ANNUAL REPORT 2019-2020

THE YEAR THE WORLD CHANGED FOREVER.
WHAT’S NEXT FOR BIOETHICS?
“IN THIS TIME OF COVID-19, DIGITAL TECHNOLOGIES HAVE AN UNPRECEDENTED CAPACITY TO ACCELERATE AND IMPROVE THE WAY THE WORLD RESPONDS TO INFECTIOUS DISEASE OUTBREAKS AND PANDEMICS.”

Ronald J. Daniels, Johns Hopkins University President

“BIOETHICS NEEDS TO DO BETTER, AND WE ARGUE THAT THIS MEANS A RENEWED FOCUS ON A GLOBAL HEALTH ETHICS THAT RECOGNIZES AND TAKES ACCOUNT OF THE REALITIES HIGHLIGHTED BY THE PANDEMIC…”

Jeffrey P. Kahn, with co-authors Anna Mastroianni and Sridhar Venkatapuram, “Bioethics in a Post-COVID World: Time for Future-Facing Global Health Ethics”
In normal circumstances, this Annual Report would include a look back at the yearlong 25th Anniversary Celebration of the Berman Institute of Bioethics that we had planned for 2020. But just as that celebration was getting underway, COVID-19 changed almost everything. Instead of celebrating the Institute’s history this year, our dedicated faculty, trainees and staff set out to write a new chapter in it, one unprecedented for impact and achievement. They have taken on ever more projects and commitments and done so collaboratively with colleagues across Johns Hopkins and around the world, all so that we can help ensure that the national and international public health response to the pandemic is ethically informed as well as effective.

Even as our nation grappled with the unprecedented challenges of COVID-19, we were shaken by another seismic event: protests arising from the senseless deaths of Black citizens at the hands of police, a reaction to decades of frustration, anger, and inaction. The racial justice protests that marked the summer of 2020 provided an acute reminder that racism and the inequalities it fosters in our society are longstanding and far from being addressed.

The Berman Institute’s mission includes taking on difficult and controversial ethical issues, to use our expertise to carry out clear analysis and make strong recommendations, to be thought leaders, to speak truth to power. Racism is unarguably a public health issue, and the pandemic has shone a light on longstanding health inequities in our country, exacerbated by the structural racism that is prevalent in so many aspects of our society.

Most of what follows in this annual report is dedicated to how the Berman Institute has responded to this year’s two epochal events and their ramifications, as well as what we will do next. Our work needs to focus more squarely and intentionally on the issues of inequality and social justice, both as they relate to the current moment and how they inform the society we want to build.

On behalf of the Berman Institute, I thank all of you for your support and look forward to expressing my gratitude in person during 2021.

All my best,

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 is striving to ensure that the international public health response to COVID-19 is ethically informed as well as effective. Through years of experience and scholarship, and tested through multiple threatened and actual epidemics, scholars at the Berman Institute have led research to identify the ethical principles that should guide the actions of governments and other institutions in a moment like this.

This special section highlights some of the many ways the Berman Institute has responded.

Digital Contact Tracing for Pandemic Response

In May, Johns Hopkins released a comprehensive report to help governments, technology developers, businesses, institutional leaders and the public make responsible decisions around use of digital contact tracing technology (DCTT), including smartphone apps and other tools, to fight COVID-19.

In the first months following its release, Digital Contact Tracing for Pandemic Response—a report led by the Berman Institute in collaboration with the Center for Health Security at Johns Hopkins, as well as leading experts worldwide—was downloaded more than 116,000 times by readers from 134 countries on six continents.

It highlights the ethical, legal, policy and governance issues that must be addressed as DCTT are developed and implemented. The report’s primary conclusions and recommendations advise that privacy should not outweigh public health goals and other values; that big technology companies should not unilaterally set terms when such broad public interests are at stake; and that decisions about the technology and its uses will have to be updated as new information becomes available.

As officials in many countries strive to find a balance between respecting civil liberties and controlling the pandemic, the report offers clear, well-supported guidance for leaders as they consider deployment and use of these technologies, as well as the data they collect, store and share.

“As we move forward in responding to the pandemic, we must strike a balance between privacy and values like equity, choice, economic well-being and solidarity,” said Jeffrey Kahn. “Too great an emphasis on privacy could severely limit the ability to gather information that is critical for effective and efficient contact tracing to help beat the pandemic, and so the full range of interests and values of the public must drive this conversation—and not just those asserted by tech companies.”

The report makes numerous recommendations, including:

- Technology design should not be static. There is no “one size fits all” approach. Design should be capable of evolving depending upon local conditions, new evidence and changing preferences and priorities.
- Technology companies alone should not control the terms, conditions, or capabilities of DCTT. Nor should they presume to know what is acceptable to members of the public.
- DCTT should be designed to have a base set of features that protect privacy, with layers of additional capabilities that users can choose to activate. A default should be that user location data are not shared, but users should be provided with easy mechanisms and prompts to allow for opting-in to this capability, especially if opting-in is critical to achieving public health goals.
- De-identified data collected through DCTT should be made available to public health professionals and researchers to support population-level studies and analyses.
- Those who authorize use of DCTT within a particular jurisdiction or institution should continuously and systematically monitor the technology’s performance in that context. This should include monitoring for effectiveness and benefit, monitoring for harms and monitoring for the fair distribution of both benefits and harms.
- Governments should not require mandatory use of DCTT given the uncertainty about potential burdens and benefits. Additional technology, user and real-world testing is needed.
- Congress should enact legislation specifically tailored to use of DCTT as part of the response to COVID-19, which would facilitate uses of DCTT to promote the public health response while protecting citizens.

