAGHAI, PhD, MA Studies that apply scientific rigor, artful skill, and practical imagination to anticipate or forecast possible futures of food systems.

REBECCA SELTZER, MD Ethical, psychosocial, and policy questions that arise when caring for children with medical complexity, particularly children in medical foster care.

MIRIAM SHAPIRO, MD Decision-making for medically complex and critically ill children, consent in pediatrics, and resource allocation and justice.

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MIRIAM SHAPIRO, MD Decision-making for medically complex and critically ill children, consent in pediatrics, and resource allocation and justice.
In addition to original research, scholarship, teaching, mentoring, and public awareness outreach, Berman Institute faculty members perform significant service within the Johns Hopkins community. Examples of this service are described below, followed by a listing of faculty members who serve in the various capacities.

As a matter of institutional policy, members of the Berman Institute faculty sit on all of the Institutional Review Boards (IRBs) of the Johns Hopkins Bloomberg School of Public Health and the Johns Hopkins School of Medicine, advising on matters of institutional policy regarding research with human participants.

Research that does not involve human participants, but does work with human pluripotent stem cells, is subject to oversight by the Johns Hopkins Institutional Stem-Cell Research Oversight (ISCOR) Committee. This includes research with human embryonic stem cells, research involving somatic cell nuclear transfer (sometimes known as therapeutic cloning), and induced pluripotent stem cell research where the cells are introduced into humans; the cells are introduced into the nervous system of non-human primates; the cells are introduced into non-human animals and there is a significant possibility of the cells giving rise to sex cells; or research that could create human sex cells or embryos.

Several faculty members provide clinical ethics consultation to both healthcare providers and patients through their service on the Hospital Ethics Committees, both at Johns Hopkins Hospital and Johns Hopkins Bayview Medical Center. In addition to addressing ethical question and concerns, these committees educate healthcare workers on how to resolve ethical dilemmas and consult on institutional ethical issues.

The Research Ethics Consulting Service (RECS), coordinated by Berman Institute faculty member Holly Taylor, PhD, MPH, is an experiment in extending ethics consultation—typically related to clinical issues—to the research setting. Prof. Taylor works with the Johns Hopkins Institute for Clinical and Translational Research to provide free, confidential ethics guidance to faculty, staff, trainees, and students from the Schools of Medicine, Nursing, Public Health, Engineering and the Kennedy Krieger Institute. Consults may be requested for ethical issues arising during study development, conduct, analysis, and publication.
In 2016 the Berman Institute inaugurated a new monthly seminar series at Johns Hopkins Hospital, in partnership with the Johns Hopkins Hospital Ethics Committee, titled “Ethics for Lunch.” This served to expand the program already underway at Johns Hopkins Bayview Medical Center.

At each seminar a medical ethics case study is presented and discussed by an expert panel, and then discussion is opened up to attendees. Past seminars have covered do-not-resuscitate orders, pediatric patients arriving late, and bias in treating pain.

Ethics For Lunch is open to the public every third Tuesday during the academic year, from 12 noon to 1:15 PM in the Johns Hopkins Hospital, Sheikh Zayed Tower, Room 2117. CME credits are available, and lunch is provided. Seminars are recorded and available for viewing on the Berman Institute’s YouTube channel. For more information on upcoming seminars, visit: http://www.bioethicsinstitute.org/efl

How Many Americans are Immunocompromised?

THEO SCHALL, MSW

The Ethics of Eating

JESS FANZO, PHD

What’s the Scientific Basis for Transgender Healthcare?

THEO SCHALL, MSW

Ebola: Nurses on the Front Line

CYNDA RUSHTON, PHD, RN, FAAN

“A Gun is Not a Disease”

ALAN REGENBERG, MBE

Berman Institute in the News

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

How Many Americans are Immunocompromised?

THIRD SCHALL, MSW

The Ethics of Eating

JESS FANZO, PHD

What’s the Scientific Basis for Transgender Healthcare?

THIRD SCHALL, MSW

Ethics: Nurses on the Front Line

CYNDA RUSHTON, PHD, RN, FAAN

“A Gun is Not a Disease”

ALAN REGENBERG, MBE

BAILEY, T. (April 2016). What to talk about when we talk about plague: Five paradigms of infectious disease control for a deliberative democracy. Aggie Argos Lecture series, Texas A&M University, College Station, TX.


BEAGLE, M.C. (August 2016). Optimizing mentoring relationships. Ioannina University School of Medicine, Ioannina, Turkey.


BENGER, Z. (December 2015). Uncertainty in shared decision making: Towards a research agenda. Informed Medical Decisions Foundation, Boston, MA.


CARRESE, J. (April 2016). Integrating ethics into health professions education and residency training including a focus on wellness in professionalism education. Annual Conference of the Academy for Professionalism in Health Care, Philadelphia, PA.


DECAMP, M. (October 2016). Meaningfully engaging patients in ACO decision-making. American Journal of Managed Care’s ACO and Emerging Healthcare Delivery Coalition Fall 2016 User Meeting, Palm Harbor, FL.


