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ANNUAL REPORT



JOHNS HOPKINS

BERMAN INSTITUTE
of BIOETHICS

MAKING AN IMPACT

ON SCHOLARSHIP, POLICY & PRACTICE

FROM THE DIRECTOR

Thank you for taking a few minutes to look through the past year's achievements and highlights at the Berman Institute. There is much to see and learn from the extraordinary body of work produced by our faculty and staff. Every year I look back with wonder at their accomplishments. This truly was another incredible year in which we marked significant milestones in the history of the Institute, and our faculty produced remarkable scholarship with real-world impact. Working in Deering Hall alongside these colleagues never fails to leave me awed and inspired. It is a privilege to serve as the Berman Institute's Director.

The crowning event of the past year, both for the Institute and for me personally, was the dedication of the Andreas C. Dracopoulos Directorship. This directorship is named for an incredible philanthropist who has a vision of a world with a firm moral foundation. That is an ideal to which all of us at the Berman Institute dedicate ourselves every day. Andreas, and his tremendous colleagues on our National Advisory Board, teach me more than I can say through their examples of leadership, philanthropy, and humanity. I hope you see that same spirit in the programs and activities described on these pages.

The Berman Institute has a singular reputation because it uses rigorous methods to approach the moral dimensions of science, public health, and clinical care. Our more than 30 faculty members consider issues that range from the nature of foundational concepts like respect and justice to how a clinical trial in a low-income country ought to be conducted. I hope the examples we include in this report demonstrate the impact of our work.

Please do not let your connection end here. I invite you to visit the Institute, attend events, learn more about the field of bioethics and explore your own views on these complex topics. Thank you for all you do to support and encourage the work of the Institute.

Warm regards,



Ruth Faden, PhD, MPH

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



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THE ANDREAS C. DRACOPOULOS DIRECTORSHIP OF THE BERMAN INSTITUTE

The Berman Institute marked a major milestone in January 2014 with the endowment of its directorship, ensuring leadership for the Institute’s programs in perpetuity. Made possible by a gift from the long-time Berman Institute supporter and board member for whom it is named, the Andreas C. Dracopoulos Directorship further distinguishes the Berman Institute as the first center of bioethics scholarship known to have this type of endowed directorship.

“Mr. Dracopoulos’ extraordinary generosity further secures the Berman Institute’s future. It will enable us to multiply the impact of our work and mission, helping to shape and respond to the pressing bioethics issues of this generation, and those to come,” said Ruth Faden, PhD, MPH, founding director of the Berman Institute and the Philip Franklin Wagley Professor of Biomedical Ethics.

Dracopoulos spoke at the directorship dedication ceremony in June, saying, “I am honored to have been a member of the National Advisory Board of the Berman Institute for almost 15 years now, honored to count everyone at the Institute as a friend, very grateful to have been blessed in my own personal life to be able to express my gratitude with this personal contribution, which is nothing more than a simple acknowledgment of how far Ruth has taken the Institute and how promising its future is, both within the Hopkins family and within society at large.”

Generosity and foresight like Dracopoulos’ help to establish and fortify the field of bioethics as a permanent feature of the academy, Prof. Faden said.

Ronald J. Daniels, President of Johns Hopkins University, also spoke at the dedication ceremony. “We are truly grateful for Andreas’ extraordinary support of the Berman Institute. This gift embodies the depth of Andreas’ commitment to Berman’s pathbreaking work in bioethics, his vision for its continued success and, most importantly, his great humanity,” he said.

In her remarks, Prof. Faden recalled her early years at Johns Hopkins when the idea of a bioethics institute with an endowed directorship “was not even a gleam in the eye.” Prof. Faden put the directorship in context, from those early days of grassroots, informal faculty lunch gatherings to the bright future she sees for the Berman Institute:

“Andreas’ remarkable gift will allow us to establish new big dreams and new big hopes for the next chapter in the Berman Institute’s history. I am convinced that, more than ever, ethics is absolutely central to many of the great challenges facing humanity, now and in the future. These challenges do not fall neatly in one bin of the academy or the other, and so frequently these challenges are completely interdependent. Health, water, food, energy — it will be impossible to solve one in isolation from the other.”



RUTH FADEN (CENTER) AND
ANDREAS C. DRACOPOULOS (LEFT) AT EVENT



JOSEPH CARRESE

MASTER OF BIOETHICS PROGRAM

In 2014 the Berman Institute took a significant step toward the long-sought goal of offering a Master of Bioethics degree, working on the required proposals for University and State approval, and moving into curriculum planning. With administrative support from the Johns Hopkins Bloomberg School of Public Health, the program plans to enroll its first students in Fall 2015.

The Master of Bioethics program will provide concrete training in the ethics of clinical care, research, science, and public health, with particular focus on the application of theory and methods of inquiry in bioethics. Consistent with the Berman Institute’s interdisciplinary faculty and scholarship, diversity will be a hallmark of both the student body and curriculum, according to Jeffrey Kahn, PhD, MPH, the Berman Institute’s Deputy Director

for Policy and Administration. With on-site and online courses, the program will prepare students to understand and address both new and long-standing ethical challenges that arise in medical, science, and public health research and practice locally and globally.

“Graduates of the Master of Bioethics program will be equipped to contribute to the discussion of, and the solutions for, ethical issues that arise in the biosciences, clinical care, and public health, whether in government, business, hospitals and clinics, or education,” says Prof. Kahn.



JEFFREY KAHN



TESTING THE EFFECTS OF SPACE FLIGHT ON THE CENTRAL NERVOUS SYSTEM.

IMPACTING PUBLIC POLICY

The contribution of bioethics to public policy can have a long-lasting positive impact on welfare and progress. Berman Institute faculty members have significant roles in influencing policy on a wide range of issues representative of the Institute’s diverse expertise and the breadth of bioethics as a field. Below are highlights from our public policy work last year.

Jeffrey Kahn, PhD, MPH, was named chair of the Institute of Medicine (IOM) Board on Health Sciences Policy in February 2014. The Board is one of the nine boards of the IOM that help guide ongoing forums and the consensus study process on a wide range of issues related to medicine, health sciences, and public health.

The analysis and recommendations produced are influential in changing policy and practice in government, public and private funders, health systems, and private industry.

Prof. Kahn also chaired an IOM committee commissioned by NASA to provide ethics guidance as the agency establishes health standards for high risk, long-duration and exploration class missions. Among the committee report’s guidelines and recommendations is the assertion that it would be “ethically unacceptable” to abandon, replace, or relax health standards for these higher-risk missions. The report included a “decision framework” for the agency’s future planning, and was well received by NASA.



