FOR THE SECOND CONSECUTIVE YEAR,
the Berman Institute’s Annual Report highlights our contributions during the Covid-19 pandemic and its impact on our work—an unprecedented event that has defined our lives both personally and professionally. As I write this letter, the Omicron variant has created a surge in cases that is now, thankfully, receding, some two years after the first outbreaks were reported, which postponed travel and in-person meetings once again.

The pandemic continues, but we are now seeing hope on the horizon, and our faculty are beginning to look ahead to what comes next both here at the Berman Institute and across the field of bioethics. In this year’s Annual Report, we’ve asked a wide-ranging collection of our faculty to not only reflect on how Covid has impacted their areas of research expertise to date, but also share what they believe will be some of the lasting and perhaps permanent changes to the field. You will see that many find cause for optimism, along with an understandable measure of caution.

As you might expect, thinking about how we can apply the lessons learned during Covid-19 to a future pandemic is a common theme. Artificial Intelligence is another, and Berman Institute faculty Debra Mathews has been named a lead in a new Bloomberg Distinguished Professors Artificial Intelligence and Society project that will bridge computer sciences, social sciences, and ethics. A similar interdisciplinary approach is in the planning stages for addressing the many ethical issues arising from climate change. And to support our continued emphasis on the public-facing aspects of our work, we recruited neuroscience researcher and documentary filmmaker Lomax Boyd as a Civic Science Fellow in partnership with the Kavli Neurodiscovery Institute. Lomax will spend the next 18 months focusing on designing new methods for engaging the public on the ethics and policy issues of emerging science.

I’m happy to share that we’re moving forward in the planning and design phase for the new Henrietta Lacks Hall, with groundbreaking and construction to begin in late 2022. We are continuing to expand our educational programming and enjoyed record enrollment in the Masters in Bioethics Program this year, and early applications suggest that interest in graduate education in bioethics continues to be strong.

The Berman Institute is fortunate to have generous supporters who have allowed us to contribute to addressing the unprecedented challenges posed by the pandemic. We’re looking forward to the time—hopefully in 2022—when we can resume working fully in-person. We’ll continue to approach our work with the strong sense of optimism and purpose that is the hallmark of the Berman Institute community.

On behalf of all of us, I thank you for your support in 2021 and look forward to what we can accomplish together in the coming year.

All my best,

Jeffrey P. Kahn, PhD, MPH
ANDREAS C. DRACOPULOS, DIRECTOR
ROBERT HENRY LEVI AND RYDA HECHT LEVI, PROFESSOR OF BIOETHICS AND PUBLIC POLICY
ADVANCING FAIR AND COMPASSIONATE HEALTHCARE THAT PUTS PEOPLE FIRST

THE COVID-19 PANDEMIC HAS INDELIBLY ALTERED THE FIELD OF BIOETHICS.
FOR ALMOST TWO YEARS THE BERMAN INSTITUTE OF BIOETHICS HAS BEEN AT THE FRONT LINES, HELPING SHAPE A RESPONSE THAT ALIGNS WITH OUR VISION OF:

> ADVANCING FAIR AND COMPASSIONATE HEALTHCARE THAT PUTS PEOPLE FIRST;
> LEADING THE CHARGE FOR EQUIitable 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.

IN THE SERIES OF Q&AS THAT FOLLOW, MEMBERS OF OUR FACULTY ADDRESS HOW THE PANDEMIC HAS ALREADY IMPACTED THEIR WORK AND CONTEMPLATE WHAT THE FUTURE MIGHT HOLD.

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RUSHTON DISCUSSES THE PANDEMIC’S IMPACT ON FRONTLINE CLINICAL WORKERS

HOW HAVE NURSES CHANGED THROUGHOUT THE COVID-19 PANDEMIC?

Nurses’ roles are now more important than ever. Nurses are often the last source of compassion for patients. They’re the ones doing the screenings, taking care of the critically ill, implementing triage protocols, communicating with families, and attending to the dying. Nurses in every role are impacted. They’re being asked to work in areas of the hospital that aren’t their normal specialty. They’re providing telehealth consultations. They’re being redeployed to learn new skills and take on new roles—as safety officers and taking care of critically ill patients. They’re making triage plans operational. We’ve had to reallocate our resources in profound ways, and nurses are innovating and leading throughout the crisis.

FROM AN ETHICAL STANDPOINT, WHAT NEW CHALLENGES ARE NURSES FACED?

For nurses, our ethical framework has focused on the well-being of individual patients. Historically, decisions were made based on the autonomy of patient’s preferences and values. That is no longer possible. That shift leaves nurses feeling like they’re abandoning their individual patients. They’re not able to provide the level of care they’re used to. The gap between what they can do and what they believe they should do creates moral distress, a sense that they’re compromising their integrity.

During this crisis, it’s necessary to reconsider what fairness and justice means, and to recalibrate our ethical obligations in response to the severe conditions.

WHAT EXACTLY ARE THOSE OBLIGATIONS?

They’re very complex. Nurses always have obligations to the patient in front of them, but the pandemic imposes so many limitations. We can’t say, “Whatever you prefer is available,” but we can say, “Here’s how I’m able to help you with the resources we have.” It might be that I can offer my knowledge and skills to relieve your symptoms and help you make decisions, or provide options for palliative care or spiritual support, or simply listen to your fears and concerns.

At the same time, nurses must consider how we can benefit more people. This often means making room for sicker patients by discharging patients who would under other circumstances be admitted. Moment-to-moment decisions are required on how to use equipment, medications, and resources when there aren’t enough for everyone.

AND WHAT OBLIGATIONS DO NURSES HAVE TO THEMSELVES AND THEIR OWN FAMILIES?

We always begin with patients as our first priority in our professional ethical framework. That doesn’t mean we don’t have obligations to our own well-being and families. Nurses are grappling with questions like, “Am I potentially causing harm to my family by coming home from work every day?” and “How do I balance the needs of my loved ones with the endless needs of patients?”

The stakes are very high, and unfortunately there are no good answers. Part of being able to find integrity here is accepting the reality of our current situation and living with uncertainty—acknowledging we’re making decisions under constrained and difficult circumstances. However, the American Nurses Association Code of Ethics is clear: Nurses have the same obligations to self as to others. Investment in one’s well-being is not optional; it’s a moral mandate.

THE RISK OF BURNOUT RIGHT NOW SEEMS ESPECIALLY HIGH.

Even before this crisis hit, burnout levels among clinicians were escalating at alarming rates. Last year, I served on a National Academy of Medicine committee charged with looking at these issues. This pandemic has stressed an already over-stressed health care system.

What I know about clinicians is that in a crisis, they show up. What’s most concerning now are the long-term consequences. It’s not only post-traumatic stress but this feeling in some people that they’re acting against their own consciences in certain actions during the crisis. The fallout of that is significant moral distress or moral injury, which accumulates over time.

We are at a tipping point in health care because what we have been doing is unsustainable. We will be forced to reassess our assumptions and the ways we have designed our health care systems in terms of resource allocation and take the allocation of human resources as seriously as we’ve taken allocation of ventilators and vaccines. We haven’t seen the worst of it, I really think there’s more to come.

CATHERINE RUSSON, ANNE AND GEORGE L. BUNTING PROFESSOR OF CLINICAL ETHICS, BERMAN INSTITUTE OF BIOETHICS, JOSHUA HOPKINS SCHOOL OF NURSING, PROFESSOR, JOSHUA HOPKINS SCHOOL OF MEDICINE, DEPARTMENT OF PEDIATRICS

A vision of bioethics after COVID
I’ve written about the concept of moral resilience for health care workers. Some strategies include using tools for ethical analysis to determine the best course of action. We also need to build our neural pathways for self-awareness and self-regulation, through practices like mindfulness. This helps our nervous system regain balance, so we don’t become stuck in fight, flight, or freeze. It also involves self-stewardship—prioritizing what nourishes our bodies, minds, and spirit, and engaging resources that have supported us through ethical challenges before.

Nurses also really benefit from finding outlets. At Hopkins, we’ve offered the Mindful Ethical Practice Resilience Academy for frontline nurses. And we created a new program, Moral Resilience Roundtable, a virtual gathering of clinicians who work in all variety of settings, who can share ethical challenges they’re facing and learn from each other.

WHAT IS GIVING YOU HOPE RIGHT NOW FOR NURSES?

I think this pandemic only highlights and elevates the central role that nurses serve in health care. We’re seeing the many ways nurses can contribute, adapt, and take the lead.

I recently listened to some of our graduates from the Johns Hopkins School of Nursing talk about how they’re adjusting to the “new normal.” To hear them talk about their growth, and the stretching they’re doing, is really inspiring. In that there’s hope.

As a parent of two young children, I experience the frustrations and struggles that will impact them directly—growth charts with weight trajectories skyrocketing since the start of the pandemic, teens with new onset depression and anxiety at alarming rates, kids falling behind in school, grief from the loss of loved ones to Covid, fears of contacting Covid, fears and uncertainty about the vaccine.

WHAT HAS BEEN THE PANDEMIC’S IMPACT ON YOU AS BOTH A PEDIATRICIAN AND THE PARENT OF YOUNG CHILDREN?

