50 YEARS
The Hastings Center | Annual Report 2019

Celebrating 50 Years of Bioethics, Shaping the Next 50

ACCOUNTABILITY • GENEROSITY • EQUALITY • INTEGRITY • BENEFICENCE • WISDOM

CONTENTS

FROM THE PRESIDENT

Mildred Z. Solomon
President and CEO

Dear Friends and Colleagues,

In 2019, The Hastings Center celebrated its 50th anniversary. We looked back at what we had accomplished since our co-founders, philosopher Daniel Callahan and psychiatrist Willard Gaylin, envisioned an institute dedicated to examining how best to deploy advances in the life sciences and health care for the betterment of humanity. And, we looked ahead, asking ourselves how best to build on the formidable foundation that had been created.

Our year of reflection was embodied in a large number of public events, scholarly symposia, internal discussions amongst staff and Hastings fellows, all in addition to our already large portfolio of research projects. Through this process, we recommitted The Hastings Center to its two core priorities: ensuring the wise use of emerging biotechnologies and securing justice and compassion in care across the lifespan. However, there were two other results of this year of reflection. First, we pledged to deepen the justice work by challenging ourselves and the field to focus more robustly on systemic, structural, and population-level issues. Second, we committed to expanding our public and professional audiences.

We had already begun to make those moves a year earlier in 2018, when—with the support of The Robert W. Wilson Charitable Trust—we published *What Makes a Good Life in Late Life: Citizenship and Justice in Aging Societies*. This important volume addressed an array of social issues, like housing, support for family caregivers and social supports for isolated older people, all of which are essential to flourishing in late life. In 2019, the Wilson Trust stuck with us by supporting our efforts to continue getting the messages in that landmark volume out to broader audiences. We were able, for example, to co-sponsor a conference on aging and housing in partnership with the Joint Center for Housing Studies of Harvard University and to hold other meetings where the findings of our special report could be debated by other scholars, policymakers, and members of the public, capable of putting our ideas into action within their own spheres of influence. You can read about this work on page 11.

In 2019, we began the process of enlarging our audiences and deploying new strategies to ensure the uptake of our ideas in health and science policy and practice. These efforts were made possible by an indispensable anchoring gift from The Donaghue Foundation and early additional donors, who have generously seeded the establishment of The Hastings Center Fund for Impact in Policy and Practice. As I write, in the midst of the Covid-19 pandemic, the impact fund is indispensable to our ability to respond with robust guidance to medical practitioners and federal policymakers. As this fund grows over time, we will continue enhancing our communications capacities and sponsoring follow-on projects.

While 2019 was a year of celebration, it was also a year of tremendous loss. On July 16, we lost Daniel Callahan. In addition to co-founding The Hastings Center, Dan is recognized the world over as a pioneer in bioethics, who helped to establish the field. A prodigious author of 47 books, he also found the time to be a generous colleague and a mentor to generations of scholars. His work and his life demonstrate how fundamental moral sensibility is to our humanness. I invite you to read "Daniel Callahan: In Memoriam" (https://www.thehastingscenter.org/daniel-callahan-in-memorium/), the statement I issued immediately upon learning of his death. Hundreds of other tributes to Dan came in from around the world. A select few appear on pages 2-3 of this report.

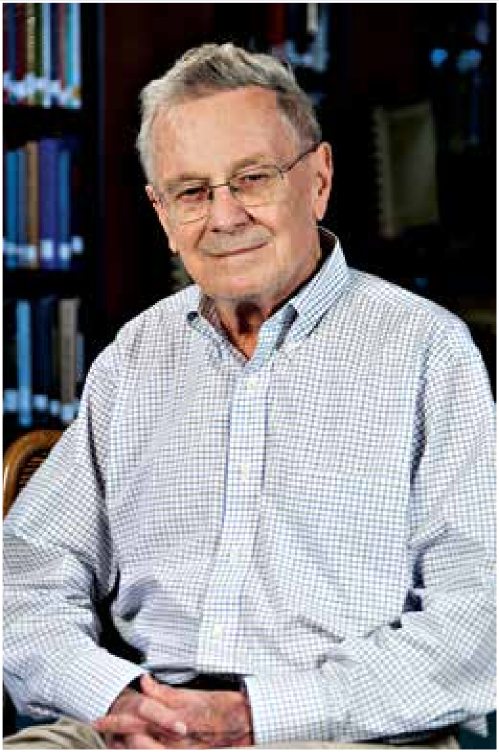
On January 3, we lost another colleague: Richard Payne, a longtime board member. A neurologist and internationally recognized palliative care expert, Rich led the selection process for The Hastings Center Cunniff-Dixon Physician Awards. Established by Andy Baxter, a visionary and longtime Hastings partner, these awards recognize physicians who give excellent care to patients near the end of life and stimulate health systems to enhance their palliative care programs.

