

1995 • 2020

25
YEARS



PUTTING
ETHICS INTO
ACTION

25-YEAR RETROSPECTIVE
AND
ANNUAL REPORT 2018-2019



JOHNS HOPKINS
BERMAN INSTITUTE
of BIOETHICS

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DIRECTOR'S MESSAGE

It is my pleasure to share with you this special version of the Berman Institute of Bioethics Annual Report that celebrates all that we have achieved in the last year, as well as throughout our entire 25-year history. As we observe this milestone anniversary during 2020, we'll reflect on those achievements while also envisioning possibilities for what is to come.

The Berman Institute's legacy over its first 25 years has been its leadership in helping to establish a young and interdisciplinary field of research, scholarship, education, service, and outreach. As bioethics has grown from its roots in medical ethics and philosophy, the Berman Institute's faculty led the expansion first into the realm of public health and subsequently into a broad range of interdisciplinary work, with a wide range of real-world applications. Today, bioethics is an integral part not only of clinical medical practice and public health, but also science, research, policymaking, and virtually every area where new biomedical and technological innovations raise important ethical and policy issues.

Two groups have been integral to the Berman Institute's growth and impact — our remarkable faculty and our engaged and generous philanthropic supporters, working together to realize our shared commitment to the betterment of human life by addressing ethical issues in science, clinical care, and public health, locally and globally.

Much of our success has been enabled by the resources provided through endowed professorships, making us unique among bioethics programs for the number of star faculty we are able to recruit as endowed faculty. That legacy will continue to grow, as in 2019 we added a second Bloomberg Distinguished Professor to our faculty, and received a gift pledge to create a new endowed professorship in bioethics education.

The renovation and eventual naming of our home, Deering Hall, was a key historical moment as it solidified our position as an interdisciplinary inter-school institute within Johns Hopkins University and created a center of gravity for bioethics at Hopkins as well as a single home for our faculty, staff, and students. This year the University announced another important moment in our history, with the plan to construct an additional new building adjoining Deering Hall and named for Henrietta Lacks. This interdisciplinary building will enable us to expand our work in significant and important ways, and partnering with programs in the School of Medicine to promote research ethics and engagement with the East Baltimore community.

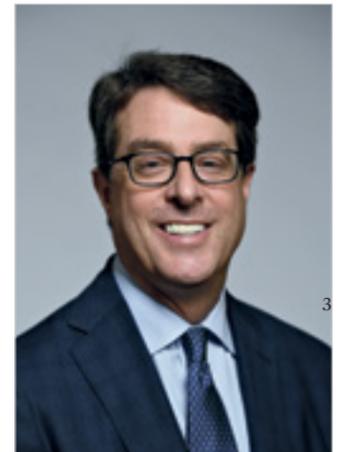
In the pages that follow, we share the history of the Berman Institute of Bioethics and proudly recognize everyone that has supported us over the past 25 years. Every name listed has played an important part in our story. I would be remiss, however, if I didn't call particular attention to a few individuals whose efforts have been foundational to our growth and success. Andreas Dracopoulos and Lynn Deering literally helped to shape our home in Deering Hall and the programs that fill it. Board Chairs over our first 25 years Morris Offit, Bud Meyerhoff and Alex Levi along with his wife Vicki have provided tireless support and wise counsel, and their philanthropy has set us on the course for success in the next 25 years and beyond. And finally, Ruth Faden, whose vision, drive, and humanity set a professional and personal standard for all who work in the institute that would not exist without her efforts.

It is an exciting time at the Berman Institute, and I look forward to sharing that excitement in the year ahead as we join together to celebrate a quarter-century of remarkable achievement and to anticipate what comes next in the field of bioethics and for us in the Institute.

Sincerely,



Jeffrey P. Kahn, PhD, MPH
ANDREAS C. DRACOPOULOS DIRECTOR
ROBERT HENRY LEVI AND RYDA HECHT LEVI PROFESSOR
OF BIOETHICS AND PUBLIC POLICY



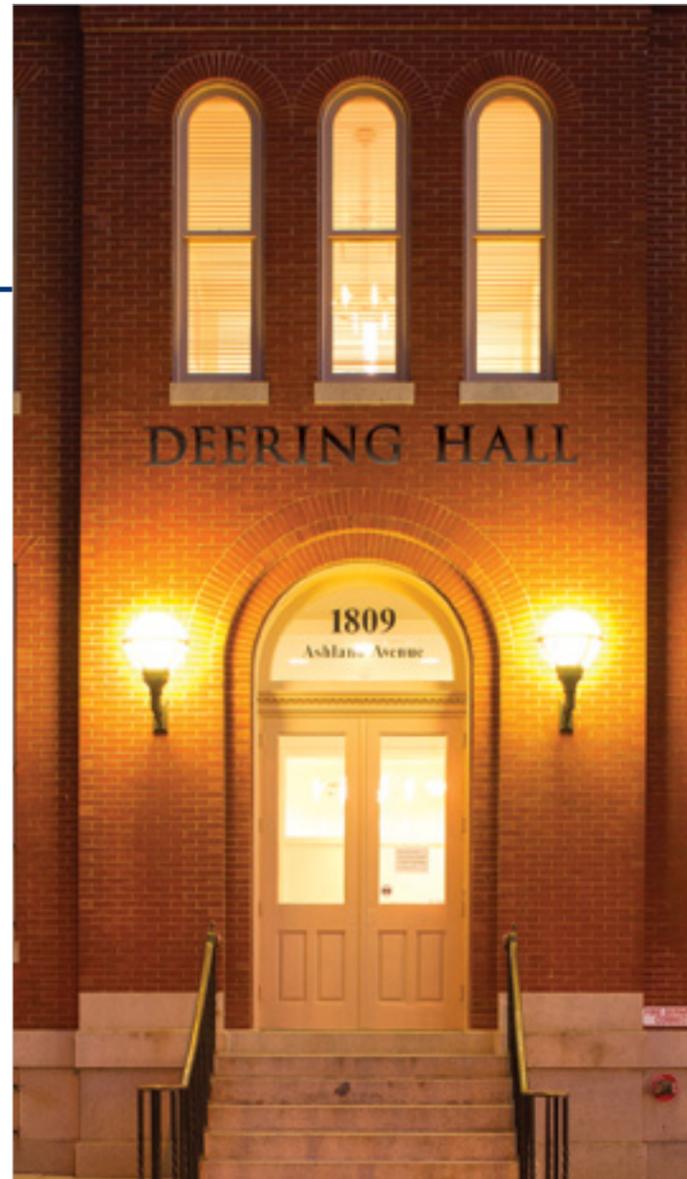
THE BERMAN INSTITUTE OF BIOETHICS: 25 YEARS OF PUTTING ETHICS INTO ACTION

From its origins as a small group of scholars from diverse fields sharing a fascination with and appreciation for the ethics of health care and science, the Berman Institute of Bioethics has grown over the past quarter-century into a global leader that helps shape policy and practices for the betterment of people around the world.

“With the creation of the Berman Institute 25 years ago, Johns Hopkins formally recognized how important it is for scholars to think systemically and critically about the ethics of health care, public health, and biomedical and behavioral research,” said President Ronald J. Daniels. “A truly interdisciplinary center, the Institute brings together expertise from across the University to collaborate and contribute substantially to the world of ideas that advance society and improve people’s lives.”

Shaped by visionary leadership and volunteer supporters, sustained by brilliant minds that continue to define a vital and ever-evolving field, the Berman Institute of Bioethics puts ethics into action to produce real world impact.

Today, as it proudly commemorates a remarkable quarter-century, the Institute stands poised for ever greater achievements in the years to come.



ORIGINS

Medical ethics is nearly as old as medicine itself. The Hippocratic Oath, for example, dates from somewhere between the 5th and the 3rd centuries, BC.

The Berman Institute of Bioethics dates back 25 years, not centuries. But modern bioethics, in which the Berman Institute has become a global leader, is much broader than medical ethics, itself now a subfield

within bioethics. Contemporary bioethics now addresses not only the ethics of medicine and nursing, but also the ethics of the biological sciences and of national and global public health policies. It is an interdisciplinary field in which philosophers, theologians, legal scholars, social and biological scientists, scholars and professionals in public health, physicians, nurses, and other health professionals work together on ethical challenges.

The field took shape in the post-World War II era, prompted in part by revelations of unethical research with human subjects. These included atrocities perpetrated in Nazi concentration camps, but also violations of human rights by American researchers, most notably the Tuskegee syphilis study. Between 1932 and 1972, the United States Public Health Service studied hundreds of poor African-American men in rural Alabama who were told only that they were receiving free health care. In reality, the purpose of the study was to observe the progression of untreated syphilis and the men received no effective care for the disease as they died, went blind, or experienced other severe health problems.

Jeffrey Kahn, the Andreas C. Dracopolous Director of the Berman Institute, also dates the formal study of bioethics to advances in medicine and the invention of medical devices that allow the once-impossible to happen. He cites kidney dialysis, a life-saving machine that was once in short supply, as well as ventilators, which kept young Karen Quinlan alive long after it was thought possible in the landmark 1970s right-to-life case.

“The birth of the field came from focusing on ethical issues in medicine, but Ruth Faden brought attention to ethical issues in public health, a focus of bioethics in which Ruth has been a longtime leader,” says Kahn. “Moreover, through her intellect, determination, energy, and grace she not only founded the Berman Institute, but also ensured its continued stature as a global leader in bioethics.”

Phoebe Rhea Berman believed there was no better place than Johns Hopkins to address the ethical dilemmas raised by advances in medical discovery: “With all the complexities of modern life — new discoveries in science, changes in medicine and medical care — medical professionals and policy makers are faced with very difficult decisions. There is a need for the teaching of ethics in our society.”

To underscore this conviction, in 1995 Berman established an endowment for the Institute that today bears her name, saying, “If you have more money than you need, you should give some of it away, shouldn’t you? And what better to support than the Bioethics Institute? The work that is being done there has great meaning for me and can make a real difference in society.”

Berman grew up on a farm and at a young age developed what she called a reverence for life. Many decades later, she and her husband went to French Equatorial Africa to work with Albert Schweitzer as long-term volunteers. Schweitzer’s work inspired her, and her commitment to the need for ethical

considerations in medical and scientific decision-making was reaffirmed and strengthened. “You have to have a strong heart and great will to make the kind of difference someone like Dr. Schweitzer made. All I am doing is making a contribution in a way that is meaningful for me,” Berman said when interviewed about this chapter in her life.

Berman had previously established the Edgar Berman Professorship in International Health and the Edgar Berman and Hubert Humphrey Fund in International Health at the Bloomberg School of Public Health to honor the memory of her husband, Edgar Berman, a pioneering surgeon, an outspoken social critic, and best-selling author. Berman was also a dedicated supporter of the arts, contributing to the Peabody Institute, the Baltimore Museum of Art, and the Baltimore Symphony.

Berman’s bequest to name the Bioethics Institute was the critical catalyst for the creation of the successful Institute we know today, and the Berman Institute of Bioethics remains indebted to her beyond measure. Mrs. Berman had the deep conviction that questions of bioethics were essential to the future of humanity, and she expressed that conviction by entrusting the institute with her legacy.



A VISIONARY LEADER

When Faden began her scholarly career in the 1970s bioethics scarcely existed as an academic discipline. At the time, she recalls, there were two bioethics institutes in the country and no doctoral programs or postdoctoral fellowships.

