

JOHNS HOPKINS

BERMAN INSTITUTE of BIOETHICS

# 2014 2015 ANNUAL REPORT

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2



- Global Food Ethics Initiative
- Bloomberg Distinguished Associate Professor 4 of Ethics and Global Food & Agriculture
- A Blueprint for 21st Century Nursing Ethics 5
  - Fellowship Reunions 6

#### **RESEARCH AND SCHOLARSHIP**

- Ethics Training for Future Physicians: 8 The Romanell Report
- Huntington's Disease and the Impact 9 of Genetic Testing
- Clinician Respect and Adherence in Patients 10 with Sickle Cell Disease
  - Selected Grants 11
  - Selected Publications 12

#### **EDUCATION AND TRAINING**

Bioethics at Homewood:	16
The Undergraduate Minor and HUBS	

- Master of Bioethics 16
- PhD in Bioethics and Health Policy 16
- Certificate in Bioethics and Public Health Policy 16
- Berman Institute Bioethics Intensive (BI<sup>2</sup>) Courses 17
  - Intensive Global Bioethics Training Program 17
  - Hecht-Levi Fellowship Program in Bioethics 18

### OUTREACH

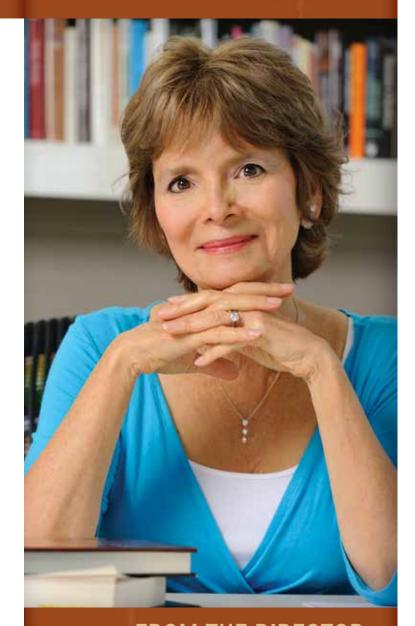
Special Report: Ebola	19
Berman Institute In The News	22

- The 2015 Robert H. Levi Leadership Symposium 23
  - The Bioethics Bulletin: Top Stories 23
    - Selected Presentations 24

### OUR COMMUNITY

- Faculty 28
- Hecht-Levi Fellows 28
- Doctoral Candidates 28
  - Staff 29
- Honors, Awards, and Promotions 29
  - National Advisory Board 30
  - Philanthropic Supporters 30





## FROM THE DIRECTOR

hank 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 ANDREAS C. DRACOPOULOS DIRECTOR, PHILIP FRANKLIN WAGLEY PROFESSOR OF BIOMEDICAL ETHICS



# GLOBAL FOOD ETHICS INITIATIVE



"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 middleincome 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."

The 7 by 5 Agenda is a collaboration between faculty of the Berman Institute, the Johns Hopkins Bloomberg School of Public Health, and the Johns Hopkins Paul H. Nitze School of Advanced International Studies, and was funded by the Stavros Niarchos Foundation.

The full report and an executive summary are available on the Berman Institute website, www.bioethicsinstitute.org/globalfoodethics.





### BLOOMBERG DISTINGUISHED ASSOCIATE PROFESSOR OF ETHICS AND GLOBAL FOOD & AGRICULTURE

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.

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.

# **A RI HEPRIN FLIK 71**S1 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





CYNDA HYLTON RUSHTON

"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."



HIGHLIGHTS



### 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.

The Berman Institute is privileged to have the opportunity to train early-career

# **FELLOWSHIP** RFUNIONS

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, ScD, 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 to the program's success.

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 210 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, LLM, Director of the Public Law and Policy Program at Arizona State University; S. Matthew Liao, DPhil, Director of the Master's Program in Bioethics and Clinical Associate Professor in the Center for Bioethics at New York University; Anne Drapkin 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'Connor, 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, ScD, 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 word '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.





"Our alumni are deeply committed to expanding bioethics teaching, research, and service in Africa."

## 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 DeCamp 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 DeCamp 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 Decamp 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.



JOSEPH CARRESE

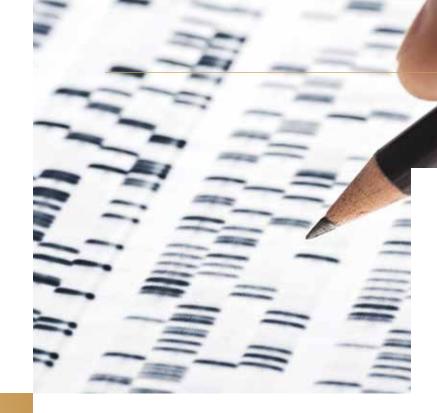
"It is crucial to have skilled and engaged faculty to teach, mentor, and assess our learners, so focusing on faculty should be a top priority," says Prof. Carrese.

GAIL GELLER

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 definitive. Huntington's is also terminal, which combined with the accuracy of the test makes it a

touchstone case for the philosophical debates surrounding genetic testing: would you want to know how you are likely to die, and when?

Participants in the 1986 trial at Johns Hopkins made the choice to be informed about their risk, and now a new study at the Berman Institute is reaching out to those participants and their families to learn firsthand how it has affected their lives over time.



DEBRA MATHEWS



JASON BRANDT

Debra Mathews, PhD, MA, faculty member and Assistant Director for Science Programs at the Berman Institute, is collaborating with Jason Brandt, PhD, a Johns Hopkins Professor of Psychiatry and Behavioral Sciences who led the original genetic testing trial. Berman Institute research staff members Juli Bollinger, MS, and Rachel Dvoskin, PhD, are also members of the project team.

"The people who participated in

this trial have more experience than anyone else in the world in living with these kinds of dramatic genetic test results. By talking with them and their families, we hope to learn about how individuals' feelings about, and understanding of, their testing experience has changed as they have progressed through life's stages, and what lessons might be taken from their experience for future testing programs," Prof. Mathews says.

The original trial at Johns Hopkins influenced subsequent thought and guidelines on genetic testing and 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 for Huntington's, and two study partners. Approximately 30 more interviews are planned for this phase of the study.

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.



JULI BOLLINGER



RACHEL DVOSKIN

**CLINICIAN RESPECT** AND ADHERENCE IN PATIENTS WITH SICKLE CELL DISEASE



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



CARLTON HAYWOOD JR



MARY CATHERINE BEACH

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. Havwood 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."

# DEFRING HAL



SFI FCTFD

and systems research

healthcare

NIH/National Institute of Drug Abuse. February 2015 - January 2020. \$992,648. This K24 award allows time for mentoring junior investigators and conducting significant original research aimed at improving communication and relationships between clinicians and patients struggling with addiction.

