Thank you for taking a few minutes with this report to learn about the accomplishments and impact of the Berman Institute of Bioethics over the last academic year. As Director, there is so much of which to be proud. The scope of our faculty’s scholarship, teaching and service never ceases to amaze me. You can search the world over and never find a more talented and dedicated group of professionals.

While the Berman Institute addresses many important issues, there was nothing that captured the public imagination in 2014 so much as the Ebola epidemic. I was struck by how many bioethics issues found their way into the public discourse. What are equitable and safe ways to make emerging treatments available? How do our ethics frameworks function in extreme circumstances? How should we protect caregivers? How can we address health care disparities in developing countries? Ebola is a tragic backdrop against which we raise complicated questions. Many faculty members have worked to address these concerns, and to share sound guidance with an anxious public.

Beyond crises like Ebola, there are many more issues the Berman Institute works on every day. From respect and dignity at the hospital bedside to the ethics of global food security; from organ transplantation policy to questions surrounding solitary confinement — all of these issues require our best thinking.

I recently announced that this next academic year will be the final one in which I serve as Director of the Berman Institute. While that decision was difficult, it was made much easier by the sure knowledge that the work of the Berman Institute is improving lives around the world and will continue to do so for many years to come. Thank you for your friendship toward the Institute and your interest in our mission.

Warm regards,

Ruth Faden, PhD, MPH
AndreA. C. drACopoulos direCtor,
philip FrAnklin WAgley proFessor oF BiomediCAl ethiCs
With the world’s population likely to exceed 9.5 billion by 2050, the global community faces an enormous challenge — how to ensure everyone will have enough nutritious and safe food to secure a desirable level of health.

So begins a landmark report issued in May 2015 by an international working group on global food ethics, organized by the Berman Institute. A diverse group with expertise ranging from agronomy to bioethics to climate science, their report outlines the initial steps they believe must be taken toward solving one of society’s most fundamental public policy challenges, and doing so ethically.

“Today over 800 million people are undernourished and two billion are obese or overweight, all of them at risk of poor health and quality of life,” says Ruth Faden, PhD, MPH, the Dracopoulos Director of the Berman Institute and a Co-Principal Investigator on the Initiative. “There is wide agreement that this state of affairs cannot be allowed to continue, but making real progress that lasts and is fair requires confronting some extremely difficult ethical issues,” she says.

“The challenge of global food security is too urgent to ignore these ethical issues, but deciding which issues are the most important, and which ones can actually be resolved, is not obvious,” Prof. Faden says.

The report is the product of a 2014 meeting of 23 diverse subject matter experts in Ranco, Italy. It outlines distinct next steps: seven projects that reflect the breadth and complexity of global food ethics. While ambitious, each can achieve real progress in a five-year timeline.

Titled the 7 by 5 Agenda for Ethics and Global Food Security: 7 Projects to Make Progress on Ethics and Global Food Security in 5 Years, the 2015 report details the motivation and plans for each project, which in brief are:

1. **Ethical Challenges in Projections of Global Food Demand, Supply, and Prices**
   Identify and make concrete recommendations to decrease bias, increase accuracy, and enhance the integrity of projections of food demand, supply, and prices upon which food and agricultural policy decisions are based.

2. **The Food Sovereignty Movement and the Exceptionality of Food and Agriculture**
   Identify and narrow disagreements over the rights of peoples to democratic control over food, agricultural, and resource policy that are specifically rooted in different views about what makes food and agriculture distinct from other economic sectors.

3. **The Case for the Professionalization of Farming**
   Reframe farming as a service-oriented profession in which farmers as professionals have obligations to the public to use their specialized skills to meet legitimate expectations for food safety and environmental, worker, and farm animal protection.

4. **Global Agricultural Research and Development: Ethics, Priorities, and Funders**
   Develop reform-oriented recommendations to help ensure that a fair share of agricultural research and development is directly responsive to the needs and preferences of disadvantaged farmers in low-income countries.

5. **Climate-Smart and Climate-Just Agriculture**
   Demonstrate why and how “climate-smart agriculture” must also be “climate-just,” distributing its benefits and burdens fairly across geographic regions and generations.

6. **Ethics of Meat Consumption in High-Income and Middle-Income Countries**
   Make specific recommendations about the ethics of public and private interventions to alter meat consumption patterns in high- and middle-income countries.

7. **Consumers, Certifications, and Labels: Ethically Benchmarking Food Systems**
   Develop the first integrated labeling system that will offer consumers easy access to trustworthy ethical information on environmental sustainability, animal welfare, labor standards, public health, and food safety.