DAVID LACKS NOTING THE HENRIETTA LACKS TILE IN JOHNS HOPKINS HOSPITAL DISPLAY

Ruth Faden, PhD, MPH, Director of the Berman Institute, worked with the family of Henrietta Lacks, senior leadership of the National Institutes of Health, and the Vice Dean for Clinician Investigation at Johns Hopkins Medicine on a historic agreement that allows researchers controlled access to the genomic sequence data of HeLa cells. This agreement, announced in August 2013, came five months after the genome was (briefly) published in an open access database without the Lacks family’s knowledge. “What followed is in important respects unprecedented in the annals of bioethics and science,” Prof. Faden wrote in an opinion article on the Bioethics Bulletin, recalling the series of meetings with the Lacks family to find a way forward.

The new policy ensures that the Lacks family will never again be left in the dark about HeLa research, as they had been in the past, and that this cell line will continue to be an important part of scientific progress. Prof. Faden was named to a newly created standing committee that reviews applications to conduct research with HeLa genome data, as were two members of the Lacks family. Additionally, NIH-supported publications making use of the HeLa genome data must include a formal acknowledgment—a statement of gratitude—to Henrietta Lacks and to her family.



Faculty member Leonard Rubenstein, JD, LLM, was the principal organizer of the Task Force on Preserving Medical Professionalism in National Security Detention Centers, and the primary author of its report, Ethics Abandoned:

Medical Professionalism and Detainee Abuse in the War on Terror, published in November 2013. The report details how the Department of Defense (DOD) and CIA policies institutionalized breaches of medical ethics by military and intelligence agency physicians and psychologists, including participation in abusive interrogation and force-feeding of detainees on

hunger strike. The task force called for new guidelines for responding to detainee hunger strikes, in line with the World Medical Association’s Declaration of Malta.

The day after the publication of the task force’s report, it was supported by a letter sent to President Obama by leading health and ethics experts, including Prof. Faden, calling for an end to force-feeding at Guantánamo Bay Prison. Prof. Rubenstein presented the task force’s findings and recommendations to the Medical Ethics Subcommittee of the Defense Health Board, an Advisory Committee to the DOD, which presents its report on adopting the recommendations in December 2014.

Jeremy Sugarman, MD, MPH, MA, and Joseph Ali, JD, are leading the Ethics and Regulatory Task Force of



PCORnet with Robert Califf, MD, of the Duke Translational Medicine Institute. PCORnet, the National Patient-Centered Clinical Research Network, seeks to improve capacity to conduct comparative effectiveness research efficiently by creating a large, highly representative data network for clinical health information. With the broad participation of patient groups and advocates, health delivery and research systems, and US federal



agencies, PCORnet is building infrastructure for coordinated research to significantly increase the evidence available to millions of patients and their clinicians for healthcare decision-making.

PCORnet is a project of the Patient Centered Outcomes Research Institute (PCORI), an independent organization authorized by Congress to support and conduct research that will provide a broad source of high quality, relevant evidence, making most effective use of the digital age’s rapid learning capacity.



BRAIN DEATH

In early 2014 two instances of reported brain death drew attention for concurrently representing opposite sides of the difficult subject — one in which the family did not want to remove “life support” medical technology, and another in which they did, but policy opposed their wishes. Berman Institute faculty members conducted outreach to help bring clarity to the issues of these different but equally tragic cases.

Jahi McMath, 13, suffered complications during a tonsillectomy, followed by cardiac arrest, and was ultimately declared brain dead. Her family fought in court to keep her on life support, and moved her to a different medical facility after the first hospital said they would discontinue the use of life support technology.

Marlise Muñoz, 33 years old and 14 weeks pregnant, collapsed due to a blood clot in her lungs. Her family attested that she was declared brain dead and would not have wanted to remain on life support. However, the hospital where she was being treated insisted that a Texas law prohibited them from removing life support technology because of her pregnancy.

Cynda Rushton, PhD, RN, FAAN, spoke with National Geographic News for their coverage of what “brain death” really means, and why it can be so confusing. “It’s hard for all of us to accept those limits because we have so much promise in our technology, and we have become so seduced by it that we actually think that it can correct things that are not possible to be corrected,” Prof. Rushton said.

In an opinion article for CNN.com, Prof. Rushton focused on the case of the pregnant Munoz, and



raised the issue of the morally difficult position of the clinicians caring for her, knowing they are working against the wishes of the family, and according to them, Munoz herself. “Medical personnel are not merely mindless robots who implement the decisions of others. They too have moral stakes in the process and outcomes of their care,” Prof. Rushton wrote.

Prof. Rushton also spoke with Alice Park at Time magazine, saying that life support technology has “created the illusion that death is optional.” Park observes that, as the cases of McMath and Munoz illustrate in different ways, this illusion “increasingly pits doctors and hospitals against families.”

Jeffrey Kahn, PhD, MPH, agrees with Prof. Rushton that, “Before we had the ability to keep people alive when they could not breathe on their own, we didn’t have these issues,” as he told LiveScience.com in the site’s in-depth exploration of the facts and issues surrounding brain death.

Prof. Kahn also spoke with The Wall Street Journal for their story on the McMath case: “Fight Over California Girl Points to Confusion About Brain Death,” saying that because young McMath would be “warm and the heart’s still beating, it’s easy to understand why there’s confusion about this,” but that according to law and policy, she fit the criteria for brain death.

Prof. Rushton also spoke with journalists from CNN for two separate news stories on these issues. Addressing the case of 13-year old McMath, she said that, “We really need to engage in a new dialogue that takes us out of the debate of faith into science, into a conversation about what are the limits of our human knowledge and technology, and how do we accept the fact that all of us will eventually die?”



CYNDA RUSHTON

The universality Prof. Rushton hits on is a key point; end of life issues truly effect everyone, and are fraught with ethical conflict, emotion and confusion. Berman Institute scholars working in this area bring some clarity to help patients, families, clinicians and society through those difficult times.



DEBRA MATHEWS (LEFT)

“THREE-PARENT” EMBRYOS

The Food and Drug Administration (FDA) held a historic public meeting in late February 2014, considering for the first time experiments that would alter the genome of human embryos. The proposed technology, which has been performed successfully in monkeys, would incorporate genetic material from three individuals: a mother, a father, and another woman who would contribute healthy mitochondria. Mitochondria, cellular bodies that contain their own DNA (mtDNA), can be the source of many debilitating genetic conditions.

The newly created DNA mix would be passed on to future generations — a permanent, heritable, man-made genetic change that has previously been viewed as an ethical line not to be crossed. By mixing new DNA into the germline (the lineage of reproductive cells that combine to create a new person), “We’re not treating humans. We’re creating humans. There’s not a model for that,” Jeffrey Kahn, PhD, MPH, was quoted in Science magazine.