BOSS R. "The Big Picture Project: Communication and Decision-making for Chronically Critically III Infants". Sojourns Scholar Leadership Award, Cambia Health Foundation October 2014 - October 2016 \$179.431 This project is a three-part intervention to promote longitudinal communication and decision-making for infants with prolonged hospitalizations due to complex congenital heart disease.

BOSS R. "Stavros Niarchos Foundation Fellowship in Pediatric Palliative Care". July 2015 - June 2018. \$616,452 This project is a novel two-year fellowship for pediatricians who seek to be clinician-scholars at the intersection of pediatric palliative care and bioethics. Year 1 fellows will complete their clinical palliative care training as approved by the ACGME; year 2 fellows will conduct empirical research regarding the ethical complexities of caring for children with life-limiting illnesses.

GRANTS



ALI J. "Ethics of Health Policy and Systems Research: Scoping Study". World Health Organization/Alliance for Health Policy & Systems Research. March 2015 - August 2015, \$23,747. This grant provides support for a systematic review of ethics issues and auidance relevant to the oversight of international health policy

BEACH MC. "Moral Conceptions of Respect and Dignity". Greenwall Foundation. July 2014 - June 2016. \$65,518. The goal of this project is to develop a more robust theoretical understanding of respect and dignity that would improve the quality, equity, and morality of

#### BEACH MC. "Communication Quality and Patient Outcomes in HIV/AIDS and Substance Abuse".

DECAMP M. "Patient-Centered Health Reform: Designing Engagement Interventions for ACOs" Agency for Healthcare Research and Quality K08 Award. September 2014 - Sept 2018. \$606.161. This project seeks to understand how patients — especially individuals who are older, experience poverty, or live in urban settings - want to be involved in Accountable Care Organizations (ACOs) governance and decisionmaking and then design new ways to make this possible

KASS N, FADEN R. "Demonstrating Respect and Acceptable Consent Strategies: What Matters to

Patients in PCOR?". Patient-Centered Outcomes Research Institute, November 2014 - October 2017, \$1.678,249 The purpose of this project is to seek patients' views about traditional vs. streamlined informed consent options for research studies comparing different types of treatments, all of which are known to be effective, including to see if patients find certain approaches more respectful than others.

MATHEWS DJH. "Families at Risk: Long-term Impact of Huntington's Presymptomatic Genetic Testing". NIH/National Human Genome Research Institute August 2014 - June 2019. \$1,329,412. This R01 project is designed to improve our understanding of the impact of presymptomatic genetic testing for Huntington's disease on families over time.

MATHEWS DJH. "Ethics and Policy in Synthetic Biology: The Development and Testing of a Massive Open Online Course". JH SOM Institute for Excellence in Education, 2014 International Faculty Education Scholar Award. July 2014 - December 2015. \$50,000. This project has a two-fold objective: first, to develop a MOOC on the ethics and policy issues related to synthetic biology: and second, to test different assessment methods within the MOOC environment.

MERRITT M. "Assessing Social Value in Economic Evaluation to Scale up Novel TB Drug Regimens". NIH. July 2014 - June 2015, \$302,298. The major goal of this R56 one-year Bridge Award project is to establish proof of concept for an innovative methodology to incorporate norms of social justice into traditional economic evaluation for the scale-up of new public health interventions, using novel drug regimens for tuberculosis (TB) as a paradiam case.

# SELECTED PUBLICATIONS

#### JOURNAL ARTICLES

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## EDUCATION AND TRAINING PROGRAMS

he 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.



#### 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.

#### MASTER OF BIOETHICS

The goal of this innovative, interdisciplinary, and cross-divisional MBE program is to prepare students from diverse individual and professional backgrounds for the bioethics challenges of professional and civic life.

Led by Travis Reider, PhD, Assistant Director of Education Initiatives, along with Elice García-Baca, Senior Academic Program Coordinator, the program is a partnership with the Johns Hopkins Bloomberg School of Public Health. Courses are taught by Berman Institute faculty in both online and in-person formats. In 2014-2015, faculty and staff successfully navigated the processes of institutional and state approvals for the program, and worked on building the curriculum. The first cohort of students begins class in September 2015.

#### PHD IN BIOETHICS AND 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 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 how they apply to public policy debates. To date 19 students have completed the certificate program.

#### BERMAN INSTITUTE BIOETHICS INTENSIVE (BI<sup>2</sup>) COURSES

Now in its third year, the Bl<sup>2</sup> Program provides an engaging opportunity for health professionals, students, 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 are held during the two-week intersession between spring and summer semesters in June, and examine both theoretical and applied aspects of bioethics. In 2015 the Berman Institute offered the courses Foundations of Bioethics; Ethics of Human Subject Research: US and International Perspectives; and Prison Health.

#### 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. 19).

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 meetings 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.







### EDUCATION AND TRAINING



THEODORE BAILEY

#### 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 MORAIN**, 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.

HECHT-LEVI FELLOWS (L-R) YASHAR SAGHAI, BRIDGET PRATT, KEVIN RIGGS, STEPHANIE MORAIN.





OUTREACH



OUTREACH



NANCY KASS, ScD, Deputy Director for Public Health at the Berman Institute, explained the crisis succinctly in the opening lines of her November 2014 opinion in Annals of Internal Medicine: "Ebola Virus Disease has ignited some of our worst fears in a globalized world. The disease spreads quickly, with high mortality, and is crossing borders. More than half of infected persons have died."

In August 2014, American news outlets began heavy coverage of the outbreak when two American volunteer aid workers, Kent Brantly and Nancy Writebol, contracted Ebola in Liberia. They were given the experimental drug ZMapp and airlifted to the United States.

"I think there are very special commitments that we must make ethically to the health care providers that are willing to go in and serve," Prof. Kass told The New York Times, when asked if the Americans received special treatment.



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 wellintentioned 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?"

JEFFREY KAHN, PhD, MPH, Deputy Director for Policy and Administration at the Berman Institute, put informed consent for a high-risk drug in context during an interview with NPR's All Things Considered. "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.

On September 8, 2014, the Berman Institute devoted its first public seminar of the academic vear 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 Roberton, 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.



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.

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."

CYNDA HYLTON RUSHTON, PhD, RN, FAAN, the Bunting Professor of Clinical Ethics at the Berman Institute and the Johns Hopkins School of Nursing, addressed the perspective of healthcare workers on the Berman Institute's Bioethics Bulletin blog. "Without compromise to patients, clinician safety must be a priority. Nurses have an ethical mandate to care for all people regardless of their diagnosis or other unique characteristics," she wrote. "Nurses and other health care workers need to be reassured that their current and future health will be protected by clarifying whether they will have access to investigational drugs, protective devices, and compensation if they become infected during the performance of their work duties."