We mourn the passing of Daniel Callahan and Richard Payne, but we are filled with gratitude to them. Each in his own way has shaped what The Hastings Center has accomplished and informs the possibilities to come.

With great appreciation,

Mildred Z Solomon

Mildred Z. Solomon



THE WORLD PAYS

Daniel Callahan, co-founder of The Hastings Center and a national voice for responsible health and science who pioneered the field of bioethics, died on July 16, 2019, three days before his 89th birthday. Callahan founded The Hastings Center with Willard Gaylin in 1969. He served as director from 1969 to 1983, president from 1984 to 1996, and President Emeritus until his death, during what he called his "so-called retirement."

Callahan's work and writing responded to the social upheavals of the last half century, including civil rights and the women's movement, as well as rapid medical advances. The topics of his research and writing were wide-ranging, beginning with Catholic thought and proceeding to the morality of abortion, the nature of the doctor-patient relationship, the promise and peril of new technologies, the scourge of high health care costs, the goals of medicine, the medical and social challenges of aging, dilemmas raised by decision-making near the end of life, and the meaning of death.

Callahan is the author or editor of 47 books, six of which won prizes or special citations. *Setting Limits: Medical Goals in an Aging Society*, a finalist for the 1987 Pulitzer Prize for Nonfiction, made the controversial argument for limiting life-prolonging medical care based on a patient's age.

> ***"If everything else is distilled out, what my career in bioethics comes down to is simple and enduring. It is an abiding fascination with the nature, scope, and validity of ethics as part of human life, and a similarly strong interest in the ways that scientific knowledge and technologies of medicine influence how we think about our health and morality and shape the ways we live our lives. Along the way, that means thinking about human finitude; about illness, suffering, aging, and death; and about the place of health in our individual and collective lives. It no less requires a recasting of our ethical traditions and ways of thinking about them."***
>
> —Daniel Callahan,
> *In Search of the Good: A Life in Bioethics*
> (MIT Press, 2012)

TRIBUTE TO DAN CALLAHAN

Reactions from around the world

"Callahan was motivated by a fundamental wariness of human power. He was deeply struck by the human proclivity for self-deception, especially concerning the potential for irresponsible use of such power in the life sciences and in the realm of biomedical technology." *—Mildred Solomon, Hastings Center president,* Hastings Bioethics Forum

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"I will say it: Dan Callahan is the most important person in Bioethics. For his ideas; for his role in creating and nurturing The Hastings Center; and for his ability to spot, encourage, and motivate talent." *—Thomas H. Murray, Hastings Center President Emeritus,* Hastings Bioethics Forum

◆

"[H]e never tired of asking, Can we, for a moment, set aside our preoccupation with better health and a longer life and think together about what we want those things for? Can we explore what a good life consists in?" *—Erik Parens, Hastings Center senior research scholar,* Hastings Center Report

◆

"Perhaps nowhere was Dan's influence, example, and friendship more important to me than when I chaired President Obama's Commission for the Study of Bioethical Issues. He was never far from my mind nor, from time to time, my email inbox." *—Amy Gutmann, president, University of Pennsylvania,* Hastings Bioethics Forum