Now, including ethics in the curriculum is required as part of medical school accreditation. Every accredited medical school in the United States teaches the subject. And bioethics is also taught at the undergraduate level in colleges and universities around the world, and in graduate and professional schools of public health and law.

Faden's initial focus was informed consent, the subject of her doctoral dissertation at the University of California. "I came from the women's angle," says Faden who, during her Berkeley years, volunteered at a women's advocacy law firm.

For one of its cases, she looked into allegations that Latino women in southern California were being sterilized without their permission after giving birth. She discovered that the hospital was giving the women a consent form written only in English, a language they didn't necessarily understand, and she reported her findings to the

law firm that was doing the work (though she never found out what was done with the information).

Following graduate school, Faden's first job was teaching public health psychology at the Johns Hopkins School of Public Health. Soon after, she began offering a graduate elective on public health ethics. One of her first students was Nancy Kass.

"I didn't enter graduate school thinking I wanted to do ethics at all," said Kass, who is today the Phoebe R. Berman Professor of Bioethics and Public Health at Johns Hopkins, as well as the Deputy Director for Public Health at the Berman Institute and the University's Vice Provost for Graduate and Professional Education. "I fell in love with the class, and fell in love with Ruth, who became my advisor. She then created a second public health ethics class on justice which I took and loved, although it was one of the hardest classes I took in graduate school."

Faden continued to expand ethics offerings in the School of Public Health and continued to attract talented people — faculty and students alike — who shared her interest in the growing field of bioethics. She organized what was then called the Bioethics Interest Group, an interdisciplinary



RUTH FADEN

collection of scholars, many of whom would comprise the Berman Institute's founding faculty. The School of Public Health began to offer a Law, Ethics and Health track.

"My vision for bioethics at Johns Hopkins was that it would be independent of and serve as a bridge between all the schools. While Medicine and Public Health were, for example, very important to what we hoped to create, to properly tackle bioethics issues we needed talent and disciplinary insight far broader than any one or even two schools

could provide. We needed to draw expertise from across the entire University. And we needed a structure that would make faculty from anywhere in the University feel equally valued and valuable. If we were a program within one School, that would have sent the wrong signal, both within the University and externally," said Faden. "We needed to stand alone."

She found champions for her idea in then-JHU President Bill Richardson and Morris Offit, Chair of the University's Board from 1990 to 1996.

RUTH FADEN



According to JHU President Ronald J. Daniels, "Twenty-five years ago, Johns Hopkins formally recognized how important it is for scholars to think systematically and critically about the ethics of health care, public health, and biomedical and behavioral research. The university reached that recognition largely because of one faculty member: Ruth R. Faden."

"Without Dr. Faden's vision, scholarship, determination, and leadership, what we know today as the Berman Institute of Bioethics would not exist. Her international reputation as a scholar and leader in bioethics has added great luster to the reputation of both the Institute and the university."

In addition to her achievements in founding and leading the Berman Institute for its first 21 years, Faden, the Philip Franklin Wagley Professor of Biomedical Ethics is renowned for her work as a bioethics scholar — including her influential book *A History and Theory of Informed Consent*, which she published in 1986 with her husband, philosopher Tom L. Beauchamp. She has continued to exert influence on both the theory and practice of bioethics, focusing her scholarly work primarily on questions of

justice. Her book, *Social Justice*, with co-author Madison Powers, is considered a landmark in the field, and the two have recently published a follow-up, *Structural Injustice: Power, Advantage, and Human Rights*.

So, too, is her work on justice in specific public policy contexts, including new biomedical technologies, threats to the public's health, allocation of resources, and the health interests of women. Faden is a leading voice in revising the moral relationship between research and practice to help bring about higher quality and more just health care systems, and in focusing attention on issues of justice in global food security.

Faden has chaired numerous national and international committees. Perhaps most notably, she was appointed by President Bill Clinton to chair

his Advisory Committee on Human Radiation Experiments whose report remains a landmark in bioethics and public policy. Faden is an elected Fellow of the Hastings Center and an elected member of the National Academy of Medicine (formerly Institute of Medicine). She has received lifetime achievement awards from the American Society for Bioethics and Humanities, The Hastings Center, and Public Responsibility in Medicine and Research. She is also a recipient of the Adam Yarmolinsky Medal, awarded to a National Academy of Medicine member from a discipline outside the health and medical sciences to honor distinguished service and contribution to the Academy's mission.



HARVEY "BUD" MEYERHOFF AND MORRIS OFFIT

ENGAGED VOLUNTEER LEADERSHIP

"An independent bioethics institute was a natural fit bringing together all the issues Johns Hopkins engages with, from medicine, public health, and arts and sciences," said Offit. "The Berman Institute's extraordinary faculty complements the breadth of Hopkins' work across these different divisions. Johns Hopkins was the ideal place to get this work started and see it further flower."

In 1995, the University formally established what was then known as the Bioethics Institute. The funds allocated were extremely small, allowing for the hiring of one staff person, and the creation of a small seminar series.

Just as Offit's chairmanship of the JHU Board was ending, Faden convinced him to serve as Chair of the new Institute's Advisory Board. His enthusiastic support helped inspire similar interest from University leadership and philanthropic supporters, as evidenced by the Advisory Board's first meeting on April 10, 1996. Seated around Offit were writers, philosophers, jurists, medical researchers and philanthropists from across the country. In addition, they were joined by Alfred Sommer, dean of the School of Public Health; Ronald R. Peterson, president of

DR. JOHN FREEMAN

John Freeman, the Lederer Professor of Pediatric Epilepsy and professor of Neurology and Pediatrics at the School of Medicine, played a pivotal role in the Berman Institute's birth as a critical supporter of what would become its mission and one of its founding faculty members. Freeman was an internationally renowned pediatric neurologist and medical ethicist whose questions of established medical practices revolutionized the treatment of pediatric epilepsy and advanced the development of modern medical ethics.

An outspoken advocate of patient rights throughout his career, Freeman wrote extensively on the ethical and medical issues surrounding the treatment of severely ill newborns with congenital defects. He showed special concern for maintaining the dignity of individual patients and striving to ensure that each had a life that was as independent, fulfilling and as close to normal as possible. He was the founding chairman of the Johns

Hopkins Hospital Ethics Committee and co-director of a course in bioethics for students at the Johns Hopkins University School of Medicine.

"John was an institutional visionary, as well as a phenomenal and extraordinary mentor," said Ruth Faden. "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. And we didn't give up, and we did get a phenomenal first-rate program here at Hopkins, and John was just critical; he had unflagging confidence in a future for bioethics at Johns Hopkins."

Freeman passed away in 2014 at the age of 80. In his memory, his wife of 57 years, Elaine Kaplan Freeman, has supported the Berman Institute's "Ethics for Lunch" series, as well as clinical ethics education, with a significant gift in his honor. This monthly conference series at Johns Hopkins Hospital attracts

attendees from across the entire hospital community — physicians, nurses, medical students, social workers, chaplains, etc. — to participate in discussion about an important clinical ethics issue.

"John Freeman was a world-famous physician, and one who always put the



well-being of his patients ahead of any other concern," said Jeffrey Kahn. "This series helps inspire other clinicians to do the same and is a fitting legacy for John's commitments to patient care and medical ethics."

Johns Hopkins Hospital and Johns Hopkins Health System; Edward Miller, CEO of Hopkins Medicine and dean of the faculty of the School of Medicine; Steven Knapp, university provost and vice president for academic affairs; Sue Donaldson, dean of the School of Nursing; and university President William R. Brody.

Offit glanced down the long conference table and asked a startling question. "What I'd like to know," he said in mock seriousness as he looked around, "is just who's running the university?"

Offit was joking, of course, and he got a laugh from those present. But the involvement of so many from among the university's top leadership bolstered Faden's confidence that she could

achieve her aspiration: that the university would support her in building an Institute that would be designed to last.

As important as his role was in the Institute's founding, Offit's largest impact might have been in identifying and recruiting the two individuals who would subsequently succeed him as Chair of the Advisory Board: Bud Meyerhoff and Alex Levi. They would both play vital roles in the Berman Institute's dramatic growth and success.

A WORLD CLASS FACULTY

Following its official creation in 1995, the Berman Institute did not have the institutional status to hire its own faculty. Rather, faculty with a primary appointment at one of the University's schools could seek to add an additional affiliation with the institute. Despite this limitation, scholars from across Hopkins jumped at the opportunity to be associated with this new place to engage in the formal study of bioethics.

"Ruth brought together a diverse group of faculty who, over the years, had come to talk with her about ethics issues in their own work. The new bioethics institute, she made perfectly clear, could offer faculty no money and provide faculty with no space. Instead, faculty would be asked to attend yet another monthly faculty meeting, held at night, after hours. And everyone flocked to join," said Nancy Kass.

"Why did we keep coming? I don't know exactly. To some degree, the ideas were compelling, and having others show up after hours to discuss them validated that ethics challenges in our work were worth thinking further about. But more importantly, I think faculty came because of Ruth. Her own sense of purpose, the clarity of her thinking, and the respect, compassion, and gratitude she exuded — to everyone, and I mean everyone — made her vision the bandwagon on which everyone wanted to jump."

Although fiercely committed to the Bioethics Institute's independence, Faden also recognized that early institutional support from Johns Hopkins Medicine played a vital role in helping establish the institute as a critical piece of the broader university. Widely respected School of Medicine faculty like John Freeman and Henry Seidel, who helped oversee all medical education as Dean of Student Affairs for 13 years, eagerly acknowledged the critical importance of bioethics training for house staff.



NANCY KASS AND RUTH FADEN

HARVEY M. "BUD" MEYERHOFF



Throughout the Berman Institute's history, most notably during his decade as Chair of the Advisory Board, Bud Meyerhoff's leadership and vision have been integral to its success. He spearheaded the Institute's strategic planning process, which helped formulate

the future vision of the Institute, develop a competitive strategy to achieve its goals, and create and organizational structure for that vision.

"Under Bud's leadership, the Bioethics Institute's Advisory Board meetings are not only widely admired at Hopkins but are considered by many to be a model for other board meetings at the university. When the faculty and board engage in conversation about bioethical dilemmas, the outcomes are unparalleled," said Steven Knapp, Johns Hopkins Provost during Meyerhoff's Board tenure.

Meyerhoff's guidance was also integral to purchase and renovation of the Berman Institute's permanent home in Deering Hall, which was dedicated in 2011.

"Without Bud, I don't think there would be a building devoted to the Berman Institute," said Ruth Faden. "Not only did he support the building philanthropically, his lifetime of experience in the construction industry proved invaluable in guiding the project forward. In a real sense, the expertise and time he invested in our building is the best gift we could have received."

In addition to his leadership on the Advisory Board, Meyerhoff made a generous commitment in 1999 to endow the Harvey M. Meyerhoff Professorship in Bioethics and Medicine. It has been held since its inception by Dr. Jeremy Sugarman, who had been the founding director of the Center for the Study of Medical Ethics and Humanities at Duke University. Dr. Sugarman's work concentrates on informed consent, research ethics, and the ethical issues associated with emerging technologies.

"As I told Bud years ago, I'm

honored to have his name on my business card," said Dr. Sugarman. When he endowed this chair, he sent a really strong message regarding the importance of ethics in the contemporary health care environment. He's incredibly important to the Berman Institute and Johns Hopkins — his dedication and leadership are unparalleled."