In a guest editorial for PLOS Medicine, Berman Institute faculty member MARIA MERRITT, PhD, BA, writing with Michelle Mello, PhD, JD, of Stanford Law School and Scott Halpern, MD, PhD, of the University of Pennsylvania, focused on the need for medical institutions 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.

**PROF. KASS** joined the debate over the use of placebo control in trials for an Ebola vaccine and other therapies in an opinion for The New York Times' Room for Debate forum. Writing with Steven Goodman, MD, MHS, PhD, she stated: "Ethics is not just figuring out which side poses better arguments; often it's best to find a third way. Given the breadth and deadly nature of the current Ebola outbreak, and unknowns about treatments, an 'adaptive approach' seems most appropriate.





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 TEGLI KARMOH, MSc BBA, EDWARD G, SMITH, MPhil BSc, of the University of Liberia Pacific Institute for Research and Evaluation IRB, and NELSON DUNBAR KONTEH. MPH, ICHD, 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."

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 some 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 Ebolainfected 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."



## **BERMAN INSTITUTE** IN THE NEWS

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.

> ABC's Good Morning America ABC News.com **ACP** Internist Advance Healthcare Network for Nurses Agence France-Presse AOL.com The Asian Age The Atlantic **Baltimore** Jewish Times **Baltimore Sun BioCentury This Week Bioethics Forum Blog** Bloomberg Businessweek **Bloomberg News** The BMJ blog BuzzFeed News **CBC** News online CBS - Baltimore WJZ CBS News.com Chicago Tribune The Chronicle of Higher Education **Climate Wire Clinical Advisor** The Conversation The Daily Cardinal **Democracy Now**

Doctor's Lounge

Ehospice.com



**EHS** Today **Fierce Healthcare** Healio

**Health Leaders Media** 

**Health News Review** 

**Health** Canal HealthDay News

Health Populi

Mother Jones

**Huffington Post** Huff Post Impact blog

Human Capital Blog Insurance News Net

Isthmus

Forbes.com Johns Hopkins

Gazette

Johns Hopkins Hub Johns Hopkins Magazine

Johns Hopkins Medicine Magazine

Johns Hopkins Newsletter

> Johns Hopkins Nursing Magazine

Johns Hopkins Public Health Magazine

Kaiser Health News Left Brain/Right Brain blog

McClatchy DC Medical Economics Mediapost.com Medscape Medical News Military Times Modern Healthcare

Marketplace

MSNBC's News Nation with Tamron Hall MSNBC's Ronan Farrow Daily

The New York Times

Nature News

Newsweek

NPR's All Things Considered

NPR's Goats and Soda blog

NPR's Shots blog NPR's Morning Edition

Nursezone

Palliativeinpractice.org

Parenting.com

**Pharmacy Choice** Politico

Psychology of Medicine blog

The Root

Scientific American

Scienceblogs.com Science Daily.com Scripps Stateline SVT (Swedish Television) US Council on Foreign Relations' Must Reads of the Week Vanity Fair Voice of America Wall Street Journal Washington Post WBUR's Here & Now WEAA's Marc Steiner WNPR's Where We Live WYPR's Midday with

## FVFRYTHI FOR SALE?

THE BIOET

TOP STORIES



Problems With How We Talk About Female Scientists Theo Schall, MSW

Is It Right to Have a Baby When You Could Adopt? (Q&A) Building Research Ethics Capacity in Africa Travis Rieder, PhD Leah Ramsay

Jeffrey Kahn, PhD, MPH; Ruth Faden, PhD, MPH; Theo Schall, MSW What Keeps Nurses Up At Night? (Video)

Cynda Rushton, PhD, RN, FAAN

Force-Feeding Detainees On Hunger Strike (Q&A) Cynda Rushton, PhD, RN, FAAN; Leonard Rubenstein, JD, LLM; Leah Ramsay

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.

Los Angeles Times

Time

USA Today

Show

WSJ Live

Morning

The Verge Vox

Wired

Dan Rodricks

## WHYY's The Pulse WYPR's Maryland

Nature Outlook

Hospitals and Health **Networks Daily** 

#### THE 2015 ROBERT H. LEVI LEADERSHIP SYMPOSIUM THE ETHICS AND ECONOMICS OF COMPENSATION FOR BODY PARTS

The panel consisted of James F. Childress, PhD, MA, Professor of Religious Studies and Public Policy at the University of Virginia; Michele Goodwin, JD, LLM, 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

Ebola Patient's Family Quarantined

Replacing Faulty Mitochondria Valeriya Gaysinskaya, MS

Don't (Always) Believe the Stem Cell Hype Alan Regenberg, MBE

Physician Payment Sunshine Act Stephanie Morain, PhD, MPH

Can ACOs Influence Referrals Ethically? Matthew DeCamp, MD, PhD



OUTREACH

## SELECTEL PRESENTATIONS

ALI J. "Promoting Research While Respecting Privacy: The Promise and Challenge of Using Patient Healthcare Data in Research". 5th International Summit on the Future of Health Privacy, Georgetown University Law Center, Washington, DC. June 2015.

ALI J. "Strategies for Teaching and Learning". JHU Fogarty African Bioethics Training Program Alumni Reunion, Johns Hopkins University, Baltimore, MD. December 2014.

ALI J. "Evaluating the Impact of Fogarty Programs for Africa". JHU Fogarty African Bioethics Training Program Alumni Reunion, Johns Hopkins University, Baltimore, MD. December 2014.

ALL J. "Lessons Learned about Evaluating Ethics Education Programs". Fogarty International Research Ethics Training Program Network Meeting, Fogarty International Center, National Institutes of Health, Bethesda MD October 2014

ALI J. "Equipoise, Health Systems Research & Cluster Randomized Trials: A Conceptual Exploration". Ethics & Health Systems Research in Low- and Middle-Income Countries (Symposium), Brocher Foundation, Geneva, Switzerland, September 2014.

BEACH MC. "Clinician Emotions and Values: Risks and Benefits of Relationship-Centered Care". Relationship-Centered Health Law and Ethics Invitational Conference. Wake Forest University School of Law, Winston Salem, NC. October 2014

BEACH MC. "Enhancing Communication and HIV Outcomes: Lessons from the ECHO Study". Center for AIDS Research's HIV Providers Meeting, Baltimore, MD. October 2014.

BEACH MC. "Developing a Scholarly Concentrations Program", Bezmialem University School of Medicine. Istanbul, Turkey. January 2015.