FADEN, R. (September 2016). Ethical considerations for food and nutrition security in context of sustainable development goals. Department of International Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD.

FADEN, R. (November 2015). Ask Ag about... The interactions between climate change and nutrition. Agnieszka and International Food Policy Research Institute, online.


GELLER, G. (November 2016). Trust, integrity and ethics in emcs research: From individual misconduct to responsible systems and cultural change. 45th Southeast Symposium on Biostatistics, Savannah, GA.

GELLER, G. (June 2016). The practice of respect: The next frontier in preventing patient harm. Israeldescr Oms Medical Center, Boston, MA.

HAYWOOD JR., C. (July 2016). Journeys in healthcare: A conversation about the healthcare system and the community. Journey in Medicine: Exploring the Roles Browns and Community. May in Shaping the GMO. Johns Hopkins University School of Medicine, Baltimore, MD.


HIGGINS, M. (October 2016). Primary pollution cannot: What every clinician should know. End of Life Care: Empowering your Patient. Oakland Medical Center, Bloomfield Hills, MI.


HIGGINS, M. (February 2016). Healer or healer or healer? Respecting to request for part 10075. Johns Hopkins Bluestein Cancer Center, Baltimore, MD.


KAHN, J. (June 2016). Sustainable public health ethics infrastructure and guidance following epidemics. 4th Slavica Narvits Foundation International Conference on Philanthropy, Athens, Greece.


KAHN, J. (July 2016). Ethics and big data research in HIV. National Institute of Allergy and Infectious Diseases Workshop on Big Data and Info. Bethesda, MA.


KAHN, J. (May 2016). Genetics, ethics, and human spaceflight. Personal Genetics Education Project Congressional Briefing, Washington, DC.


KAHN, J. (June 2016). Human space flight ethics and obligations: Options for monitoring, diagnosing, and treating for marronic space. Space-Spectrumi Committee Hearing, Washington, DC.


MATHES, B. (June 2016). Explore the ethical, social, policy, and legal implications impacting the adoption of genomics in healthcare. Friends of Genetics, Boston, MA.


HENRY, M. L. (June 2016). Examining mature minor consent for participation in HIV research. Department of Health of the National Institutes of Health, Bethesda, MD.
**SELECTED PRESENTATIONS**


ROGERS, J. (October 2015). Organizing judge. Annual Victor Cohn Prize for Medical Reporting, Council for the Advancement of Science Writing, Cambridge, MA.


RUBINSTEIN, L. (June 2015). Health needs of populations displaced by conflict and political upheaval. Call For Papers – The Health Crisis of Displaced Population Displaced by Conflict in the Middle East, Middle East Institute, Washington, DC.


RUBINSTEIN, L. (February 2016). National security, ethics, and global health. George Mason University, Washington, DC.


RUBINSTEIN, L. (June 2016). Health impacts of the war in Syria. Role of Science Diplomacy in International Crisis: Syria as a Case Study, American Association for the Advancement of Science, Washington, DC.


SAGHAI, Y. (February 2015). Embodied health and wellness nuggets in the workplace from Abaranai polytechnic to workplace democracy: Annual Meeting of the American College of Preventive Medicine, Washington, DC.


SAGHAI, Y. (June 2016). Building an innovative research agenda for global food ethics. Meeting of the International Association of Bioethics, Edinburgh, Scotland.


SUGARMAN, J. (September 2015). Reconsidering Old Habits: Addressing the Ethical and Regulatory Issues in Pragmatic Clinical Trials and Comparative Effectiveness Research. Western HIV-Careers Group Annual Training, Seattle, WA.

SUGARMAN, J. (September 2015). Master Series on Core Research, 2015 United States Conference on AIDS, Washington, DC.

SUGARMAN, J. (October 2015). Ethical issues in Advancing the Use of Stem Cells to Treat Motor Neuron Disease. Viva Neuro-Disease Symposium, University of Queensland, Brisbane, Australia.


SUGARMAN, J. (December 2015). Making Ethical Social Science: Progress The Role of Human Subjects Protection Programs in the United States. Tokyo Medical and Dental University, Tokyo, Japan.


SUGARMAN, J. (May 2016). Fogarty International Center China Biethics Workshop, Shanghai University of Traditional Medicine and University of Pittsburgh, Shanghai, China.


UNGURU, Y. (October 2015). Navigating the challenges when there is disagreement in care. 50th Annual Meeting of the American Society for Pediatric Hematology/Oncology, Minneapolis, MN.


UNGURU, Y. (June 2016). When drugs are short, but the ethical challenges are long: The absurdity of having to choose which children with cancer receive life-saving chemotherapy. International Society for Pharmacological Engineers, Data Integrity and Quality Manufacturing Conference, Bethesda, MD.

UNGURU, Y. (June 2016). Ethical considerations in clinical research: A child-centered approach. Hydrophobia: Together Toward Tomorrow, Hydrophobia Association’s 16th Annual Conference, Minneapolis, MN.