I’m working with colleagues at the BI and Oxford on a project that looks at how policies impacted the families of children with chronic conditions. That’s grown into thinking about how the voices of these children and their families can be used in creating policies in the future. We’re trying to create a new methodology that will better include families’ lived experience in shaping the policies that will impact them directly.

WHAT ETHICAL QUESTIONS HAS COVID HIGHLIGHTED IN YOUR WORK?

There were already problems with fragmented systems of care that didn’t properly promote optimal health and wellbeing for children with medical and/or social complexities. Covid exacerbated these underlying challenges and disparities. It brought to light that some people are impacted differently, and more significantly. But through this pandemic, we’ve seen one-size-fits-all policy decisions made by governments that don’t even talk about, let alone account for, these disparate impacts.

Ethics needs to be a part of policymaking. Ethics brings language and a framework for thinking through benefits and harms. Ethics professionals are good at recognizing that different people have different values, and at helping evaluate and prioritize competing interests and obligations, particularly when policies have different impacts on different populations.

I’m still worried about those children who are unprotected. The narrative that Covid doesn’t impact children as much as adults doesn’t give enough attention to all the challenges they continue to face. While all children are vulnerable, there are pediatric populations that have been disproportionately impacted by the pandemic. Children of color have been more likely to be hospitalized or develop severe illness from Covid. Children in foster care missed visiting in-person with their biological parents or had adoptions put on hold due to court delays. And not only were children with medically complex conditions at greater risk of medical complications with Covid, but they faced challenges in all aspects of life. Access to and delivery of care was impacted by Covid policies, such as cancelling elective procedures. School based services, like speech and physical therapies, were abruptly stopped with school closures. Existing shortages in pediatric home nursing were exacerbated by illness and fears of exposure, leaving parents unable to sleep or work as they provided for their child’s 24/7 care needs without home nursing supports.

It is morally problematic that the voices and experiences of these populations don’t seem to matter in discussions about Covid-related policies.
LEADING THE CHARGE FOR EQUITABLE AND EFFECTIVE PUBLIC HEALTH POLICIES AND PRACTICES

KASS ADDRESSES WAYS IN WHICH THE PANDEMIC HAS UPENDED TRADITIONAL ASSUMPTIONS ABOUT PUBLIC HEALTH ETHICS

BEFORE COVID-19, HOW DID EXPERTS IN PUBLIC HEALTH ETHICS APPROACH THE IDEA OF MANDATING PUBLIC BEHAVIOR?

There has always been a tension in the ethics of public health regarding how far to go to help make sure that the public can be healthy. When should we simply provide health education and when should certain behaviors be required or prohibited? How should approaches differ when someone’s behavior can threaten the health of others? And how can we best be mindful of who are the winners and who are the losers when policies are put forward—or when they are not?

The tagline of public health has been “Assure the conditions in which everyone can be healthy.” A key factor for public health is whether certain health threats can be managed or controlled by individuals making choices on their own. If, despite their actions and best intentions, people can’t be healthy because of choices that others make, that becomes a moment in the ethics of public health when we consider stronger policies like a mandate. It’s why so many places in the U.S. moved from educating people about the dangers of smoking to prohibiting smoking in restaurants and stores. It’s why many schools and businesses have said you can’t go there unless you’ve been vaccinated.

HAS THE PUBLIC RESPONSE TO COVID CHANGED THAT APPROACH?

At the beginning, most of us were approaching Covid the way we had always approached public health threats: provide information, equip people on how best to protect themselves; and, as it quickly became clear that this was a contagion threat that people could die from, put some restrictions in place to make sure people aren’t at risk from others who choose not to follow recommendations.

As the last two years have unfolded, we have had to consider a very different set of questions: How do we value public health? We have always just assumed that people want to be protected from threats like toxic food or rabid animals or someone walking around with TB or Ebola. Is that really true?

The most significant question for our current situation is where do we cross the line from recommendation to mandate. It’s a hard question because people will draw that line in different places and that’s okay. Like different parents will draw the line in different places with questions about keeping their children safe, like curfew, or what age to get a cell phone, or providing access to alcohol. All parents want to keep their kids safe, and it’s okay for different parents to make different decisions about how to do that.

But how do we approach that question that needs to be explored by those of us who want to tie that into public health messaging? Some might call it manipulation, but I don’t. I really think it’s important to know what people care about and to be able to tap into that—public health needs to be relevant. Vaccines might appeal to some people because they want to go out with their friends again; another person wants a vaccine to feel less anxious going back to work; another wants to safely visit or take care of an elderly parent. There’s nothing wrong ethically with trying to figure out which reasons best resonate with different people.

Public health, politics, psychology all need to come together in understanding what people value and use that to inspire behavior that will produce healthy conditions for everyone. Public health people figured out a long time ago that one of the best arguments for getting teens to stop smoking is that they would have bad breath. They cared much more about that than envisioning a day in the distant future when they might get lung cancer. There’s nothing manipulative about the messages you use when all of them are true.
LEADING THE CHARGE FOR EQUITABLE AND EFFECTIVE PUBLIC HEALTH POLICIES AND PRACTICES

FADEN DISCUSSES LESSONS FROM THE PANDEMIC ABOUT HOW ETHICS CAN SHAPE PUBLIC POLICY

Public policy is a blunt instrument. Ethically, how do you wield this blunt instrument in the context of very high stakes decisions? I hope that what comes out of this pandemic is a renewed commitment of the professional ethics community to work with policymakers, to help them by providing relevant information in whatever form they find most useful.

WHAT PRACTICAL STEPS CAN ETHICISTS TAKE TO INSPIRE POLICY MAKERS TO MAKE MORE ETHICAL DECISIONS? I am working with Anne Barnhill on an extraordinary research project, looking hard at understanding how ethics guidance reasoning did or did not play a role and was or was not helpful in decisions about Covid response that happened across the United States. And we’re also looking at engagement with the public on these decisions. This kind of work needs to be done in countries around the world, and also done for international institutions, like the World Bank and WHO and WTO, and the big philanthropes. While the context for this project is the pandemic, we want to understand what did and didn’t work, and why, with implications for public health policymaking more broadly as we move forward.

We need to make this an area of scholarship, so we can better understand the kinds of tools that policymakers will or will not find useful. When we came out with our framework for the ethical reopening of public schools during the early days of the pandemic, we didn’t have an opportunity to figure out how it would help, or if it would be useful. So, we need to collaborate with international and national level organizations and work with policymakers who might welcome the opportunity to make progress in this area. We need to form creative partnerships with organizations that already work well with policymakers. Some organizations have figured out how to provide useful legal tools, policy tools, research tools. We need to figure out how to do the same in the ethics space.

Let’s not shy away from this work, let’s own it. A defining characteristic of our work in the Berman Institute has always been and remains a deep commitment to doing work that assists policymakers and shapes public policy. We need to think strategically about getting people with ethics expertise around the table. Within government, civil society organizations, at the grass roots, figure out how to help us help you in making ethical decisions.

OTHER THAN COVID, WHAT BIG ISSUES ARE SHAPING THE FUTURE OF THE FIELD OF BIOETHICS? It’s as close to a truism as we have in public health to say that in an emergency or crisis of any kind, it’s the worst-off groups that suffer the most—whether in a war, or a tsunami, or a pandemic. It’s almost equally as banal to say this pandemic has shined a light on and widened the already unacceptable fault lines of injustice, within this country and globally. And yet, at least in the beginning, it sometimes still needed to be pointed out how the pandemic has hurt already disadvantaged people and how much worse it is for them now. The other recent catalyzing national event was George Floyd’s murder and how that horrific injustice catalyzed national attention and forced a realization among privileged people of how pervasive and pernicious a force racism is in American society. Just as the pandemic shined a light on structural injustice, with disadvantaged people suffering more, people subjected to systemic racism obviously suffered more as well.

So, with the combination of the dramatic, societal-stopping experiences of a multi-year pandemic and upheaval in response to structural racism both in policing and more broadly, now what happens? Narrowly, within bioethics and the academy, we are experiencing a massive response: the IDARE movement, rewriting of our curricula, looking hard at our own conduct, history, and processes. This is wonderful. But how much will change, how sustained will it be, what will the impact of change be? There’s already a deeply troubling backlash against parallel efforts to respond to structural racism in K-12 arenas, which you see in the politicizing of Critical Race Theory, the politicizing of how to treat U.S. history in the context of the experience of people of color. Those of us who work in ethics have an obligation not to walk away from the tragic consequences of the pandemic, or the tragic insight that too many people are dying at the hands of systemic racism, even though we can see the path ahead is not going to be easy.
LEADING THE CHARGE FOR EQUITABLE AND EFFECTIVE PUBLIC HEALTH POLICIES AND PRACTICES

JOSEPH ALI, JD
ASSOCIATE DIRECTOR FOR GLOBAL PROGRAMS
BERMAN INSTITUTE OF BIOETHICS
SCHOOL OF PUBLIC HEALTH

HOW HAS THE PANDEMIC HIGHLIGHTED WAYS IN WHICH PRE-EXISTING SYSTEMS TO ADDRESS A GLOBAL PUBLIC HEALTH CRISIS WERE INADEQUATE?