“One of the reasons it is controversial is that you would be modifying the genetics of future generations who do not have the ability to make a decision about it,” Debra Mathews, PhD, MA, told Voice of Russia radio.

“It will be important to emphasize what the consent form looks like so it’s very clear what the potential future rights of all the different people are,” Berman Institute faculty member Michelle Huckaby Lewis, JD, MD, told HealthDay. “The potential benefits are huge, but the potential harms are also huge.”

Pediatrician and Berman Institute faculty member Margaret Moon, MD, MPH, agrees, saying that just as children who are enrolled by their parents in bio-banking (cord blood) studies should be re-consented at an age of maturity, so should any children that result from these gene transfer clinical trials the FDA is considering. “I imagine there will be a lot done to encourage them to stay in the research program until they reproduce. Their offspring will be the point of much interest,” Prof. Moon says.



MAGGIE MOON

While the technology itself is breaking unprecedented ground in science and health, the ethical debate looks much like one encountered time and again with the introduction of new technologies: when a discovery with potential to improve human life also holds risk of serious harm.

The DNA transfer technology “sounds very much like a science fiction plot already. Somewhere between Margaret Atwood (*The Handmaid’s Tale*) and P.D. James (*The Children of Men*),” says Prof. Moon.

For Prof. Moon and others, the concern is that if the FDA allows for germline modification to prevent passing on conditions like Leigh’s Disease through mtDNA, it will open the door to allowing genetic engineering for an increasing range of uses, including custom-made children.

At the other end of the spectrum, there could be considerable debate as to which conditions are classified as “debilitating” enough to be engineered out of the gene pool. The deaf community, for example, includes some who object to the classification of their condition as incapacitating and even prefer to have deaf children.

“If we stop a particular avenue of science in its track and say ‘this may not go forward,’ we don’t know what the opportunity cost is,” Prof. Mathews told Voice of Russia. “We may think what we’re doing is preventing this particular application that we’re quite concerned about, which may be a legitimate concern, but we sometimes fail to realize there may be opportunity costs with not allowing that science to move forward.”

In addition to conditions like blindness and epilepsy, some propose that the new technique could also be used to treat age-related infertility, as other IVF treatments do. This application would widen the potential pool of patients beyond women carriers of mitochondrial conditions to include millions of women wanting to conceive. “Once it’s used, it will be used in all sorts of ways for all sorts of people. That’s the reality of this kind of medicine,” Prof. Kahn told Science magazine.

The FDA has previously left IVF technology largely unregulated, making their decision potentially precedent setting from both the science and policy perspectives. The procedure could have unintended health

consequences for newborns, for future generations, and for the concept of the family, as the genetic tinkering reverberates through time, Prof. Lewis told HealthDay. She noted, “When you use a technology in a new way like this, it really challenges our notions of what it means to be a parent and what it means to be a family.”





SHORTAGES OF LIFE-SAVING DRUGS

It's a nightmare scenario that is becoming all too common: there is a drug that could save a patient's life, but it is out of stock.

With philanthropic support, Berman Institute faculty member and pediatric oncologist Yoram Unguru, MD, MA, MS, took the lead in organizing an expert working group to tackle the daunting prospect of ethical decision-making in this dire circumstance. Prominent healthcare experts gathered at the Berman Institute to launch their discussion, including representatives from the Food and Drug Administration (FDA), leadership of the Children's Oncology Group and The American Society of Pediatric Hematology/Oncology, patient advocacy groups, legal scholars, and pharmacists.

Using the example of shortages of chemotherapy drugs for treating children with cancer — therapies proven to have high survival rates for the most common childhood cancers — the group developed “a comprehensive blueprint for action” they say is critical for managing and preventing future drug shortages. The consensus statement was published in the journal *Pediatrics* in February 2014.



Berman Institute faculty member Matthew DeCamp, MD, PhD, was lead author. He says, “This statement is significant both for the consensus found by such a diverse group of experts, and for being the first to take seriously the ethical rationale to prevent shortages in the first place.”



The statement makes six recommendations and notes potential barriers to implementation for each. The recommendations are:

- 1. SUPPORT CURRENT MEASURES** (and develop innovative new ones) to prevent future drug shortages at the national level.
- 2. OPTIMIZE AND EFFICIENTLY USE SUPPLIES** to reduce the likelihood and mitigate the effects of future shortages.

- 3. DEVELOP EXPLICIT POLICIES** that give equal priority during a drug shortage to evidence-based use of chemotherapy agents, whether patients are receiving treatment within or outside a clinical trial.
- 4. CREATE AN IMPROVED, CENTRALIZED CLEARINGHOUSE** for sharing information about drug availability and shortages.
- 5. EXPLORE VOLUNTARY SHARING** of drugs at the state, regional, and national levels.

- 6. DEVELOP A STRATEGY** for ongoing stakeholder engagement regarding managing drug shortages, with specific emphasis on patients and patient advocacy groups.

“The reasons for drug shortages are complex, but we must not lose sight of the fact that without access to these life-saving drugs, children and adults with cancer will almost certainly die,” Prof. Unguru says. “It is untenable for this situation to continue any longer. We have a clear moral obligation to act to address this critical issue.”



NANCY KASS

OBESITY AND THE “NANNY STATE”

Obesity is a serious public health problem in America, and policy solutions are fraught with ethical challenges; how can this multi-faceted problem be tackled while maintaining individual freedom of choice and avoiding stigmatization?

Fairness, respect, and consistency in government public health policies are crucial to the answer, according to an opinion from experts at the Berman Institute and California Food

Policy Advocates published in the American Journal of Public Health in March 2014.

“Obesity is truly an epidemic in the United States, affecting one in three adults and one in six children,” says Nancy Kass, ScD, a co-author of the opinion along with Berman Institute doctoral candidate Amy Paul. “We focus on sugar-sweetened beverages because they are the largest single contributor to Americans’ caloric intake.”



AMY PAUL

Regarding accusations of “nanny state” governmental interference in individual choice, the authors suggest that framing is incorrect, and that in addition to the health implications of being overweight, the wide economic disparities of obesity create a government duty to enact policies to prevent injustice.

“[T]he systematically higher rates of obesity among food-insecure individuals compared with the food-secure raise questions whether public policy around obesity prevention should be labeled government interference with individual preference, or government responsibility in the name of social justice,” the opinion states.

A ban on school sales of sugar-sweetened beverages (SSBs) and, to a lesser degree, taxation of SSBs, score well in terms of fairness, the opinion says, because they apply across demographics, while the proposed food stamp ban targets SNAP participants exclusively. Such a practice, proposed in California, Florida, Missouri, Wisconsin and Texas, would not “pass ethical acceptability.”