BEACH MC. "International Collaborative Research on the Impact of Empathy". Verona Network on Sequence Analysis Annual Invitational Meeting, Verona, Italy, February 2015.

BERGER ZD. "Expanding on Engel". Medicine X, Stanford University School of Medicine, Palo Alto, CA, 2014.

BERGER ZD. "Is Autonomy Dependent on Communication? The Patient's "I Must Fat" in Mishnah Yoma 8:5 in the Light of Contemporary Bioethics" 46th Annual Conference of the Association of Jewish Studies, Baltimore, MD. December 2014.

BERGER ZD. "Ethics, Emotions, Effectiveness, and Efficiency: A Clinically Useful Introduction to Doctor-Patient Communication" Baltimore City Medical Society, Baltimore, MD, 2014.

BERGER 7D. "Evidence-Based Practice Guidelines and Shared Decision Making: Conflicting or Complementary Strategies for "Doing the Right Thing" in Health Care?" Society of General Internal Medicine 38th Annual Meeting, Toronto, Canada. April 2015.

BERGER ZD. "Uncertainty 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. "Uncertainty in Decision Making: Towards a Normative and Empirical Ethics". Medicine Grand Rounds, Dandenong Hospital, Melbourne, Australia, 2015

BLACK BS. "Building an Evidence Base for Education on Advance Care Planning". Outreach. Recruitment & Education Core at the Alzheimer Disease Research Centers Fall Meeting, Baltimore, MD. October 2014.

BLACK B, TAYLOR HA, Karlawish J. "The Role of Study Partners in Dementia Research and its Implications for IRBs" Advancing in Ethical Research Annual Meeting 2014. Public Responsibility in Medicine and Research. Baltimore, MD, December 2014.

#### BLACK B, TAYLOR HA, RABINS P, Karlawish J.

"Caregivers' Perspectives on Their Role as Study Partner in Dementia Research". American Society of Bioethics & Humanities Annual Meeting 2014, San Diego CA October 2014

BLACK B. TAYLOR HA. RABINS P. Karlawish J. "Caregivers' Perspectives on Their Role as Study Partner in Dementia Research". Presented at the Gerontological Society of America's 67th Annual Meeting, Washington, DC. November 2014.

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

BOSS R. "Neonatal MRI after Whole Body Hypothermia, Ethical Considerations". Children's National Medical Center, Washington, DC. October 2014.

BOSS R. "Decision-Making Consensus in the NICU: What Does Parent-Clinician Collaboration Actually Look Like?" American Academy of Hospice and Palliative Medicine 2015 Annual Meeting, Philadelphia, PA. February 2015

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

CARRESE J. "Bioethics and Professionalism Education in Medical School: Key to Fostering a Sense of Social Accountability". Medical Education: Emerging Needs and Trends, World Health Summit, Berlin, Germany October 2014

CARRESE J. "Operationalizing Professionalism: A Direct Observation Study of Treating Patients and Family Members with Respect and Dignity in the Intensive Care Unit" 3rd Annual Meeting of the Academy for Professionalism in Healthcare, Louisville, KY. May 2015.

DECAMP M, Pullen A, Gaglani S, Kenerson J, Todd P. "Implementing Technology to Advance Medical Knowledge Across Borders". Association of American Medical Colleges 2014 Annual Meeting, Chicago, IL. November 2014

DECAMP M, Leonard C, Barry M. "Ethical Issues in Medical Volunteerism". American College of Physicians Internal Medicine, Boston, MA, May 2015.

DECAMP M. "Ethics, the IRB, and Use of Social Media in Clinical Research". Association for Research in Vision and Ophthalmology 2015 Annual Meeting, Denver, CO. May 2015.

DECAMP M. "Ethical Challenges of Accountable Care". Zurick-Davis Learning from Leaders - National Online Educational Webinar. April 2015.

DECAMP M. "Meaningfully Engaging Patients in ACO Governance". American College of Healthcare Trustees, Washington, DC. September 2015.

FABI R. "Ethical and Policy Implications of State-Level Variation in Access to Publicly-Funded Prenatal Care for Undocumented Immigrants", 21st Annual National Research Service Award Trainees Conference Minneapolis, MN, June 2015.

### FABI R, KASS N, MORAIN S, HALLEZ K, FADEN R.

"Alternative Consent Models for Comparative Effectiveness Research: Patient Perspectives", 21st Annual National Research Service Award Trainees Conference, Minneapolis, MN, June 2015.

#### FABI R. KASS N. MORAIN S. HALLEZ K. FADEN R.

"Alternative Consent Models for Comparative Effectiveness Research: Patient Perspectives' Academy Health Annual Research Meeting, Minneapolis, MN, June 2015.

> FADEN R. "Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science". J. Rhodes Haverty Lecture, Georgia State University, Atlanta, GA. October 2014

FADEN R. "Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science". University of Minnesota, Minneapolis, MN, November 2014

FADEN R. "Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science" Distinguished Class of 1960s Speaker, Williams College, Williamstown, MA. April 2015.

FADEN R. "What is a Learning Healthcare System?" Healthcare Lecture Series, Broadmead Community, Cockeysville, MD. April 2015.

FADEN R. "Sustainable Food Politics and Ethics". 4th Annual Stavros Niarchos Foundation International Conference on Philanthropy, Athens, Greece. June 2015. GELLER G. "The Past. Present and Future of the Ethical, Legal, and Social Implications (ELSI) Program of the National Human Genome Research Institute" Humanities and Social Science Department. The Wellcome Trust, London, England. June 2015.

GELLER G. "'Training for Certainty' Revisited: The (Pre) Medical Socialization Process and the Risks to Moral Character Development", Johns Hopkins University Department of Sociology, Baltimore, MD. April 2015.

GELLER G. "The Role of Research Institutions in Promoting Trustworthiness: Community Relationships and Stewardship". Provost's Forum: Creating a Culture of Excellence and Trustworthiness in Higher Education. University of California at Davis, Davis, CA. November 2014

GELLER G. "The Role of Genomics in the Prevention and Treatment of Infectious Disease: Ethical, Legal & Social Implications for Public Health and Clinical Practice". American Society for Bioethics & Humanities. San Diego, CA. October 2014.

GELLER G. RUSHTON CH. Moral Distress Seminar Ethics for Lunch, Johns Hopkins Bayview Medical Center, Baltimore, MD. March 2015.

HAYWOOD C. Congressional Briefing on Sickle Cell Disease. American Society of Hematology and the Sickle Cell Disease Association of America, in cooperation with the Sickle Cell Disease Congressional Caucus, Washington, DC. September 2014.