Tragically, much of Meyerhoff's initial interaction with the Berman Institute was motivated by witnessing the suffering of his beloved wife Lyn during her final days. That

experience fueled his deep conviction that bioethics is essential to a responsible future for medicine.

"When you've seen someone you love die from a terminal illness, it becomes very clear that we have to balance the possibilities technology offers to extend life with the individual's right to end the terminal illness in the manner and time of his or her choosing. We have to dialogue," said Meyerhoff.

“EXTRAORDINARY TALENT FROM OUR VERY FIRST DAYS”

For School of Medicine Professor Joseph Carrese, a core member of the Berman Institute faculty since its beginning and now Chair of the Johns Hopkins Bayview Medical Center Ethics Committee, the timing of his 1994 arrival at Johns Hopkins proved auspicious.

“I had done a fellowship in bioethics and wanted to make clinical ethics a major part of my career. But it was unclear how to do that without colleagues, structure and support. Then, within a year, the Berman Institute had formed, providing me a community of faculty colleagues,” he said.

“I benefited from senior faculty members involved in the Berman Institute who were not themselves trained in bioethics but were champions of educating residents and medical students about ethics. I’m very proud to have helped establish the Program on Ethics in Clinical Practice. In conjunction with the School of Medicine, this program has enabled us to teach ethics to hundreds and hundreds of residents in more than a half-dozen programs and been able to sustain that for almost 15 years.”

Pairing young faculty with experienced and supportive mentors was one important way of beginning to build the Institute’s top-notch faculty. Another was

identifying philanthropic supporters willing to endow professorships. Endowed chairs help attract and retain outstanding scholars, publicly endorsing and honoring the achievements of faculty and advancing the Institute’s expertise in particular areas of research. The support of Advisory Board members proved essential in helping advance the Berman Institute to a higher level of achievement.

“We were this new, tiny little part of Johns Hopkins and yet in relatively short order we are able to raise philanthropic support for five endowed chairs,” said Faden. “The chairs helped us hire and retain extraordinary talent and were critical to securing our future. Attracting outstanding people and finding the funds to keep them are a big part of how you make a new venture at a university a permanent one.”

One of the holders of the Institute’s now eight endowed faculty positions, Cynda Hylton Rushton is the Anne and George L. Bunting Professor of Clinical Ethics in the Berman Institute and the School of Nursing. A founding member of the Berman Institute, Rushton co-chairs the Johns Hopkins Hospital’s Ethics Consultation Service.



CYNDA HYLTON RUSHTON

“Mine is one of a very few chairs in the country that combines clinical ethics and nursing. It has provided an incredible platform for engaging the nursing community and broader healthcare community in discussions about that intersection,” she said.

“I couldn’t think of better people to represent than George and Anne Bunting. I would never have had the opportunities I’ve had without the endowed professorship, and I feel a great responsibility to leverage it for the profession of nursing and the field of bioethics.”



JOSEPH CARRESE

ANDREAS C. DRACOPOULOS



In 2014, the Berman Institute marked a milestone in its history, and in the field of bioethics, as Ruth Faden was installed as the inaugural Andreas C. Dracopoulos Director of the Berman Institute. University President Ronald Daniels spoke at the installation, acknowledging the groundbreaking achievement of an endowed directorship for a bioethics institute, the first such position in the world for the young, interdisciplinary field of scholarship.

The historic directorship was made possible by a generous gift from Mr. Dracopoulos, the Berman Institute Advisory Board member and Johns Hopkins trustee for whom it is named. Dracopoulos also spoke at the ceremony, recounting his first meeting with a Berman Institute faculty member in 1999, ophthalmologist Daniel Finkelstein, discussing “bedside manners” and the importance of treating the whole person. Finkelstein

introduced Dracopoulos to Faden, and he soon joined the Institute’s advisory board. “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 acknowl-

edgment of how promising the Institute’s future is both within the Hopkins family and within society at large,” said Dracopoulos at the ceremony for Faden’s installation. In 2016, Jeffrey Kahn succeeded Faden as the Berman Institute’s Director and assuming the Dracopoulos Directorship, saying at his own installation event: “Being named Andreas C. Dracopoulos Director of the Berman Institute is a dream

come true for me. I get to wake up every day and think about what is the right thing to do and how we might achieve it. What could be more fulfilling than leading the world’s leading bioethics institute full of talented colleagues with an opportunity to have a real effect on the world?”

A NEW GENERATION OF SCHOLARS

As the Berman Institute completed its first decade, a final hurdle to clear was providing a pathway for the next generation of junior faculty to succeed, developing young up-and-coming scholars to help sustain excellence in the field. The process is complicated since the Institute does not make its own tenure track appointments, and must make such hires in conjunction with one of the University's nine schools.

"We very much want this to be an environment where faculty can be successful. So we've worked hard to help interdisciplinary faculty be successful in the promotion and tenure process, which can be complicated for anyone let alone faculty with multiple academic homes," said Jeffrey Kahn. "We've helped demonstrate that bioethics is an area of scholarship that is valuable to broader fields like medicine and public health. Fortunately, the schools of medicine and public health work together closely here at Hopkins, and as a result bioethics and our interdisciplinary approach have been well received and our faculty have been very well supported in their careers."

Kahn cites the Berman Institute's Assistant Director for Science Programs, Debra Mathews, who is an Associate Professor in the School of Medicine's Department of Genetic Medicine, and School of Public Health Associate Professor Maria Merritt, who leads the JHU Exploration of Practical Ethics, as examples. In addition, the Institute may now make non-tenure track faculty appointments, such as



DEBRA MATHEWS

Assistant Director for Education Initiatives Travis Rieder, who directs the Master of Bioethics Program.

"With 44 faculty, we're larger than we've ever been and we continue to grow," said Kahn. "In addition to our traditional strengths in public health, clinical practice, and biomedical science, we're reinforcing connections with philosophy and other humanities departments and forging new relationships with other schools like business, engineering, and international affairs. Ethics is central to many of the great challenges facing humanity, challenges that do not fall neatly into one academic discipline or another. And our outstanding, interdisciplinary faculty prepares us to address these challenges as well as anyone."

JEFFREY KAHN



Following a global search to find the leader that would continue to guide the Berman Institute forward, Jeffrey Kahn was named Andreas C. Dracopoulos Director of the Berman Institute in 2016.

A renowned leader in bioethics whose work explores the intersection of ethics and health and science policy, Kahn came to the Berman Institute in 2011 as the inaugural Robert Henry Levi and Ryda Hecht Levi Professor of Bioethics and Public Policy, and served from 2011-2016 as the deputy director for policy and administration at the Berman Institute. Prior to joining the faculty at Johns Hopkins, Kahn was Director of the Center for Bioethics at the University of Minnesota where he held the Maas Family Endowed Chair in Bioethics. He was also founding president of the Association of Bioethics Program Directors, serving in that role from 2006 to 2010. Among the honors he has received, he is an elected member of the National Academy of Medicine (NAM), and an elected fellow of the Hastings Center.

Kahn has served on numerous state and federal advisory panels. He is currently chair of the NAM's Board on Health Sciences Policy, and chaired the Institute of Medicine's (now NAM) Committee on the Use of Chimpanzees in

Biomedical and Behavioral Research, the Committee on Ethics Principles and Guidelines for Health Standards for Long Duration and Exploration Spaceflights, and the Committee on Ethical and Social Implications of Mitochondrial Replacement Techniques. He also served on the NIH Recombinant DNA Advisory Committee, the National Academy of Sciences International Committee on Human Gene Editing: Scientific, Medical, and Ethical Considerations, and is currently a member of the International Science Academies International Commission on the Clinical Use of Human Germline Genome Editing.

During his more than 25-year career, he has been consistently funded to carry out groundbreaking interdisciplinary bioethics research. Most recently, the NIH awarded him and co-principal investigator Gail Geller a four-year, \$4.15 million award to launch the Johns Hopkins Center of Excellence in Ethical, Legal, and Social Implications of Genomic Uses in Infectious Diseases and Epidemics.

He has published over 125 articles and is the co-editor of four books including *The Oxford Handbook of Public Health Ethics*, *Contemporary Issues in Bioethics*, and *Beyond Consent: Seeking Justice in Research*. He speaks around the world on a range of bioethics topics, and is frequently quoted in the media. From 1998 to 2002, he penned the biweekly "Ethics Matters" column on CNN.com.

ENDOWED FACULTY POSITIONS

THE BERMAN INSTITUTE IS FORTUNATE TO HAVE SEVEN FACULTY HOLDING ENDOWED PROFESSORSHIPS, ALONG WITH THE DRACOPOULOS DIRECTORSHIP. ENDOWED PROFESSORSHIPS HELP ATTRACT AND RETAIN OUTSTANDING SCHOLARS, PUBLICLY ENDORSING AND HONORING THE ACHIEVEMENTS OF FACULTY AND ADVANCING THE INSTITUTE'S EXPERTISE IN PARTICULAR AREAS OF RESEARCH.

PHILIP FRANKLIN WAGLEY CHAIR IN BIOMEDICAL ETHICS
CURRENT CHAIR:
Ruth R. Faden
Established in 1995 by the Johns Hopkins Medical Institutions, Harvey M. Meyerhoff, and family and friends in honor of Dr. Philip Franklin Wagley

PHOEBE R. BERMAN PROFESSORSHIP OF BIOETHICS AND PUBLIC HEALTH
CURRENT CHAIR:
Nancy Kass
Established in 1996 by Phoebe Rhea Berman

ROBERT HENRY LEVI AND RYDA HECHT LEVI PROFESSORSHIP IN BIOETHICS AND PUBLIC POLICY
CURRENT CHAIR:
Jeffrey P. Kahn
Established in 2000 by the Levi Family in memory of Robert H. Levi and in honor of Ryda H. Levi

HARVEY M. MEYERHOFF PROFESSORSHIP IN BIOETHICS
CURRENT CHAIR:
Jeremy Sugarman
Established in 2004 with a commitment made in 1999 by Harvey M. Meyerhoff

ANNE AND GEORGE L. BUNTING PROFESSORSHIP IN CLINICAL ETHICS
CURRENT CHAIR:
Cynda Hylton Rushton
Established in 2012 by the Bunting Family

BLOOMBERG DISTINGUISHED ASSOCIATE PROFESSORSHIP OF ETHICS AND GLOBAL FOOD AND AGRICULTURE
CURRENT CHAIR:
Jessica Fanzo
Established in 2014 by Michael R. Bloomberg

BLOOMBERG DISTINGUISHED PROFESSOR OF PHILOSOPHY AND BIOETHICS
CURRENT CHAIR:
Hanna Pickard
Established in 2019 by Michael R. Bloomberg

MAKING CHANGE IN THE WORLD

“While the Berman Institute is a place of diverse scholarship and perspectives, there is a very core commitment to manifesting change in the world. Everyone is really oriented to making a difference,” said Rushton. “We might approach it in different ways, and employ different methodologies, but our unifying principle is let’s not sit around and talk about it, let’s do something.”

One key way that the Institute’s faculty bring ethics into the real world is through empirical research. Unlike many other bioethics programs that are largely populated by clinicians or philosophers, the Berman Institute’s broadly interdisciplinary faculty — and historic roots in public health — create a culture in which scholarly research, including the collection of empirical data, yields actionable insights.