“We are committed to making these projects a reality. It is possible to make progress on divisive ethical issues in global food security and food systems by focusing on a set of problems that are both significant and tractable,” says Yashar Saghai, PhD, the Project Director. “Our group presents a cohesive research and policy agenda that paves the way for a new approach to food and agricultural ethics on a global scale.”
As the trials and bravery of nurses made front-page news during the Ebola crisis in 2014, leaders in the field gathered at Johns Hopkins for the inaugural National Nursing Ethics Summit, organized by Berman Institute faculty member Cynda Hylton Rushton, PhD, RN, FAAN. The summit resulted in an unprecedented report on the ethical issues facing the profession. Published in November 2014 and available in full online at www.bioethicsinstitute.org, A Blueprint for 21st Century Nursing Ethics: Report of the National Nursing Summit covers issues including weighing personal risk with professional responsibilities and moral courage to expose deficiencies in care.

“This blueprint was in development before the Ebola epidemic really hit the media and certainly before the first US infections, which have since reinforced the critical need for our nation’s healthcare culture to more strongly support ethical principles that enable effective, ethical nursing practice,” says Prof. Rushton, the Bunting Professor of Clinical Ethics at the Berman Institute and the Johns Hopkins School of Nursing.

The report makes both overarching and specific recommendations in four key areas: Clinical Practice, Nursing Education, Nursing Research, and Nursing Policy. Among the specific recommendations are:

- **Clinical Practice:** Create tools and guidelines for achieving ethical work environments, evaluate their use in practice, and make the results easily accessible.
- **Nursing Education:** Develop recommendations for preparing faculty to teach ethics effectively.
- **Nursing Research:** Develop metrics that enable ethics research projects to identify common outcomes, including improvements in the quality of care, clinical outcomes, costs, and impacts on staff and the work environment.
- **Nursing Policy:** Develop measurement criteria and an evaluation component that could be used to assess workplace culture and moral distress.

“It’s our hope this will serve as a blueprint for cultural change that will more fully support nurses in their daily practice and ultimately improve how healthcare is administered — for patients, their families, and nurses,” says Prof. Rushton. “We want to start a movement within nursing and our healthcare system to address the ethical challenges embedded in all settings where nurses work.”

Jessica Fanzo, PhD, a nutritionist and expert in the fields of biodiversity and food security, became Johns Hopkins’ first Bloomberg Distinguished Associate Professor in 2015 as a faculty member at both the Berman Institute and the Paul H. Nitze School of Advanced International Studies. Before joining Johns Hopkins, Prof. Fanzo was a faculty member at Columbia University, but was already an integral member of the Global Food Ethics Initiative Working Group, helping to develop the 7 by 5 Agenda.

“At Hopkins, where there is such a strong international focus, there is a unique opportunity to build a food security and food systems program between the Berman Institute and the School of Advanced International Studies,” says Prof. Fanzo. The prestigious Bloomberg Distinguished Professorships are the centerpiece of Johns Hopkins’ focus on strengthening the University’s “capacity for faculty-led interdisciplinary collaboration,” as outlined in President Ronald J. Daniels’ Ten by Twenty vision plan. A total of 50 endowed professorships, to be appointed over five years, are supported by a gift to the University from Johns Hopkins alumnus and former New York City Mayor Michael Bloomberg.

Prof. Fanzo says she is especially looking forward to creating new courses to get students interested in ethical issues around global food systems. “For example, how do we ensure people in low-income countries have enough animal-source food, and that people in high-income countries don’t eat too much? How can we balance demand for these foods with planetary health? There are a lot of moral and ethical issues to understand,” she says.
Fellowship Reunions

The Berman Institute is privileged to have the opportunity to train early-career bioethics scholars, broadening the Institute’s impact, bioethics scholarship itself, and the Berman Institute community. Last year the Berman Institute was able to host reunions for two long-running fellowship programs, the Johns Hopkins-Fogarty African Bioethics Training Program (FABTP) and the Greenwall Fellowship Program in Bioethics and Health Policy, bringing old friends and colleagues together to reminisce and catch up on each other’s work.

In early December 2014, fellows, advisory board members, institutional partners, and Berman Institute faculty and staff gathered to look back on 15 years of the FABTP. Thirty-three fellows and partners from 14 countries — representing every cohort of fellows to complete the program so far — gathered to review the evolution of bioethics in Africa, present trainees’ original empirical and scholarly work, identify new pathways for advancing bioethics capacity in Africa, and explore opportunities for networking and collaboration.