“In this time of COVID-19, digital technologies have an unprecedented capacity to accelerate and improve the way the world responds to infectious disease outbreaks and pandemics,” said Johns Hopkins University President Ronald J. Daniels. “The digital contact tracing technologies represent great opportunity. They also present significant ethical, legal and governance concerns that we, as a society, must grapple with. I’m grateful to the Berman Institute of Bioethics together with the Center for Health Security for leading this effort and galvanizing some of the nation and the world’s foremost leaders on these issues to share their knowledge on this complex and timely set of issues.”
Planning How to Ethically Allocate and Distribute COVID Vaccines

Berman Institute faculty co-authored a report providing an ethical framework for making decisions about allocation and distribution of a COVID-19 vaccine during the initial period when such a vaccine has first been authorized for use and is still in limited supply.

Released by the Center for Health Security at Johns Hopkins Bloomberg School of Public Health, the report, Interim Framework for COVID-19 Vaccine Allocation and Distribution in the United States, proposes specific tiers of high-priority candidates for receiving a first vaccine based on this framework, including recognizing the contributions of essential workers who have been overlooked in previous allocation schemes:

Tier 1 includes those:
- Most essential in sustaining the ongoing COVID-19 response;
- At greatest risk of severe illness and death, and their caregivers;
- Most essential to maintaining core societal functions.

Tier 2 includes those:
- Involved in broader health provision;
- Facing greater barriers to access care if they become seriously ill;
- Contributing to maintenance of core societal functions;
- Whose living or working conditions give them elevated risk of infection, even if they have lesser or unknown risk of severe illness and death.

The framework is guided by the following ethical principles, which the report authors believe should guide COVID-19 vaccine allocation and help identify more specific policy goals and objectives around vaccine policies:

- Promotion of the common good, by bolstering public health while enabling social and economic activity;
- The importance of treating individuals fairly and promoting social equity; for example, by addressing racial and ethnic disparities in COVID-19 mortality, and by recognizing the contributions of essential workers who have been overlooked in previous allocation schemes;
- The promotion of legitimacy, trust and a sense of community ownership over vaccine policy, while respecting the diversity of values and beliefs in our pluralist society.

Employing Greek Tragedy to Help Medical Professionals Cope with COVID

Frontline medical workers continue to confront unprecedented professional and personal challenges of the COVID-19 pandemic. From their own inadequate access to personal protective equipment to facing impossible decisions about allocating limited lifesaving resources among their patients, clinicians have experienced feelings of betrayal, anger, and fear.

Now, by combining one of the pandemic’s newest forms of communication—the Zoom webinar—with the ancient art form of Greek tragedy, an innovative project is reaching frontline medical workers who may be struggling in isolation, providing them the opportunity to name and communalize their experiences, connect with colleagues, and access available resources.

Theater of War for Frontline Medical Providers—developed by Theater of War Productions, the Johns Hopkins Berman Institute of Bioethics, and the Johns Hopkins Program in Arts, Humanities & Health—presents dramatic readings by acclaimed actors of scenes from ancient Greek plays for audiences of frontline medical providers to open up powerful dialogue about difficult subjects. In an article published by The Lancet, the project’s organizers write “we have found that presenting scenes from ancient tragedies about complex ethical situations for frontline medical providers generates an open, non-threatening space in which health personnel can begin to process, interrogate, share, and bear witness to experiences of loss, betrayal, grief, and other forms of moral suffering during the COVID-19 pandemic.”

Theater of War for Frontline Medical Providers events begin with a live reading of scenes carefully curated to address themes and issues that medical providers may be facing during the pandemic, such as personal risk, abandonment, deferred grief, deviation from standards of care, helplessness, and complicity in creating suffering. After the performance, the actors are replaced by four panelists—a diverse group of front-line medical providers—who respond to what they heard in the plays that resonated with their own experiences of caring for patients during the pandemic. After the panelists’ remarks, a skilled facilitator prompts the audience to join the discussion with a series of questions encouraging reflection and dialogue about themes raised by the plays. The discussion provides an opportunity for the medical workers in the audience to take center stage, sharing the impact of COVID-19 on their lives and finding solace in the community of their peers.

The project premiered on May 24, with 417 clinicians from the Baltimore area logging onto Zoom for a performance featuring Frances McDormand, Jesse Eisenberg, David Strathairn, and Frankie Faison. In a post-performance evaluation, 93% of respondents reported that the program offered new insights about their experience during COVID. 92% said the program made it easier to talk about difficult subjects related to COVID. Following that success, the Arts in Health Initiative of the Laurie M. Tisch Illumination Fund provided a grant to Theater of War and the Berman Institute to fund 10 performances of the project in New York City attended by hundreds of frontline medical workers, as well as the general public.

“Ancient tragedies provide a new entry point for clinicians to process moral suffering generated by the pandemic,” wrote Theater of War Artistic Director Bryan Doerries and Berman Institute faculty Cyndy Aulichon, Jeremy Greene, and Gail Geiker in The Lancet. “While individual cognitive reframing can be helpful in the treatment of traumatic disorders, there is also a role for collective social interventions in responding to collective trauma. Ancient Greek plays about chronic and terminal illness, moral distress, the challenges of witnessing suffering, and end-of-life care can be used to forge a common vocabulary for openly engaging doctors, nurses, students, and other health-care professionals in creating constructive dialogue, fostering understanding, compassion, and a renewed sense of community.”
Berman Institute Creates Course for Medical Students Disrupted by COVID

The education of students at Johns Hopkins School of Medicine was among the many disruptions caused when the COVID-19 pandemic first struck in March, as new safety measures suddenly prohibited medical students who would normally have been on clinical rotations from accessing the hospital and patients. Seeing an opportunity to provide a meaningful and timely alternative, the Berman Institute of Bioethics quickly created and offered a new elective, “Ethical and Policy Challenges in the Era of Covid-19: Implications for Clinical Practice, Research and Public Health,” that immersed students in independent scholarly research projects studying the pandemic’s impact in real time.