“By doing so much empirical work, so much primary data collection around bioethics issues, we’re gathering data that can make big difference in public policy conversations. Very often it’s the descriptive data that becomes a springboard for people to realize that a particular issue is an ethics problem,” said Nancy Kass, whose research about the treatment of HIV-positive patients early in her career is an example.

“When you collect empirical data showing that people with HIV are being treated differently by medical providers when they come in with other medical problems, like a heart attack or a broken leg or some other condition completely unrelated to HIV — that might be signaling discrimination. And once you isolate and identify such a problem, then you can test interventions that will provide solutions.”

The primary way Berman Institute faculty have helped provide solutions is through their scholarship and its application to policy. Over the past 25 years,

they have published thousands of papers in leading academic journals, as well as scores of books — including some of the defining works in the field of bioethics — and hosted hundreds of conferences, symposia and seminars, aimed at addressing key ethical issues of the day (see The Berman Institute of Bioethics at 25: A Timeline, starting on page 26 for specific examples).

Additionally, the Berman Institute’s emphasis on real world impact takes faculty far beyond the halls of academe. Berman faculty help promote more ethically sensitive treatment of patients

at Johns Hopkins and Bayview Hospitals. They shape policy through service on national and international commissions, provide expert legislative testimony in Maryland and on Capitol Hill, and help inform the general public through robust media relations outreach.

“We’ve set a standard for bioethics scholarship and education that combines research, public health, science policy, clinical ethics, and fellowship training, and can serve as a model for centers nationally and internationally,” said Gail Geller, the Director of Education Initiatives.



ASSOCIATE DIRECTOR FOR GLOBAL PROGRAMS JOSEPH ALI REPRESENTING THE BERMAN INSTITUTE ON CAPITOL HILL

The Stavros Niarchos Foundation (SNF) is one of the world’s leading private, international philanthropic organizations, making grants to diverse nonprofit organizations around the world that have the potential for broad, lasting and positive social impact.

SNF has been a generous supporter of the Berman Institute throughout its history, helping us put ethics into action to effect positive change in the programs and projects that they support.

Most recently, SNF made possible the creation of the Stavros Niarchos Foundation Bioethics Academy, a Berman Institute initiative to support and enhance knowledge awareness of and training in bioethics in Greece. Other current and past projects supported by the SNF include the JHU Exploration of Practical Ethics, addressing new ethical issues that cross academic disciplinary lines and take place in a wide range of real-world circumstances, and the Berman Institute’s Rapid Response Initiative, which helped ensure the Institute’s leadership is at the front line of important debates with timely and wide-reaching distribution of high-quality research and analysis. SNF has also funded the Berman Institute’s 7 by 5 Project (see p. 21 for more information) in which an interdisciplinary and international group of experts in food and agriculture identified the most pressing ethical issues in global food, helping to launch the Institute’s Global Food Ethics and Policy Program (GFEPP).

“The SNF’s commitment to projects that make an impact in improving society makes it a natural fit with the Berman Institute,” said Jeffrey Kahn. “We are fortunate to have such a visionary and generous source of support for our work.”



INCREASING THE GLOBAL IMPACT OF BIOETHICS

Offering first-class fellowship training in bioethics has been a defining feature of the Institute almost from its inception. From 1995 through 2012, the Institute was the home of the Greenwall Fellowship Program in Bioethics and Health Policy. A collaborative effort of Johns Hopkins University and Georgetown University funded by the Greenwall Foundation, this Program provided an unparalleled opportunity, helping to launch almost 60 multi-disciplinary, post-doctoral fellows into careers in bioethics. The program and its faculty covered much of the waterfront of issues and methodologies in bioethics, from ethics and advances in biomedical science, to ethics and public health and health policy, to ethics and clinical care.

The distinguishing focus of the Program, however, was bioethics and public policy. All Greenwall Fellows were required to have a summer internship in a public policy setting, ranging from local to state and federal levels.

“During my internship at the New York City Department of Health and Mental Hygiene, I worked on the ethics of a policy proposal that considered excluding sugary drinks from the Supplemental Nutrition Assistance Program,” said Anne Barnhill, now a Research Scholar in the Berman Institute’s Global Food Ethics and Policy Program.

“That opportunity launched me on a line of researching regarding the ethics of obesity prevention and enabled me to develop a new expertise in food ethics. I can draw a line from those experiences to my current position.”

Barnhill is one of nine former Greenwall Fellows who have gone on to become members of the Institute’s faculty, while others have become frequent collaborators.

“The Greenwall Fellowship helped establish post-doctoral training as the prime pathway for young scholars in medicine, law, philosophy and the social and biological sciences who want to transition their talents towards bioethics,” said Faden. “Many of the alums of this intensely competitive program are among today’s most distinguished scholars and leaders in bioethics.”

Crucially, the Berman Institute’s training programs transcend international borders. Since 2000, with funding from the National Institutes of Health Fogarty International Center, the Institute is home to the Fogarty African Bioethics Training Program which supports collaborative training partnerships with institutions in sub-Saharan Africa to develop institutional capacity in research ethics and bioethics.

“The need for enhanced capacity in international research ethics and global bioethics is important, especially in low- and middle-income countries



FOGARTY AFRICAN BIOETHICS TRAINING PROGRAM STUDENTS

where there are huge leaps in health systems research but not as much parallel work on ethical implications,” said Joe Ali, the Berman Institute’s Associate Director for Global Programs. “From HIV to Malaria to Ebola, health and medical research with human participants in Africa — and the ethical evaluation of that research — has long been conducted by non-African scholars, a circumstance that can present its own ethical challenges.”

The Fogarty Training Program provides a combination of individual-level training and mentorship in bioethics for professionals from partner institutions — with training occurring both at Johns Hopkins and at partner African institutions — and strategic planning to enhance the quality and efficiency of research ethics systems at partner institutions. Thus, the goal is to collaboratively

facilitate the pursuit of institutional bioethics objectives to improve local capacity and sustain bioethics initiatives that are identified to be of critical importance in Africa.

“Bioethics continues to be an ever more vital field of study. The fastest growing sectors of our nation’s economy, primarily healthcare, science, and technology pose enormous ethical questions for today, and the future,” said Kahn. “Across the country and around the world, the Berman Institute is recognized as uniquely qualified to train individuals who will continue to provide the analysis, insights, and approaches to help shape the responses to these questions in ways that promote responsible policies and practices that benefit humanity.”

FACULTY BOOKS

BERMAN INSTITUTE FACULTY ARE LEADERS IN SCHOLARSHIP, PUBLISHING SCORES OF ARTICLES ON CONTEMPORARY BIOETHICS ISSUES EACH YEAR. IN ADDITION, THEY HAVE WRITTEN NUMEROUS GROUNDBREAKING BOOKS IN THE FIELD SINCE THE INSTITUTE’S FOUNDING.

1996

Ruth Faden and Nancy Kass, editors, *HIV, AIDS and Childbearing: Public Policy, Private Lives*

2001

John M. Freeman (with Kevin McDonnell), *Tough Decisions: Cases in Medical Ethics* (2nd edition)

2006

Ruth Faden (with Madison Powers), *Social Justice: The Moral Foundations of Public Health and Health Policy*

Jeffrey Kahn and Jeremy Sugarman (with Anna Mastroianni), editors, *Beyond Consent: Seeking Justice in Research* (2nd edition)

2009

Debra Mathews and Hilary Bok (with Peter Rabins), *Personal Identity and Fractured Selves*

Mark Hughes (with David Kern and Patricia Thomas), editors, *Curriculum Development for Medical Education: A Six-Step Approach* (2nd edition)

2010

Jeremy Sugarman (with Daniel Sulmasy), editors, *Methods in Medical Ethics* (2nd edition)

2012

Jeremy Greene, *Prescribed: Writing, Filling, Using, and Abusing Prescriptions in Modern America*

2013

Jessica Fanzo (with Danny Hunter), editors, *Diversifying Food and Diets: Using Agricultural Biodiversity to Improve Nutrition and Health*

Jeffrey Kahn (with Tom Beauchamp, LeRoy Walters and Anna Mastroianni), *Contemporary Issues in Bioethics* (8th edition)

Zackary Berger, *Talking to Your Doctor: A Patient’s Guide to Communication in the Exam Room and Beyond*

2014

Jeremy Greene, *Generic: The Unbranding of Modern Medicine*

Karen Rothenberg, *The Drama of DNA: Narrative Genomics*

2015

Mark Hughes (with David Kern, Patricia Thomas and Belinda Chen), editors, *Curriculum Development for Medical Education: A Six-Step Approach* (3rd edition)

2016

Zackary Berger, *Making Sense of Medicine: Bridging the Gap between Doctor Guidelines and Patient Preferences*

Jeremy Greene, editor, *Therapeutic Revolutions: Pharmaceuticals and Social Change in the 20th Century*

2018

Anne Barnhill (with Mark Budolfson and Tyler Doggett), editors, *The Oxford Handbook of Food Ethics*

Jessica Fanzo (with David Barling), editors, *Advances in Food Security and Sustainability* (Volume 3)

Cynda Hylton Rushton, editor, *Moral Resilience: Transforming Moral Suffering in Healthcare*

2019

Ruth Faden (with Madison Powers), *Structural Injustice: Power, Advantage, and Human Rights*

Jessica Fanzo (with David Barling), editors, *Advances in Food Security and Sustainability* (Volume 4)

Jeffrey Kahn and Nancy Kass (with Anna Mastroianni), editors, *The Oxford Handbook of Public Health Ethics*

Travis Rieder, *In Pain: A Bioethicist’s Personal Struggle with Opioids*

A LASTING LEGACY

As the Berman Institute grew in prestige and achievement, one significant challenge persisted — the lack of a permanent and dedicated physical home that would bring together faculty, staff, and students to promote not only collaborative scholarship, but also operational efficiency.

“We would lose hours of travel time attending meetings in East Baltimore or Homewood campus space,” said Faden. “Beyond the hassles of being so dispersed, we were missing out on those informal opportunities to collaborate with other members of the Institute.”

She and the Institute’s leadership were constantly searching for and weighing possible solutions. At various times, moves to dedicated space in other of the University’s East Baltimore schools were considered but ultimately rejected. Finally, Anthony Deering a board member of East Baltimore Development, Inc. (EBDI) and the husband of long time Berman Institute Advisory Board member Lynn Deering, suggested the Berman Institute consider moving to one of the few 19th century structures left in East Baltimore. Most recently, the building at 1809 Ashland Ave. had been EBDI’s headquarters as it worked with Johns Hopkins to revitalize the neighborhood adjacent to the University’s East Baltimore campus.



“Having a floor in someone else’s building would undermine our founding principle — that the Berman Institute was independent and university-wide. We had to hold out, not just for enough space, but for the right space, one with our own front door; we were holding out for an architecture that communicated our unique place in the university,” said Faden.

“This was a pivotal moment. Would our experiment succeed? Establishing an external physical identity in the landscape of Johns Hopkins answered that question literally, in bricks and mortar. The Berman Institute finally had its own building.”

The Institute’s new home was a wholly renovated red brick former police station, originally built in 1876. The 11,000-square-foot building is recognized by the Maryland Historical Trust and is one of the few original structures that remains amid Hopkins’ East Baltimore redevelopment. Glimpses of the building’s former life remain: Heavy cutaways of the original radiator that once warmed handlebar-

mustachioed police officers now hang as wall art just inside the main entrance. And at the building’s southeast corner, an attached garage-size structure that serves as flex space for PhD students, interns and bioethics trainees is nicknamed after its original charge: “the carriage house.”