◆

"Dr. Callahan was widely credited with helping change the way physicians and patients view death and dying. He helped promote palliative care, in which patients with serious illnesses receive care designed to maximize the quality of their remaining life, rather than undergoing last-ditch interventions that may extend their life but only briefly, and in less comfort. Caring, he emphasized, was often as or more meaningful than curing." *—Emily Langer,* Washington Post *obituary*

◆

"He felt strongly that with limited resources, society should be helping the young grow old, not keeping the old alive. Often lost in the rush to extend life, he believed, was the question of what the purpose of living longer would be." *—Katharine Q. Seelye,* New York Times *obituary*

◆

"Both of us had found academia dry and stultifying…It was a time when interdisciplinarity wasn't fashionable. We felt it was essential." *—Willard Gaylin, co-founder of The Hastings Center, quoted in* The Lancet *obituary*

◆

"Dan's legacy will live on in both his scholarly achievements and the field he helped mold, both as an institution builder and a dedicated mentor." *—Joseph J. Fins, chief of the Division of Medical Ethics, Weill Cornell Medical College, and Hastings Center fellow and board member,* Cambridge Quarterly of Healthcare Ethics

How Can Bioethics Help Mitigate Climate Change?
Callahan's Final Meeting Explores Options

Climate change has been called the greatest challenge humanity has ever faced. It is already affecting human health in the form of a decline in air quality and an increase in disease-causing insects such as ticks and mosquitoes. How might bioethics help address the threats posed by climate change?

Dan Callahan convened a two-day meeting at The Hastings Center in June to explore this question. The meeting brought together political scientists, bioethicists, directors of university programs on health and climate change, and teachers of courses on climate change. The aim was to take an inventory of present research and education efforts, forge bonds between programs in health and climate science, and consider next steps for research and policy.

Callahan noted that climate change and bioethics both arose from the human quest for progress. For health care, there is a tension between preventive medicine and high-tech care. In the case of global warming the tension is between changing climate-affecting behavior, such as burning down forests, and technological and economic solutions, such as solar panels and windmills.

"While both ways are being pursued, the technological routes are socially attractive," he continued. "They do not require behavior changes of any magnitude, and even better they are economically attractive. There is good money to be made on solar panels and wind machines. The seduction here is that the greater ease of technological solutions for global warming may minimize difficult cultural change."

Participants in the climate change meeting; (r.) Dan Callahan and Dale Jamieson; (below) Dan Callahan and Mildred Solomon

Mildred Solomon with Christopher Gibson (left), CEO of Recursion Pharmaceuticals, and Eric Topol, executive vice president of Scripps Research, at the **Aspen Ideas: Health Festival**.

Mildred Solomon with Andrea Renda, a member of an expert European Union group that proposed ethics guidelines for AI in Europe, at the "Data Science and the Right Science" conference.

Hastings research scholar Carolyn Neuhaus spoke at Arizona State University about deliberations on releasing genetically modified organisms.

From Aspen to Dubrovnic: Hastings Center Events

Is ethical AI in health care an oxymoron? What should we consider before having a genetic test? How should we address structural injustice? How can technology promote or thwart flourishing lives for people with disabilities? These are some of the weighty topics of events featuring Hastings Center scholars. And on the light side: The Hastings Center kicked off its 50th anniversary celebration with a 50th birthday party.

■ **Is Ethical AI an Oxymoron?** As artificial intelligence transforms health care, what should be done to assure that it brings about improvements and greater equity? Hastings Center President Mildred Solomon spoke at the Aspen Ideas: Health Festival on June 22 on a panel called "Ethical Artificial Intelligence: Oxymoron or Possibility?" "Like other technologies, AI is neither all good nor all bad. It's all in how we decide to deploy it," she said and then offered key principles to guide AI's development: AI systems should benefit people, not just profits; keep humans in the loop; ensure privacy; resist surveillance; and achieve fairness. Solomon also expressed ethical concerns about affect recognition, where AI applications make assumptions about a user's emotions from facial, voice and gestural sensors.

■ **Genomics Enters the Clinic** Sixteen years after completion of the Human Genome Project, and more than half a century after the discovery of the structure of DNA, genetics is now being incorporated into clinical use. But as this new technology is integrated into mainstream applications, what do potential users of genomics need to know?

