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. DRAÇOPOULOS DIRECTOR
PHILIP FRANKLIN WAGLEY PROFESSOR OF BIO MEDICAL ETHICS

CONTENTS

2 MILESTONES
3 The Andreas C. Dracopoulos Director of the Berman Institute
4 Master of Bioethics Program
5 Impacting Public Policy

6 ISSUES IN BIOETHICS
6 Brain Death
8 “Three-Parent” Embryos
10 Shortages of Life-Saving Drugs
12 Obesity and the “Nanny State”

14 PUBLICATIONS
18 EDUCATION AND TRAINING
18 Academic Programs
19 Intensive Global Bioethics Training Program
19 Hecht-Levi Fellowship Program in Bioethics

20 OUTREACH
20 The Berman Institute Asks: What Would You Do?
20 Berman Institute in the News
20 Bioethics Bulletin: Top Stories
21 Presentations

24 OUR COMMUNITY
24 In Memoriam: John M. Freeman
25 Honors, Awards, and Promotions
25 Faculty
26 Staff
27 Donors
28 National Advisory Board
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.”

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.
The Berman Institute of Bioethics annual report 2013-2014

milestones

S P A C E
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related to medicine, health sciences, and public health.

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 Institute-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 sponsored missions. The report included a “decision framework” for replacing, or relaxing health standards for these higher-risk missions. The committee established health standards for high risk, long-duration missions. Among the committee’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.

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 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.

Marilise 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?”

The universality Prof. Rushton hits on is a key point, and 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.
“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.”

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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 Huckabay 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.

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 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.”
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.”

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

NANCY KASS

OBESITY AND THE “NANNY STATE”

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.”
The Berm

S

T

Lifesaving Resources during Disasters”.

A Pilot Study Comparing Patient Statements To Chart Reports”.

Oct 2013.

Beck DM, Dossey BM, ...

of Health Literacy on Desire for Participation in Healthcare, Medical ...

Intern Med

Faden

Review”.

Black B

Journal of the American Geriatrics Society

Complex Cardiac Disease: Searching for Threshold Benefit”.

Boss

for Critically Ill Newborns: “It makes me question my own morals”.

Doukas DJ, McCullough LB, Wear S, Lehmann LS, Nixon LL, ...

From Caregiving to Widowhood”.

New England Journal of

Effectiveness and Learning Health Care”.

Bosd FR, Kass NE, Goodman SN, Provost P, Tunis S, Beauchamp TL.

For Ethical Book for a Leukemia NICU Patient”.

Departure from Traditional Research Ethics and Clinical Ethics”,


Bosd FR, Kass NE, Whicker D, Steward W, Tunis S. “Ethics and Informal Consent for Comparative Effectiveness Research with Prospective Electronic Clinical Data”.

Medical Care 53(3): 337-37 2015.

Farley JE, Landers TF, Godfrey L, Lyke V, Suarez J. “Optimizing the Protection of Research Participants and Personnel in HIV-related Research Where TB is Prevalent: Practical Solutions for Improving HIV-related Research”.


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 HUSB

Hilary Bisk, 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 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 Witches, PhD, MHS, on her graduation from the program. Dr. Witches’s dissertation looked at balancing two concerns: 1) protecting and respecting individuals who might be asked to participate in comparative effectiveness research (CEER) 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 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.

HECHT-LEVY 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, MD, PhD, MPH, the program combines intensive coursework with applied, skill-oriented learning to develop participants’ knowledge and skills in international research ethics.

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.

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, MPH, PhD, and Jeffrey Kahn, PhD, MPH, spoke to a packed house of film and television producers and screenwriters, 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.

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 Kao, Sc.D. and Jeremy Sugarman, MD, MPH, joined Prof. Faden and Kahn for a redux of the program at Johns Hopkins Alumni Reunion Weekend in Baltimore. Neil Greenfield, a 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.
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 members, John M. Freeman, MD, the Lieberman 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 Johns 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.

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-disciplinary and interdisciplinary work.

Jeffrey Kahn, PHD, MPH Deputy Director for Policy and Administration, Johns Hopkins Berman Institute of Bioethics; Robert Henry Levi and Ryda Hecht Levi Professor of Bioethics, Associate Professor, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health

Nancy Kass, ScD Deputy Director for Public Health, Johns Hopkins Berman Institute of Bioethics; Phoebe R. Berman Professor of Bioethics and Public Health; Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health

Debra Mathes, MA Assistant Director for Science Programs, Johns Hopkins Berman Institute of Bioethics; Assistant Professor, Department of Pediatrics, Johns Hopkins School of Medicine

Margaret Moon, MD, MPH Freeman Family Scholar in Clinical Medical Ethics, Johns Hopkins Berman Institute of Bioethics; Assistant Professor; Department of General Pediatrics and Adolescent Medicine, Johns Hopkins School of Medicine
The Beren Institute is grateful for the generous support of its donors in fiscal year 2024. Listed below are all the individuals and foundations that supported our mission during the past year.

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