HAYWOOD C. "Patient-Physician Relationship: Determinants for Compliance, and Physician Attitudes toward Patients with Sickle Cell Disease" 2nd National Canadian Conference on Sickle Cell Disease. Toronto. Ontario. September 2014.

HENRY LM. "Minor Consent: A Survey of State Laws". Examining Mature Minor Consent for Participation in HIV Prevention Research Conference co-sponsored by the National Institute of Allergy and Infectious Disease (NIAID) National Institute of Mental Health (NIMH) and National Institute of Child Health and Development (NICHD), Rockville, MD. June 2015.

HENRY LM. "Just Compensation: A No-Fault Proposal for Research-Related Injuries". Trans-NIH Bioethics Advisory Committee (T-NBC), National Institutes of Health, Bethesda, MD. January 2015.

HENRY LM. "The Law and Ethics of Digital Experimentation". American Health Lawyers Association and Drexel School of Law, Philadelphia, PA. October 2014

HENRY LM. "The Ethics of Digital Experimentation". The Conference on Digital Experimentation, MIT, Boston, MA. October 2014.

HUGHES M. "Ethical Dilemmas in Aging in Place: Avoiding Perils, Pitfalls, While Supporting Preferences" Maryland Gerontological Association, Columbia, MD. September 2014.

HUGHES M. "Assessing Decision Making Capacity" Geriatrics-Palliative Care Grand Rounds, Veterans Affairs Medical Center, Washington, DC. September 2014.

HUGHES M. "The Ethical Dilemmas of the Employed Physician". Maryland State Medical Society Ethics Forum Baltimore MD October 2014

HUGHES M. "Ethical Dilemmas in Aging in Place: Avoiding Perils, Pitfalls, While Supporting Preferences" Eastern Shore Area Health Education Center, Easton, MD. March 2015

HUGHES M. "The Who, What, Where, When, How, and Why of Goals of Care Discussions". Sibley Memorial Hospital Ethics Grand Rounds, Washington, DC. March 2015

HUGHES M. Venokvan G. Sulmasy DP. Kub J. Johnson J, Lehmann L, Astrow A, Clawson L, TERRY P, Lee MC, Heinze K, NOLAN MT. "Effect of the TAILORED ICD Facilitated Discussion on Patient and Family Decision-Making about CIED Deactivation at the End of Life: A Pilot Randomized Controlled Trial". Society of General Internal Medicine Annual Meeting Poster Presentation, Toronto, Canada, April 2015.

JAMAL L. "Barriers to Clinical Utility when Using Genomic Testing in Patients with Non-European Ancestry" Conference on Translation in Healthcare - Exploring the Impact of Emerging Technologies, Oxford, England. June 2015.

KAHN J. "Sustainable Public Health Ethics Infrastructure and Guidance Following Epidemics". 4th Annual Stavros Niarchos Foundation International Conference on Philanthropy, Athens, Greece. June 2015.

KAHN J. "Science and Ethics of Genetically Engineered Human DNA". House Subcommittee on Research and Technology, Washington, DC. June 2015.

KAHN J. "Fear and Confusion in the Time of Ebola: Ethics, Communication, and Public Perception". Johns Hopkins University Alumni Weekend. Baltimore, MD, April 2015.

KAHN J. "Challenges for the Role of Law and Policy in Clinical Research — a Global Perspective". International Conference on Justice in Clinical Research, Nagova University, Nagoya, Japan, March 2015.

KAHN J. "Ethics and Citizen Science". NIH Workshop on Citizen Science, Bethesda, MD. January 2015. KAHN J. "Ethics and Biotechnology". National

Defense University, Washington, DC. January 2015.

KAHN J. "Ethics and Penile Transplants". Intimacy after Injury Conference, Washington, DC. December 2014.

KAHN J. "A Critical Conversation: Ethics and the Ebola Response". Johns Hopkins Bloomberg School of Public Health Dean's Alumni Reception, Washington, DC. November 2014

KAHN J. "Animal Research Ethics: Maternal Deprivation Studies on Infant Monkeys". University of Wisconsin, Madison, WI. October 2014.

KAHN J. "Chimpanzee Research: Ethics and Policy" University of Wisconsin, Madison, WI, October 2014.

KASS NE. "The SUPPORT Trial and Ethical Issues Raised by Comparative Effectiveness Trials". Seattle, WA. July 2014.

KASS NE. "When is the Learning Healthcare System 'Clinical Care' and When is it 'Research'?" Conference United for Evidence-based Healthcare, Washington, DC. July 2014.

KASSINE, HYDER A. PRATTIB, ALL J. "Ethics of Cluster Trials in Health Systems Research". Ethics of Health Systems Research in Low and Middle Income Countries. Geneva, Switzerland, September 2014.

KASS NE. "Training Leadership for Ethical Review of Research". Fogarty Programs Network Meeting, Bethesda, MD. October 2014.

KASS NE. "Introduction to Ethical Principles for Research: Guidelines to Protect Research Participants and Enhance Partnerships". Skill Building Workshop for Community Advisory Boards and Researchers. Johns Hopkins School of Nursing, Baltimore, MD. November 2014.

KASS NE. "Global Research Ethics: Challenges and Strategies - Past, Present, and Future". Public Responsibility in Medicine & Research, Baltimore, MD. December 2014

KASS NE. "Issues Related to the HIV/AIDS Epidemic and the Populations Affected" Public Responsibility in Medicine & Research, Baltimore, MD, December 2014.

KASS NE. "Ethics in the Time of Ebola" Public Responsibility in Medicine & Research, Baltimore, MD. December 2014.

KASS NE. "Ethical Issues Associated with Research in the Context of a Public Health Emergency". Presidential Commission for the Study of Bioethical Issues, Washington, DC. February 2015.

KASS NE. "Ethics. Consent and Comparative Effectiveness Research". Johns Hopkins Medicine IRB Retreat, Baltimore, MD. February 2015.

KASS NE. "Ethics for a Learning Health Care System: The 'Common Purpose' Framework". Texas Medical Center Distinguished Lecture Series Houston TX March 2015.

KRUBINER CB. "Advancing Research on Pregnancy and HIV: Ethics and Engagement". American Society for Bioethics and Humanities, San Diego, CA. October 2014.

KRUBINER CB. "Assessing How Strengthening Health Services in LMIC Can Empower Nurses and Midwives: Preliminary Findings from the Global Landscape" Institute of Medicine: Empowering Women and Strengthening Health Systems and Services through Investing in Nursing and Midwifery, Bellagio Center, Bellagio, Italy. September 2014.