“[A] SNAP exclusion, implemented alone, sends a public policy message that poor people require government intervention to manage their food choices whereas higher-income persons do not,” the opinion states.

The authors dismiss the objection that a sales tax is unfair to lower-income individuals, writing, “regressive taxation becomes most troubling from a fairness perspective when applied to basic necessities — such as clothing, housing, or food. Sugar-sweetened beverages, containing no nutritional value, are not a basic necessity.”

Rather, taxes reflect the preferences of a society valuing free choice, opting for disincentives rather than prohibitions, with SSBs remaining widely available on the market, the opinion states. It goes on to say that taxation would be most fair if those who “enable and benefit” from the sale of SSBs share in the burden through excise taxes, with the portion passed on to the consumer only adding to the disincentive of a sales tax.

Finally, the opinion underscores that not all liberties are created equal. Governments have essential duties to protect our fundamental freedoms. But in providing disincentives to unhealthy products such as SSBs, the government simply is discouraging the consumption of less healthful products.

“Although a central responsibility of government is to protect foundational liberties from unwarranted intervention, it does not necessarily follow that fundamental liberties are threatened when public policy discourages consumption of unhealthy products or prohibits government spending on them,” the opinion states. “The personal pleasure to be derived from consumption of SSBs is absolutely worthy of consideration, and yet such pleasure does not rise to the level of a fundamental freedom.”





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EDUCATION AND TRAINING

ACADEMIC PROGRAMS

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 renowned faculty provide a dynamic educational experience that makes the most of the Berman Institute's position at Johns Hopkins, an institution that includes leading schools of medicine, nursing, and public health, along with one of the world's best hospitals.

BIOETHICS AT HOMEWOOD: THE UNDERGRADUATE MINOR AND HUBS

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 34 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

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.

In May 2014 the Berman Institute was proud to congratulate Danielle Whicher, PhD, MHS, on her graduation from the program. Dr. Whicher's dissertation looked at balancing two concerns: 1) protecting and



respecting individuals who might be asked to participate in comparative effectiveness research (CER) trials and 2) the public health goal of generating evidence to improve health. She is now Program Officer in the Department of CER Methods and Infrastructure at the Patient Centered Outcomes Research Institute (PCORI).

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 further public policy debate concerning those moral problems.

BERMAN INSTITUTE BIOETHICS INTENSIVE (BI²) COURSES

Now in its third year, the BI² 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. Courses examine both theoretical and applied aspects of bioethics and include: Foundations of Bioethics; Teaching Bioethics; Ethics, Policy, and Emerging Biotechnologies; Social Media, Ethics and Health; Public Health Ethics; and Ethics of Human Subjects Research.

In 2014, courses were offered in January and June, with six courses and 54 students attending. Single day and week-long courses have been offered; the format and offerings change each term. For more information on future courses visit bioethicsinstitute.org/intensives.

INTENSIVE GLOBAL BIOETHICS TRAINING PROGRAM

The Berman Institute launched the Intensive Global Bioethics Training Program (GBTP) in June 2014 — an annual, month-long opportunity for scholars to learn from experts at the Berman Institute on-site in Baltimore, MD. Directed by Nancy Kass, ScD and Adnan Hyder, MD, PhD, MPH, the program combines intensive coursework with applied, skill-oriented learning to develop participants' knowledge and skills in international research ethics.

"This program is a response to the expressed need from our colleagues in low and middle income countries for greater exposure to core knowledge in research ethics and their application to real world research ethics issues," Prof. Hyder says.

Program participants are enrolled in two different non-credit, week-long intensive courses: Foundations of Bioethics and Introduction to Research Ethics (with options to substitute other courses), taught by Berman Institute faculty.

Program participants also interact with key personnel from JHU Institutional Review Boards (IRBs) and participate in special seminars, mock IRB sessions, expert-led case discussions, student-led presentations, and meetings with bioethics faculty to provide mentorship and guidance related to educational, career, and research goals.

In addition to formal coursework, GBTP activities include structured meetings with bioethics personnel at the US National Institutes of Health, US Food and Drug Administration, and the US Office for Human Research Protections. Informal activities orient visitors to Johns Hopkins and the Baltimore-Washington area, providing plenty of opportunity for trainees to engage with each other outside the classroom.



JUNE 2014: TRAINEES VISIT THE OFFICE OF HUMAN RESEARCH PROTECTIONS (OHRP) IN WASHINGTON DC

HECHT-LEVI FELLOWSHIP PROGRAM IN BIOETHICS

The Berman Institute has welcomed two new fellows: Miriam Shapiro, MD, also a clinical fellow in the division of Pediatric Critical Care Medicine, is studying the complex issues of decision-making, consent, and justice in the pediatric intensive care unit; Travis N. Reider, PhD, is studying various ethical issues related to human procreation, ranging from adoption to population impact on climate change.

Designed to support early career development in bioethics, this two-year fellowship program is focused on individual research and publication, with Berman Institute faculty 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.

For information on the future Master of Bioethics program, see page 3.



**THE BERMAN INSTITUTE ASKS:
WHAT WOULD YOU DO?**

In a series of events across the country, the Berman Institute is putting audiences in the hot seat, confronting them with tough ethical questions to help illustrate what bioethics is and what bioethicists do.

Berman Institute faculty members joined other interdisciplinary experts in Hollywood in October 2013, in a joint event with the Science and Entertainment Exchange of the National Academy of Sciences. Ruth Faden, PhD, MPH, and Jeffrey Kahn, PhD, MPH, spoke to a packed house of film and television producers and scriptwriters, including Johns Hopkins alumni, about the allocation of scarce medical resources in a disaster, human enhancement, and the implications of big data for health and privacy.

Profs. Faden and Kahn were joined by Michael Miller, PhD, Director of the Center for Imaging Science at Johns Hopkins University Whiting School of Engineering, and Reed Tuckson, MD, a healthcare industry consultant who was formerly Chief Medical Officer for UnitedHealth Group, as well as Commissioner of Public Health for the District of Columbia.

Screenwriter Jon Spaihts moderated the discussion. Audience members used an interactive polling program to respond to questions posed by Spaihts. As more details were provided and the ethical dilemmas became more complex, audience members had the opportunity to change their responses.

For example, the audience was initially asked to choose which patient should have access to one

available ventilator in the midst of a flu epidemic — a 63 year-old man or a eight year-old girl. Later they learned that the man was a physician assisting in the disease outbreak, and were asked the question again.

In April 2014, fellow faculty members Nancy Kass, ScD, and Jeremy Sugarman, MD, MPH, joined Profs. Faden and Kahn for a redux of the program at Johns Hopkins Alumni Reunion Weekend in Baltimore. Nell Greenfieldboyce, an NPR science correspondent and graduate of the Johns Hopkins Science Writing Program, served as moderator. The engaged audience laughed and called out questions, particularly when the discussion turned to a fictional drug that could make you irresistibly attractive.