There’s been a very clear demonstration that communities in different countries experience disparities in applying recommendations for handling the outbreak. Things like social or physical distancing have vastly different implications in different countries and different societys. Similarly, communities have different levels of capability to test and monitor for the virus, and of course, essential resources—including PPE and vaccines—are very unevenly distributed due in part to economic and sociopolitical issues. Having a basic claim of access to a known prevention during a pandemic is something every country has an interest in. You could even argue it’s a fundamental right of societies to have equal access to something that’s as effective as the Covid vaccines are in a dire public health situation. When countries around the world are marshalling tremendous resources to develop and provide these really valuable vaccines, there needs to be a robust means of distributing them effectively and equitably. Unfortunately, we’ve created a situation for ourselves where there are seemingly endless technical and regulatory barriers preventing that.

From one perspective, then, the pandemic has really highlighted national differences, rather than commonalities. At the same time, it’s generated a lot of discussion about a more central role for bioethics here. Many of us specialize in work that seeks to align the potential of technology with the public’s interest, while minimizing associated risks. That, in my view, is where we make some of our best contributions.

RESEARCHERS IN SOUTH AFRICA ALERTED THE WORLD ABOUT THE OMICRON VARIANT OF COVID-19, BUT INSTEAD OF GAINING RENOWN FOR THEIR WORK, IT SEEMS RESIDENTS OF SOUTH AFRICA WERE BLAMED FOR OMICRON’S SPREAD. WHAT DID YOU TAKE AWAY FROM THAT GLOBAL RESPONSE?

The South Africa case came at a time of heightened attention to issues of de-colonialization of global health, and recognition of epistemic injustices that pervade many of our systems of research, along with international aid and other forms of global cooperative work in health. This case was interesting because there was a clear capacity and scientific strength that the country had, but that wasn’t initially given its due recognition and value. Instead, there appeared to be a knee jerk response of “We, the experts outside South Africa are the ones in best position to judge the conditions and risk, and until we’re able to do so, we will isolate countries in that region of the world.” Of course, that didn’t work. There’s a lot more to say about this situation, but fundamentally, it raises the question of who gets to meaningfully contribute to the process of managing and judging risk, globally. That ties back to the broader issue of what kind of knowledge and scientific capacity is recognized in global public health.

WHAT OTHER SIGNIFICANT GLOBAL PUBLIC HEALTH ISSUES DO YOU SEE COMING OUT OF THE PANDEMIC?

We have developed many capabilities for data capture and public health communication through digital and mobile technologies that will long outlive the pandemic and could be used in other areas of public health. For example, technological capabilities that were developed to support use of mobile phone features for contact tracing have the potential to be applied to a much wider range of health and social conditions. This might include using similar technological capabilities to identify exposure to environmental hazards in the workplace or in public; or, to even identify behavioral patterns that relate to non-communicable diseases or injuries.

WHAT CAN WE LEARN FROM THE PANDEMIC ABOUT HOW TO EQUITABLY DISTRIBUTE HEALTHCARE RESOURCES?

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WHAT CAN WE LEARN FROM THE PANDEMIC ABOUT THE BETTER IN ITS WAKE?

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VISIONS OF BIOETHICS AFTER COVID

ADDRESSING DISPARITIES ARISING FROM GLOBAL SUSTAINABILITY CHALLENGES

FANZO HIGHLIGHTS SIMILARITIES BETWEEN THE COVID-19 PANDEMIC AND POSSIBLE FUTURE FOOD AND CLIMATE CALAMITIES

DURING THE PANDEMIC, WE HAVE WITNESSED PEOPLE WHO OCCUPY POSITIONS OF POWER PUBLICLY QUESTION AND REFUTE SCIENCE. HAS THIS PROVIDED A LEARNING EXPERIENCE FOR UNDERSTANDING WHAT A “GLOBAL CRISIS” MEANS?

As somebody working on food systems for a while now, people always ask, “Why take a systems approach?” And to me, Covid-19 is such a great example of a shock that hit a system, the health system, that had implications on every other system: the global economic system, food systems, education systems. It’s an unfortunate example of how these systems interact and can quickly become dismantled.

One of the other things that I find so incredibly interesting about Covid-19 is how quickly governments acted in early 2020—lockdowns, curfews, mandated social distancing. Whether we agree with those approaches or not, it’s astonishing how quickly governments can act when they feel threatened.

And what I find fascinating is that climate change, hunger in the world, and rising obesity don’t elicit the same response. The question is why. Is it that Covid has created such a reaction? It maybe won’t be the most devastating pandemic we’ll see in our lifetime.

I find I had discounted governments a long time ago, thinking they don’t act swiftly in tackling some of the biggest challenges we face—but clearly for certain things they do, and they can take action. So, my question still is: Why don’t governments care enough about food and climate to make big, bold changes?

FANZO EXPLORES GLOBAL FOOD SYSTEMS IN TWO NEW BOOKS

THE BERMAN INSTITUTE’S JESSICA FANZO HAS PUBLISHED MORE THAN 100 ARTICLES ON GLOBAL FOOD POLICY AND ETHICS DURING CAREER, AND IN 2021 SHE ADDED TWO NEW BOOKS, AIMED AT TWO DIFFERENT AUDIENCES.

In the textbook Global Food Systems, Diets, and Nutrition: Linking Science, Economics, and Policy (Palgrave Studies in Agricultural Economics and Food Policy), Fanzo explains how interconnected food systems and policies affect diets and nutrition in high-, middle-, and low-income countries. In tandem with food policy, food systems determine the availability, affordability, and nutritional quality of the food supply, which influences the diets that people are willing and able to consume. And in Can Fixing Dinner Fix the Planet? (JHU Press) Fanzo shares her scholarly expertise with a broad general audience, relating how consumers, nations, and international organizations can work together to improve food systems before our planet loses its ability to sustain itself and its people.

“Global food systems touch on every aspect of society in both positive and negative ways. The challenges facing food systems are critical ones that demand urgent attention. As Covid-19 and climate change are showing, our food systems are fragile and inequitable. The textbook tackles why that is, and what can be done about it,” said Fanzo.

Meanwhile, Can Fixing Dinner Fix the Planet? is a clarion call for both individual consumers and those who shape our planet’s food and environmental policies.

“By providing a narrative about research I’ve done on five continents, I hope to raise readers’ food and environmental literacy and empower them to contribute to immediate and long-term changes by informing their decisions in restaurants, grocery stores, farmers markets, and kitchens,” she said Fanzo.
VISIONS OF BIOETHICS AFTER COVID

GUIDING THE ETHICAL DEVELOPMENT AND USE OF NEW TECHNOLOGIES

MATHEWS DISCUSSES THE PANDEMIC’S IMPACT ON GENETIC RESEARCH AND LESSONS IT CAN OFFER FOR REGULATING ARTIFICIAL INTELLIGENCE AND OTHER EMERGING TECHNOLOGIES

Debra Mathews, Ph.D., MA
Assistant Director for Science Programs
Berman Institute of Bioethics
Johns Hopkins University School of Medicine

How has the COVID-19 pandemic impacted genetic research and ethics? The pandemic provided an incredible scientific opportunity to better understand genetic variation in response to infectious disease. There are many conditions that appear to be genetic conditions, but are complex and involve not only genes but also environment. A very specific example is pyloric stenosis—a condition in infants that blocks food from entering the small intestine—which my daughter had and needed surgery for at three weeks of age. Her doctor said it’s the most common reason for surgery in kids younger than a year, and they’ll see no cases for months followed by a whole bunch of cases in a single month. The suspected reason is that a virus has gone through the population and triggered the condition in kids who had the genetic susceptibility. But identifying that susceptibility is incredibly difficult, we don’t know what the virus that triggers it is, and we don’t know who has and hasn’t been exposed.

With Covid, the whole world is being exposed to a single known infectious disease, which is allowing us to do studies on what genetic variations within us humans lead to more severe or less severe disease. It’s sort of like shaking up a snow globe of what we think of as genetic disease versus infectious disease. Also due to Covid, we have and are continuing to collect and share millions of samples, like blood and saliva, under a public health emergency. There is a particular set of justifications for collecting and sharing human samples in the context of such a global emergency. One of the big questions is what happens to those samples once the emergency is over. Are universities and other research institutions going to make them available for other kinds of research, not related to the pandemic?

Are there any lessons from the pandemic that are applicable to your work in the ethics of artificial intelligence? One concrete and optimistic policy lesson for me is that we can make big changes quickly when needed. Pandemic response has shown that our policy apparatus can be a lot more flexible than we maybe had assumed or appreciated—or had previously been possible. That creates opportunity. Regarding how we think about some of these emerging technologies, a lot of times we assume “This is the way we’ve always done it,” so it’s impossible for us to be proactive about changing regulatory systems to accommodate AI or some other new technology that doesn’t fit into the buckets that we have available to us. Covid has shown us that we can be creative when we need to be.

The need to think differently about the governance of emerging technologies makes it an exciting space to be in. Science and technology always move faster than policy and ethics, and that is absolutely true with Artificial Intelligence. But the size and scope and speed with which AI has expanded and permeated society blows previous examples out of the water. It has shaped our society in ways that we didn’t anticipate and not necessarily for the good. For example, the kind of manipulation of people’s emotions and behaviors on social media—the way social media feeds are designed, the way we’re incentivized to stay online looking and scrolling, the way bots are designed to share particular kinds of content with us. It’s starting to force us to think about the broader societal implications of what technology companies often would like to say are neutral technologies.