Nancy Kass, Sc.D., Co-Director of the program with Adnan Hyder, MD, PhD, MPH, welcomed everyone by saying that she felt that she was hosting a family reunion, including some cousins who haven’t met each other yet. She added that she and Prof. Hyder were especially pleased to include Barbara Sina, Program Officer at the National Institutes of Health Fogarty International Center, who has been invaluable for networking and collaboration. Prof. Kass presented data on the substantial accomplishments of the group, which have significantly bolstered research ethics capacity across Africa. Over the past 15 years, FABTP trainees have authored 250 bioethics-related publications, played key roles in 151 research studies, and participated in 362 bioethics workshops or conferences. Alumni also remain committed to passing on the knowledge gained through the program, teaching 111 bioethics-related courses in Africa since 2000.

“Our alumni are deeply committed to expanding bioethics teaching, research, and service in Africa. As leaders in their home countries and institutions, many have developed new and innovative training programs, research portfolios, institutional and national frameworks, ethics review committees, and more,” Prof. Hyder said.

In May 2015, 32 former fellows of the Greenwall Fellowship Program in Bioethics and Health Policy attended their own reunion at the Berman Institute. The Greenwall program, which ran from 1995-2012, was a collaborative effort of Johns Hopkins University and Georgetown University and provided an unparalleled opportunity for over 50 multidisciplinary, post-doctoral fellows to launch their careers in bioethics. Nine Greenwall fellows became members of the Berman Institute faculty, while others have become frequent collaborators.

Greenwall fellowship alumni hold leadership positions in bioethics and health law programs around the country including: Jonathan Marks, BCL, MA, Associate Professor of Bioethics, Humanities, Law, and Philosophy, and Director of the Bioethics Program at the Rock Ethics Institute at Penn State University; James Hodge, Jr., JD, LL.M., Director of the Public Law and Policy Program at Arizona State University; S. Matthew Loo, PhD, Director of the Master’s Program in Bioethics and Clinical Associate Professor in the Center for Bioethics at New York University; Anne Dropping Lyerly, MD, MA, Associate Professor of Social Medicine and Associate Director of the Center for Bioethics at the University of North Carolina - Chapel Hill; Leslie Wolf, JD, MPH, Professor of Law and the Director for the Center for Law, Health & Society at Georgia State University’s College of Law; and Debra DeBruin, PhD, Associate Professor and Director at the Center for Bioethics at the University of Minnesota.

Greenwall Fellowship alumni have also gone on to positions at academic institutions such as The George Washington University, Moravian College, Ohio State University, University of Delaware, University of Edinburgh, University of Kent, University of Maryland, University of Oregon, University of Pennsylvania, and University of South Carolina. Other alumni have gone on to senior positions in law firms, public policy organizations, the private sector and charitable foundations. For example, Greenwall alumna Elisa Hurley, PhD, is the Executive Director of Public Responsibility in Medicine and Research (PRIM&R), and alumnus Dan O’Conner, PhD, is the Head of Medical Humanities at The Wellcome Trust.

Seven current fellows in the Berman Institute’s successor fellowship program, the Hecht-Levi Fellowship in Bioethics, joined in the reunion as well.

“It was gratifying to watch the Greenwall and Hecht-Levi fellows blend seamlessly and learn from one another,” said Gail Geller, Sc.D., MHS, Co-Director of both programs. “We were all inspired to hear about the many ways the Greenwall alumni are contributing to the field of bioethics around the world, and to anticipate the contributions the Hecht-Levi fellows will make.”

During the reunion, the fellows and faculty of both programs had the opportunity for continuing education and professional development. The internationally renowned public relations firm Burness Communications offered a day-long intensive training program on giving Ted Talk-style presentations, working with policymakers, and persuasive op-ed writing.

“Bringing participants in these important programs together, you really get the full meaning of the worst ‘fellowship’. It was an incredible opportunity to have these scholars here as fellows, and wonderful now to see where they have taken that training since,” said Ruth Faden, PhD, MPH, the Dracopoulos Director of the Berman Institute.
ETHICS TRAINING FOR FUTURE PHYSICIANS: THE ROMANELL REPORT

When it was published by the New England Journal of Medicine in 1985, the article “Basic Curricular Goals in Medical Ethics,” now known as the DecCamp Report, was the first to argue that ethics training should be required for all medical students. To accommodate 21st century ethical concerns and begin resolving discordant approaches to medical ethics training, Berman Institute faculty members joined scholars from leading medical schools across the US to issue updated recommendations.