LEWIS MH. "Changing Environment from the State Perspective", 2014 Newborn Screening Translational Research Network Meeting, Bethesda, MD. September 2014

OUTREACH

#### SELECTED PRESENTATIONS (CONT.)

LEWIS MH. "Malpractice Issues in Return of Genomics Results". Clinical Sequencing Exploratory Research (CSER) Consortium Meeting, Bethesda, MD. October 2014.

LEWIS MH. "Counteracting 'Lockdown'". Application of Law to Public Health Information Workshop, Public Health Law Conference, Atlanta, GA. October 2014.

LEWIS MH. "Newborn Screening: Policies for the Retention and Use of Residual Dried Bloodspots". Public Health Law Conference, Atlanta, GA. October 2014.

LEWIS MH. "The Changing Legal Facets of Newborn Screening". Public Health Law Conference, Atlanta. GA. October 2014.

LEWIS MH. "Introduction to Newborn Blood Spot Issues and Discussion of H.R. 1281". Secretary's Advisory Committee on Human Research Protections, Rockville, MD. March 2015.

LEWIS MH. "Potential Implications of Defining De-identified Residual Newborn Screening Dried Blood Samples as Human Subjects Research" Secretary's Advisory Committee on Human Research Protections, Washington, DC. March 2015.

MATHEWS DJH. "Long-Term Impact of Presymptomatic Genetic Testing for HD". Presidential Commission for the Study of Bioethical Issues Bi-weekly Bioethics Series. Washington, DC. August 2014.

MATHEWS DJH. "Long-Term Impact of Presymptomatic Genetic Testing for HD". Maryland Genetics, Epidemiology, and Medicine Training Program Seminar Series, Baltimore, MD, October 2014.

MATHEWS DJH. "Articulating the Goals and Assessing the Impact of Bioethics Research: A Report from the ABPD Working Group". American Society for Bioethics and Humanities Annual Meeting, San Diego, CA. October 2014.

MATHEWS DJH. "Ethics Integration across Scientific Training". American Society for Bioethics and Humanities Annual Meeting, San Diego, CA. November 2014.

MATHEWS DJH. "Sc2.0 Statement of Ethics and Governance" Macquarie University Centre for Agency, Values and Ethics Synthetic Biology Workshop, Sydney, Australia. December 2014.

MATHEWS DJH. "Personalized Medicine". TEDxBaltimore, Baltimore, MD, January 2015.

MATHEWS DJH. "Articulating the Goals and Assessing the Impact of Bioethics Research". NIH Coordinating Committee on Bioethics Research and Training, Bethesda MD April 2015

MATHEWS DJH. "Human Germline Genetic Modification". Institute for Genetic Medicine Journal Club, Baltimore, MD. April 2015.

MATHEWS DJH. "Ethical Issues in Genetics and Genomics". Fogarty and Global Berman Institute Trainees Seminar, Baltimore, MD, June 2015.

MATHEWS DJH. "Genetic and Genomic Services: Challenges for Translation". American College of Medical Genetics, A Dialogue: Addressing and Paying for Genetic Services in Integrated Delivery Systems. Bethesda, MD, June 2015.

MERRITT MW, Jacobson J, Tanner M, Stone C, Tediosi F. "Impacts of Investments to Reach Elimination of Onchocerciasis, Lymphatic Filariasis, and Human African Trypanosomiasis". American Society of Tropical Medicine and Hygiene Annual Meeting, New Orleans, LA. November 2014.

MERRITT M. PAUL A. TAYLOR H. "A Responsible Exit: Using Theories of Justice to Inform Donor Practices of Transitioning Health Programs to In-Country Partners". American Public Health Association Annual Meeting, New Orleans, LA, November 2014.

MERRITT M, Sripad P, Abuya T, Ozawa S, Warren C. "Exploring Trust in Maternity Care: A Qualitative Study in Peri-Urban Kenya" 3rd Global Symposium on Health Systems Research, Cape Town, South Africa. September - October 2014

RABINS PV. "Update on Alzheimer's Disease", 16th Annual Stein Lecture on Alzheimer's Disease, The Jewish Home Lifecare Sarah Neuman Center, Mamaroneck, NY. October 2014.

RIEDER T, SHAPIRO MC. "Chronic Critical Illness -How Does our Evaluation of a Child's Best Interest Change?" Berman Institute National Advisory Board Spring Meeting, Baltimore, MD, May 2015.

RIEDER T. "Toward a Small Family Ethic". Sigma Delta Epsilon Graduate Women in Science Washington, DC Chapter, Washington, DC. May 2015.

**RIEDER T.** "Saving the World through Making Fewer People". St. Albans High School, Washington, DC. January 2015.

RIEDER T. "It's Time to Have 'The Talk': The Case for Combatting Climate Disruption through Population Reduction". Southern Illinois University Edwardsville, Department of Philosophy Lecture Series. Edwardsville, IL, November 2014.

ROTHENBERG K. BUSH L. "Clinical Genomics in Play-The Drama of DNA". Festival of Genomics. Frontline Genomics, Boston, MA. June 2015.

ROTHENBERG K. "All the World's a Stage: Exploring Bioethical Challenges with Theatre". Cultural Programs of the National Academy of Sciences, Performing Science, DC Art Science Evening Rendezvous, Washington, DC, June 2015.

ROTHENBERG K, Bush L. "Bioethics in Play: The Drama of DNA". Berman Institute of Bioethics Intensive Johns Hopkins University, Baltimore, MD, June 2015.

RUBENSTEIN LS. "Protection of Health in Armed Conflict". Defenders of Medical Neutrality Meeting, Beirut, Lebanon. August 2014.

RUBENSTEIN LS. "Health Under Attack in Syria and Bevond: What Is Happening and What Can Be Done" Center for Public Health and Human Rights, Baltimore, MD. October 2014.

RUBENSTEIN LS. "Preservation of Mental Health Care in Times of Conflict". The United Nations NGO Committee on Mental Health, New York, NY. October 2014.

RUBENSTEIN LS. "Violence and Health Security". UPMC Center for Health Security, Baltimore, MD. October 2014.

**RUBENSTEIN LS.** "Afghanistan: Conflict and Protection of the Medical Mission". Agency Coordinating Body for Afghan Relief, Kabul, Afghanistan. December 2014.

RUBENSTEIN LS. "Risking Lives to Save Lives: The Ordeal of Syrian Healthcare Professionals". 4th Annual National Conference of the Syrian American Medical Society Scottsdale AZ February 2015

RUBENSTEIN LS. "The Syria Health Crisis and Response: A 4th Year Report Card: Medical Care Under Assault". The Royal Society of Medicine and London School of Tropical Medicine, London, England. March 2015.

**RUBENSTEIN LS.** "Protection of Health Workers in Conflict". 6th Annual Conference of the Consortium of Universities in Global Health, Boston, MA. March 2015.