It’s difficult but not impossible. In general, in emerging technology and emerging science, we need to do a better job of implementing the ethical principles that should be guiding these advances in the first place. When we don’t, we simply take the attitude that everyone is responsible for proper use, and then nobody’s actually responsible for how the new developments impact everything. I often say each new emerging technology is an opportunity for us to get governance right. AI is the current opportunity, and there’s a lot of interest and excitement and fear around this technology right now. I think that’s one of the reasons that faculty in the Berman Institute has gotten drawn into the space.

Unlike basic scientists who often have some exposure to ethics through human subjects training, computer scientists don’t have an infrastructure around them that exposes them to that kind of thinking. There are a lot of people working in Artificial Intelligence and in Machine Learning who fully recognize they need to be concerned about ethics and are reaching out because they want to know more. I recently had a conversation with a brand-new Johns Hopkins computer science faculty member who reached out to me. She understands there are ethical issues associated with her work and wants to learn more about them. Just as medical students receive bioethics training, it would absolutely be my hope that we can provide training to computer science students at the beginning of their careers, so they are already thinking in these terms when they go out into their professions and begin to shape the world we live in.
Prior to Covid, there was increasing attention on the use of Artificial Intelligence in health care, including how AI might inadvertently perpetuate disparities we see in health care. Now, while in the midst of the pandemic, it has become apparent that AI is an important set of tools that can affect medicine and public health. For example, I was part of an advisory board for the American Association for the Advancement of Science, and there was a report that was released in May 2021 that described the myriad uses of AI in the fight against Covid-19, from forecasting technologies to using AI for drug development and treatment. For example, the digital contact tracing apps raise issues of privacy and consent that mirror concerns we already have with other applications of technology in medicine.

**HAS THE PANDEMIC BROUGHT ANY CONCERNS ABOUT DIGITAL HEALTH TO THE FOREFRONT?**

One important example from the intersection of digital health and health disparities is the pulse oximeter. It’s a device that’s on the finger and it reads your blood oxygen level. Because Covid-19 is a respiratory disease, measuring blood oxygen levels is obviously very important, because people may need ventilators if their blood oxygen levels become very low. Unfortunately, there is some evidence that pulse oximeters are less accurate for people with darker skin because the mechanism involves light reflecting off skin. So we have to consider that this digital health tool potentially could have potentially significant impacts during Covid, with potential errors stemming from differences in patients’ skin color.

The potential for harmful impacts is similar when thinking about algorithms that are classified as artificial intelligence—here there are multiple, complex algorithms that are using inputs and producing outputs that may be inescapable to even their human designers. And if there are biases in clinical data, those biases can get baked in and reproduced in AI algorithms. Here’s a concrete example. In 2019, a group of researchers examined a model that’s used for millions of patients around the U.S. that allocates additional health care resources to sicker patients. The model uses health care expenditures as a proxy to gauge how sick a patient is, with the assumption that higher costs would indicate increased illness. When the model was audited to see how it was treating different racial groups, it found really interesting differences between groups, such as that African Americans are more likely than other groups to request non-palliative end of life care. This pattern was revealed using AI, so we can think of AI as a diagnostic tool for health inequity to try to explain why there might be these differences among groups.

So it’s not just doom and gloom. These are really promising tools that humans can use to process data faster than we can, to uncover correlations that we didn’t know about, and give us a chance to think about what they mean to us. Machines aren’t interpreters, we are. They will lead us down a pathway of innovation to show us what is really going on in health care in many different domains, which will enable us to innovate, produce solutions, and hopefully help us to achieve health equity.
HOW HAS COVID-19 IMPACTED IMPORTANT ONGOING MEDICAL RESEARCH?
As of January 29, 2021, more than 2,000 trials registered with ClinicalTrials.gov had been terminated, withdrawn, or suspended because of Covid-19, affecting more than 129,000 participants and interrupting plans to recruit more than 4 million future participants. Those numbers have only grown over the past year, so the impact of Covid-19 on research unrelated to it is enormous. However, we simply can’t just stop doing research during the pandemic. For example, the HIV epidemic has been persistent for a really long time, so we can’t pay attention only to Covid, because other diseases are not just going to go away. Therefore, we have to ask what changes have to be made to conduct research ethically during the pandemic.

WHAT CHANGES HAVE TO BE MADE TO MAKE SURE CLINICAL RESEARCH CAN CONTINUE ETHICALLY?
Researchers must protect the rights and well-being of participants, even during the extenuating circumstances of a global pandemic. Doing that raises a host of ethical issues: participants may face increased economic and social risks and compounded vulnerability due to other medical conditions. There are also challenges with engaging with the community and preserving the scientific validity of the research being conducted during such a tumultuous time. The pandemic can create unpredictable major disruptions to a study at any stage, from planning to implementation to post-trial access.

By increasing everyday risks, Covid forces us to consider the acceptability of any additional risks posed by the research. If continuing a research study substantially raises the risks to participants, by putting them at increased risk of exposure to Covid for example, researchers should consider modifying or even halting part or all of the research. And similar consideration should be given to minimizing the risk posed to the research staff conducting the study as well.

The pandemic can pose challenges affecting multiple stages of research. Infrastructure and collaborations that were established prior to the pandemic might need to be modified if personnel involved have been reassigned to pandemic-related functions. Researchers might get infected, requiring them to isolate, or quarantine, or stop working altogether. Participants may face new barriers to participation, including their own illness, or need to care for others who get infected. People might be wary of visiting hospitals or other study sites where they fear contagion. Researchers need to do everything they can to mitigate risk for participants and staff alike.

WHAT DO YOU DO ABOUT ONGOING STUDIES THAT WERE IMPACTED BY COVID?
While some health regulatory agencies released guidance on trial modifications that might be needed due to the pandemic, no consensus exists on how such changes and their implications should be reported. Last year, I was part of a panel of 37 international experts that published some specific guidelines, building upon the internationally recognized CONSORT and SPIRIT guidelines for clinical trials, addressing what researchers should do when they encounter circumstances in which changes to a trial were prompted by unavoidable situations beyond the control of study investigators, sponsors, or funders.

In general, we recommended that rather than abandoning trial data and the investments that contributed to data collection, it’s better to report the unanticipated circumstances and trial modifications rigorously and transparently along with the research findings. And while the Covid-19 pandemic is what promoted this work, the approach will be applicable to other extenuating circumstances that result in important modifications to a trial, such as natural disaster, personnel disruptions, regulatory changes, or changes to the clinical standard of care.
HOW HAS THE PANDEMIC IMPACTED THE BERMAN INSTITUTE’S APPROACH TO TEACHING STUDENTS?

In Spring 2020, we—like everybody else—had to pivot on a dime but the transition to virtual, synchronous education was really seamless. Nobody was happy to be doing it that way. But I’m proud of how well the students and faculty both did. We already knew those students from almost a full year, or more, of in-person teaching. We were able to finish the year with virtual meetings and happy hours, as we all became familiar with the Zoom experience. The students that came in during the 2020-21 academic year were the ones that had a radically different experience. I never met some of them in person as they came, completed the one-year Master of Bioethics (MBE) program, and graduated.

During that time, the incredible commitment of the Berman Institute’s faculty to do something interesting with virtual learning was striking. People tried many different techniques to be world class teachers using the online modality. And finally, after vaccines started becoming available, we had some outdoor coffees and finally saw the students faces in 3D, not just on a screen.

After the pandemic there’s no way higher education is going back to solely in-person learning. The Berman Institute invested in virtual classroom technology that’s afforded us a state-of-the-art facility in Deering Hall that makes it just as easy to host virtual speakers as in-person. Now, with our seminar series, if we want to have someone from Kenya speak there’s no reason to cross them off the list because they can’t get to Baltimore at noon on a Monday. The same is true for doing teaching swaps with colleagues across the country. If someone assigns my work for class, I’ll join their classroom to discuss the chapters they’ve read.

HOW HAS COVID-19 IMPACTED ENROLLMENT IN THE MBE PROGRAM?

This year’s cohort is the third in a row that’s been affected. The first, who were near graduation when the pandemic hit in March 2020, had eight students. That had been our largest class to date. The following year we grew to 12 students, and we’ve just kept going, bringing in 20 students this year. That’s great growth for a program that started with a class of three students in 2015.

This year’s 20 students have had a very dynamic educational experience, as we try desperately to educate them in a post-pandemic modality, even as waves like delta and omicron force us into a fully online mode for short stretches. This group has been on-campus and in the same room with their professors plenty of times, but they’re facing a different kind of challenge, having to pivot back and forth between in-person and online as the pandemic situation changes. I’ve been so impressed with their adaptability. When I email the day before a class that we’re back in-person, they show up with masks on and ready to go.

HOW HAS YOUR TIME AT THE BERMAN INSTITUTE PREPARED YOU FOR A CAREER IN BIOETHICS?