BERMAN INSTITUTE IN THE NEWS

A selection of the media outlets that have featured the Berman Institute and its experts:

ABCnews.com	Marketplace, NPR
Agence France-Presse	Maryland Morning with Sheilah Kast, WYPR
AirTalk, KPCC	Medical Economics
Al Jazeera America	MedPage Today
All Things Considered, NPR	MedicalXpress
The Atlantic	Medscape Oncology
Baltimore Jewish Times	Motherboard
Baltimore Times	MSNBC
The Baltimore Sun	Nature podcast National Geographic News
Berman Bioethics Bulletin	The Nation's Health
CBS News.com	NBC Nightly News
CNN.com	News Medical
The Daily Circuit, MPR News	The New York Times
Daily Mail	Pittsburgh Tribune-Review
The Diane Rehm Show, NPR	Providence Journal
Elle Magazine	The Public Record
Fox Business News	Quartz
The Gazette (JHU)	Science Daily
The Gupta Guide	Scope, Stanford University
Health Service Journal	Shots blog, NPR.com
Hopkins Medicine Magazine	Slate
Howard Scripps	Space.com
Huffington Post	The Takeaway, WNYC
iHealthBeat	Time Magazine
Infection Control Today	The Verge
IRIN News	Voyage North, CBC Radio
JAMA Medical News & Perspectives	The Wall Street Journal
Johns Hopkins Magazine	Washington Post
KevinMD.com	WNEW
Los Angeles Times	

BIOETHICS BULLETIN: TOP STORIES

The Berman Institute's blog, the **Bioethics Bulletin**, presents original content, including analysis and opinion articles, along with a roundup of bioethics-related news from around he web. In nearly four years the **Bioethics Bulletin** has developed a loyal and growing following of visitors from around the globe, as well as hundreds of subscribers who receive a weekly digest of top stories.

What Keeps Nurses Up at Night? Cynda Rushton , PhD, RN, FAAN
What Do We Gain or Lose by Regulating 23andMe? Leila Jamal , ScM
A New Chapter in Henrietta Lacks' Never Ending Story Ruth Faden , PhD, MPH
Bioethicists: Patient Consent Not Always Necessary Leah Ramsay
The Scarecrow Leah Ramsay
Tweeting Science Alan Regenberg , MBe
Johns Hopkins Brings Bioethics to Hollywood Leah Ramsay
Potential HIV Cure Raises New Ethical Questions Leah Ramsay and Saad Anjum
Gru and His Minions Teach Bioethics Saad Anjum

PRESENTATIONS

Beach MC . "Doctors Feel, Doctors Think, Doctors Communicate". Keynote Address, Well-being and Performance in Medical Practice (Well-Med), Alexandroupolis, Greece, May 2014.
Beach MC . "How can we study the effect of empathy on patient outcomes?". Invitational Lectures, Guest Faculty, Oslo Communication in Healthcare Education and Research (OCHER) Annual Course, Oslo, Norway, Jan 2014.
Beach MC . "Improving Communication for Better Patient Outcomes". Best Practices in Patient-Centered Care Conference, Baltimore, MD, Sept 2013.
Beach MC . "Linking Empathic Communication to Patient Outcomes: An International Proposal for Collaborative Research". Verona Network on Sequence Analysis Annual Meeting, Verona, Italy, Feb 2014.
Beach MC . "Methodological Innovations in Coding Clinical Communication: Improving Specificity and Sensitivity for Appropriate Analysis of Particular Communication Functions". International Conference on Communication in Healthcare, Montreal, Canada, Sept 2013.
Beach MC . "Moral Implications of Physician Attitudes, Bias, and Stereotyping". Keynote Address, Protecting Vulnerable Persons in Health Care Invitational Workshop, Geneva, Switzerland, Sept 2013.

Beach MC . "Patient-Provider Communication in HIV Care". 9th International Conference on HIV Treatment and Prevention Adherence, Miami, FL, June 2014.
Beach MC . "Quality of Care for Underserved Populations: A Roadmap for Improvement". The Quality Crusade, Geisinger Health Plan, Scranton, PA, Nov 2013.
Beach MC . "The use of mixed methods to study clinical effects of communication in medicine". Invitational Lectures, Guest Faculty, Oslo Communication in Healthcare Education and Research (OCHER) Annual Course, Oslo, Norway, Jan 2014.
Berger ZD . "Bridging Evidence-Based Medicine and Patient-Centered Care: The Case of Localized Prostate Cancer". Peking University Medical College Hospital, Beijing, China, Dec 2013.
Berger ZD . "Public Reporting and the American Health Care System". Peking University Medical College Hospital, Beijing, China, Dec 2013.
Berger ZD . "Bridging Evidence-Based Medicine and Patient-Centered Care: The Case of Localized Prostate Cancer". One Medical Group, Washington, DC, Jan 2014.

Berger ZD . "Bridging Evidence-Based Medicine and Patient-Centered Care: The Case of Localized Prostate Cancer". University of Maryland Family Medicine Grand Rounds, Baltimore, MD, Mar 2014.
Berger ZD . "Spirituality and Uncertainty in the Primary Care of the Cancer Patient". Spirituality and Medicine Initiative, Mercy Medical Center, Baltimore, MD, May 2014.
Black BS . "Perspectives of Research Subjects". 18th Annual Summer Research Institute for Geriatric Mental Health, Weill Cornell Institute of Geriatric Psychiatry, Baltimore, MD, 25 July 2013.
Black B, Taylor H, Rabins P , Karlawish J. "The Critical Role of Study Partners for Persons with Dementia who Participate in Research". American Society of Bioethics & Humanities Annual Meeting 2013, Atlanta, GA, Oct 2013.
Boss R . "Difficult Conversations: When Life is Short". Grand Rounds, Shady Grove Adventist Hospital, 11 Dec 2013.
Boss R . "Courageous Conversations: Talking with NICU Parents". NICN Foundations, Johns Hopkins Department of Pediatrics, 30 Apr 2014.
Boss R . "Incidental Detection of Adult-Onset Disease in Newborns". Citywide Neonatology Conference, Johns Hopkins School of Medicine, 4 June 2014.



PRESENTATIONS (CONT.)

Boss R. “Maryland MOLST for Newborns and Infants”. Citywide Neonatology Conference, Johns Hopkins School of Medicine, 4 Sept 2013.

Boss R. “Money Talks: Discussing Medical Care Costs at the Bedside”. Grand Rounds, Johns Hopkins Department of Pediatrics, 20 Nov 2013.