UNGURU, Y. (January 2016). Refusing the refusal: Saying “no” to parents and children who refuse care for favorable prognosis cancer. Pediatric Grand Rounds, Sinai Hospital, Baltimore, MD.


UNGURU, Y. (October 2015). Navigating the challenges when there is disagreement in care. 50th Annual Meeting of the American Society for Pediatric Hematology/Oncology, Minneapolis, MN.
In fall 2015, Prof. Saloner was one of five Anniversary Fellows named to the National Academy of Medicine, specifically selected to be the inaugural Greenwall Fellow in Bioethics. For two years, Prof. Saloner will continue his work at Johns Hopkins while working with the National Academy’s Health and Medicine Division. He is analyzing ethical issues related to proposals to include social risk factors in value-based payments in the Medicare program. The Anniversary Fellows Program is designed to assist early career health and science scholars in furthering their careers as future leaders in the field.

“Healthcare policy raises ethical questions about how we can use limited resources to fairly meet the needs of diverse, and often marginalized, communities. Combining my ethics background with empirical methods enables me to simultaneously frame these difficult questions and measure the possible tradeoffs,” Prof. Saloner said.
ADNAN HYDER, MD, MPH, was named to the Lancet Commission on Reframing Non-Communicable Diseases and Injuries for the Poorest Billion.

NANCY KASS, ScD, was named chairperson of the institutional review board for the Precision Medicine Initiative Cohort Study.

MARIA MERBRITT, PhD, received recognition from the Johns Hopkins Bloomberg School of Public Health for excellence in teaching for her course Ethics of Public Health Practice in Developing Countries.

MARGARET MOON, MD, MPH, was appointed Associate Vice Chair for Professional Practice for the Johns Hopkins Children’s Center and Physician Advisor for the Department of Pediatrics. With this new role, Prof. Moon joins the Division of Quality and Safety within the Johns Hopkins Children’s Center.

LEONARD RUBENSTEIN, JD, LL.M, was appointed to be a member of the American Psychological Association’s Commission on Ethics Processes.

BRENDAN SALONER, PhD, was selected as the inaugural recipient of the Greenslade Fellowship in Bioethics at the National Academy of Medicine.

THEO SCHALL, MSW, was named Managing Editor of AJOB Empirical Bioethics.

HOLLY TAYLOR, PhD, MPH, was named Editor-in-Chief of AJOB Empirical Bioethics.

YORAM UNGURU, MD, MS, MA, achieved “All Star Champion Status” through the LifeBridge Health Champion of Care program.

RECHT-LEVI FELLOWS

JANET CHILSEER, PhD, MA
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STEPHANIE MORKIN, MD, MPH
AMY PAUL, PhD, MPH
YASHAR SAGHAJ, MD, PhD
REBECCA SELTZER, MD
MIRIAM SHAPIRO, MD

GLOBAL BIOETHICS TRAINEES

GLORIA MASON, BA
CURTIS TAYLOR, BSC
DARICE WILLIAMS, MPH MD BSC

FOGARTY AFRICAN BIOETHICS TRAINEES

ERIKA HANAKA, MSc, MA
INELDA NAMASEMBE, MPH, MscE
DOULLN NESMIEKE, PhD
ESTHER SULWUYI, PhD MBA MSC MD

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DANIELLE EDWARDS, JD, MS
RACHEL FARIS
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Senior Administrative Coordinator
ABBY KIPP, MBE
Research Program Coordinator
RACHEL TIGNAN
Research Program Coordinator

FACULTY

MARK HUGHES, MD, MA
was elected as a Fellow of the American College of Physicians.

JESSICA FANZO, PHD
was appointed Associate Faculty in the Berman Institute doctoral program, were inducted into Delta Omega, Alpha Chapter. Delta Omega is the national honor society for public health.

LENA-LEE ELLIS, PHD
was named member of the editorial board of the journal The Patient — Patient-Centered Outcomes Research.

MATTHEW DECAMP, MD, PhD, was elected as a Fellow of the American College of Physicians.

YORAM UNGURU, MD, MS, MA,
achieved “All Star Champion Status” through the LifeBridge Health Champion of Care program.

JOSEPH ALI, JD,
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ZACKARY BERGER, MD, PhD,
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MARY CATHERINE BEACH, MD, MPH,
was promoted to Professor of Medicine in the Johns Hopkins School of Medicine.

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JUDY STARKEY

“I am deeply committed to developing improved practices and policies for delivering the best and most effective healthcare. I am proud to support the work of Dr. Renee Boss, a neonatologist and bioethicist who wrestles with the most difficult questions of all: how best to care for children with serious health conditions. With Dr. Boss’ help, I look forward to a day when we have a healthcare system that cares for all in a just and meaningful way.”

For 23 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 Judy Starkey, 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 Judy Starkey and others who understand the critical need for bioethics scholarship and research. The week 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.