It’s only been two years, so trends still have time to change. The first year following Covid’s arrival, we did have a big increase in students who wanted to think about the ethics of infectious disease. It was new and scary, and we got a lot of applications late in the cycle. And it felt irresponsible not to devote a great deal of time to the topic. Two years later, students—I like almost everyone—are pretty burned out. All you ever read or talk about is Covid. While there is still more interest in infectious disease ethics than there was three years ago, a lot of students who mentioned Covid in their application’s personal statement get here and realize there’s a lot more to bioethics.

HOW WAS TRAINING AT THE BERMAN INSTITUTE SHAPED HER CAREER TRAJECTORY

YOU WERE RESEARCHING VACCINE HESITANCY AMONG HEALTHCARE WORKERS LONG BEFORE THE SPREAD OF COVID-19. HOW WAS THE PANDEMIC IMPACTED YOUR WORK?

As you can imagine, Covid has taken control of this topic. I’d been thinking about it for years but never imagined the question getting the traction it has. From the time vaccines became available, health care workers were prioritized for vaccination. But most people are surprised to learn that health care workers are one of the most hesitant populations when it comes to vaccination; they’re as hesitant, or more, than the average person. They’re people too, with their own beliefs. The general public sees them in their white coats, assume they’ll “go with the science,” and get vaccinated more than others. But we don’t apply the expectation that health care workers will have different behaviors than the general public when it comes to other actions, like exercising, or smoking, or eating healthy food. And there is an apparent societal consensus not to dictate those behaviors for health care workers. So, what are the limits and expectations we can set for health care workers when it comes to vaccination behavior?

HOW DO YOU APPROACH SHAPING AN ETHICAL FRAMEWORK FOR VACCINE DELIVERY AMONG HEALTH CARE WORKERS?

Like the American Medical Association Code of Ethics, many countries have definitive codes of ethics for health care workers. So, for the preliminary stages, we collected medical ethics codes from at least one country in every region of the world, then read them all to identify themes relevant to vaccination for health care workers. This method of empirical data collection is unique in the context of Covid-19 vaccine hesitancy. Medicine and public health tend to capitalize on health professionals abiding by general principles in these codes, like “Do no harm,” and “Always protect patients,” without examining their practical implications too deeply. Now we’re exploring the limits of professional obligations in the context of fighting Covid-19. Is it the professional obligation of all health care workers to get vaccinated to protect us? Where does the line get drawn between personal choice and professional responsibility?

You were researching vaccine hesitancy among healthcare workers long before the spread of Covid-19. How was the pandemic impacted your work? As you can imagine, Covid has taken control of this topic. I’d been thinking about it for years but never imagined the question getting the traction it has. From the time vaccines became available, health care workers were prioritized for vaccination. But most people are surprised to learn that health care workers are one of the most hesitant populations when it comes to vaccination; they’re as hesitant, or more, than the average person. They’re people too, with their own beliefs. The general public sees them in their white coats, assume they’ll “go with the science,” and get vaccinated more than others. But we don’t apply the expectation that health care workers will have different behaviors than the general public when it comes to other actions, like exercising, or smoking, or eating healthy food. And there is an apparent societal consensus not to dictate those behaviors for health care workers. So, what are the limits and expectations we can set for health care workers when it comes to vaccination behavior?

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Carlton Haywood, Jr. MA, PhD, was a beloved colleague, an assistant professor in the Berman Institute of Bioethics and in the Division of Hematology at the Johns Hopkins School of Medicine, and core faculty at the Welch Center for Prevention, Epidemiology, and Clinical Research.

Born January 26, 1976, in Atlanta, Georgia, Carlton was diagnosed with sickle cell disease as a young child. Despite repeated hospitalizations for painful crises, Carlton remained a straight-A student and was diagnosed with sickle cell disease as a young child. His scholarship highlighted issues of extreme injustice, challenged assumptions (such as lack of interest in clinical trial participation), and paved the way for improving quality of care for the sickle cell disease population. In 2015, he was selected as one of the first recipients of the highly competitive Johns Hopkins University Catalyst Awards to examine how to improve the quality of nursing care for sickle cell disease patients.

Carlton published many papers on the intersection of bioethics and clinical research, and informed policies related to quality of care for sickle cell patients. He served on numerous federal and national professional society advisory committees convened to provide advice on, or oversight of, federal or professional society sponsored sickle cell disease-based initiatives including the Health Resources & Services Administration’s Sickle Cell Disease Treatment Demonstration Program; National Heart, Lung & Blood Institutes (NHLBI) Sickle Cell Disease Healthy People 2020 Working Group; the CDC and NHLBI joint Steering Committee for the Registry and Surveillance for Hemoglobinopathies (RuSH) project; the National Human Genome Research Institutes Sickle Cell Trait Systematic Review Project Work Group; and the Food & Drug Administration’s Expert Workshop to Accelerate Drug Development for Sickle Cell Disease.

Carlton’s work has been featured in a number of plenary sessions and invited keynote addresses at institutional, state-based, and national bioethics or sickle cell disease research meetings. Carlton was driven to highlight sickle cell disease as an important public health problem and would often travel to give these lectures when he was in pain or “not feeling his best.” Carlton also fought tirelessly to bring attention to how underfunded sickle cell disease research in comparison to similar disorders.

Carlton received many honors and accolades for his accomplishments and is especially remembered for his selfless commitment to others. In 2014, Carlton was recognized by Ebony Magazine on its Power 100 list—an annual celebration of the most influential and inspiring men and women in the African American community. Additionally, Carlton was one of three national sickle cell disease experts to participate in a congressional briefing on Capitol Hill.

Carlton was an exceptionally talented, creative, and selfless person, who will be remembered by family, friends, and mentors for his brilliance, generosity, kindness, compassion, and humility. Those who loved him will also remember with a smile his love of science fiction and pink lemonade, and his extensive comic book collection. Carlton maintained an eternal faith in the goodness of others, and he left all who encountered him better than they were.
Faculty Spotlight: In New Book Perilous Medicine, Len Rubenstein Seeks to Pervasive Violence Against Health Workers in Modern War

Pervasive violence against hospitals, patients, doctors, and other health workers has become a horrifically common feature of modern war. These relentless attacks destroy lives and the capacity of health systems to tend to those in need. Inaction to stop this violence undermines long-standing values and laws designed to ensure that sick and wounded people receive care.

In his new book, Perilous Medicine: The Quest to Restore Protections for Health Workers, Leonard Rubenstein—a human rights lawyer who has investigated atrocities against health workers around the world and core faculty member at the Berman Institute of Bioethics—offers a gripping and powerful account of the dangers health workers face during conflict and the legal, political, and moral struggle to protect them.

“I wrote it, first and foremost, for those who take enormous risks to provide care in the midst of war, so that their commitment to health can be matched by a commitment to rights to their protection,” said Rubenstein. “At the same time, I wanted to enhance understanding of the pervasiveness of the violence, the logics animating it, and its devastating impacts for millions of people already suffering in war. Another goal was to seek to engage the public health, nursing, and foreign policy communities—and the wider public—in stopping it.”

In a dozen case studies, he shares the stories of people who have been attacked while seeking to serve patients under dire circumstances including health workers hiding from soldiers in the forests of eastern Myanmar as they seek to serve oppressed ethnic communities, surgeons in Syria operating as the patient—yet he felt the added pain of not being able to do his medical duty to the patient. He said: “I thought if she died that day, perhaps I would be responsible for her death. Yes, I could provide care, but I couldn’t do anything else. I felt powerless.” It is a common experience for health workers at high personal risk of violence—but carrying the additional moral burden of not being able to carry out deeply felt obligations to patients.

Bringing together extensive research, firsthand experience, and compelling personal stories, Perilous Medicine also offers a path forward, detailing the lessons the international community needs to learn to protect people already suffering in war and those on the front lines of health care in conflict-ridden places around the world.

Rubenstein has spent his career, spanning four decades, devoted to health and human rights. A graduate of Harvard Law School he is a core member of the Berman Institute faculty, Professor of the Practice at the Bloomberg School of Public Health, and Director of the Program in Human Rights, Health and Conflict at its Center for Public Health and Human Rights.

Although pregnant people are at an elevated risk of severe Covid-19 disease and death, countries around the world vary widely in their policies on Covid vaccination in pregnancy, according to the Johns Hopkins Covid-19 Maternal Immunization Tracker (COMIT), an online resource launched by Berman Institute faculty and their collaborators to provide a global snapshot of public health policies that shape access to Covid-19 vaccines for pregnant and lactating people.

“Data about Covid vaccines’ safety for pregnant people and their offspring have generally been reassuring. But countries around the world have taken a variety of positions on Covid vaccination and pregnancy—ranging from highly restrictive policies that bar access to vaccines, to permissive positions in which all pregnant or lactating people can receive vaccine and, in some cases, are recommended and encouraged to do so,” said Ruth Faden, the Philip Franklin Wagley Professor of Biomedical Ethics and founder of the Berman Institute. “Our hope is that COMIT might convince policy makers worldwide to expand access to vaccination for pregnant people. We are seeing some momentum in that direction, but we need to see more.”

COMIT is the first resource that provides a global snapshot of public health policies that influence access to Covid-19 vaccines for pregnant and lactating people, enabling users to explore policy positions by country and by vaccine product. Through maps, tables, and country profiles, COMIT provides regularly updated information on country policies as they respond to the dynamic state of the pandemic and emerging evidence.