“The most important aspect of the building is that, for the first time in our history, the Berman Institute had a distinct identity and place to call its own,” said Kahn. “Since so many of our faculty hold joint appointments in other schools, this space provides an opportunity for them to spend time in a physical place for them to work on bioethics, a rich mix of ideas and shared expertise.”

EDUCATING THE NEXT GENERATION OF BIOETHICS LEADERS

A permanent home also made it easier for the Institute to grow in another vitally important area — educating students in bioethics; its doctoral students matriculate in the bioethics and health policy concentration of the Bloomberg School of Public Health’s Department of Health Policy and Management. Deering Hall quickly became the centralized home base for those bioethics PhD students. In addition, soon after the move, the Berman Institute expanded to offer a Master of Bioethics degree in collaboration with the School of Public Health, as well as several summer intensive courses. In addition, Institute faculty

direct a an undergraduate minor in bioethics on the Homewood campus.

“As befits our historical background, the Berman Institute’s doctoral program is truly distinguished from other bioethics PhD programs in two ways: a focus on bioethics in public health and policy, and on rigorous quantitative and qualitative empirical research,” said Director of Education Initiatives Gail Geller, herself an early PhD graduate from the School of Public Health who wanted to focus on the burgeoning field of bioethics but before the concentration was created.

After the Greenwall Fellows Program ended, the Berman Institute acted quickly to remain a home for post-doctoral training of the next generation of bioethics leaders, launching the Hecht-Levi Fellowship Program in Bioethics which continues to the present. The Hecht-Levi Program provides two-year fully funded research positions for promising scholars from a wide range of bioethics-related fields with the focus on preparing them for academic careers in bioethics.

“The Hecht-Levi Program differs from the Greenwall Program in important ways. Whereas the Greenwall Program emphasized health policy and required Fellows to complete a health policy internship, the Hecht-Levi Program does not. In an effort to broaden the range of interests and backgrounds among the next generation of bioethicists, we now

ANTHONY AND LYNN DEERING



In both visionary leadership and philanthropic support, Anthony (Tony) and Lynn Deering were key in securing the building that is the permanent home of the Institute. A longtime Baltimore civic and business leader and an emeritus member of the Johns Hopkins University and Johns Hopkins Medicine boards of trustees, Tony helped oversee the university’s redevelopment efforts in East Baltimore and was the first to conceive of an almost 150-year-old former police station as the right place to house the Berman Institute’s cutting-edge faculty, research and administrative staffs, fellows, and students.

Deering Hall was named for Lynn Deering in honor of her extraordinary years of service to the Berman Institute and the major gift made by the Deerings that helped finance the purchase of the building. Deering Hall was dedicated during a day-long celebration in 2011. Tony Deering passed away

in 2017, and Lynn remains a member of the Institute’s National Advisory Board.

“Tony Deering was one of a kind,” said Ruth Faden. “In extraordinary ways, ways only Tony could do, he made Johns Hopkins a better place, he made Baltimore a better place, he made the world a better place. So often, Tony allowed others, indeed he intended for others, to take credit for the change he initiated. His eyes were always on the prize, not the credit.”

Deering spent most of his career at the Rouse Company, which he first joined in 1972, and as chairman and CEO from 1997 to 2004, he helped lead its growth into one of the nation’s largest commercial real estate developers.

Under his leadership, the Rouse Company operated with a philosophy that improving the quality of life in the communities it developed was an essential part of doing business. In that spirit, when the company was sold in

2004, Deering designated \$25 million to the Rouse Company Foundation, quadrupling the charity in size and enabling its ongoing support of local housing and job training initiatives. Tony and Lynn created the Charlesmead Foundation decades ago to support many Rouse Company Foundation initiatives in the city.

Dr. Alexander Levi, a trustee emeritus of Johns Hopkins University and chair of the Berman Institute of Bioethics' national advisory board, and his wife Vicki, have been



visionary supporters of the Institute for longer than it has formally existed.

From helping create the leadership symposium that was one of the Institute's first formal programs, to supporting both the Hecht-Levi Fellowship Program and endowing a

professorship devoted to bioethics and public policy, to contributing to the renovation of Deering Hall, the Levis have been trailblazers in helping the Berman Institute expand its offerings and reach.

Equally important has been Alex's leadership on the Berman Institute's Advisory Board, which he joined in 1995 and has chaired for almost a decade. "It's been my job to keep the Board engaged," he said. "If there's an area they've expressed some curiosity in, I'll link them with faculty who are experts in it."

Alex, a clinical psychologist and a clinical assistant professor at the Cornell University Medical College, maintains a practice in Manhattan. Vicki, an author, expert on Cuban culture, and a photo professional, is equally tireless in support of the Berman Institute, hosting the Board's annual winter dinner in New York City and watching for bioethics issues in the media for Institute faculty to address.

As if their other their long and deep commitments to the Institute were not enough, the Levis made a landmark gift to the Berman Institute in 2018, establishing the Ruth R. Faden Endowment for Education in Bioethics. In addition, they subsequently pledged funds to endow a professorship in Faden's honor dedicated to bioethics education.

"I've been involved with the Berman Institute for a long time, and I feel like it's given back more to me than I could ever give to it. Vicki and I wanted to find a way to honor Ruth's lifetime of service, to creating the Berman Institute, to bioethics at Hopkins, and to the field," said Levi. "This gift will create new leaders who will change the world in ways we can't yet foresee."

ALEX AND VICKI LEVI

recruit social scientists and humanities scholars, as well as philosophers, clinical fellows, and lawyers," said Geller. "We've made a real effort to partner with other relevant programs at Johns Hopkins, identifying people who can straddle more than one world and bring a more inclusive, interdisciplinary group of people to the table. It's been very fruitful."

The program is made possible through a grant from the Hecht-Levi Foundation, longtime supporters of bioethics and medicine efforts at Johns Hopkins. Robert H. Levi graduated from the Johns Hopkins School of Arts and Sciences in 1936 and went on to become a trustee of both the university and hospital. His son, Alex Levi, himself a longtime university trustee, has served for the past decade as chair of the Berman Institute's National Advisory Board.

In 2018, he and his wife, Vicki, acted to honor Faden's legacy and assure the Berman Institute's long-term pre-eminence in education and training in bioethics by making a \$15 million commitment, the largest ever to a bioethics program. The gift established the Ruth R. Faden Endowment for Education in Bioethics, expanding the Hecht-Levi Fellows Program, funding multiple scholarships for Master's in Bioethics students each year, and launching the Faden Scholars Program to provide advanced leadership training for one Hecht-Levi Fellow per year.

"The gift is unprecedented in the field of bioethics," said Kahn. "There are no other bioethics institutes with endowed resources dedicated to the education and training of the next generation of leaders in bioethics. It's a groundbreaking gift, breathtaking in its generosity, and a fitting tribute to Ruth and all she's done for bioethics, the Berman Institute, and Johns Hopkins."

Alex Levi has also been instrumental in the Berman Institute's continued growth in size, scope, and resources. He played a leading role in the move to Deering Hall, helped lead the search that resulted in Kahn being appointed the Institute's current director, inspires engagement and support from members of the Advisory Board, and provides sage counsel to the Institute's leadership.

"Where is the Berman Institute headed next? Being a part of Johns Hopkins, it has to have a significant role in both clinical care and public health. It also has an important role in educating the public," Levi says. "With Jeff charting the course, the Berman Institute has its finger on the pulse of some of the most pressing challenges our species faces. That includes genetic engineering and newer areas, like artificial intelligence, climate change, and sustainability. The Institute needs to remain on the cutting edge, helping shape conversation and policy going forward."

Kahn echoes Levi's conviction about the need for the Berman Institute to explore new realms of bioethics, even while maintaining investment and focus on its traditional areas of expertise. He points to the work of Jessica Fanzo, Bloomberg Distinguished Associate Professor of Ethics and Global Food and Agriculture (jointly appointed in the Berman Institute and the School of Advanced International Studies), on the ethical production of food for a burgeoning global population. Likewise, the JHU Exploration of Practical Ethics has been a successful university-wide effort to explore contemporary ethical issues that cross academic disciplinary lines and take place in a wide range of real-world circumstances.

The Berman Institute's commitment to real-world, interdisciplinary work will take another major

practical and symbolic step forward in 2023, when as part of its growth will add a new multidisciplinary building named in honor of Henrietta Lacks, who was the source of the HeLa cell line that has been critical to innumerable advances in medicine. The building, which will adjoin Deering Hall, will include space for the growing Berman Institute along with programs from the School of Medicine that enhance participation and partnership with the community in research, as well as extend the opportunities to further study and promote research ethics and community engagement in research.

"Our twenty-fifth anniversary provides a wonderful opportunity to pause and reflect on all the Berman Institute has achieved. Arising from an idea — that there were unaddressed questions surrounding the ethics of healthcare, biomedical science and public health — we have grown into a world-leading, university-wide institute, with resources to match. We bring the incredible range of resources at Johns Hopkins to bear on finding solutions to pressing real-world ethics issues," said Kahn.

"The most exciting part is that the Berman Institute is just getting started. As technological advances accelerate, and bioethics questions become more complex and more urgent, we are positioned to help provide answers and have a truly worldwide impact."

TAKING THE FIELD OF BIOETHICS IN NEW DIRECTIONS

In 2012, the Berman Institute launched the three-year Global Food Ethics Project in collaboration with the Bloomberg School of Public Health and the Nitze School of Advanced International Studies. With funding support from the Stavros Niarchos Foundation, the project aimed to address conflicting visions of how to feed the world ethically and identify ways to do so, even without consensus about ethical commitments and values.

The project team developed the 7 by 5 Agenda for Ethics and Global Food Security by convening a diverse, international, and influential working group of experts to

build a research and policy agenda for global food ethics. This unprecedented undertaking aimed to make a significant, practical contribution to global food security. The report proposed seven projects to make progress on ethics and global food security in five years.

In 2015, at the conclusion of the Global Food Ethics Project, the Berman Institute launched the Global Food Ethics and Policy Program (GFEPP) under the direction of Jessica Fanzo and with funding from the Stavros Niarchos Foundation. Dr. Fanzo has led GFEPP in continuing and building on the priorities outlined in the 7 by 5 Agenda.

Current research that evolved from the Global Food Ethics Project include the Choose Food, and Beef, Food Choice, and Values projects. The Choose Food project identifies the core ethical commitments that should undergird the food system and help guide choices of consumers and the practices of agriculture and food companies and producers. The Beef, Food Choice, and Values project examines ethically acceptable ways to shift beef consumption and production in order to improve human health and animal and environmental wellbeing.