“When I was doing background research, ethics felt like a very academic and philosophical subject,” said Laura Pugh, a third-year medical student with an interest in internal medicine. “In the course, I really appreciated the application of ethics and the way it was not just used to explore theoretical ideas, but to bring it into practice and make recommendations for ways things could and should be done in a better way.”

During the course, Pugh conducted two projects related to allocation frameworks for rationing life-saving care. One compared systems of allocation, especially for people with disabilities, and the other created an intellectual history of changes in thinking about allocation frameworks from the early 2000s to the start of the pandemic.

Each of the seven students in the course was paired with a Berman Institute faculty member whose research interests aligned with the student’s. Formal courses meetings occurred virtually once a week for two hours from mid-April until late May. The majority of the course was the students’ independent research work on their projects, guided by weekly meetings with their faculty mentors.

“Bioethics is not just a theoretical field,” said Gail Geller, the Berman Institute’s Director of Educational Programs, who created the course. “These medical students learned that it’s also a place to do serious, rigorous empirical research projects.”

Students Katie Clark and Megan Hunt teamed to conduct an empirical assessment of healthcare workers’ attitudes about self-infection/immunity passports, as well as a state-by-state comparison of plans to end social distancing. Their paper “Safer Infection Sites: Moral Entitlement, Pragmatic Harm Reduction Strategy, or Ethical Outrage?” has been accepted for publication by the Journal of Medical Ethics.

“I became especially concerned about disparities that came up in some of our projects, and how we could create policies that provide everyone equal access to healthcare, and even augment care for those already facing disparities,” said Hunt. “Particularly in the project focusing on allocation of scarce resources, we found it very enlightening to delve into the principles of how people are justifying medical decision-making, deciding who is entitled to what, and what risk we’ll accept for ourselves and for other people.”

Other projects included:
• Qualitative interviews with obstetrics and pediatric providers to assess their views of home versus hospital births in light of the COVID-19 pandemic;
• Assessing the impact of infection prevention and control policies, in particular visitor restrictions, in an inpatient labor and delivery setting on exacerbating disparities in obstetric outcomes for black women;
• Studying the impact of school closings on access to school-based health centers (SBHCs) for families that rely on them; and
• Reimagining the role of SBHCs in increasing access to care during COVID-19 through expansion of telehealth services, enhancing SBHC parental communication and engagement, and improving continuity of care through SBHC-community partner relationships.

“As a future physician, a lot of my experience with ethics is cases, the one-on-one patient perspective. I was rarely thinking about public health on a larger scale, but rather dealing with it on a micro level,” said Janeth Abdul-Rahme, who worked on the SBHC projects. “What drew me into bioethics was delving deeply into the health implications of how COVID is affecting everything on a macro level.”

The Berman Institute faculty mentors included two physicians, Megan Collins and Marielle Gross, and three faculty trained in philosophy, psychology, public health, and bioethics, Anne Barnhill, Ruth Faden, and Alan Ilegben.

“The interdisciplinary nature of the elective’s mentors demonstrates how COVID has blurred boundaries in a beneficial way,” said Geller. “Both within the University and between experts in fields like bioethics, medicine, and public health, we’re all working together in new and effective ways.”

Reopening Policy Tracker for K-12 Schools

A multidisciplinary team of Johns Hopkins University researchers, led by Berman Institute faculty Megan Collins and Ruth Faden and the School of Education’s Annette Campbell Anderson, launched a new website that provides a range of tools dedicated to assessing and guiding K-12 school reopening plans across the United States, including a School Reopening Policy Tracker that provided real-time analysis of the latest guidance documents from every state.

Dubbed the eSchools initiative, the effort is a cross-disciplinary collaboration between JHU’s Consortium for School-Based Health Solutions, the Berman Institute, the Bailes Center for the Integration of Health and Education, and schools of Education, Medicine, and Public Health to provide actionable real-world information and guidance that has characterized the University’s response to the COVID-19 pandemic.

“What children lose by not being in school is enormous; school attendance is a life-defining experience that is critical for educational, social and emotional development. School-age children, who very rarely die or become seriously ill from COVID-19, are being denied the benefits of attending school to protect the rest of us, particularly those at greatest risk of contracting the virus,” said Faden.

eSchools analyzed plans from 46 state Boards of Education regarding policy guidance about reopening K-12 schools. One-third of reopening plans did not initially mention equity considerations for disadvantaged students at all, and most plans mention them with little detail.

“Schools are a nexus of health and well-being for children, particularly in less resourced communities where the burdens of the pandemic are being borne disproportionately,” said Collins, co-director of the Hopkins Consortium for School-Based Health Solutions.

SERVING THE JHU COMMUNITY

In addition to its work across the globe, the Berman Institute rallied to serve the Johns Hopkins campus community during the pandemic. Along with the course highlighted in this story, faculty also taught in new COVID-focused courses in the School of Public Health. COVID-related faculty services at the university included:

- **JOHNS HOPKINS MEDICINE / JOHNS HOPKINS INTEGRATED SYSTEM ALLOCATION OF SCARCE RESOURCES COMMITTEE:**
  - Mark Hughes
  - Jeffrey Kahn
  - Cynda Myers

- **COVID-19 JOHNS HOPKINS MEDICAL CENTERS AND THE COVID-19 JOHNS HOPKINS STEERING COMMITTEE:**
  - Jeremy Sugarman

- **Mary Catherine Beach**

FOLLOWING THE UNIVERSITY’S CLOSING OF THE PHYSICAL CAMPUS IN MARCH, ALL TEACHING OF Berman Institute students took place virtually for the remainder of 2020. Faculty and students alike rose to the challenge and were able to sustain the meaningful personal instruction that is a hallmark of the Institute’s educational program. Those efforts paid off, with a record enrollment of 12 new Master of Bioethics students for the 2020-21 academic year.
Virtual Resilience Rounds Help Clinicians Navigate Moral Distress

Many health professionals on the front lines of COVID-19 care are facing enormous workplace stresses and many have stepped outside their normal roles. They have been worried about how to allocate already scarce resources and about contagion for themselves, their patients, and their families. Many have also been faced with professional conflicts of how to provide care when basic personal protective equipment is not available.