RUBENSTEIN LS. "Global Action to Protect Health Care in Emergencies". Health and Well-being in Emergencies. sponsored by the Netherlands. New Zealand, Iraq, Liberia. Lebanon, Norway, Mozambigue, Sierra Leone, UAE. US, ILO, UNFPA, UNHCR, and the Safeguarding Health in Conflict Coalition, Geneva, Switzerland. May 2015.

RUBENSTEIN LS. "Delivering Health Care in Situations of Conflict". Cut Off from Care — The Health Crisis of Populations Displaced by Conflict in the Middle East, the Middle East Institute, Washington, DC. June 2015.

RUSHTON CH. "Nursing Ethics & Moral Courage: Doing the Right Thing". National Student Nurses Association's 63rd Annual Convention, Phoenix, AZ, April 2015.

RUSHTON CH. "Integrity: Creating, Sustaining, and Changing Ethical Environments". American Nursing Association Ethics Symposium, Baltimore, MD, June 2015.

SUGARMAN J. "Training Program in Research Ethics in the Americas". FLACSO (Facultad Latinoamericana de Ciencias Sociales — Latin American University of Social Sciences), Buenos Aries, Argentina. May 2015.

SUGARMAN J. "Navigating the Ethical Issues in HIV Prevention Research". Fordham HIV & Drug Abuse Prevention Research Ethics Training Institute, Fordham University, New York, NY. July 2014.

SUGARMAN J. "Analytic Treatment Interruption in HIV Cure Research" International AIDS Society's Towards an HIV Cure Symposium, Melbourne, Australia, July 2014.

SUGARMAN J. "Towards the Responsible Clinical Translation of Stem Cell Research". University of Melbourne, Melbourne, Australia, July 2014.

SUGARMAN J. "Informed Consent: Why Ought We Care?" Informed Consent and Health Literacy: A Workshop. Roundtable on Health Literacy, Institute of Medicine, Washington, DC, July 2014.

SUGARMAN J. "Ethical Challenges in the Responsible Clinical Translation of iPSCs". Uehiro-Carnegie-Oxford Conference: Ethics for the Future of iPS/Stem Cells, Kvoto, Japan, August 2014.

SUGARMAN J. "Ethical Issues in Clinical Translation of Stem Cell Research". 16th Annual Human Subject Protection Conference, Schulman Associates IRB, the University of Kentucky, Cincinnati Children's Hospital Medical Center, and the University of Cincinnati. Covington, Kentucky. September 2014.

SUGARMAN J. "Ethics & PrEP. Controlling the HIV Epidemic with Antiretrovirals: Avoiding the Cost of Inaction". International Association of Providers of AIDS Care, London, UK. September 2014.

SUGARMAN J. "Ethics and IRB Operations Training" International Clinical Studies Support Center Cape Town South Africa October 2014

SUGARMAN J. "Ethical and Regulatory Challenges of Pragmatic Clinical Trials, Coming to a Unit Near You: Cluster-Randomized Trials in Hemodialysis". American Society of Nephrology Kidney Week 2014, Philadelphia, Pennsylvania. November 2014

SUGARMAN J. "Ethical Considerations in Determining and Disclosing Reasonably Foreseeable Risks, Ethical Review and Oversight Issues in Research Involving Standard of Care Interventions". Institute of Medicine, Washington, DC. December 2014.

SUGARMAN J. "Empirical Ethics Research on Research in Usual Settings". Advancing Ethical Research Conference. Public Responsibility in Medicine and Research, Baltimore, Maryland. December 2014.

SUGARMAN J. "Patient-Centered Outcomes Research (PCOR): Opportunities and Challenges Related to Having Patients as Collaborators". Advancing Ethical Research Conference, Public Responsibility in Medicine and Research, Baltimore, Marvland, December 2014.

SUGARMAN J. "Using Empirical Evidence to Reduce Consent Form Length", Advancing Ethical Research Conference, Public Responsibility in Medicine and Research, Baltimore, Maryland, December 2014.

SUGARMAN J. University of Malaya-Longwood Medical International Foundation Short Course on Translational Medicine, Kuala Lumpur, Malaysia. December 2014

SUGARMAN J. "Recruitment and Post-Trial Access" Clinical Trial Recruitment: Problems, Misconceptions, and Possible Solutions, Brocher Foundation, Geneva. Switzerland. January 2015.

SUGARMAN J. "Ethics in Translational Research Lessons from History". Universidad Nacional Autónoma de México, Mexico City, Mexico. February 2015.

SUGARMAN J. "Perspectives in Stem Cell Therapy" Hopkins Biotech Network Affinity Group, New York. New York, March 2015.

SUGARMAN J. "Fundamentals of International Clinical Research Training". International Clinical Studies Support Center, Cape Town, South Africa. March 2015.

SUGARMAN J. "Pragmatic Clinical Trials in Complimentary and Integrative Medicine: Promises and Challenges". Global Clinical Research Summit, Seoul, Korea, April 2015.

SUGARMAN J. "Ethical Challenges with Innovation in Medicine and Surgery". Surgery Grand Rounds, Rady Children's Hospital, San Diego, CA. April 2015.

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

SUGARMAN J. "Ethics and the Use of Antiretroviral Agents for the Prevention of HIV". SUNY Downstate. Brooklyn, NY. June 2015.

SUGARMAN J. "Promise, Progress & Hype" International Society for Stem Cell Research Annual Meeting, Stockholm, Sweden, June 2015.

TAYLOR HA. "Tough Questions about Ebola: Scientific, Regulatory, and Ethical Issues with Experimental Treatments and Vaccines". Advancing in Ethical Research Annual Meeting 2014. Public Responsibility in Medicine and Research, Baltimore, MD. December 2014.

TAYLOR HA. Rutkow L, Barnett DJ. "Developing Ethical Standards to Improve Local Response Capacity to Infectious Disease Events". Annual Meeting of National Association of County and City Health Officials 2014, Atlanta, GA. July 2014.

UNGURU Y. "Chemotherapy Shortages: The Not So Good. The Bad, and The Ugly". Translational Research in Hematology/Oncology/Bone Marrow Transplantation Seminar Series, Nationwide Children's Hospital, The Ohio State University, Columbus, OH. July 2014.

UNGURU Y. "Treating Terrorists: Clinicians' Responsibilities," A September 11 Anesthesia Grand Rounds Annual Ethics Lecture Sinai Hospital of Baltimore, Baltimore, MD. September 2014.

UNGURU Y. Rho Chi Induction Ceremony, Notre Dame of Marvland University. School of Pharmacy. Baltimore, MD, October 2014.