The Romanell Report, published by the journal Academic Medicine in April 2015, builds on the DecCamp Report to address contemporary concerns, including cultural diversity, clinician work-life balance, and team-based healthcare coordination. Both reports are named for their funding agencies: the Patrick and Edna Romanell Fund for Bioethics Pedagogy at the University of Buffalo, and the Ira W. DeCamp Foundation.

The Romanell Report also highlights the enduring goals of medical professionalism, citing the need for “sustaining medicine as a public trust, rather than a guild primarily concerned with protecting the economic, political, and social power of its members.”

“We all want medical students and doctors in training to abide by ethical norms and conduct themselves professionally, the question is, how do we get there?” says Joseph Carrese, MD, MPH; faculty member at the Berman Institute and lead author on the Romanell Report. “We need to have some agreement on educational goals, methods to teach, and assessment strategies if we want to train all future medical professionals effectively,” he says.

The Romanell Report expands the DecCamp Report’s list of learning objectives for medical ethics education and addresses new issues including teaching methods, assessment strategies, learning environment, and ensuring sufficient support and rewards for faculty.

“It is crucial to have skilled and engaged faculty to teach, mentor, and assess our learners, so focusing on faculty should be a top priority,” says Prof. Carrese.

The report discusses the difficulty of assessing crucial desired character attributes of professionalism like humility, compassion, and integrity. “If assessment is limited only to what is formally taught, to what can be quantitatively assessed, or to the requirement of positive change, we risk a much less nuanced evaluation of some of the most important qualities of professionalism,” the report states, calling for a hybrid assessment strategy incorporating both quantitative and qualitative methods.

“We need to recognize the limitations of quantitative assessment strategies and be flexible enough to adopt novel strategies that better fit the outcome of interest,” says Gail Geller, ScD, MHS, a co-author on the Romanell Report and faculty member at the Berman Institute.

“Ultimately, all medical education and training is about preparing future doctors to provide excellent and respectful care, broadly defined, to their patients and making patients’ needs their top priority,” says Prof. Carrese. “That’s the main goal of ethics education, and that’s the main focus of a true medical professional.”

HUNTINGTON’S DISEASE AND THE IMPACT OF GENETIC TESTING

Evidence regarding how genetic testing affects patients is in short supply, as the science itself is only about a generation old. A study currently underway at the Berman Institute aims to add to this knowledge base by collecting the first-hand accounts of participants in one of the nation’s first genetic testing trials.

In 1986, Johns Hopkins was one of the first two sites in the US conducting a research trial using genetic testing for individuals at risk for Huntington’s disease. The gene that causes the disease was the first to be mapped using genetic “markers,” so it was the first that could be tested genetically.

The first tests were 95% accurate; today they are only about a generation old. A study currently planned for this phase of the study at Johns Hopkins influenced the delivery of results for adult-onset neurodegenerative diseases, Prof. Mathews explains, and revisiting the study to look at the long-term impact on individuals and their families will help to determine if that thinking has held up over time.

Thus far the research team has spoken with ten research participants who tested negative, two who tested positive, and what lessons might be taken from their experience and what lessons might be taken from their experience and what lessons might be taken from their experience. The study is funded by a grant from the National Human Genome Research Institute’s Ethical, Legal, and Social Implications (ELSI) program, at the National Institutes of Health.
Sickle Cell Disease (SCD) is the most common genetic condition detected by newborn screening in the United States, a physically devastating and painful illness affecting an estimated 100,000 individuals nationwide. Problems of no cure and few treatment options are compounded by the fact that many patients don’t take available medications correctly, according to Berman Institute faculty members Carlton Haywood Jr., PhD, MA, and Mary Catherine Beach, MD, MPH.

The professors are co-authors of a study showing that of 273 adult SCD patients, those reporting experiences of discrimination in the healthcare system were 53% more likely to also report not following physician recommendations.

The results are published in the Journal of General Internal Medicine, published by Springer.

“This study provides real evidence that, in addition to research into new treatments for Sickle Cell Disease, it is crucial to develop methods for improving trust and interpersonal relationships between patients and healthcare professionals,” says Prof. Haywood, who both studies and suffers from SCD.

Prof. Haywood explains that the unfortunate combination of the predominance of SCD in people of African descent, the necessity of strong pain medications to treat the disease, and the history of race relations in the United States complicate and in some cases inhibit the physician-patient relationship that is essential to effective management of the illness. The study notes that even among patients who did adhere to physician recommendations, over 40% reported having at least one experience of discrimination in the prior two-year period, which Prof. Haywood and his colleagues conclude “suggests a high underlying magnitude of perceived discrimination among SCD patients overall.”