Morality for Medical Professionals: The Importance of Ethical Understanding and Decision-Making in the COVID-19 Pandemic

The COVID-19 pandemic has presented unprecedented ethical challenges for healthcare professionals. The rapid development and implementation of new policies and guidelines have increased the complexity of ethically navigating these times. This has led to a need for increased moral resilience and ethical understanding among healthcare providers.

Johns Hopkins Hospital and the Berman Institute launched the Moral Resilience Rounds program to address these challenges. The program was initiated in response to COVID-19 in recognition of the isolation and distress felt by many colleagues. It was developed to provide a safe and supportive environment for clinicians to share the challenges they have been facing.

The program includes six core components to address moral distress in physicians and other health professionals:

1. **Musical Interlude:** A five-minute interlude by musicians from the Peabody Institute to create a calm and supportive atmosphere.
2. **Safe Space:** Participants are encouraged to speak without identifying themselves to foster a sense of security.
3. **Mindfulness Practice:** A five-minute activity to help participants find a place of rest.
4. **Review of Themes:** A review of the previous week’s discussions to provide a sense of continuity.
5. **Open Discussion:** An opportunity for clinicians to share concerns and struggles.
6. **Closing:** Participants are asked to share what they will take away from the session.

The program has been well-received, with between five and 30 participants participating in each session. These sessions have been instrumental in providing clinicians with a platform to express their thoughts and receive support from their peers.

The importance of moral resilience in healthcare cannot be overstated. As the pandemic continues, it is crucial for healthcare professionals to have the tools and support to navigate the ethical challenges they face. The Moral Resilience Rounds program is a valuable resource in this regard, providing a safe and supportive environment for clinicians to grow and thrive.

"We started moral resilience rounds in response to COVID-19 in recognition that a lot of our colleagues felt isolated and distressed," said Cynda Hylton Rushton, the Anne and George L. Bunting Professor of Clinical Ethics. "It came out of the concern that people needed a place that was safe and supportive to share the challenges they have been facing."

"Moral resilience rounds have offered an opportunity for members of the clinical team to come together to share concerns and support each other as a community," added Mark Hughes, who created the program with Rushton and fellow Berman Institute faculty member Hanna Pickard.

There are the six core components included in the Moral Resilience Rounds to address moral distress in physicians and other health professionals.

Musical interlude: Moral Resilience Rounds occur twice a week for an hour using Zoom, which allows physicians and other health professionals to join from anywhere. Each session has seen between five and 30 participants who have experienced some form of moral distress since the pandemic began.

To begin the virtual session, musicians from the Peabody Institute perform a five-minute interlude to set the tone as participants join the call.

Create a safe space to share: The session then moves to speaking about being together while stressing confidentiality. It is also the opportunity to emphasize the importance of creating a safe space for people to share.

“We want people to share, so we need to make sure it’s psychologically safe,” said Pickard, a Bloomberg Distinguished Professor of Philosophy and Bioethics, who facilitates the sessions, adding that participants have the option not to include their name on the Zoom list or to change it to something else that doesn’t identify them. They are also not required to turn their camera on unless they want to when they speak. If they don’t want to speak out loud, there is also the option to share their thoughts in the chat box.

Mindfulness practice and purpose: For about five minutes, participants in the session practice mindfulness to help them find a place of rest in the midst of their day. After the mindfulness practice, everyone is asked to write a word in the chat box about how they are doing. This is to gain a better understanding of what people are carrying that day.

Review of the themes of the week before: Each week, the sessions also review the themes from the previous week to give people a sense of what topics were discussed.

“A number of the themes have to do with the changes in visitation with families, particularly the distress around patients dying alone or not being able to have their family members there, and family members and patients being upset about that,” said Hughes. “There has been a very clear theme about worrying about their own health and worried about their family.”

Open discussion of concerns and struggles: The session then opens to the community. Physicians and other health professionals can share what is staying with them or what ethical concerns are on their minds.

“We leave it very open and facilitate the discussion,” said Rushton. “We want it to be not about us having answers or having the expertise but being able to get insights from people in the group.”

Leave feeling supported: At the end of every meeting, participants are asked to use the chat box to share what they are going to take away from the session.

“We generally try to have an arc of the session so that we’re leaving people in a resourced state—we don’t want to end it on some big, complex, emotional issue,” said Rushton. “We try to help people to not ignore that, but to really honor it and then try to move toward how we can resource ourselves and what we can draw upon so that when we leave, people are feeling supported, not devastated.”

“One of the things that distinguishes moral resilience rounds from a support group or a debriefing is that it really is focused on addressing the ethical challenges that people are experiencing,” she said. “Part of our goal is to create a space for that, but also to give people vocabulary to name the things that they’re struggling with.”
The ethics of pausing a vaccine trial in the midst of a pandemic: Rachel Levine was quoted.

Insider Higher Education | October 16
Winter is Coming.

The BMJ | December 4
COVID-19 vaccines not expected for pregnant women.

NURSING | October 25
Should Americans be paid to get COVID-19 vaccine? Idea gains steam among some experts.

The Baltimore Sun | October 29
Black leaders in Baltimore work to overcome resistance to participating in COVID trials.

ORCID | November 2
Does the world need a new Global Health Organization?

The New Republic | October 21
A COVID-19 Vaccine Doesn’t Need to Be Perfect.

The New York Times | October 20
A Viral Theory Cited by Health Officials Grass-Fed from Scientists.

The BMJ | December 3
COVID-19 vaccines not expected for pregnant people for some time.

The Washington Post | December 4
Black leaders in Baltimore work to overcome resistance to participating in COVID trials.

The BMJ | December 3
COVID-19 vaccines not expected for pregnant people for some time.