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 Elizabeth Moser
 Diana and J. Frederick Motz
 Mariette Pathy Allen
 Kimberly and David Mullarkey
 Andres Murai, Jr.
 Jeanne Murphy

Peter Myers
 Karin Nelson
 Betsy and David Nelson
 Marie and Patrick Nolan
 Jane and David Novak
 Brenda and Irwin Nudelman
 Margaret and Charles Obrecht
 Edward Obstler
 Thea and David Obstler
 Sonia Obstler
 Michelle and Larry Ochfeld
 Nancy and Lawrence Odette
 Bill O'Reilly
 Dennis O'Shea
 Mary and William Page
 Sheila and Lawrence Pakula
 Stephen Palacios
 Mariette Pathy Allen
 Ellen Patz
 David B. Pearce
 Mary Ellen Pease and Charles Scheeler
 Patsy Perlman
 Anthony Perlman
 Charles R. Perrin
 Karen and Basil Petrou
 Karen and Charles Phlegar
 Marcia and Joseph Pines
 Leslie and Lawrence Polakoff
 Joanne and Mark Pollak
 Helen and Donald Price
 Karen and Peter V. Rabins
 Natalie Ram
 Lauren B. Randel
 Jonas Rappeport
 Cecelia and Barry Rascovar
 Scott Rembold
 Steffi Resnick and Bernard Liberman
 Roberta and Scott Richard
 Risinger & Fields Family Fund
 John Rivers
 Joann Rodgers
 Judith M. Rohde
 Bernice S. Rosenthal
 Ellen J. Rosenthal
 Jane S. Rowan
 Alan Rubel
 Leonard Rubenstein
 Cynda Rushton
 Elizabeth Russell-Mina
 Joan Salim and Peter Terry
 Charles Sanders
 Lorraine and Mark Shapiro

Amy Schroeder and Frederic Schroeder III
 May Seidel
 Amy Sepimwall
 Jamie and Matt Seward
 Martin Shahbazian
 Barbara and M. Sigmund Shapiro
 Susan and Eric Sheinberg
 Diane and Thomas Sherlock
 Carole and Hanan Sibel
 Andrew W. Siegel
 Jane M. and Benjamin V. Siegel
 Barbara and Charles Silberstein
 William Sirota
 Elaine Snyder
 Solomon Snyder
 Richard Soffer
 Rikki and Louis Solomon
 Nessa Spitzer
 Roberta Strickler and David Meyers
 Patricia and Seymour Strongin
 William Stubing
 Jeremy Sugarman
 Marilyn and D. Winston Tabb
 Judith and Alan Tapper
 Holly Taylor
 Wudassie Teklehaimanot
 Margie and Reed Tuckson
 Yoram Unguru
 Katherine Villa
 Walter von Wartburg
 Mary Frances P. Wagley
 Susan and James F. P. Wagley
 Leslie and Robert Waldman
 Joanne and Edward Wallach
 Ronnye and Sidney Weiman
 Nina and Walter Weiner
 Deborah A. Wells
 Jacqueline R. Werner
 Danielle M. Whicher
 Patricia and James White
 Danita and Emerson Wickwire
 Christopher Wilkerson
 Sydney and Ronald Wilner
 Cooper Wingard
 Marian and John Witkiak
 John A. Wolf
 Leslie Ellen Wolf and Kai Keasey
 Judy Wolff
 Warren Woo
 Jan and James Wood
 Jean Wyman
 Joanne Katz and Scott Zeger

VOLUNTEER LEADERS

THE TIME, INSIGHT AND VISION OF VOLUNTEER LEADERS HAS BEEN INTEGRAL TO THE BERMAN INSTITUTE'S SUCCESS. WE EXPRESS OUR GRATITUDE TO ALL WHO HAVE SERVED ON THE INSTITUTE'S NATIONAL ADVISORY BOARD SINCE ITS INCEPTION 25 YEARS AGO.

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 Phillip Wagley, M.D.
 L. John Wilkerson, Ph.D.



ALEX LEVI

1995 • 2020

25

YEARS

During its 25-year history the Berman Institute's people and programs have made an immeasurable impact on humanity. It has grown into a world leader in the field of bioethics. This timeline highlights a few of the institutional milestones that have marked that progress.



Harvey M. "Bud" Meyerhoff named Chair of National Advisory Board

1996



FADEN AND WAGLEY

1995

Bioethics Institute established as a Johns Hopkins University-wide institute with director reporting directly to the Provost

Ruth Faden named Director and inaugural Philip Franklin Wagley Chair in Biomedical Ethics

Morris Offit, outgoing Chair of the Johns Hopkins Board of Trustees, launches National Advisory Board

White House Advisory Committee on Human Radiation Experiments, chaired by Faden, issues its final report



OFFIT



Nancy Kass appointed inaugural Phoebe R. Berman Professor of Bioethics and Public Health at Johns Hopkins Medicine and School of Public Health

1999

First students in Health Policy and Ethics track graduate with doctoral degrees from the School of Public Health

2001

Institutional requirement adopted to include at least one Berman Institute faculty member on all Johns Hopkins Medicine and School of Public Health Institutional Review Boards



Program in Ethics and Brain Sciences established

2003

Institute renamed in honor of Phoebe Berman following her landmark gift

Greenwall Fellowship in Bioethics and Health Policy Program inaugurated

Robert H. Levi Leadership Symposium in Bioethics and Health Policy established

1997



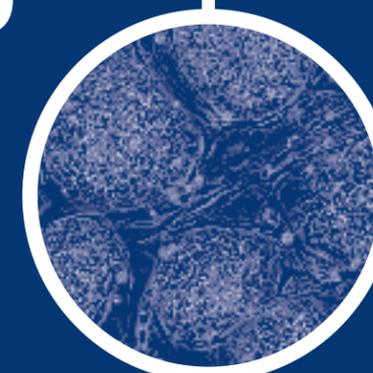
BERMAN

Johns Hopkins Fogarty African Bioethics Training Program established

2000

Stem Cell Policy and Ethics Program established

2002





Alex Levi named
Chair of National
Advisory Board

Program on Ethics
in Clinical Practice
established in
conjunction with
JHU School of
Medicine residency
programs

2006



2011

Deering Hall dedicated,
providing the Institute
a permanent and
independent home

Jeffrey Kahn
appointed inaugural
Robert Henry Levi
and Ryda Hecht Levi
Professor in Bioethics
and Public Policy

2013

Hecht-Levi
Fellowship
Program
created,
providing a
two-year
postdoctoral
fellowship
focusing on
preparing
trainees for
careers in
academic
bioethics



Monthly case
presentation and
discussion series,
"Ethics for Lunch,"
initiated at Johns
Hopkins Hospital

Master of
Bioethics
Degree
Program
launched

2018

Plans announced
for construction of new
interdisciplinary building
adjacent to Deering Hall,
to be named in honor of
Henrietta Lacks



Ruth R. Faden
Endowment
for Education
in Bioethics
established by
bequest from
Alex and Vicki
Levi

28

Hinxton
Group
created

Jeremy
Sugarman
appointed
inaugural
Harvey M.
Meyerhoff
Professor in
Bioethics

2004



2007

JHU President
William Brody
announces
University-wide
Bioethics Week
featuring keynote
address on ethics
and science by
Michael Crichton



Cynda Hylton Rushton
appointed inaugural
Anne and George L.
Bunting Professor of
Clinical Ethics

2012



Ruth Faden
appointed
inaugural Andreas
C. Dracopoulos
Director, nation's
first endowed
bioethics
directorship

2014



Jessica Fanzo
named Bloomberg
Distinguished
Associate Professor
of Ethics and
Global Food
and Agriculture

Global Food
Ethics and
Policy Program
launched

2016

Jeffrey Kahn named
Andreas C. Dracopoulos
Director of Berman Institute

Berman Institute awarded
an NIH grant as a Center of
Excellence for Ethical, Legal,
and Social Implications
Research in Genomics and
Infectious Disease



Funds pledged to
create professorship
in bioethics
education in honor
of Ruth Faden

Hanna Pickard
named Bloomberg
Distinguished
Professor of
Philosophy and
Bioethics

2019



29



ANNUAL REPORT

2018-2019

NEW BERMAN INSTITUTE BUILDING TO HONOR AN IMMORTAL CONTRIBUTION



Johns Hopkins University President Ronald J. Daniels and Paul B. Rothman, CEO of Johns Hopkins Medicine and dean of the medical faculty of the Johns Hopkins University School of Medicine, along with Berman Institute Director Jeffrey Kahn and descendants of Henrietta Lacks, announced plans during fiscal year 2019 to name a new multidisciplinary building on the Johns Hopkins East Baltimore campus in honor of Henrietta Lacks, who was the source of the HeLa cell line that has been critical to numerous advances in medicine.

Surrounded by descendants of Lacks, Daniels made the announcement in October 2018 at the 9th annual Henrietta Lacks Memorial Lecture in the Turner Auditorium in East Baltimore.

“Through her life and her immortal cells, Henrietta Lacks made an immeasurable impact on science and medicine that has touched countless lives around the world,” Daniels said. “This building will stand as a testament to her transformative impact on scientific discovery and the ethics that must undergird its pursuit. We at Johns Hopkins are profoundly grateful to the Lacks family for their partnership as we continue to learn from Mrs. Lacks’ life and to honor her enduring legacy.”

Henrietta Lacks’ contributions to science were not widely known until the 2010 release of the book *The*

Immortal Life of Henrietta Lacks by Rebecca Skloot, which explored Lacks’ life story, her impact on medical science and important bioethical issues. In 2017, HBO and Harpo Studios released a movie based on the book, with Oprah Winfrey starring as Deborah Lacks, Henrietta Lacks’ daughter.

Several Lacks family members attended the announcement of the new building’s name. “It is a proud day for the Lacks family. We have been working with Hopkins for many years now on events and projects that honor our grandmother,” said Jeri Lacks, granddaughter of Henrietta Lacks. “They are all meaningful, but this is the ultimate honor, one befitting of her role in advancing modern medicine.”

Lacks Hall, adjoining Deering Hall, will support programs that enhance Johns Hopkins University’s participation and partnership with members of the community in research that can benefit local residents, as well as extend opportunities to further study and promote research ethics and community engagement through an expansion of the Berman Institute and its work.

The story portrayed in *The Immortal Life of Henrietta Lacks* points to several important bioethical issues, including informed consent, medical records privacy, and communication with tissue donors and research participants.

“The story of Henrietta Lacks has encouraged us all to examine, discuss and wrestle with difficult issues that are at the foundation of the ethics of research, and must inform our relationships with the individuals and communities that are part of that research,” said Jeffrey Kahn, Andreas C. Dracopoulos Director of the Berman Institute. “As a result, students, faculty and the entire research community at Johns Hopkins and around the world do their work with a greater sensitivity to these critical issues.”

In 2013, Johns Hopkins worked with members of the Lacks family and the National Institutes of Health (NIH) to help broker an agreement that requires scientists to receive permission to use Henrietta Lacks’ genetic blueprint in NIH-funded research.

The NIH committee tasked with overseeing the use of HeLa cells now includes two members of the Lacks family. The medical research community has also made significant strides in improving research practices, in part thanks to the lessons learned from Henrietta Lacks’ story.

The design phase for Lacks Hall will begin in early 2020, with planned completion in late 2023.

RUTH FADEN RECEIVES HASTINGS CENTER'S MOST PRESTIGIOUS AWARD FOR LIFETIME CONTRIBUTIONS TO ETHICS AND LIFE SCIENCES



Ruth Faden, founder of the Berman Institute and Philip Franklin Wagley Professor of Bioethics, received the 2019 Beecher Award for Lifetime Achievement, the Hastings Center's most prestigious award recognizing individuals who have made a lifetime contribution to ethics and the life sciences and whose careers have been devoted to excellence in scholarship, research, and ethical inquiry.

The Award was presented at the annual meeting of the American Society for Bioethics and Humanities, accompanying a conference session dedicated to Faden's work and views on the field of bioethics.