“There are complex factors that inhibit effective management of Sickle Cell Disease, including patients’ trust in their physicians and taking medication properly,” Prof. Haywood says. “Studying the root of these issues and working to resolve them will help to make the best use of the tools we do have to combat Sickle Cell Disease, relieving suffering and saving lives.”

The study was a collaboration between scholars at the Berman Institute, the School of Medicine and Bloomberg School of Public Health at Johns Hopkins, as well as Howard University Hospital and the University of Maryland, Baltimore County.

In summing up their study, the authors conclude, “The interpersonal problems in healthcare interactions experienced by persons with SCD are of significant, intrinsic concern given the implications of what it means to treat patients with respect and trust, as well as what it means to adhere to principles of justice in the healthcare system. In order to improve SCD patient trust, it is important for the healthcare system and healthcare providers to demonstrate that they are worthy of the SCD patient’s trust.”


The Berman Institute is committed to training the next generation of leaders in bioethics and preparing students in healthcare, research, and science to address the ethical issues in their fields.

Unique interdisciplinary programs and faculty provide a dynamic educational experience that makes the most of the Berman Institute’s position at Johns Hopkins, an institution that includes schools of medicine, nursing, and public health that are among the world’s best.

**Education and Training Programs**

**Master of Bioethics and Public Health Policy**

A joint program of the Berman Institute and the Department of Health Policy and Management in the Johns Hopkins Bloomberg School of Public Health, the PhD program provides unparalleled training, education, and mentoring to the next generation of bioethics scholars. Nancy Kass, ScD, directs the program, and she joins faculty members Holly Taylor, PhD, MPH, Maria Merritt, PhD, and Jeffrey Kahn, PhD, MPH, in advising and mentoring the students.

The Berman Institute was proud to graduate two students in the 2014-2015 academic year: Drs. Amy Paul and Lee-Lee Ellis.

**Certificate in Bioethics and Public Health Policy**

In partnership with the Johns Hopkins Bloomberg School of Public Health, the Berman Institute offers the certificate program to any graduate student already enrolled at Johns Hopkins University. Students complete 10 graded course units, with the aim of developing skill at recognizing and analyzing moral problems in public health practice, research and health policy, and how they apply to public policy debates. To date 30 students have graduated with a certificate.

**INTENSIVE GLOBAL BIOETHICS TRAINING PROGRAM**

The Berman Institute’s Intensive Global Bioethics Training Program hosted a diverse group of scholars in June 2015 for a month-long training in the ethics of research in low- and middle-income countries. Directed by Nancy Kass, ScD, and Adnan Hyder, MD, PhD, MPH, the program combines intensive coursework with applied, skill-oriented learning, as well as trips to federal agencies in Washington, DC.

This year trainees came from Zambia, Botswana, Uganda, Ethiopia, Pakistan, and with a supplemental grant from the National Institutes of Health (NIH), three additional trainees were able to attend from Liberia.

The faculty training program coordinator, Joseph Ali, JD, says that the Ebola outbreak in Liberia and other West African countries was a frequent topic of discussion during training sessions. The Liberian trainees were able to share their first-hand experiences of the outbreak and response, as members of an Institutional Review Board and as a government health policy official, with their fellow trainees and instructors, they later gave a seminar presentation for the broader Hopkins community at the conclusion of their training (for more on this, see the special outreach report on Ebola, p. 18).

The trainees enrolled in the Berman Institute’s Bioethics Intensive Courses, and also met with key personnel from Johns Hopkins Institutional Review Boards (IRBs) and 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 meetngs with bioethics personnel at the NIH, the US Food & Drug Administration, and the DHHS Office for Human Research Protections, as well as organized excursions to orient visitors to Johns Hopkins and the Baltimore-Washington area.

**BIOETHICS AT HOMEWOOD: THE UNDERGRADUATE MINOR AND HUBS**

Faculty member Hilary Bok, PhD, directs the Bioethics Minor Program, offered in collaboration with the Department of Philosophy of the Johns Hopkins Zanvyl Krieger School of Arts and Sciences. To date 30 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 campus community, including debates, movie nights, mock institutional review boards, deliberative democracy sessions and talks on bioethics topics.