Boss R. “Palliative Care”. American Academy of Pediatrics National Conference and Exhibition, Orlando FL, 28 Oct 2013.

Boss R. “Palliative Care for Infants and Young Children — Enhancing Quality of Life No Matter the Disease Trajectory”. Grand Rounds, Yale Pediatric Ethics Department, 12 Sept 2013.

DeCamp M. “Social media and medical professionalism: What physicians need to know.” American College of Physicians IM Panel, Orlando, FL, 10 Apr 2014.

DeCamp M, Brennan KF, Judge J. Moderated by Les Levinson, Chair, Healthcare Practice Group at Edwards Wildman Palmer LLP. “Ethics in Unique Partnerships”. Pennsylvania Institute of Certified Public Accountants, 10 June 2014.

Faden R. “Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science”. Colorado College, 27 Aug 2013.

Faden R. “Justice and Health: What’s theory got to do with it?”. Merrimon Lecture in Medicine, University of North Carolina — Chapel Hill, 4 Oct 2013.

Faden R, Kass N, Beachamp T. “A New Ethical Framework for the Learning Healthcare System”. PRIM&R (Public Responsibility in Medicine and Research), 7 Nov 2013.

Faden R. “Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science”. American Society for Microbiology, Department of Education’s Annual Biomedical Conference for Minority Students, Nashville, TN, 15 Nov 2013.

Faden R. “Henrietta Lacks: Ethics at the Intersection of Health Care and Biomedical Science”. St. Louis College of Pharmacy, 23 Jan 2014.

Faden R. “HeLa Cells, Social Justice and the Ethics of Science”. International Association of Bioethics 12th World Congress of Bioethics, Mexico City, Mexico, 26 June 2014.

Faden R, Kahn J, Miller M, Tuckson R. “Bioethics: Killer Conundrums, Deadly Dilemmas”. Panel event for NAS Science and Entertainment Exchange, Los Angeles, CA, 8 Oct 2013.

Geller G, Merritt MW. “From Tradition to Innovation in the Moral Development of Health Professionals: Designing Educational Experiences That Cultivate a ‘Capacity for Wonder’”. American Society for Bioethics and Humanities annual meeting, Atlanta, GA, 24 Oct 2013.

Harrison K, **Taylor H.** “Going Forward: Prototype Guidance for Addressing Ethical Challenges in Health Care Resource Allocation and Policy Decision-Making”. American Society of Bioethics & Humanities Annual Meeting 2013, Atlanta, GA, Oct 2013.

Harrison K, **Taylor HA.** “Organizational Values in the Provision of Access to Care for the Uninsured”. American Public Health Association Meeting 2013, Boston, MA, Nov 2013.

Henry LM. “Just Compensation: Taking Research-Related Injuries Out of the Litigation Lottery”. Presidential Commission for the Study of Bioethical Issues, Invited Speaker Series, Washington, D.C., 20 June 2014.

Henry LM. “Taking Research-Related Injuries Out of the Litigation Lottery”. 37th Annual Health Law Professors’ Conference, UC-Hastings College of Law, San Francisco, California, 6 June 2014.

Henry LM. “Moral Gridlock: Conceptual Barriers to Compensation for Injured Research Subjects”. Johns Hopkins Berman Institute of Bioethics Seminar Series, Baltimore, MD, 10 Mar 2014.

Kahn J, Kass N. “Ethics and Philanthropy”. Invited panel presentation, 3rd Annual Stavros Niarchos Foundation Philanthropy Conference, Athens, Greece, 27 June 2014.

Kahn J. “Emerging Issues in Research Integrity”. AAAS Train the Trainers Workshop, Annapolis, MD, 11 June 2014.

Kahn J. “Genomics, Public Health, and Big Data: What’s Ethics Got to Do with It?”. Keynote Address, Medical College of Wisconsin Genomics and Ethics Conference, Milwaukee, WI, 19 May 2014.

Kahn J. “Prometheus and Bioethics”. Invited panel presentation for NAS Science and Entertainment Network, Science Café DC, Washington, DC, 15 May 2014.

Kahn J. “Health Care Reform: Nanny State or Responsible Stewardship?”. Keynote Address, Peninsula Medical Center Medical Ethics Forum, Salisbury, MD, 1 May 2014.

Kahn J. “Humans First? On the Use of Chimpanzee vs Human Subjects in Biomedical Research”. NIH Grand Rounds (with Francis Collins), Bethesda, MD, 30 Apr 2014.

Kahn J. “Ethics and Research on non-Human Primates”. Invited presentation for NRC Workshop on Biodemography, Washington, DC, 8 Apr 2014.

Kahn J. “The Future of Genetic Testing: From the Supreme Court to Personalized Medicine”. Mt. Sinai Community Foundation Annual Event Keynote Address, Minneapolis, MN, 3 Nov 2013.

Kahn J. “Informed Consent and Health Research Online”. Panel presentation at Medicine 2.0, London, England, 23 Sept 2013.

Kahn J. “Informed Consent for Research in Online Environments.” Invited presentation to Secretary’s Advisory Committee on Human Research Protections, Washington, DC, 11 July 2013.

Kass N. NIH HCS Collaboratory Cluster Randomized Trials meeting, Bethesda, MD, 29 July 2013.

Kass N. “Regulatory Requirements to Studying Standard of Care Interventions”. HHS Public Meeting, Washington, DC, 28 Aug 2013.

Kass N. Armstrong Institute Patient Safety Grand Rounds, Baltimore, MD, 12 Sept 2013.

Kass N. Johns Hopkins C-RAC/Advisory Board Training, Baltimore, MD, 10 Oct 2013.

Kass N. “The Increasingly Blurry Distinction between Medical Research and Practice”. PRIM&R Conference Panel, Boston, MA, 7 Dec 2013.

Kass N. Fogarty Africa training Consortium Meeting, University of Botswana, Botswana, 11 Jan 2014.

Kass N. “SUPPORT: Legal and Ethical Issues in Clinical Effectiveness Research”. Washington, DC, 23 Jan 2014.

Kass N. NIH HCS Collaboratory Steering Committee Meeting, Bethesda, MD, 24 Feb 2014.

Kass N. Penn State Rock Ethics Institute, University Park, PA, 26 Feb 2014.

Kass N. PCORI Workshop Learning Network Meeting, Washington, DC, 5 Mar 2014.

Kass N. PRIM&R APREC Conference, Singapore, 26 Mar 2014.

Kass N. “Health System Leaders Working Towards High Value Care through Integration of Care and Research”. IOM workshop, Washington, DC, 23-24 Apr 2014.

Kass N. NIH Department of Bioethics Seminar, Bethesda, MD, 28 May 2014.

Kass N. AcademyHealth Workshop, Washington, DC, 24 June 2014.