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For too long, the field of bioethics has failed to forcefully confront our society’s structural racism. As a statement issued this summer by the Association of Bioethics Program Directors declared, “We have not spoken out as a profession about the profound impact of racism on medicine, on public health, on clinical care, and on medical research, despite the centrality of justice as a guiding principle for our field.”

Today, and in the years to come, the Berman Institute commits to changing that, individually and collectively, through concrete action.

This special section, along with many of the actions detailed in this report’s COVID-19 section, shares how we have begun and will continue to address this shortcoming.

Diversifying Bioethics, and Bioethics Education

“The events of 2020 provided a stark reminder of the fear, hurt, racism and oppression that the Black community, Indigenous Peoples, and people of color have lived with for centuries in our society,” said Jeffrey Kahn, Director of the Berman Institute. “As an academic institution, we are committed to dismantling structural oppression and racist policies and practices within our institution, community, and in bioethics.”

To formalize that commitment and coordinate efforts, Kahn created a new committee of faculty, staff, and students, providing leadership on inclusion, diversity and anti-racism issues for the Berman Institute and its programs. Chaired by Assistant Director for Science Programs Debra Mathews, the group is liaison to the Bloomberg School of Public Health’s Inclusion, Diversity, Anti-Racism and Equity (IDARE) Committee, with members also working on University-wide efforts.

The members of the Berman Institute IDARE Committee have a shared commitment to helping the BI engage in difficult conversations about racism in all its forms, exploring the ways racism plays out within our communities, identifying opportunities for growth, and enacting change to foster and build a strong, diverse community of scholars, professionals, and trainees in which every member feels they belong and can thrive.

Mathews has played a prominent role in leading a number of previously existing Berman Institute initiatives aimed at promoting diversity and equity within biomedicine and bioethics, including the Genomics and Society Mentorship Program, a research-focused mentorship program to build a regional pipeline to enhance diversity in Ethical, Legal, and Social Implications (ELSI) research.

Since its launch in summer 2019 with NIH funding, the program has provided intensive training for 5-6 students per year in ELSI research. Faculty from the Berman Institute mentor trainees on bioethics, both broadly and in the context of a 10-week summer research project, which enables students to identify and analyze morally relevant issues in science, medicine, and public health. Students continue their connection to the program throughout the academic year (for a total of 15 months), co-lead the planning of an activity related to their interests in Genomics and Society at their home institution, and return to Hopkins for one week the following summer for additional training, mentorship, and connection with their Hopkins network and the next cohort of trainees.

Kahn said the Genomics and Society Mentorship Program is just one example of the initiatives that the Berman Institute will undertake and build on in the coming months to help to address the structural racism in society through the work of bioethics and the Berman Institute.

Issues of justice, of ethics more generally, and of public policy are all features of what bioethics is and what the Berman Institute exists to do,” he said. “Our work needs to focus more squarely and intentionally on the issues of inequality and social justice, both as they relate to the current moment and how they inform the society we want to build.”
Addressing Social Justice Through the Lens of Henrietta Lacks on Bioethics’ Biggest Stage

Among the many disruptions of the pandemic, one particular disappointment was the cancellation of the in-person annual meeting of the American Society for Bioethics and Humanities (ASBH), scheduled for Baltimore and set to coincide with the Berman Institute’s 25th Anniversary Celebration and the centennial of Henrietta Lacks’s birth. Yet despite the switch to a virtual format, the Berman Institute was able to host a plenary session that was the talk of the meeting and continues to reverberate.

“Social Justice and Bioethics Through the Lens of the Story of Henrietta Lacks,” was moderated by Jeffrey Kahn and featured Ruth Faden as a panelist. She was joined by Henrietta Lacks’s granddaughter, Jeri Lacks, architect Victor Vines, and Georgetown University Law Center bioethicist Patricia King.

Faden began the session by providing an overview of the Henrietta Lacks story, framed in the context of structural injustice.

“The structural injustice of racism defined in pretty much every way how this story unfolded,” she said. “What is wrong about what happened to the Lacks family engages every core element of human well-being. There were assaults on the social basis of respect, and of self-determination, on attachments, on personal security and on health. Mrs. Lacks and her children were poor Black people in a segregated world in which the most profound injustices of racial oppression were daily features of their lives.”

Faden was followed by Jeri Lacks who expressed the importance of continuing to let the world know about her grandmother’s story.

“Her cells were used to develop the polio vaccine and to treat HIV, and in creating in vitro fertilization. She is a person who continues to give life, and to preserve life,” said Lacks. “No matter what your race, your age, your social circumstances, she continues to improve your life.”

Victor Vines, an architect who was part of the architect team leading programming and planning for the National Museum of African American History and Culture and led the feasibility study for what will be Johns Hopkins University’s Henrietta Lacks Hall, spoke next about addressing racial injustice through architecture and design.

“When we started work on Lacks Hall, we didn’t talk a lot about architecture or design. We talked about what that story is that we want to tell through the building. Meeting with the Lacks family was critically important to that,” Vines said. “We had to understand what they went through and what they care about. The building still has to function and house the Berman Institute, so we had to meet their needs. And we discovered a third client, the East Baltimore community. At the end of the day, this building and university resides within that community, and they will be called to embrace this project—or not.”

King concluded the panel with a riveting and wide-ranging discussion that touched upon intersectionality, segregation, the Tuskegee experiments and participation in clinical trials, COVID, race as a social construct, and the role of consent, all within the framework of Henrietta Lacks’s story.

“Our narratives are important and should be thought of as lessons or homework for institutions,” she said. “They not only document the deep distrust we bring to health encounters but also convey relevant aspects of our lives that should be appreciated.”