**PhD in Bioethics and Health Policy**

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Education and training

Special report: Ebola

The outbreak of Ebola Virus Disease that began in West Africa in late 2013 brought discussions of global public health, bioethics, drug and vaccine trials, and disaster response into the public discourse with rare and sustained urgency. Berman Institute faculty authored opinion articles, worked with journalists to clarify key points, and collaborated with colleagues on scholarly work and public discussions.

Outreach

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.

Below are the 2014–2015 Hecht-Levi Fellows and the diverse research topics they are pursuing.

**THEODORE BAILEY, MD, JD, MA** — Ethical issues at the intersection of human genomics and the control of infectious diseases.

Dr. Bailey completed the fellowship in June 2015 and accepted a position as an attending physician at York Regional Medical Center, while continuing work on collaborative bioethics research with Berman Institute faculty members.

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

**BRIDGET PRATT, PhD, MA** — Obligations of justice of external researchers from high-income countries to health systems research participants and their communities in developing countries.

Dr. Pratt completed the fellowship in June 2015 and is in the final year of a post-doc at the University of Melbourne.

**TRAVIS RIEDER, PhD** — Moral issues related to procreating, including radically collaborative reproduction, and the relation between population and climate disruption.

In June 2015 Dr. Rieder accepted a position on the Berman Institute faculty as Assistant Director of Education Initiatives.

**KEVIN RIGGS, MD, MPH** — Healthcare cost containment, utilizing quantitative, qualitative, historical, and conceptual methodologies.

Dr. Riggs completed the fellowship in June 2015 and is in his final year of a clinical fellowship with the Division of General Internal Medicine at Johns Hopkins.

**YASHAR SAGHAI, PhD, MA** — Normative, conceptual, and policy issues in food and agriculture, public health, reproductive health, and medical research. Dr. Saghai is also Project Director of the Global Food Ethics Initiative.

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

**THEODORE BAILEY, HECHT-LEVI FELLOWS (L-R) YASHAR SAGHAI, BRIDGET PRATT, KEVIN RIGGS, STEPHANIE MORAIR.**

Photo courtesy Centers for Disease Control and Prevention
Outreach

mortality, and is crossing borders. More than half of infected persons have died. "The New health care providers that are willing to go in and serve," I think there are very special commitments that we must make ethically to the contracted Ebola in Liberia. They were given the experimental drug ZMapp and in August 2014, American news outlets began heavy coverage of the outbreak. In West Africa, healthcare workers faced threats beyond infection. Misinformation and fear, along with a history of mistrust of government in the affected countries, compounded the trials and danger facing healthcare workers. In September 2014, eight members of a health team were attacked and killed in the Guinean community of Wome.

In West Africa, health infrastructure campaigns to explain their actions, in ways leaders to allocate necessary resources to communities living with understandable fear and suspicion. JEFFREY KAHN, PhD, MPH, Deputy Director for Policy and Administration at the Berman Institute, put informed consent into account in the US to support their employees who want to volunteer in West Africa. "First and most obviously, facilitating the deployment of medical personnel to affected regions in the near future could make the difference between turning the tide of the epidemic and forfeiting the opportunity to avert regional and even global catastrophe," the editorial states.

On September 8, 2014, the Berman Institute devoted its first public seminar of the academic year to the topic: "Ethics & Ebola: Challenges for Care Givers and for Public Health." Students, clinicians and others packed the room, standing or sitting in the aisles to hear the panel discussion with Prof. Kass, Trish Perl, MD, MSc; Senior Epidemiologist for Johns Hopkins Health System, and Tim Robertson, a fourth-year doctoral student at the Johns Hopkins Bloomberg School of Public Health, who travelled to Guinea in July as a Red Cross consultant and observed the crisis response first-hand. The University also broadcast the seminar live on its Ustream channel.

When Dr. Brantly and Ms. Writebol recovered, some called for ZMapp to be quickly distributed in West Africa without clinical trials. In speaking to Bloomberg News, Prof. Kass explained the possible damage this well-intentioned drug dispersal could cause: "It’s really, really important to do nothing to harm the public health system, and the local population’s trust," Prof. Kass said. "A narrative that has been prominent in previous epidemics has been, Why are those Americans coming and testing their experimental drugs on us?"

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Berman Institute faculty member LEONARD RUBENSTEIN, JD, LLM, commented on these and other attacks on the blog of Physicians for Human Rights, writing with Susannah Sirkin, MEd, "We urge national and international leaders to allocate necessary resources to implement massive education and information campaigns to explain their actions, in ways that are socially and culturally acceptable, to communities living with understandable fear and suspicion.