Morain S. “Best Practices for Managing Faculty-Industry Consulting Relationships: Results of a Delphi Study”. Podium Presentation, American Society for Bioethics & Humanities Annual Meeting, Atlanta, GA 26 Oct 2013.

Morain S. “Obesity Policy, Legitimacy, and Public Engagement”. Panel Session, American Society for Bioethics & Humanities Annual Meeting, Atlanta, GA, 25 Oct 2013.

Morain S. “Public Opinion, Public Engagement, & Public Health Policy”. Invited Presentation, National Policy & Legal Analysis Network to Prevent Childhood Obesity, San Francisco, CA, 10 Oct 2013.

Nolan MT. “Educational Collaborations in a Global World”. American Association of Colleges of Nursing, Faculty Development Conference, Fort Worth, TX, 6 Feb 2014.

Pratt B. “The Ethics of Priority Setting for Health Systems Research in Developing Countries: Should Global Priorities Drive National Priorities?”. 12th World Congress of Bioethics, Mexico City, Mexico, 25-27 June 2014.

Pratt B. “Ethical Issues in Health Systems Research in Low and Middle-Income Countries: A Global Justice Perspective”. 2014 Global Health Conference. Washington DC, 10 May 2014.

Richardson HS, **Merritt MW,** Largent E, Capron AM. “Medical Researchers’ Ancillary-Care Obligations: Working Out a Philosophical Account That Is Empirically Informed and Practically Useful”. American Society for Bioethics and Humanities annual meeting, Atlanta, GA, 25 Oct 2013.

Rubenstein LS. “Professional Ethics and the Values of Medicine”. National Academy of Sciences, Washington, DC, Oct 2013.

Rubenstein LS. “Protection of Health Workers in Conflict”. Global Forum on Human Resources for Health, Recife, Brazil, Nov 2013.

Rubenstein LS. “Protection of Health in Armed Conflict”. American Public Health Association, Boston, MA, Nov 2013.

Rubenstein LS. “Paradoxes of Health Security in an Age of Terrorism”. Royal Society of Medicine, London England, 2014.

Rubenstein LS. “Protection of Health in Armed Conflict”. Switchpoint Conference, Raleigh, NC, 2014.

Rubenstein LS. “Dual Loyalty in Military Medicine”. Defense Health Board, Washington, DC, 2014.

Rubenstein LS. “Protection of Health in Armed Conflict”. Defenders of Medical Neutrality in the Middle East, Beirut Lebanon, 2014.

Rushton CH. “They Don’t Believe Me”: The Voice of Patients living with the Pain of Sickle Cell Disease”. The Patient’s Voice, 10th Annual International Conference on Clinical Ethics Consultation, Paris, France; Apr 2014.

Sugarman J. “Bio-PIN: Bioethical and Practical Considerations for Biorepositories”, National Cancer Institute, Bethesda, MD, 25 July 2013.

Sugarman J. “Clinical Ethics at the End-of-Life”. Committee on Approaching Death: Addressing Key End of Life Issues, Institute of Medicine, Houston, TX, 22 July 2013.

Sugarman J. “Consent: Processes, Criteria, and Considerations for Obtaining Informed Consent”. Public Responsibility in Medicine and Research, Asia Pacific Research Ethics Conference, Singapore, 26 Mar 2014.

Sugarman J. “Doctor Knows Best? Risk and Consent when Research Involves “Standard of Care” Interventions [Moderator]”. Public Responsibility in Medicine and Research, 2013 Advancing Ethical Research Conference, Boston, MA, 8 Nov 2013.

Sugarman J. “Ethical and Policy Issues in Stem Cell Research”. EPFL, Lausanne, Switzerland, 19 Aug 2013.

Sugarman J. “Ethics and Regulatory Task Force, PCORnet: Building Evidence through Innovation and Collaboration”. The Brookings Institution, Washington, DC, 22 Jan 2014.

Sugarman J. “Ethical Challenges in Medical and Surgical Innovations, Society for Ear, Nose, and Throat Advances in Children”. Long Beach, CA, 6 Dec 2013.

Sugarman J. “Ethical Issues in Global Health Initiatives”. 6th Annual Alliance for Surgery and Anesthesia Presence Meeting, Durham, NC, 6 Sept 2013.

Sugarman J. “Ethical Issues in Unrelated Donations”. National Marrow Donor Program Council Meeting 2013, Minneapolis, MN, 18 Oct 2013.

Sugarman J. “Ethical Hazards of Stem Cell Tourism”. World Marrow Donor Association and International Donor Registry Conference, London, UK, May 17, 2014.

Sugarman J. “Fundamentals of International Clinical Research”. International Clinical Studies Support Center, Bangkok, Thailand, 16-17 Sept 2013.

Sugarman J. “Fundamentals of International Clinical Research”. International Clinical Studies Support Center, Santiago, Chile, 27-28 Feb 2014.

Sugarman J. Moderator: “Pediatric Medical Countermeasure (MCM) Research: Enumerating Ethical Considerations to Aid with Policy Decisions”. Public Responsibility in Medicine and Research, 2013 Advancing Ethical Research Conference, Boston, MA, 7 Nov 2013.

Sugarman J. “Research Ethics and Institutional Review Board/Ethics Committee Operations”. International Clinical Studies Support Center Workshop, Shanghai, China, 8-9 Apr 2014.

Sugarman J. “Responsibility in Global Clinical Research”. Global Clinical Research Summit 2013, Daegu, Korea, 1 Oct 2013.

Sugarman J. Panelist: “Think Outside of the ERC: A Reflection on How to Move Towards Better Research Ethics Systems”. Global Forum on Bioethics in Research, Mexico City, MX, 24 June 2014.

Sugarman J. “Wrestling with the Bioethics of TasP in a World without Universal ART, Controlling the HIV Epidemic with Antiretrovirals: From Consensus to Implementation”. International Association of Providers of AIDS Care, London, United Kingdom, 23 Sept 2013.

Taylor HA. “Conduct and Oversight of Research after a Natural/Man-Made Disaster”. Public Responsibility in Medicine and Research 2013, Boston, MA, Nov 2013.

Taylor HA. Panelist: “Addressing Institutional Review Board Barriers to Health Research Implementation Forum on Medical and Public Health Preparedness for Catastrophic Events”. Institute of Medicine, Bethesda, MD, June 2014.

Taylor HA. Panelist: “Bioethics Funding at the National Institutes of Health (NIH)”. Public Responsibility in Medicine and Research 2013, Boston, MA, Nov 2013.

Taylor HA. “Teaching and Learning Empirical Bioethics: Resources from the Presidential Bioethics Commission”. Association for Professional and Practical Ethics Annual Meeting 2014, Jacksonville, FL, Feb 2014.