In its citation, the Hastings Center states "Dr. Faden's work has profoundly influenced innumerable aspects of our field and, perhaps more importantly, helped to shape public policy on some of the nation's most pressing issues: from HIV testing of pregnant women to food and agriculture policy, and many aspects of science policy, including stem cell and embryo research. She has also powerfully critiqued the prevailing research ethics paradigm in the United States, encouraging major shifts in how we think about the oversight of comparative effectiveness research."

In 2011, Faden was the recipient of Lifetime Achievement Awards from both the American Society for Bioethics and Humanities (ASBH) and Public Responsibility in Medicine and Research (PRIMR).

EXPANDING BIOETHICS EDUCATION IN BALTIMORE AND AROUND THE WORLD

The Berman Institute continues to expand its bioethics educational programs, in Baltimore and around the world, establishing three new programs this year.

With support from the Stavros Niarchos Foundation, and in conjunction with the Bioethics Chair at the Swiss Federal Institute of Technology, the Berman Institute created the Stavros Niarchos Foundation Bioethics Academy, an intensive bioethics summer

course for biomedical researchers and healthcare professionals in Greece. As the program grows, the summer course will be supplemented with annual in-depth winter workshops, alternating between Baltimore and Zurich.

The Berman Institute also worked to help the University of Malaya launch a master's degree program for Malaysia and Southeast Asia funded by the NIH Fogarty International Center. And the Institute started an NIH-funded undergraduate mentorship program that will expand diversity among future ethical, legal, and social implications researchers in the field of genomics.

MORAL PSYCHOLOGY EXPERT HANNA PICKARD JOINS BERMAN INSTITUTE

Hanna Pickard, a leading applied philosopher in the fields of philosophy of psychiatry and moral psychology, joined Johns Hopkins as a Bloomberg Distinguished Professor of Philosophy and Bioethics in 2019. She holds joint appointments in the Berman Institute and the Krieger School of Arts and Sciences' Department of Philosophy.

"Through her work, Dr. Pickard shares profound insights into individual and collective human behavior," said Johns Hopkins University Provost Sunil Kumar. "We are thrilled to welcome her to our faculty, where her unique brand of applied philosophy will help us grapple with the pressing questions of our time and break new ground in a variety of interdisciplinary fields."

As the university's 45th Bloomberg Distinguished Professor, Pickard joins an interdisciplinary cohort of scholars at Johns Hopkins working to address major world problems and teach the next generation. The program is backed by a \$350 million gift from JHU alumnus Michael R. Bloomberg.

Pickard comes to Johns Hopkins from the University of Birmingham in the U.K., where she was Chair in Philosophy of Psychology, and from Princeton University, where she served as a visiting research scholar in cognitive science for the past two years. Previously, she'd been a research fellow at the University of Oxford and served for 10 years as an assistant team therapist at the Oxfordshire

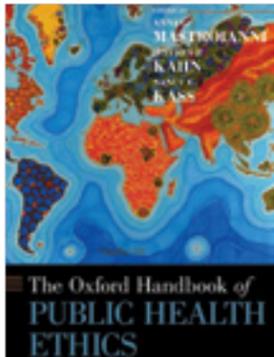


Complex Needs Service, where she worked clinically in an outpatient therapeutic community for patients with personality disorders and other complex mental health needs.

Berman Institute Director Jeffrey Kahn said Pickard's joint appointment will strengthen the Institute's "vital connection" with the Department of Philosophy.

"We are thrilled to have Hanna Pickard as our newest Bloomberg Distinguished Professor," said Kahn. "Her research embodies the Berman Institute's emphasis on utilizing interdisciplinary approaches to explore pressing ethical issues in real-world settings."

NEWLY PUBLISHED OXFORD HANDBOOK OF PUBLIC HEALTH ETHICS PROVIDES SWEEPING AND AUTHORITATIVE REVIEW OF FIELD



Representing the culmination of a multi-year scholarly effort, this summer's publication of *The Oxford Handbook of Public Health Ethics* provides for the first time a sweeping and authoritative review of public health ethics, with faculty from the Johns Hopkins Berman Institute of Bioethics leading its creation.

The Handbook's three editors include Jeffrey Kahn, Director of the Berman Institute, and Nancy Kass, Vice Provost for Graduate and Professional Education, and Phoebe R. Berman Professor of Bioethics and Public Health at Johns Hopkins. Berman Institute faculty wrote 23 of the book's chapters and edited 11 of its 15 sections.

While medical ethics has a rich history dating back thousands of years, an explicit focus on public health ethics is much more recent. And as public health seeks to gain increasing benefits for populations — from improving diets and vaccination rates to reducing injuries and violence — critical questions that focus on how far the reach of public health intervention should go, and how to ensure that public health benefits are realized by all become increasingly critical to address.

“Public health practitioners and policymakers face questions of ethics routinely in their work, and they must navigate sometimes competing responsibilities to the public with other important values such as privacy, autonomy, and prevailing cultural norms,” wrote the editors, who also include Anna

Mastroianni, Professor of Law at the University of Washington School of Law and Associate Director of the university's Institute for Public Health Genetics.

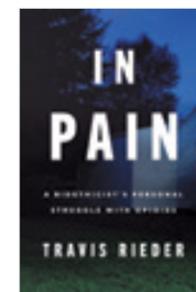
The *Handbook* provides an authoritative review of public health ethics in topics including genetics, violence, pandemics, global issues and many more. The 73 chapters are organized into 15 sections, each prefaced with an original essay by a leading scholar highlighting the ethics issues in that particular area of public health. Berman Institute-affiliated chapters authors are:

- Anne Barnhill
- Claire Davis
- Mike DiStefano
- Ruth Faden
- Jessica Fanzo
- Gail Geller
- Leslie Meltzer Henry
- Nancy Kass
- Carleigh Krubiner
- Michelle Huckaby Lewis
- Debra Mathews
- Maria Merritt
- Maggie Moon
- Brendan Saloner
- Andrew Siegel
- Holly Taylor (completed contribution while on Berman Institute faculty, now at Dept. of Bioethics, Clinical Center, National Institutes of Health)

For more than a decade, the Oxford University Press' Handbook series has published cutting-edge research by the world's leading scholars across more than a dozen disciplines. Each volume offers an authoritative and state-of-the-art survey of current thinking in a particular subject area. *The Oxford Handbook of Public Health Ethics* fills a critical gap, joining previously published Oxford Handbooks devoted to a wide range of related areas, including Bioethics, Clinical Research Ethics, Reproductive Ethics, Psychiatric Ethics, and Animal Ethics.



IN HARROWING MEMOIR, BERMAN BIOETHICIST EXAMINES HIS OWN EXPERIENCE WITH OPIOID DEPENDENCE



For Travis Rieder, experience with opioids began after a 2015 motorcycle accident. The medication helped him through six operations but, as he recovered from the injuries, he discovered that withdrawal from the drugs cause excruciating pain of its own. Rather than risk addiction by following his doctors' advice to

return to the opioids, Rieder endured the struggle of withdrawal.

In his 2019 book, *In Pain* (HarperCollins), Rieder, a research scholar and director of the Master of Bioethics Program at the Berman Institute, combines this harrowing experience with his professional training.

Rieder's experience exposes a dark secret of American pain management: a health care system that is so conflicted about opioids and so inept at managing them that the crisis of addiction and

overdose is both unsurprising and inevitable. As he recounts his story, Rieder unpacks the history of the drugs, which were first invented in the 1800s, as well as the changing attitudes about pain management over the following decades and the implementation of the pain scale at the beginning of the 21st century. He explores both the science of addiction and the systemic and cultural barriers that must be overcome in order to address the problem effectively in the contemporary American health care system.

NPR named Rieder's book one of its best of 2019. Kirkus Reviews called *In Pain* “a bioethicist's eloquent and riveting memoir of opioid dependent and withdrawal — a harrowing personal reckoning and clarion call for change not only for government but medicine itself, revealing the lack of crucial resources and structures to handle this insidious nationwide epidemic.”

WITH *STRUCTURAL INJUSTICE*, FADEN CALLS FOR BIOETHICS TO EXPAND ITS UNDERSTANDING OF JUSTICE



In her recently published book, *Structural Injustice: Power, Advantage, and Human Rights* (Oxford University Press), Berman Institute founder Ruth Faden and co-author Georgetown University professor Madison Powers build on their longstanding call for bioethics to expand its understanding

of justice to put forward a groundbreaking theory of social injustice, more broadly. Their theory forges links between human rights and fairness norms and is built to fit a real world characterized by deprivation, human rights violations, disadvantage, and unfair power relations, both within and across nations.

Unlike theories of structural injustice tailored for largely benign social processes, Powers and Faden's theory addresses typical patterns of structural injustice — those in which the wrongful conduct of identifiable agents creates or sustains mutually reinforcing forms of injustice. These patterns exist both within nation-states and across national

boundaries. However, this theory rejects the claim that for a structural theory to be broadly applicable both within and across national boundaries its central claims must be universally endorsable.

Instead, Faden and Powers find support for their theory in examples of structural injustice around the world, and in the insights and perspectives of related social movements. Their theory also differs from approaches that make enhanced democratic decision-making or the global extension of republican institutions the centerpiece of proposed remedies. Instead, the theory focuses on justifiable forms of resistance in circumstances in which institutions are unwilling or unable to address pressing problems of injustice.

“My hope is that the insights developed in *Structural Injustice* will interest not only scholars and students in a range of disciplines from political philosophy to feminist theory and environmental justice, but also activists and journalists engaged with issues of social justice,” said Faden.

JESSICA FANZO HELPS TO SHAPE LANCET FOOD SYSTEMS REPORT

The average person's daily diet will need to change drastically during the next three decades to make sure everyone is fed without depleting the planet, a panel of experts including the Berman Institute's Jessica Fanzo has concluded.

Global consumption of foods such as red meat and sugar will have to decrease by about half to make sure the Earth will be able to feed a growing population of 10 billion people by 2050, according to the EAT-Lancet Commission on Healthy Diets from Sustainable Food Systems.

Written by 37 scientists from 16 countries and published in the medical journal *The Lancet*, the report was funded by the Wellcome Trust and Stordalen Foundation. In addition to the recommendations on meat, it calls for curbing food waste, a major source of greenhouse gas emissions,

and overhauling agriculture so it doesn't worsen deforestation and the depletion of scarce water.

“It's not a blanket approach, but when you look at the data there are certain individuals or populations that don't need that much red meat for their own health,” Fanzo, Bloomberg Distinguished Associate Professor of Global Food & Agricultural Policy and Ethics, said in a *New York Times* interview. “There's a real inequity. Some people get too much. Some people get too little.”

Fanzo serves as the Director of the Global Food Ethics and Policy Program at the Berman Institute, and plays key advisory roles in Johns Hopkins' Alliance for a Healthier World on the food security and nutrition theme, as well as the Bloomberg American Health Initiative on obesity and food systems.

She is currently serving as the co-Chair for the Global Nutrition Report's independent expert group, and is the Team Leader for the High-Level Panel of Experts for Food Systems and Nutrition for the UN Committee on Food Security.



CAN PHYSICIANS WORKING IN DETENTION FACILITIES UPHOLD THEIR HIPPOCRATIC OATH?



In August, Berman Institute faculty Nancy Kass and Len Rubenstein, along with Paul Spiegel of the Bloomberg School of Public Health's Center for Humanitarian Health, published “Can Physicians Work in US Immigration Detention Facilities While Upholding Their Hippocratic Oath?” in the online edition of *JAMA Viewpoint*.