"The community is broken or breaking down because of fear and lack of health infrastructure. The individuals whose informed consent we would seek to obtain don’t seem to be in a position to give it. Freedom of choice, well, there’s nothing else to offer," Prof. Kahn said.

Ethical issues surrounding quarantine were also addressed. When the government of Sierra Leone announced it would put the entire nation under strict “lockdown” for at least three days, prohibiting citizens from leaving their homes, RUTH FADEN, PhD, MPH, Dracopoulos Director of the Berman Institute, spoke out via the Bioethics Bulletin. “When people live hand to mouth, when they have no running water, when they are already food insecure and without reliable communication, any government policy of lockdown cannot ethically go forward without the logistics and resources to ensure that the basic needs of people who are already systematically disadvantaged are met,” Prof. Faden said. “Public health measures must always take the rights and interests of disadvantaged groups into account as part of a serious commitment to social justice.”

After Thomas Eric Duncan traveled from West Africa to Dallas, Texas, and became sick with Ebola in the United States suggested a travel ban. On the Bioethics Bulletin and Johns Hopkins Hub news site, Berman Institute faculty member HOLLY TAYLOR, PhD, MPH, responded, “There is no evidence that travel bans have been effective in limiting the spread of infectious disease in any previous infectious outbreak disease and it is unlikely that any such ban on Ebola-infected countries will limit the spread of Ebola. Indeed, our attention should be on how best to help Ebola-infected countries where the outbreak is raging rather than spending any human or financial resources required to enforce a travel ban.”

On June 18, 2015, three Liberian trainees attending the Berman Institute’s Global Bioethics Training Program, thanks to a grant from the National Institutes of Health, delivered a seminar on their experiences in the trenches of the Ebola outbreak. JEMEE TEGLE KARMOH, MSc BBA, EDWARD G. SMITH, MPH BSc, of the University of Liberia Pacific Institute for Research and Evaluation IRB, and NELSON DUNBAR KONTEH, MPH, KCHD, of the Liberian Ministry of Health and Social Welfare provided invaluable first-hand accounts. Mr. Smith explained how the local culture has changed — that people now avoid touching and shaking hands. He said that they are “cautiously free” of Ebola in Liberia... but again emphasized, “Everyone is very cautious.”
The Berman Institute and its faculty were quoted or mentioned in over 100 media outlets in FY 2015. Many of these reports were syndicated, and not every outlet that picked up stories is accounted for below — so the actual reach was much greater.

**BERMAN INSTITUTE IN THE NEWS**

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**Outreach**

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**THE 2015 ROBERT H. LEVI LEADERSHIP SYMPOSIUM**

**THE ETHICS AND ECONOMICS OF COMPENSATION FOR BODY PARTS**

For the 2015 Robert H. Levi Leadership Symposium, the Berman Institute partnered with the Johns Hopkins Carey Business School to hold a discussion on this intriguing and important topic at the intersection of bioethics and business economics.

The Symposium is part of the Robert H. Levi Leadership Program in Bioethics and Public Policy, established by the Levi family to honor the late Johns Hopkins trustee and Baltimore civic leader. Scholars meet to discuss issues and also participate in a public forum, through which the Berman Institute fosters ethical discussion on critical medicine and social policy issues, both among the public and those in positions of responsibility for resolving them.

The panel of renowned experts in the fields of ethics and economics addressed the problem of supply and demand: the current system of organ donation has not been able to resolve the gap between the much greater number of those in need of organs than those donating.

The panel consisted of James F. Childress, PhD, MA, Professor of Religious Studies and Public Policy at the University of Virginia, Michele Goodwin, JD, LL.M., Professor of Law at the University of California-Irvine, Alvin Roth, PhD, Professor of Economics at Stanford University and Harvard University, and Debra Satz, PhD, Professor of Ethics in Society and Senior Assistant Dean at Stanford University.

Jeffrey Kahn, PhD, MPH, the Levi Professor of Bioethics and Public Policy at the Berman Institute, moderated the discussion. Topics included shifting the organ donation model from opt-in to opt-out, and the possibility of covering more of the donor’s expenses, which can add up to thousands of dollars.

The Symposium was followed by a two-day workshop among the panelists and 15 other invited scholars and practitioners, to discuss new approaches for, and research on, addressing the critical shortage of available organs and the ethical and policy issues such approaches might face.


BERGER  ZD. "Unorthodoxy in Decision-Making Towards a Normative and Empirical Ethics." Center for Values, Ethics, and the Law in Medicine, University of Sydney, Sydney, Australia. 2015.