As the session ended Kahn noted that perhaps it was fortunate the session had been virtual, so the recording “could be shared with others for posterity. I’m not quite speechless, but maybe close,” he said.
Since its inception, the Berman Institute’s Seminar Series has brought leading bioethics scholars to lecture at Johns Hopkins and hold in-depth conversations with graduate students and fellows. With travel made impossible by the pandemic, series organizers reimagined its focus while broadening its scope, inviting speakers from around the globe to share their insights through online Zoom sessions.

“We knew that it was important for this year’s series to focus on and address vitally important issues of inequity. At the same time, the virtual format imposed by COVID meant speakers from around the world were suddenly accessible to us and our students,” said Joe Ali, who chairs the Berman Institute Seminar Series Committee.

Former Baltimore City Health Commissioner Leana Wen started this year’s series with her talk “COVID-19, Public Health and Environmental Justice,” which she said was sparked by conversation with the Berman Institute’s Hecht-Levi Fellows.

“While it’s a challenge not to have these conversations in person, we’ve realized the high quality of discussion that is still able to take place,” said Ali.

In all, the Berman Institute hosted more than two dozen seminars, lectures, symposia and other public academic events during the year. Recordings of all Seminar Series talks and many of the other events are available on the Berman Institute’s website and YouTube channel.

In her most recent book, Structural Injustice, Faden Takes Work on Justice Theory to New Level

In her most recent book, Structural Injustice: Power, Advantage, and Human Rights (Oxford University Press), Johns Hopkins Berman Institute of Bioethics founder Ruth Faden and co-author Madison Powers build on their longstanding work on justice to put forward a groundbreaking new, broader 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.

“In our first book we put forward a theory of justice that we situated in bioethics, and public health more generally. This book has significantly elaborated upon that theory to address questions of structural injustice across all spheres of social and political life,” said Faden, who previously co-authored Social Justice: The Moral Foundations of Public Health and Health Policy with Powers in 2006.

“While many of the examples, and all of the insights, in Structural injustice address questions of health, it is one of six core elements of well-being that provide the grounding for the theory we put forward in the book. And we examine three ways in which structural arrangements can be unfair: power, exclusion, and exploitation.”

Faden notes that the new book also makes good on the claim in Social Justice that their theory is intended to apply globally, both within nation-states and across national boundaries. She adds that theory also 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.

For a full list of academic publications by Berman Institute faculty this year, visit: bioethics.jhu.edu/2020_research.

In early 2021, the design phase will begin for Henrietta Lacks Hall, a new multidisciplinary building on the university’s East Baltimore campus.

The building will occupy the site adjacent to Deering Hall, located at the corner of Ashland Avenue and Rutland Avenue, north of The Johns Hopkins Hospital. It will be named in honor of Henrietta Lacks, the Baltimore resident whose HeLa cell line has contributed to many significant advances in medicine, including the development of the polio vaccine to the study of HPV, HIV/AIDS, and leukemia. Lacks Hall will not only memorialize the impact Henrietta Lacks has had on modern medicine, but will also create a new front door to neighborhoods surrounding the Johns Hopkins medical campus, with a portion of the space planned to be multi-purpose and available for use by local community organizations.

“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,” said University President Ronald J. Daniels.

Groundbreaking is tentatively anticipated for late 2020, with planned completion in 2024.
Berman Institute Launches Public Bioethics Initiative with Creation of the Dracopoulos-Bloomberg iDeas Lab

The COVID-19 pandemic has demonstrated in unprecedented ways the critical need of the public, governments, and the private sector to access clear, accurate and timely information about the ethical issues surrounding decision-making in science, medicine, and public health. To help provide such vital information more broadly and effectively than ever before, the Berman Institute of Bioethics today announced its intention to create a new program in public bioethics, funded by $3 million in philanthropic support to establish The Dracopoulos-Bloomberg Bioethics iDeas Lab.

“Virtually every aspect of our nation’s response to COVID involves an issue of bioethics: the balance between personal freedom and public safety in wearing masks; whether and when to close or reopen schools and businesses; allocating scarce medical resources; safely developing vaccines; using new contact tracing technologies, and much more,” said Jeffrey Kahn.

“Our public bioethics effort will significantly increase understanding about critically important issues in bioethics and ethics in science more generally. Higher levels of engagement with bioethics issues that impact our communities, locally, nationally, and internationally, will inform public discussion and debate and ultimately impact policy decisions.”

Welcome Kadija Ferryman

Dr. Kadija Ferryman, a cultural anthropologist and bioethicist who studies the social, cultural, and ethical implications of health information technologies, will join the Berman Institute next year with a joint appointment in the School of Public Health’s Department of Health Policy and Management. Her research examines how genomics, digital medical records, artificial intelligence, and other technologies impact racial disparities in health. She is currently Industry Assistant Professor at New York University’s Tandon School of Engineering. As a Postdoctoral Scholar at the Data & Society Research Institute in New York, she led the “Fairness in Precision Medicine research study, which examines the potential for bias and discrimination in predictive precision medicine.

Ferryman traces her interest in the topic back to her graduate school days, when excitement was building about the Human Genome Project and the possibility of identifying and mapping every gene. There were, she realized, ethical pitfalls in having that type of data, given its potential for misinterpretation or misuse.

Although her research focuses specifically on health information technologies, she explains that developing and using any type of tech requires careful consideration of the moral dilemmas it may pose and the ways it may negatively affect marginalized groups.

Ferryman wants her students to understand that the ethical dilemmas they could face as designers and engineers do not take place in a vacuum but within the context of broader social hierarchies. She stresses to them that technology is not separate from society, but rather, a product of society, and she feels confident that they’ll graduate prepared to make thoughtful and equity considerations as they embark on a career path.

She earned a BA in Anthropology from Yale University, and a PhD in Anthropology from The New School for Social Research. Before completing her PhD, she was a policy researcher at the Urban Institute where she studied how housing and neighborhood impact well-being, specifically the effects of public housing redevelopment on children, families, and older adults.