TAYLOR HA. "Late Breaking Session. Ebola: A

Humanitarian Crisis and New Lessons for Public Health, Research and Team-based Care". American Society of Bioethics & Humanities Annual Meeting 2014, San Diego, CA, October 2014.

UNGURU Y. "Ethical and Clinical Challenges in Caring for Children with Cancer in the Era of Chemotherapy Drug Shortages: The Not so Good, the Bad, and the Ugly" Seventh Annual Pediatric Bioethics Conference Wolfson Children's Hospital, Jacksonville, FL. November 2014.

UNGURU Y. "Unreasonable Standard of Care or Simply Unreasonable: Clinical and Ethical Challenges in Caring for Children with Cancer in the Era of Chemotherapy Shortages". Johns Hopkins Berman Institute of Bioethics Seminar Series, Baltimore, MD. January 2015.

UNGURU Y. "Caring for Children in the Era of Chemotherapy Shortages: The Not So Good, the Bad, and the Ugly." Yale University School of Medicine, Pediatric Grand Rounds, New Haven, CT. March 2015.

UNGURU Y. "Challenging Case Conference." Division of Pediatric Hematology, Oncology and Bone Marrow Transplantation at Children's Mercy, Kansas City, MO. March 2015.

UNGURU Y. "An Ethical Framework for Allocating Scarce Life-Saving Chemotherapy: When 'Eeny, Meeny, Miny, Mo' Just Won't Cut It", Children's Mercy Bioethics Center, Kansas City, MI. 2015.

UNGURU Y. "Ethical Allocation of Scarce Life-saving Chemotherapy" 'Eeny, Meeny, Miny, Mo' or Pre-meditation?" Johns Hopkins Hospital, Oncology Grand Rounds, Baltimore, MD. May 2015.

UNGURU Y. "Improving Upon 'Eeny, Meeny, Miny, Mo:' Ethical Allocation of Scarce Life-saving Chemotherapy for Children with Cancer". Sinai Hospital of Baltimore, Pediatric Grand Rounds, Baltimore, MD, 2015.

UNGURU Y. "Cases that Keep Us Up at Night" Semi-Annual Ethics Lecture, Anesthesia Grand Rounds, Sinai Hospital of Baltimore, Baltimore, MD. May 2015.



LEONARD RUBENSTEIN

#### OUR COMMUNITY

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Joseph Ali, JD Research Scholar, Johns Hopkins Berman Institute of Bioethics

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MARY CATHERINE BEACH, MD, MPH, received the David M. Levine Excellence in Mentoring Award from the Department of Medicine at the Johns Hopkins School of Medicine. Prof. Beach was also promoted to Professor of Medicine in the Department of Medicine at the Johns Hopkins School of Medicine.

Foundation

Disease Management."

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GAIL GELLER, ScD, MHS, received a joint faculty appointment in the Department of Sociology at the Krieger School of Arts and Sciences.

of Law.



#### HONORS, AWARDS, AND PROMOTIONS

**RENEE BOSS**, MD, received a Sojourns Scholar Leadership Award from the Cambia Health

RACHEL DVOSKIN, PhD, won second place in the Burroughs Wellcome Fund Maryland-Genetics, Epidemiology, Medicine (MD-GEM) Training Program's 2015 Genetics Research Day Poster Competition in the Postdoctoral Fellows category with a poster entitled "Ethical, Legal and Social Implications of Genomics in Infectious

DANIELLE EDWARDS, MS, was awarded a CLF-Lerner Fellowship by the Johns Hopkins Bloomberg School of Public Health Center for a

CARLTON HAYWOOD, JR., PhD, MA, received a Johns Hopkins Catalyst Award for his work on improving nursing care for sickle cell disease.

LESLIE MELTZER-HENRY, JD, MSc, was promoted to Professor of Law with tenure at the University of Maryland Carey School

JEFFREY KAHN, PhD, MPH, was named chair of the Institute of Medicine of the National Academies' Committee on the Ethical and Social Policy Considerations of Novel Techniques for Prevention of Maternal Transmission of Mitochondrial DNA Diseases.

DEBRA JH MATHEWS, PhD, MA, was promoted to Associate Professor in the Department of Pediatrics at the Johns Hopkins School of Medicine

MARIA MERRITT, 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. Bioethics and Health Policy doctoral student Danielle Edwards, MS, served as TA for this course.

MARGARET MOON, PhD, MPH, was promoted to Associate Professor in the Department of Pediatrics at the Johns Hopkins School of Medicine, Prof. Moon was also named the Associate Vice Chair for Professional Practice at the Johns Hopkins Children's Center.

STEPHANIE MORAIN, PhD, MPH, received an Outstanding Junior Scholar Award (2nd place) at the 2015 Public Health Law Research Program's Annual Meeting.

LEONARD RUBENSTEIN, JD, LLM, was honored for his work to bring attention to the danger facing Syrian healthcare professionals at the 4th Annual National Conference of the Syrian American Medical Society. Prof. Rubenstein also received a Distinguished Service Award from the International Health Section, American Public Health Association.

CYNDA HYLTON RUSHTON, PhD, RN, FAAN, was 2015 Brocher Institute Visiting Scholar for the month of February in Geneva, Switzerland.

YORAM UNGURU, MD, MS, MA, received the LifeBridge Health All Star Champion of Care award.

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Names highlighted in italics indicate those donors who are members of the Berman Society. 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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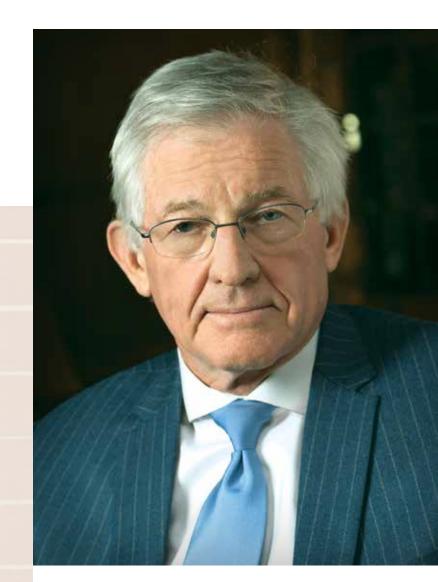
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or 20 years, the Johns Hopkins Berman Institute of Bioethics has tackled moral challenges that have no easy resolutions. As an independent, interdisciplinary center of scholarship and research, the Berman Institute stands as one of the world's leading 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.

"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 designing educational programs to offer the vital training those executives need. I am thrilled to support this effort and to know that my gifts will have a real impact on our society."

L. John Wilkerson, PhD Berman Institute National Advisory Board Member

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 Bowden, CFRE, at gbowden@jhu.edu or 410-614-5651



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