“This is an extremely valuable resource for anyone concerned with the health of pregnant women and their offspring anywhere in the world. By compiling and updating countries’ policy positions regarding Covid-19 vaccination for pregnant and lactating people, COMIT makes it possible to track the ongoing global changes in this rapidly changing sphere at a glance,” said Alejandro Cravioto, Chair of the Strategic Advisory Group of Experts on Immunization, the international panel of experts making Covid-19 vaccine recommendations to the World Health Organization.

COMIT’s interactive global map conveys whether pregnant or lactating individuals are allowed or encouraged to receive any vaccine currently authorized for use in individual countries. Other features include:

- Tables that enable visitors to compare vaccine policies across countries, including any special requirements (e.g., a doctor’s note with various sort and filter features to understand how individual country policy positions compare across geography and vaccine products).
- Maps that filter by product and policy position, with an easy toggle between pregnancy and lactation to see how recommendations differ for pregnant and breastfeeding individuals.

The COMIT policy tracker was developed by members of the Johns Hopkins Berman Institute of Bioethics and the Johns Hopkins Center for Immunization Research, with support from the Bill & Melinda Gates Foundation and Wellcome Trust.

Individual Country Pages that give a detailed account of policy positions, and changes over time, and provide links to source documents.
ANALYSIS OF MEDICAL RECORDS FINDS PHYSICIANS ARE MORE LIKELY TO DOUBT BLACK PATIENTS

With the implementation of the 21st Century Cures Act earlier in 2021, healthcare providers are now required to give their patients free access to all the health information in their electronic medical records. Black patients are much more likely than white patients to discover language in those records that indicates they are not believed by their physicians, according to a new study published by the Berman Institute’s Mary Catherine Beach in the Journal of General Internal Medicine.

“We set out to see if we could identify linguistic mechanisms through which physicians communicate disbelief of patients in medical records and, if so, to explore racial and gender differences in the use of such language,” said Beach, also a faculty member in JHU’s Schools of Medicine and Public Health, whose research was supported by a grant from the Robert Wood Johnson Foundation’s Building Trust and Mutual Respect to Improve Healthcare Program. “Our analysis of medical record language suggests Black patients are less likely to be believed by physicians. The bias reflected in those medical records may in turn affect care from future clinicians.”

Beach and her Hopkins Medicine colleague Somnath Saha first noticed in the medical records of patients with sickle cell disease that doctors and nurses were signaling disbelief in their patients’ reports of pain. They began examining additional records to see if this phenomenon extended to patients receiving treatment for other conditions. Working with a linguist and a computer scientist they identified three aspects of language in clinic notes by which physicians communicate disbelief of patients:

- Quotation marks around patients’ words (e.g., had a “reaction” to the medication)
- Specific judgment words that suggest doubt (e.g., “claims” or “insists”)
- “Evidentials,” a sentence construction in which patients’ symptoms or experience is reported as hearsay.

“We evaluated the prevalence of these features in over 9000 notes in one clinic, then tested differences by race and gender. We found all three of these forms of language more often in the records of Black patients than white patients,” said Beach. “Women’s records were somewhat more likely than men’s to have quotes, but not judgment words or evidentials,” said Beach. “Some of this language reflects how clinicians are taught to document things, and there are reasons to use quotes and evidentials that don’t necessarily cast doubt on what patients are saying. But if it’s just benign word use, why would we see a difference in their application by patients’ race and gender? That’s what makes such language so insidious.”

Beach and Saha note that the prevalence of electronic medical records means that one clinician’s notes will follow a patient whenever they go in the healthcare system and could adversely impact the patient’s care moving forward. According to Beach, Hopkins Medicine has been extremely receptive to addressing the impact of biased language on patient care, asking her to speak at Grand Rounds, to residents, and to all current medical students about her and Saha’s research.

“Clinicians know that patients are sometimes mistaken or even deceptive,” said Beach. “But if we also know there is racial bias in the way patients’ credibility gets assessed, we must revisit the certainty we have in our own impressions. We have to question ourselves before we question the statements of others.”

THREE FACULTY ELECTED FELLOWS OF THE HASTINGS CENTER

Three members of the Berman Institute faculty have been recognized for their achievements with election as Fellows of The Hastings Center in 2021.

Debra Mathews is well known for her scholarship and contributions to national and international thought and debates at the intersection of emerging biomedical technologies, ethics, and policy. Mathews is the Assistant Director for Science Programs for the Berman Institute, and an associate professor in the Department of Genetic Medicine, Johns Hopkins School of Medicine. In addition to her academic work, she has spent time at the Genetics and Public Policy Center, the U.S. Department of Health and Human Services, the Presidential Commission for the Study of Bioethical Issues Under President Obama, and the National Academy of Medicine, working in various capacities on science policy. Her academic work focuses on ethics and policy issues raised by emerging technologies, with particular focus on genetics, stem cell science, neuroscience, Artificial Intelligence, and synthetic biology. She currently serves as the chair of the Maryland Stem Cell Research Commission, is a member of the board of directors and executive committee of the International Neuroethics Society and is an academic collaborator helping to shape and guide the work of the National Academy of Medicine’s new Committee on Emerging Science, Technology, and Innovation in Health and medicine.

Maria Merritt is an associate professor at the Berman Institute and Bloomberg School of Public Health in the Department of International Health’s Health Systems Program. She is a bioethicist whose home discipline is philosophy, specializing in moral philosophy. Her research focuses on two areas of inquiry: delineating health researchers’ ethical responsibilities in relation to participants’ health needs in low resource settings and representing social justice concerns in the economic evaluation of public health programs. Merritt leads teams with expertise in health economics, social science, and infectious diseases, and has recently focused on developing an innovative formal methodology to assess social justice impacts in the economic evaluation of novel treatment regimens for multidrug-resistant tuberculosis and of new technologies to diagnose and treat neglected tropical diseases. Merritt is an alumna of the Greenwall Faculty Scholars program and is affiliated with the National Institutes of Health as a 2020-2021 postdoctoral Fellow and a 2020-2021 visiting scholar.

Mary Catherine Beach is a professor of medicine at the Johns Hopkins University School of Medicine and a core faculty member of the Berman Institute. She has been a Greenwall Fellow, a Health Policy Fellow in the office of Senator Hillary Rodham Clinton, and a recipient of the Robert Wood Johnson Foundation’s Generalist Physician Faculty Award. Beach’s scholarship about respect and relationships in health care encompasses both empirical and conceptual dimensions. Her empirical work focuses primarily on respect and communication between patients and clinicians. For the last several years, most of her research has centered on people living with HIV/AIDS and sickle cell disease, and on how respect is conveyed (or not) in patient medical records.

These Center Fellows are a group of more than 200 individuals of outstanding accomplishment whose work has informed scholarship and public understanding of complex ethical issues in health, health care, science, and technology. According to the Center, “Their common distinguishing feature is uncommon insight and impact in areas of critical concern—how best to understand and manage the inevitable values questions, moral uncertainties, and societal effects that arise because of advances in the life sciences, the need to improve health and health care for people of all ages, and mitigation of human impact on the natural world.”

These faculty join a growing list of Berman Institute faculty colleagues as Hastings Center fellows:

Joseph Carsee
Bryan Garland
Gail Geller
Jeffrey Kahn
Nancy Kass
Cynthia Wiston Reihl
Jeremy Sugarman

These Faculty Join a Growing List of Berman Institute Faculty Colleagues as Hastings Center Fellows:
CIVIC SCIENCE FELLOW LOMAX BOYD TO HELP BOOST PUBLIC ENGAGEMENT WITH BERMAN INSTITUTE RESEARCH

Lomax Boyd has joined the Berman Institute as the 2021-23 Johns Hopkins Berman Institute Civic Science Fellow, in partnership with the Kavli Neurodiscovery Institute, supported by the Kavli Foundation. Boyd will spend the next 18 months focusing on designing new methods for engaging the public on the ethics and policy issues of emerging science.

Boyd is one of a network of 22 Civic Science Fellows, supported by host partners around the world, who will utilize their expertise in science, media, education, civic engagement, and other fields to forge new relationships between science and diverse communities, using a variety of innovative, evidence-based approaches. The program, created in 2020, embeds Fellows for 18 months within organizations that prioritize strengthening the links between science and society, delving into questions about creating and communicating knowledge, designing for equity and inclusion, and scaling up networks and collective action for impact. This focus is a natural fit for the growing emphasis in the Berman Institute on public-facing bioethics, including the Drosophila-Bloomberg Drex Lab.

Boyd’s previous research developing neuroscientific tools to probe the evolutionary and developmental origins of the human brain has provoked curiosity and wonder about the brain, but also raised questions about how to seek, understand, and embed public values into scientific research and technological advancement. Boyd held a postdoctoral appointment at the Laboratory of Neurogenetics of Language at Rockefeller University and was co-trained at the Center for Documentary Studies at Duke University. His creative practice seeks to explore how experimental, interactive, and traditional media can create new pathways for public engagement with science. He has previously held creative residencies at the National Film Board of Canada, BioInteractive and Tangled Bank Studios at the Howard Hughes Medical Institute. Boyd holds an M.S. in Biology from the College of William & Mary and received his PhD training in genetics and genomics at Duke University.