Collaboration with Oxford University to Establish Global Program Addressing Ethics and Infectious Disease Treatment

Thanks to a generous grant from the Wellcome Trust, the Berman Institute and the Wellcome Centre for Ethics and Humanities at Oxford University will form a partnership that will build on collaborative research interests in the ethics of infectious disease research, as well as public health preparedness and response. The partnership will create the go-to program for rapidly identifying and analyzing ethical and policy issues arising in infectious disease treatment, research, response, and preparedness, and will allow its members to engage in research on the profound ethical challenges presented by infectious diseases across the globe.

The work of the partnership, set to launch in January 2021, will establish the Oxford-Johns Hopkins Global Infectious Disease Ethics Collaborative, which will identify important issues for policy response and a program of global health ethics research focusing on infectious disease. Faculty, students, and post-docs will work collaboratively across the Atlantic to bring a level of expertise to bear in ways that very few academic organizations anywhere else in the world can.

The COVID-19 pandemic has demonstrated in unprecedented ways the critical need of the public, governments, and the private sector to access clear, accurate and timely information about the ethical issues surrounding decision-making in science, medicine, and public health. To help provide such vital information more broadly and effectively than ever before, the Berman Institute of Bioethics, national advisory board, and former chair of the University’s Board of Trustees Michael R. Bloomberg, is an important first step in this effort. The Lab will enable the Berman Institute to pioneer new approaches for creating bioethics content, taking advantage of new media strategies, the latest media technologies, and innovative approaches to visualization of information and research results.

The $3 million gift will support new physical space to house the iDeas Lab, provide new technology, and support new faculty and professional staff devoted to the creation and distribution of engaging digital, audio, and video content with a focus on dissemination professionals, policymakers, and critically important, the public. Dracopoulos previously funded creation of a similar and very successful lab at the Center for Strategic & International Studies (CSIS) in Washington, DC, one of the nation’s leading national security think tanks. The CSIS iDeas Lab was an early leader in bringing together their scholars with content producers, developers and designers to create a compelling range of digital products of research.

“The iDeas Lab will make possible for the work of bioethics, and ethics and science more generally what the creation of the Johns Hopkins Coronavirus Resource Center provided for political leaders, journalists and the public looking for authoritative thought leadership,” said Kahn. “We will employ cutting edge techniques and technologies to share the research and analysis of our faculty on the most pressing issues facing our society.”

Additional components of the public bioethics program will unfold in coming years. The Berman Institute will reach policymakers with a series of high-profile bioethics events in Washington, DC. Experts from the iDeas Lab will work with faculty across Johns Hopkins to devise new ways of sharing academic research with the public, and the Berman Institute will seek to add additional faculty with expertise in assessing the societal impact of increased public dissemination of bioethics findings and research.
Climate change continues to prove itself a real and tangible threat, especially when considering the feedback loop formed by climate change and food systems, says Jess Fanzo, Bloomberg Distinguished Professor of Global Food Policy and Ethics at the Berman Institute of Bioethics, Johns Hopkins SAIS, and the Department of International Health in the Bloomberg School of Public Health.

“Climate change destabilizes earth systems, which disrupts food systems,” she says. “But food systems also contribute to environmental degradation. What do we do about that?”

Fanzo has dedicated her career to studying the ways food systems, economics, and climate affect access to healthy, environmentally sustainable, and equitable diets, especially in areas of the planet where resources are limited or constrained. She says she doesn’t think there’s a huge window to act to prevent climate change anymore, and we could be headed for a climate catastrophe in which earth systems take over and humans are no longer able to make a difference.

“We have more knowledge than ever before,” Fanzo says. “So why haven’t we seen an impact when we know so much?”

Last year, she joined a commission of 37 scientists from around the world to publish a report that described a “planetary health diet.” According to the report, the diet could feed 10 billion people while also operating within planetary boundaries—a healthy diet that would not exacerbate climate change. But the diet was intended to be a vision, not a plan.

“The diet got policymakers thinking about interconnectedness, thinking about how much will it cost, what policies it would take,” Fanzo says. She expects the United Nations Food Summit, which will take place in October 2021, to be consumed with the issue of food affordability. Everyone has to work together to take action, she says, but with the ongoing economic crisis caused by the coronavirus pandemic, will the nations of the world come together to enact effective policies?

“The food supply is moving more reliably again, but can people afford food?” she says. “A year from now is when we’ll really see the free fall of the global economy. What we’re seeing now is just the proverbial tip of the iceberg.”

One of Fanzo’s current projects, in collaboration with several other partners, is a food systems dashboard. With the dashboard (www.foodsystemsdashboard.org), the goal is to make the data we have on food systems more digestible, more accessible to policymakers and people who can make decisions that affect what kind of food is produced and what kind of food is eaten.

She believes that despite how much is known about food systems and climate, more data are still needed—the right kind of data, which are harder to come by. Scientists still don’t really know what people are eating around the world, for example, or why they make the choices they do and where they get their food from. There’s a section of the food systems dashboard called “Consumer Behavior,” which is broken into four sub-sections—acquisition, preparation, meal practices, and storage—for which no data is available. Fanzo hopes that the dashboard’s “no indicator available” message will signal to other researchers the data gaps that exist and the kinds of research that needs funding.

“What you don’t know, you can’t manage,” she says.

The other problem with data, aside from the gaps, is the steady undermining of research in the current political climate. “It’s openly disregarded,” says Fanzo. There are plenty of solutions that can address the problem, and she hopes to see governments take charge in issues surrounding food system security.

“Assuming that consumers will make the right choice is just not true,” Fanzo says. “Governments need to help people make easy, good choices.”

Still, she says, there are reasons to be hopeful for the future. Agroecology and regenerative agriculture are gaining traction. Producers discuss how to intensify—or grow more food on the same land—sustainably, and there are technologies that can help. Better seeds and integrated pest management hold a lot of promise, for example.