Taylor HA. “The Current Landscape in Human Subjects Protections”. Workshop on Contemporary Issues in Human Subject Research, National Cancer Policy Forum, Institute of Medicine, Washington, DC, Feb 2014.

Unguru Y, DeCamp M, Adamson P, Joffe S. “Childhood Cancer and Chemotherapy Shortages: Ethical Challenges and Tragic Choices”. American Society for Bioethics and Humanities 2013 Annual Meeting, Atlanta, GA, 25 Oct 2013.

IN MEMORIAM: JOHN M. FREEMAN

The Berman Institute family is deeply saddened but also proud to honor and remember one of the Institute’s founding faculty members, John M. Freeman, MD, the Lederer Professor Emeritus of Pediatric Epilepsy and Professor of Neurology and Pediatrics, who passed away on Friday, January 3, 2014.

A true pioneer in both medicine and biomedical ethics, Prof. Freeman was instrumental in the creation of several parts of Johns Hopkins that have forever changed its culture and quality of care for the better: the Division of Pediatric Neurology, the Johns Hopkins Hospital Ethics Committee and Consultation Service, and the Johns Hopkins Berman Institute of Bioethics.

“John was an institutional visionary, as well as a phenomenal and extraordinary mentor,” says Berman Institute Founding Director Ruth Faden, PhD, MPH. “He was absolutely certain that we could have a world-class bioethics program at Hopkins if we never gave up. ‘Build it and they will come,’ was something John said to us time and time again,” Prof. Faden recalls. “And we didn’t give up, and we did get a phenomenal first-rate program here at Hopkins, and John was just critical; he was the person who had the unflagging confidence in a future for bioethics at Johns Hopkins.”

Prof. Freeman was also a steadfast advocate of two long-abandoned but highly effective therapies for treating epilepsy — a strict high-fat ketogenic diet, or “KD,” and hemispherectomy, surgery to remove or disable portions of one hemisphere of the cerebrum. His commitment to these therapies led to a resurgence in their acceptance and dramatic improvement in the lives of countless seriously ill children.

Guy McKhann, MD, founding head of the Hopkins’ Department of Neurology, explains that Prof. Freeman’s “resurrection of KD,” which completely eliminated the epileptic seizures of many patients, was accomplished “virtually all by himself, against great skepticism and opposition.”

Margaret Moon, MD, MPH, the Freeman Family Scholar in Clinical Medical Ethics at the Berman Institute, remembers Prof. Freeman as “a wonderful teacher.” She says, “His gift was in his tremendous intellectual curiosity, his clear-eyed pragmatism and his open challenge to respect, investigate and then overcome obstacles.” Prof. Moon worked with Prof. Freeman and other Berman Institute faculty members to build an active program in clinical ethics education for trainees throughout Johns Hopkins Medicine.

In addition to his skill as a pediatrician and neurologist, Prof. Freeman’s colleagues at the Berman Institute remember his humor, generosity and powerful understanding of compassion toward patients and their families. “John was a wonderful friend and a mentor who personified intelligence energized by vision and bounded by humility,” Prof. Moon says.



HONORS, AWARDS, AND PROMOTIONS

Renee Boss was promoted to Associate Professor in the Division of Neonatology, Department of Pediatrics, at the Johns Hopkins University School of Medicine. Dr. Boss also became the Co-Director of the Hecht-Levi Fellowship Program at the Johns Hopkins Berman Institute of Bioethics. She also served as the Chair of the Ethics Consultation Standards Sub-Committee for the Johns Hopkins Hospital Ethics Consultation Service.

Joe Carrese was promoted to professor in the Department of Medicine.

Matthew DeCamp became an Associate Faculty member of the Berman Institute.

PhD student **Lauren Ellis** was awarded the Jane Culley Doctoral Scholarship in Health Policy and Management and was a Centers of Excellence in Regulatory Science and Innovation (CERSI) Scholar.

PhD student **Rachel Fabi** earned the Marcia Pines Prize for best ethics paper by a Johns Hopkins School of Public Health student.

Ruth Faden was installed as the inaugural Andreas C. Dracopoulos Director of the Berman Institute.

Adnan Hyder and PhD student **Bridget Pratt** were awarded the 2014 Mark S. Ehrenreich Prize in Healthcare Ethics Research (awarded at 12th World Congress of Bioethics in June 2014) for the paper “Global Justice and Health Systems Research in Low and Middle-Income Countries”.

Jeff Kahn was elected as a member of the Delta Omega Honorary Society in Public Health, Alpha Chapter (Johns Hopkins Bloomberg School of Public Health) and was appointed Chair of the Board on Health Sciences Policy at the Institute of Medicine (IOM).

Maria Merritt was selected to participate in the Johns Hopkins Medicine Leadership Program for Women Faculty for 2014-15.

Leonard Rubenstein received the Distinguished Service award from the International Health Section of the American Public Health Association.

Cynda Rushton was elected as a fellow at the Hastings Center. Dr. Rushton was also listed as one of the Top 100 Women in Maryland by The Daily Record of Baltimore, Maryland, and received the Center for Health Care Ethics Milestone Award for Bioethics Leadership from Lakehead University in Ontario, Canada.

Jeremy Sugarman was honored as a member of the Association of American Physicians and received the Robert Rubin Award from the Society for Ear, Nose & Throat Advances in Children.

Yoram Unguru was promoted from Associate to Core Faculty in the Berman Institute. Dr. Unguru was also selected by Baltimore Magazine as a Top Doctor in Pediatric Hematology and Oncology.

CORE FACULTY

The heart of the Berman Institute is its people, particularly the faculty we have assembled. We offer the distinction of “core faculty member” to anyone who commits 30% of their professional time to advancing the field of bioethics. Most also hold appointments in other divisions across Johns Hopkins University, underscoring our commitment to cross-divisional and interdisciplinary work.

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Names highlighted in italics indicate those donors who are members of the Berman Society, a new group initiated in the past year. Dr. John M. Freeman, one of the 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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As a member of the Berman Institute's National Advisory Board, I value the research initiatives and discussions that are actively shaping a global approach to ethics in medicine. As a medical marketing professional, I often debate the role of ethical principles when necessary in the marketing of prescription products, including equal access to healthcare and prescription drug costs as areas of relevance. I am honored to give my time to support the Berman Institute's commitment to the advancement of ethics in clinical practice, biomedical science and public health.”

- Julia Kirkland



With support from committed partners like Julia Kirkland, the Berman Institute will continue to have a significant impact on scholarship, policy and practice. 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 Julia Kirkland and others who understand the critical need for bioethics scholarship and research. Bioethics is ultimately concerned with doing what's right in the fields of biomedical science, public health, and clinical practice.

And that is important to all of us.

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