BERGER  ZD. "Unorthodoxy in Decision-Making Towards a Normative and Empirical Ethics." Medicine Grand Rounds, St. Vincent’s Hospital, Melbourne, Australia. 2015.

BLACK  BS. "Building an Evidence-Based Case for Adult Care Planning." Research, Outcomes & Education Care at the Alzheimer Disease Research Center Fall Meeting, Baltimore, MD. October 2014.


BOSS  R. "Perinatal Palliative Care." Grand Rounds, All Children’s Hospital, St. Petersburg, FL. September 2014.


BOSS  R. "Courageous Conversations: Filling your Toolbox with Evidence-Based Communication Skills." Bobbi Monahan Memorial Lecture, Johns Hopkins School of Medicine, Baltimore, MD. April 2015.


DEACHP  Fulkner, C. Barry, M. "Clinical issues in Medical Volunteerism." American College of Physicians Internal Medicine, Boston, MA. May 2015.


HEWITT  MO. "Caregiver’s Perspectives on Their Role as Study Partner in Dementia Research." Presented at the Gerontological Society of America 67th Annual Meeting, Washington, DC. November 2014.


KASS  NE. "Violence Prevention Strategies: Key to Fostering a Sense of Social Accountability." Medical Education X, Stanford University, San Diego, CA. October 2014.


KASS  NE. "Caregivers’ Perspectives on Their Role as Study Partner in Dementia Research." Presented at the Gerontological Society of America 67th Annual Meeting, Washington, DC. November 2014.


KENN  NE. "When is the Learning Healthcare System ‘Clinical Care’ and when is it ‘Research?’" Conference United to Easidase Integrated Healthcare, Washington, DC. July 2014.


KENN  NE. "Building an Evidence Base for Education and Care Planning." Research, Outcomes & Education Care at the Alzheimer Disease Research Center Fall Meeting, Baltimore, MD. October 2014.

KENN  NE, illustrated by 72 x 81. "Mishnah Yoma 8:5 in the Light of Contemporary Communication? The Patient’s ‘I Must Eat’ in Analysis Annual Invitational Meeting, verona, Italy. AIDS Research’s HIv Providers Meeting, Baltimore, MD. December 2014.

KENN  NE. "Expanding on Engel’s ‘Embodied Mind’ in Medical School: Key to Fostering a Sense of Social Accountability." Medical Education X, Stanford University, San Diego, CA. October 2014.

KENN  NE. "Caregivers’ Perspectives on Their Role as Study Partner in Dementia Research." Presented at the Gerontological Society of America 67th Annual Meeting, Washington, DC. November 2014.


SUGARMAN J. “Ethical Considerations in Determining, Discussing and Disposing Reassembled Removable Ethical Risks, Ethical Oversight and Research Issues” Investigating Standards of Responsibility in Medicine, Washington, DC. December 2014.


SUGARMAN J. “Ethics in International Collaborative Research.” Division of Microbiology and Infectious Diseases, National Institute of Health, Bethesda, MD. May 2015.


SUGARMAN J. “Internal Control, the Right Thing.” National Student Nurses Association’s Annual Meeting, San Antonio, TX. April 2015.


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John M. Freeman, MD, one of the Berman Institute’s founding faculty members, had a vision for such a society, and we are proud to carry on his legacy through this leadership group. Berman Society membership is achieved on an annual basis with a gift of $1,000 or more in the fiscal year. Additional programs are offered to Berman Society members in recognition of the positive impact they have on the mission of the Institute.

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The Berman Institute of Bioethics has tackled moral challenges that have no easy resolutions. As an independent, interdisciplinary center of scholarship and research, the Berman Institute stands as one of the world’s leading centers for collaborative scholarship and teaching on the ethics of clinical practice, public health and biomedical science, impacting policy in areas of tremendous humanitarian importance.

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With support from committed partners like John Wilkerson, the Berman Institute is poised to continue its mission of training, research, and scholarship — ultimately serving patients and the public through improved practices and policies that respect the rights 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 John Wilkerson 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 our Senior Director of Development Greg Bowlen, CFRE, at gbowlen@jhmi.edu or 410-614-5651.

“"As biomedical advances accelerate, there is a real need for an educational program that provides industry leaders the tools they need to navigate challenging ethical circumstances. Development of drugs and devices; work across global markets; allocation of scarce resources; attention to both individuals and populations — these are real world questions that leaders face every day. The Berman Institute is designed to provide programs that serve our executives. The critical need for a bioethics program that will lead to more ethical, safe, and respectful practice is important to all of us.”

L. John Wilkerson, PhD
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