“There’s a lot of climate-friendly technology where we can be more sustainable right now, but the incentives are not there yet,” Fanzo says. “It’s not just a fantasy. It’s possible.”

This story was originally written by Christine Grillo for the Johns Hopkins Center for a Livable Future.
Considering a Future-Facing Global Health Ethics

Can the discipline of bioethics, and ethics more broadly, contribute to analyzing and stabilizing the world order, or even to making it better? And, more specifically, can ethical resources and reasoning help address the role that health could or should have in stabilizing or reforming the post–COVID world?


“The pandemic has highlighted our interconnectedness and interdependency; it has compelled thinking about ethics and its relationship to health within and across countries, which requires greater coordination and cooperation in a world that seems geopolitically fractured. It has also exposed the limitations of the historically dominant approaches to bioethics, pointing to a need for approaches that take seriously and engage deeply the concerns of social justice and health equity—concerns that, during the COVID-19 response, have relevance for everything from decisions about the triage of lifesaving resources to global health policy,” wrote Kahn and his co-authors.

“Bioethics needs to do better, and we argue that this means a renewed focus on a global health ethics that recognizes and takes account of the realities highlighted by the pandemic: focusing on health, not just health care, health equity, not just allocation of scarce resources, and social justice, not just distributive justice.”

The book is the product of a two-day virtual forum hosted by the Johns Hopkins School of Advanced International Studies in June that gathered a multidisciplinary group of exceptional scholars, thinkers, and leaders to consider collectively the future of our world order after COVID-19. In a series of essays, international experts in public health and medicine, economics, international security, technology, ethics, democracy, and governance imagine a bold new vision for the future.

“When the pandemic is under control, societies will be left with the knowledge that social structural inequities produce inequalities in health, along with the understanding that global pandemic responses and resilience require governments and societies to be more just,” wrote Kahn and his collaborators.

“Unfair global and social orders are not just bad for health. Health inequalities, and social responses necessary to sufficiently address pandemic threats, can devastate countries for years, affecting generations, and they threaten the global order. Health equity and human well-being must, therefore, be more of a central concern of global transformations under way and likely will need to be so for the foreseeable future.”

HONORS AND AWARDS

Benita D. Boss, associate professor of pediatrics/neonatology and core faculty at the Johns Hopkins Berman Bioethics Institute, has been appointed the inaugural Berman Brandom Foundation Professor of Pediatric Palliative Care. This professorship was endowed by the generosity of Mr. Mayo A. Shattuck III through the Brandom Foundation.

Jeremy Greene was awarded the 2021 Nicholas Davies Memorial Award by the American College of Physicians. Dr. Greene receives the award for “outstanding scholarly activities in history, literature, philosophy, and ethics and contributions to humanism in medicine.”

Jeffrey Kahn was named to a new National Academy of Medicine committee, The Committee on Emerging Science, Technology, and Innovation in Health and Medicine (CESTI) with address the potential societal, ethical, legal, and workforce implications of such technologies, with the goal of developing a multi-sectoral governance framework. In addition, Debra Mathews, the Institute’s Assistant Director for Science Programs, has been selected as an Academic Collaborator for CESTI.

Jeffrey Kahn also was elected to the National Academy of Medicine Council (board of directors).

Jeffrey Kahn, Mark Hughes, and Cynda Hylton R bushon were appointed to the Johns Hopkins Medicine/Johns Hopkins Health System Allocation of Scarce Resources Committee.

Mario Macis was promoted to full Professor at the Carey Business School.

Debra Mathews became a Member of the Johns Hopkins University School of Medicine Biopsychosocial Transfer Committee.

Leonard Rubenstein was promoted to Professor of the Practice in the Bloomberg School of Public Health.

Cynda Hylton R bushon’s book, Moral Resilience: Transforming Moral Suffering in Healthcare, was chosen as a book of the year for Nursing Professional Issues by the American Journal of Nursing.

Johns Hopkins Bloomberg School of Public Health appointed Brendan Saloner as a Bloomberg Associate Professor of American Health in the Department of Health Policy and Management. This is an endowed position supported by the Bloomberg American Health Initiative through a gift from Bloomberg Philanthropies. Saloner is an associate professor in the Department of Health Policy and Management, with a joint appointment in Mental Health. He is also core faculty in the Berman Institute of Bioethics.

Hecht-Levi Postdoctoral Fellow Brandi Scully was awarded the 2019 Cardiothoracic Ethics Forum Scholarship. The Cardiothoracic Ethics Forum is the joint entity of the American Association for Thoracic Surgery and the Society of Thoracic Surgeons that is responsible for ethics education in cardiothoracic surgery.

Jeremy Begeman was appointed to COVID-19 Johns Hopkins Clinical Research Coordinating Committee and the COVID-19 Johns Hopkins Steering Committee.

Berman Institute 25th Anniversary Celebration Postponed

Just as the Berman Institute’s yearlong 25th anniversary commemoration was kicking into high gear, pandemic struck. As a result, the celebration was postponed and will resume when conditions allow.

“Our marking of the Berman Institute’s 25th anniversary will be an opportunity to celebrate, reflect upon, and share the Institute’s important achievements and leadership in bioethics, but we should do so only when we have overcome the pandemic,” said Jeffrey Kahn.

“The quality, range of topics, and impact of the Berman Institute’s response to the pandemic demonstrate that our work is more vital than ever before. These ongoing efforts will add another very meaningful chapter in our history to commemorate.”

A number of the previously scheduled 25th anniversary events will be resched-
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- Advancing fair and compassionate healthcare that puts people first.
- Leading the change for equitable and effective public health policies and practices.
- Guiding the ethical development and use of new technologies.
- Addressing disparities arising from global sustainability challenges.
- Preparing the next generation of leaders in bioethics.

For information about supporting the Berman Institute’s work, contact Andrew Rentschler at 410-614-5651 or visit bioethics.jhu.edu.