The authors state that medical ethics “have been strikingly consistent from Hippocrates to modern-day guidance. Whatever the future of US immigration policy, decent and humane treatment of children, as well as all other detainees, and preservation of the independence of physicians and other health professionals to meet patients' medical and psychological needs are essential. Now is not a time to change the commitments, reputation, and integrity of physicians and the medical profession.”



The authors put forward a number of concrete steps that should be taken to ensure appropriate treatment of individuals receiving medical care in U.S. Health and Human

Services (HHS) facilities run by the Office of Refugee Resettlement (ORR). They included:

- Health care professionals' insistence on and adherence to clinical independence to ensure they are able to provide the highest standards of care that are in the best interests of the patient;
- Creation of an independent health oversight body that monitors all aspects of preventive and curative health services, outcomes, and standards in DHS and ORR/HSS immigration detention facilities; and
- Required regular reporting by DHS and ORR/HHS on how they are meeting their own and international standards for each facility for which they are responsible.

Kass is the Phoebe R. Berman Professor of Bioethics and Public Health and the Berman Institute's Deputy Director for Public Health. Rubenstein is core faculty at the Berman Institute and the Director of the Program on Human Rights, Health and Conflict at the Bloomberg School's Center for Public Health and Human Rights.

BERMAN INSTITUTE DIRECTOR NAMED TO INTERNATIONAL COMMISSION ON HUMAN GERMLINE GENOME EDITING

Jeffery Kahn, Andreas C. Dracopoulos Director of the Berman Institute, has been appointed to an international commission convened by the U.S. National Academy of Medicine, the U.S. National Academy of Sciences, and the Royal Society of the U.K., with the participation of science and medical academies around the world, to develop a framework for scientists, clinicians, and regulatory authorities to consider when assessing potential clinical applications of human germline genome editing. The framework will identify a number of scientific, medical, and ethical requirements that should be

considered, and to inform the development of a potential pathway from research to clinical use — if society concludes that heritable human genome editing applications are acceptable.

Prof. Kahn has served on numerous such national and international advisory panels. He is currently chair of National Academies of Sciences, Engineering, and Medicine's Board on Health Sciences Policy. He also formerly served as a member of the National Institutes of Health (NIH) Recombinant DNA Advisory Committee.

The commission is the latest action from the international science community to address issues around human genome editing. It follows the Second International Summit on Human Genome Editing in Hong Kong — convened last November by the U.S. National Academies, the Royal Society, and the Academy of Sciences of Hong Kong. The topic became a focus of global attention when a scientist from China revealed at the summit that as a result of his research, twins had been born whose embryonic genomes had been edited. The scientist was widely condemned by the global scientific community for violating long-standing scientific principles and ethical norms.

The commission will hold public meetings and an international workshop and will also issue a call for public input to inform their work. The commission's final report is expected to be issued in the spring of 2020.



CYNDA RUSHTON RECEIVES MULTIPLE NATIONAL RECOGNITIONS

Cynda Hylton Rushton, the Anne and George L. Bunting Professor of Clinical Ethics, received multiple

national awards in 2019 recognizing her careerlong impact in the fields of bioethics and nursing.

She was inducted into the Sigma Theta Tau International Honor Society of Nursing's International Nurse Researcher Hall of Fame in recognition of her contributions to the nursing profession and her sustained research efforts to improve the care and health of people, specifically in the areas of aging and nursing ethics.

Later in the year, she received the same honor society's Daniel J. Pesut Spirit of Renewal Award, given to a nurse leader whose purposeful reflection in practice and mindful understanding of human relationships displays a futuristic vision for nursing practice.

"This is a tremendous honor because I feel it so accurately encapsulates what I strive to do as a nurse and educator," Rushton said. "My work in ethics is about understanding our personal and professional values, how we live those out in our work, and the impact they have on our patients and colleagues. A clear and unwavering moral compass is foundational to the stability and integrity of clinicians faced with complex ethical questions in their everyday practice. It is incredibly gratifying to receive an award that recognizes ethical practice as central to the nursing profession's future."

With expertise in moral suffering, resilience of clinicians, and designing cultures of ethical practice, Rushton has been internationally recognized and served as an advisor for numerous national nursing, health care, and governmental organizations. Her career has largely focused on bioethics, ethics education, and clinical ethics consultation.



DEBRA MATHEWS NAMED CHAIR OF MARYLAND STEM CELL COMMISSION

Debra Mathews, Assistant Director for Science Programs and Associate Professor at the Johns Hopkins

Berman Institute of Bioethics, has been named to a two-year term as Chair of the Maryland Stem Cell Research Commission. The Commission is focused on identifying and fostering cutting-edge research and innovation in the field of regenerative medicine in Maryland.

"I am excited for the opportunity to help ensure that both public and private research entities keep Maryland at the forefront of this vitally important field," said Mathews.

The Commission's Accelerating Cures initiative comprises programs that help transition human stem cell-based technologies from the bench to the bedside as well as mechanisms to build and grow stem cell companies in Maryland. Additionally, the Commission establishes criteria, standards, and

requirements to ensure that stem cell research funded by the Maryland Stem Cell Research Fund complies with state law.

At the Berman Institute, Dr. Mathews is responsible for overseeing the Stem Cell Policy and Ethics program and the Program in Ethics and Brain Sciences, as well as other bench research-related endeavors. She is also a member of the steering committee of The Hinxton Group, an international collective of scientists, ethicists, policymakers and others, interested in ethical and well-regulated science, and whose work focuses primarily on stem cell research.

"Debra Mathews is a national leader on the ethical and science policy issues surrounding stem cell research. In her role as chair, Debra's experience and expertise will serve the Commission well," said Jeffrey Kahn.

BERMAN INSTITUTE FACULTY ARE REGULARLY SOUGHT TO OFFER BIOETHICS INSIGHT AND ANALYSIS BY JOURNALISTS FROM LEADING MEDIA OUTLETS AROUND THE WORLD (SEE A SELECTION OF THEIR QUOTES ON PAGES 42-43). IN 2019, PROFESSOR YORAM UNGURU UTILIZED THE *NEW YORK TIMES*, NPR, AND OTHER NEW SOURCES AS A PLATFORM TO HELP COMBAT A PRESSING PUBLIC HEALTH CRISIS.

FIGHTING BACK AGAINST A CRITICAL SHORTAGE OF VITAL PEDIATRIC DRUGS

Berman Institute faculty member Yoram Unguru, an assistant professor at the Johns Hopkins School of Medicine and a pediatric hematologist/oncologist at The Children's Hospital at Sinai, has spent years sounding the alarm about the skyrocketing number of drug shortages in the United States.

But even he wasn't prepared for the notice he received one Sunday evening in October. Unguru, along with pediatric oncologists across the country, were notified of an imminent national shortage of vincristine, the single most widely used chemotherapy agent in childhood cancer.

"This was truly a nightmare situation. Vincristine is utilized by children with nearly every type of cancer, including leukemias, lymphomas, brain tumors, bone tumors, musculoskeletal tumors, neuroblastoma, and more," said Unguru.

"In 2016, colleagues and I published a paper in the *Journal of the National Cancer Institute* about the ethical allocation of childhood cancer drugs during a shortage. We came up with two hypothetical worst-case scenarios to set the stage — the primary case was a vincristine shortage and now was coming true."



Unguru swung into action that evening, contacting a *New York Times* reporter who had interviewed him previously about drug shortages. A story in the next morning's paper, "Faced With a Drug Shortfall, Doctors Scramble to Treat Children With Cancer," followed by an appearance on NPR, helped launch a news cycle that created national awareness of the impending shortage and its potential impacts.

"This will inevitably result in many difficult decisions in the coming weeks as nearly every child with cancer in the United States will be affected by this shortage," said Unguru, who traced the origins of the shortage to earlier in 2019 when Teva, one of only two pharmaceutical companies manufacturing vincristine sulfate injection, made a business decision to discontinue production. Afterward, the other and sole producer of vincristine, Pfizer, faced manufacturing delays.

Teva immediately faced a major backlash. A petition calling upon the company to resume manufacturing gathered more than 215,000 signatures. Another petition sent to the White House asking the government to intervene in the shortage gathered more than 100,000 signatures. In the face of public pressure, Teva announced in November that it will resume production of vincristine.

"I was pleasantly surprised to see the announcement, and it's the right decision. Patients are going to benefit but it won't help immediately," Unguru told *Forbes* in an interview. "The cynic in me says that this will be one more story that people forget about. But I'm hoping that through advocacy work, the recent federal Mitigating Emergency Drug Shortages Act that Senators Collins and Smith have introduced might make a difference. I don't believe drug shortages will be resolved until the government steps in."

“If it’s true as reported then it’s an extremely premature and questionable experiment in creating genetically modified children. There’s much to understand and discuss about oversight or lack thereof.”

JEFFREY KAHN IN THE WASHINGTON POST ON REPORTS THAT A CHINESE SCIENTIST HAD EDITED THE DNA OF HUMAN EMBRYOS TO CREATE TWIN BABY GIRLS

“People who can set up a good crowdfunding site are generally sophisticated. They’re good storytellers, attractive people, the kind of people who will get someone’s attention. But a lot of people who have the same kinds of desperate need aren’t that way. They don’t have access to the internet. They don’t have skills in creating a compelling story or website. In a world full of disparities, this is just another way to create disparities.”

MAGGIE MOON IN THE ALLENTOWN MORNING CALL ON THE ETHICS OF CROWDFUNDING MEDICAL EXPENSES

“Procreating both contributes to climate change and creates a new victim of climate change. I don’t know whether people should have kids, or whether they should have a big family, but I do believe that climate change should be part of their deliberation, because the consequences of bringing a new person into a changing world are really morally serious.”

TRAVIS RIEDER TO NBC NEWS

“What I focus on is the value of the information offered by these tests, the complexity of it, and the interpretation of that information. There are several companies performing direct-to-consumer genetic testing, and many of them, unfortunately, are not to be trusted.”

DEBRA MATHEWS IN HEALIO

“Developing a Lassa fever vaccine that can be offered to pregnant women will be an important double win for global health. It will not only help ensure that pregnant women and their infants are protected against a deadly disease but will also provide a model for future development of vaccines for use in epidemics.”

RUTH FADEN IN A CO-AUTHORED STAT NEWS OP-ED

“Many of the same people who struggle with extra weight also regularly go to bed hungry. That may sound like an impossible contradiction, but dig deeper, and it quickly becomes clear how hunger and obesity are related. Both are often rooted in poverty.”

JESS FANZO IN BLOOMBERG NEWS

“Looking someone in the eye, getting a sense of whether they’re with you, and even asking them to repeat back what they understand is the most likely strategy to achieve a meaningful understanding.”

NANCY KASS IN BIOEDGE ON THE COMPLEXITY OF PATIENT CONSENT FORMS

“U.S. drug shortages have become the new normal. According to the FDA, shortages are occurring with greater frequency and lasting longer, causing a significant public health impact. The lack of available lifesaving chemotherapeutics and supportive care agents represents a true national crisis.”

YORAM UNGURU IN THE BALTIMORE SUN

“When clinicians hear that their efforts have produced benefit to their patients or families and that it has made a difference in the lives of others, it can reinforce that their efforts matter and are appreciated. With burnout being reported at alarming levels, helping clinicians to reconnect to the meaning of their work is vital for sustaining the healthcare workforce.”

CYNDA RUSHTON IN REUTERS

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