JESSICA FANZO RECEIVES MULTIPLE GRANTS TO ADVANCE FOOD SYSTEMS WORK

Jessica Fanzo, Bloomberg Distinguished Professor of Global Food & Agricultural Policy and Ethics, received multiple grants dedicated to her work with global food systems, including $3.8 million for the first phase of a planned 20-year project, “People-centered Food Systems: Fostering Human Rights-based Approaches.”

The project aims to characterize constraints globally and within countries for peasants and other rural dwellers to claim their rights to food security, adapt to and mitigate against climate change, and preserve the agrobiodiversity fundamental to their livelihood. The Swiss Agency for Development and Cooperation will contribute half of the grant funding, with the remainder funded jointly by the multidisciplinary project consortium’s member organizations, including Johns Hopkins University, CIAT of Colombia, the International Institute of Rural Reconstruction, and Rikokito.

Fanzo also received grants from the Global Alliance for Improved Nutrition to work on pilot food systems dashboards in Senegal and Ethiopia.

GRANTS

| GRANTS SECURED BY BERMAN INSTITUTE FACULTY FROM 1/1/20 - 6/30/21 |
|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| JDE ALI | Fogarty International Center |
| [AGS] Research Ethics Training Program (Ethiopia) | Multi-disciplinary Training Program |
| Nagoya University | National Human Genome Research Institute |
| Enabling Ethical Analysis and Public Justification in State-Level Pandemic Responses |
| Greenwall Foundation | Ethical, Legal, Social, and Policy Implications of Whole Organisms Genetic Testing |
| RUTH RAZAVI AND CARLIE L KNOEBEL | Jackson Laboratory |
| Integrating Ethics and Equity into Priority-Setting for Universal Health Coverage: A Proof-of-Concept Study in South Africa |
| Welcome Trust | Epidemic Intelligence Unit |
| JEREMY SUGARMAN | Jackson Laboratory |
| Countdown to 2030 Report on Transforming Food Systems |
| Food Systems Dashboard | Developing an International Master’s Research Ethics Program in Malaysia |
| Food Systems Dashboard (USAID) | Fogarty International Center |
| Ethiopia Pilot | Integrating Ethics and Equity into Priority-Setting for Universal Health Coverage: A Proof-of-Concept Study in South Africa |
| Food Systems Dashboard (UNAIDS) | National Film Board of Canada, BioInteractive and Tangled Bank Studios |
| Senegal Pilot | Jackson Laboratory |
| Global Alliance for Improved Nutrition | The laboratory of neurogenetics of Language at Rockefeller University |
| Human Rights in Food Systems | The Swiss Agency for Development and Cooperation |
| Swiss Agency for Development and Cooperation | The Rockefeller University |
| JEFFREY KAHN | Benaroya Research Institute |
| A Collaboration platform and network for responsive infectious diseases bioethics |
| Welcome Trust | Fogarty International Center |
| Kavli CiRC Science Fellow |
| The Kavli Foundation |

BARNHILL AWARDED GRANT TO RESEARCH ETHICS OF STATE-LEVEL PANDEMIC RESPONSES

Anne Barnhill was awarded a grant from The Greenwall Foundation, along with a Fiscal Year 2022 grant from the National Science Foundation, to pursue the project, “Enabling Ethical Analysis and Public Justification in State-Level Pandemic Responses in the United States.” During the Covid-19 pandemic, state governments adopted policies that profoundly affected personal and public life, in some cases imposing costs, curtailing freedom and exacerbating inequities. It’s often claimed that such high-stakes policy decisions should be ethically assessed, should account for the diverse perspectives and values held by the public, and should be clearly explained and justified to the public. This project aims to improve the frequency and quality of such activities by creating ethics guidance and tools that are fine-tuned to real-world pandemic policy-making contexts.

GRANTS

| JOSEPH GARRISON | Fogarty International Center |
| Biology from the College of William & Mary and received his PhD in Neuroscience from the National Film Board of Canada, BioInteractive and Tangled Bank Studios |
| NANCY KASS | Jackson Laboratory |
| Fogarty African Health Initiative Post-Doctoral Fellowship Program |
| Enabling Ethical Analysis and Public Justification in State-Level Pandemic Responses |
| National Human Genome Research Institute | Jackson Laboratory |
| Ethical, Legal, Social, and Policy Implications of Whole Organisms Genetic Testing |
| National Film Board of Canada, BioInteractive and Tangled Bank Studios |
| Jackson Laboratory | Jackson Laboratory |
| Integrating Ethics and Equity into Priority-Setting for Universal Health Coverage: A Proof-of-Concept Study in South Africa |
| Welcome Trust | The Rockefeller University |
| Epidemic Intelligence Unit | The Rockefeller University |
| Developing an International Master’s Research Ethics Program in Malaysia |
| Fogarty International Center | National Film Board of Canada, BioInteractive and Tangled Bank Studios |
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| Fogarty International Center | National Film Board of Canada, BioInteractive and Tangled Bank Studios |

JESSICA FANZO RECEIVES MULTIPLE GRANTS TO ADVANCE FOOD SYSTEMS WORK

Jessica Fanzo, Bloomberg Distinguished Professor of Global Food & Agricultural Policy and Ethics, received multiple grants dedicated to her work with global food systems, including $3.8 million for the first phase of a planned 20-year project, “People-centered Food Systems: Fostering Human Rights-based Approaches.”

The project aims to characterize constraints globally and within countries for peasants and other rural dwellers to claim their rights to food security, adapt to and mitigate against climate change, and preserve the agrobiodiversity fundamental to their livelihood. The Swiss Agency for Development and Cooperation will contribute half of the grant funding, with the remainder funded jointly by the multidisciplinary project consortium’s member organizations, including Johns Hopkins University, CIAT of Colombia, the International Institute of Rural Reconstruction, and Rikokito.

Fanzo also received grants from the Global Alliance for Improved Nutrition to work on pilot food systems dashboards in Senegal and Ethiopia.

BARMHILL AWARDED GRANT TO RESEARCH ETHICS OF STATE-LEVEL PANDEMIC RESPONSES

Anne Barnhill was awarded a grant from The Greenwall Foundation, along with a Fiscal Year 2022 grant from the National Science Foundation, to pursue the project, “Enabling Ethical Analysis and Public Justification in State-Level Pandemic Responses in the United States.” During the Covid-19 pandemic, state governments adopted policies that profoundly affected personal and public life, in some cases imposing costs, curtailing freedom and exacerbating inequities. It’s often claimed that such high-stakes policy decisions should be ethically assessed, should account for the diverse perspectives and values held by the public, and should be clearly explained and justified to the public. This project aims to improve the frequency and quality of such activities by creating ethics guidance and tools that are fine-tuned to real-world pandemic policy-making contexts.

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YEAR IN REVIEW SELECT HIGHLIGHTS

BERMAN INSTITUTE LAUNCHES GLOBAL INFECTIOUS DISEASE ETHICS COLLABORATIVE WITH UNIVERSITY OF OXFORD

Through a grant from the Wellcome Trust, the Berman Institute of Bioethics and the Wellcome Centre for Ethics and Humanities at the University of Oxford have established the Oxford-Johns Hopkins Global Infectious Disease Ethics Collaborative (GLIDE) to provide a flexible collaborative platform for identifying and analyzing ethical issues arising in infectious disease treatment, research, response, and preparedness, through the lens of global health ethics.

Bringing together scholars, trainees, and partners from around the world, GLIDE undertakes both responsive research on pressing issues and forward-looking projects with longer timeframes.

“The creation of GLIDE was well underway before the emergence of Covid-19, and the pandemic brought issues of ethics and infectious disease to the forefront,” said Berman Institute director Jeffrey Kahn. “This new bioethics research and training program will serve as a platform for collaboration among leading global researchers and provide opportunities to develop the next generation of leaders as well.”

The partnership has supported the appointment of four Postdoctoral Fellows in Ethics and Infectious Diseases who will spend time in residence at both Johns Hopkins and Oxford, pandemic permitting. GLIDE is working to create a platform for open-access publication of articles focused on global health ethics, and is organizing the June 2022 Oxford Global Health and Bioethics International Conference, with the theme of advancing knowledge and capacity in global health ethics.
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.

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 appointed 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 Debra Mathews, the group is also represented on the Bloomberg School of Public Health’s Inclusion, Diversity, Anti-Racism and Equity (IDARE) Committee, whose members are also working on the creation of the reading group are just two examples of the initiatives that the Berman Institute will undertake and build on in the coming months to help to address structural racism in society.

“The work of the IDARE Committee will never be complete,” reads a portion of the body’s mission statement. “We continuously and iteratively establish goals and work to achieve them, but our ultimate purpose is to incorporate IDARE values into the mission and vision of the Berman Institute itself and into bioethics as a discipline. Though the multiple catastrophic events of 2020 served as our catalyst, we are not a special interest group. Rather, we exist to hold our institution, discipline and, importantly, ourselves, accountable to these values in perpetuity. Our structure and our independence ensure that this work will continue well beyond this moment.”

The Berman Institute also has an Anti-Racism Reading Group, the focus of which is not inward, on the institution, but rather outward, on the broader intellectual community of which the Institute is a part. The Reading Group is oriented towards questions of the role of inclusion, diversity, anti-racism, and equity in the field of bioethics and our scholarship.

Kahn said the IDARE Committee’s establishment and the creation of the reading group are just two examples of the initiatives that the Berman Institute will undertake and build on in the coming months to help to address structural racism in society.

“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 inequity and social justice, both as they relate to the current moment and how they inform the society we want to build.”

BERMAN INSTITUTE LAUNCHES INCLUSION, DIVERSITY, ANTI-RACISM AND EQUITY COMMITTEE

HONORS & AWARDS

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PUBLICATIONS ARE LISTED CHRONOLOGICALLY FROM SEPTEMBER 1, 2020 TO AUGUST 31, 2021 WITH BERMUDA INSTITUTE OF SCIENCE, TECHNOLOGY, AND STUDENTS LISTED IN BOLD.


Hefn CF, Clark KT, GELLER B, BARNHALL A. SARS-CoV-2 vaccine effects on: moral embodiment, personal responsibility, public health crises, and ethical or unclear efficacy? Journal of Medical Ethics. 2020 Dec 9;1-14.


Fanzo J. Food and Climate. Healthy World. 2020 Dec 2;13(12):221-231.

GREEN JA. Knowledge in Mediated Events Toward a Media History of Science, Medicine, and Technology. History and theory of Science. 2020 Dec 15:1-90.

INFORMING PUBLIC UNDERSTANDING OF ETHICS AND THE PANDEMIC

Berman Institute faculty play a vitally important role in informing the public about bioethics issues and helping shape policy by sharing their insight and expertise through media interviews.

From authoring commentaries on key topics, to appearing on network news broadcasts, and responding to hundreds of media inquiries, their engagement and impact reached new heights this year.

The following is a partial list of faculty media appearances from September 1, 2020 to August 31, 2021, is below, providing an intriguing timeline of the pandemic’s ongoing impact on society.

OP-EDS AND COMMENTARIES

THE BALTIMORE SUN | OCTOBER 21, 2020
Kids with Certain Medical Conditions Should Not Attend In-Person School While Covid-19 Continues to Spread
by Megan Collins and Ruth Faden

NEW YORK DAILY NEWS | NOVEMBER 23, 2020
America’s Vaccine Conundrum
by Ruth Faden and Nancy Kass

STAT NEWS | DECEMBER 9, 2020
FDA. Leave the Door Open to Covid-19 Vaccination for Pregnant and Lactating Women
By Ruth Faden and Carleigh Krubiner

THE BALTIMORE SUN | JANUARY 4, 2021
A blue ribbon commission is needed to chart a path to reopening for schools
by Megan Collins and Ruth Faden

WASHINGTON POST | FEBRUARY 8, 2021
The best vaccination strategy is simple: Focus on Americans 65 and older
By Ruth Faden

THE BALTIMORE SUN | FEBRUARY 22, 2021
Kids already know ‘stop, drop and roll’ for fire emergencies; it’s time to teach ‘stop, wash and mask on’ for Covid-19
by Megan Collins

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by Megan Collins

THE CONVERSATION | APRIL 20, 2021
There are plenty of moral reasons to be vaccinated — but that doesn’t mean it’s your ethical duty
by Travis Rieder

THE HILL | MAY 25, 2021
Jails shrunk during the pandemic—here’s how to keep them small
by Brendan Salmer

THE BALTIMORE SUN | MAY 29, 2021
Should employers make vaccination mandatory?
by Ruth Faden and Nancy Kass

NEW YORK TIMES | AUGUST 18, 2021
The Truth About Long Covid Is Complicated. Better Treatment Isn’t
by Zackary Berger

NETWORK BROADCAST APPEARANCES

MSNBC WITH HALLIE JACKSON | NOVEMBER 19, 2020
COVID-19 Vaccines and Pregnant Women
with Ruth Faden

NPR | JANUARY 15, 2021
Covid-19 Supply Deal Lets Vaccine Maker Earmark Doses for Employees and Their Families
with Ruth Faden

“GOOD MORNING AMERICA” | JANUARY 19, 2021
I’m pregnant and a doctor: This is why I got the Covid-19 vaccine
with Ruth Faden

NPR’S “ALL THINGS CONSIDERED” | JANUARY 30, 2021
How States Are Prioritizing Limited Vaccine Supplies
with Ruth Faden

NPR | FEBRUARY 6, 2021
Is It Ever OK to Jump Ahead in the Vaccine Line?
with Ruth Faden

NPR | FEBRUARY 22, 2021
The Line for the Shot: The Ethics of Covid-19 Vaccination
with Nancy Kass

CBS NEWS | MARCH 3, 2021
Should you get a coronavirus vaccine if you’re pregnant? Experts say medical trials need to change
with Ruth Faden

FOX NEWS | MARCH 5, 2021
Teacher vaccinations go untracked amid school reopening push
with Megan Collins

BBC NEWS | MARCH 10, 2021
Covid: The man with ‘super antibodies’
with Jeffrey Kahn

INFORMING PUBLIC UNDERSTANDING OF ETHICS AND THE PANDEMIC

START NEWS | MARCH 6, 2021
Using the new Johnson & Johnson Covid-19 vaccine to create equity and trust
by Ruth Faden

EDUCATION WEEK | APRIL 9, 2021
Absenleism is the Wrong Student Engagement Metric to Use Right Now
by Ruth Faden

THE CONVERSATION | APRIL 20, 2021
There are plenty of moral reasons to be vaccinated — but that doesn’t mean it’s your ethical duty
by Travis Rieder

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THE BALTIMORE SUN | MAY 29, 2021
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BERMAN INSTITUTE TO UPDATE DEERING HALL DONOR WALL

For the first time since the dedication of Deering Hall a decade ago, the Berman Institute will update its donor wall to recognize the ongoing generosity of its most dedicated benefactors and honor its more recent supporters. All donors who have made leadership gifts the Berman Institute by the end of the 2021-22 fiscal year on June 30, 2022 will have their name inscribed on our donor display in the lobby of Deering Hall. The names of those already listed on the wall will be updated to reflect their lifetime support.

The display will be highlighted by a Founders panel, paying tribute to those generous individuals whose lifetime support of the Berman Institute has met or exceeded Phoebe Berman's $6 million gift that founded the Institute. The original donor wall recognized about 25 supporters, all of whom had made at least $100,000 in lifetime gifts to the Berman Institute before the 2011 dedication of Deering Hall. The revised wall will grow substantially, as we plan on recognizing every donor who has given $1,000 or more to the Berman Institute at any point in our first 25 years.

ANYONE WITH QUESTIONS IS INVITED TO CONTACT ANDREW RENTSCHLER AT ANDREW.RENTSCHLER@JHEDU.EDU OR 443-307-3814.
BERMAN INSTITUTE’S NATIONAL ADVISORY BOARD WELCOMES NEW MEMBERS

THE BERMAN INSTITUTE WAS FORTUNATE TO ADD FIVE OUTSTANDING NEW MEMBERS TO ITS NATIONAL ADVISORY BOARD IN 2021:

BARRY S. COLLER, M.D., is the David Rockefeller Professor of Medicine; Head, Allen and Frances Adler Laboratory of Blood and Vascular Biology; Physician-in-Chief of The Rockefeller University Hospital; and Vice President for Medical Affairs at The Rockefeller University. He is also founding Director of the Rockefeller University Center for Clinical and Translational Science and Principal Investigator of the University’s Clinical and Translational Science Award from the National Center for Advancing Translational Sciences.

DAVID GOLDSTEEN, M.D., is a successful former practicing physician, healthcare executive and serial medical technology entrepreneur. Dr. Goldsteen was the founder or founding financial backer of among other companies, Vascular Science, SurvivaLink and MediaDVX. He is the co-founder and currently serves as Chairman and CEO of VigiLanz, a real time clinical intelligence and analytics company for healthcare provider organizations.

SYLVIA MORRIS, M.D., M.P.H., BSPH ’97, is an Internist at Kaiser Permanente. Her goal is to utilize media to improve our nation’s public health by combining her training in internal medicine, holistic medicine, and public health, making guest appearances on the Weather Channel’s “Weekend View,” CNN International, and formerly contributing to the US News & World Report’s Medical School Admissions blog. Dr. Morris, a Kaiser Permanente Brand Ambassador, serves on Western Governors University College of Health Professions Nursing Advisory Council. Most recently, Dr. Morris was a Senior Medical Director on the Revenue Cycle Solutions team at The Advisory Board Company.

AMY ENGEL SCHARF ’90 is a project manager for Memorial Sloan Kettering Cancer Center Ethics Consultation Service and a member of their Ethics Committee. She is also Chair of the Board of Trustees for Children’s Aid, a social service non-profit that provides comprehensive health, education, and social supports to New York City’s most vulnerable children.

MAXWELL THANHOUSER is the managing partner of Fenorton, LLC, a single-family office managing the assets of four generations based in Owings Mills, Maryland. Fenorton focuses on traditional investment activities in addition to private real estate, private equity, and private debt markets. Mr. Thanhououser manages this privately held company.


Make a Gift Today.

The Johns Hopkins Berman Institute of Bioethics fulfills its mission by:
- Advancing fair and compassionate healthcare that puts people first.
- Leading the charge 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.