This question was the focus of a public event at the New York Academy of Sciences on June 11, presented by NYAS, The Hastings Center, and the Aspen Brain Institute to a capacity in-person audience of about 200 people and livestreamed for a broader reach. The event was supported in part by The Donaghue Foundation. Mildred Solomon moderated the discussion. Panelists included Josephine Johnston, director of research and a research scholar at The Hastings Center.

Genomic sequencing in newborns was among the technologies discussed. Johnston explained the reasoning behind recent recommendations from a NIH-funded project in which she was an investigator—recommendations not to sequence all newborns at this time, since the results would not be fully understood. However, the recommendations supported the use of genomics to aid in the diagnosis of sick newborns. "That's the optimal context for using this technology," she said.

■ **Data Science and the Right Science** How do we ensure that advances in data science benefit all of us, and not just private interests? How do we ensure truthfulness, inclusiveness, and equity in large databases and in a growing array of artificial intelligence applications? Mildred Solomon was a member of the scientific committee and a speaker at an international conference, "Data Science and the Right to Science," which took place in Dubrovnik, Croatia, in May, to address these issues. She emphasized the need to develop structures for global governance and ways to build in public participation so that large data systems and AI applications reflect key value commitments, like inclusivity and nondiscrimination.

Integrity compassion

Equality AUTH


Mildred Solomon presents The Hastings Center's 2019 Henry Knowles Beecher Award for lifetime achievement in bioethics to Ruth Faden, founder of the Johns Hopkins Berman Institute of Bioethics.


At "Genomics Enters the Clinic" at the **New York Academy of Sciences** in June: (l.to r.) Mildred Solomon, Christopher E. Mason, Josephine Johnston, Samuel Sternberg, Jonathan Moreno, and Sandra Soo-Jin Lee.


Marion Danis, Virginia Brown, and Mary Bassett at a plenary session on addressing structural injustice organized by The Hastings Center at the American Society for Bioethics and Humanities annual meeting.

■ **Beyond My Backyard: Who Should Be Involved in Deciding Whether to Release Gene-Edited Organisms? Why?** If scientists wanted to release genetically modified mice or mosquitoes into your town to reduce the risk of illnesses such as Lyme disease or Zika, who should be able to weigh in on whether, and how, this should happen? Hastings Center research scholar Carolyn Neuhaus said that participation in such decisions should extend beyond people who live in the affected community. Gene modifications could have lasting consequences outside the immediate area, many of the harms and benefits might be unforeseen or inequitably distributed, and the moral stakes of editing organisms are high. Neuhaus made her remarks at the "Governing of Emerging Technologies & Science" conference at the Sandra Day O'Connor College of Law at Arizona State University in May.

■ **Addressing Structural Injustice** The Hastings Center has committed to intensifying its effort to address structural injustices. Ideas for doing so emerged in a plenary session organized by Hastings at the annual meeting of the American Society for Bioethics and Humanities in October, one of the key 50th anniversary events.

Mary Bassett, former Commissioner of Public Health for the City of New York and currently the director of the Center for Health and Human Rights at the Harvard T.H. Chan School of Public Health, began by discussing structural racism as one of the drivers of injustice. Uprooting racism, she said, requires data followed by action. Attending to the context that gives rise to disparities in risk factors and disease is the starting point of addressing structural racism and other kinds of injustice.

Mildred Solomon said that justice has always been a canonical principle for bioethics, but "too often, we bioethicists tend to focus only on distributional justice, wanting for example, to ensure fair access to technology's benefits or to protect some groups from bearing disproportionate burdens in a research context. Our field tends to give far less attention to structural injustices that are a function of power differentials, economic disparity, and longstanding discrimination." Hastings is placing issues of justice at the front lines of its concern, and Solomon urged the field to move in this direction.

■ **Honor for Lifetime Achievement** Ruth Faden, PhD, MPH, founder of the Johns Hopkins Berman Institute of Bioethics and the Philip Franklin Wagley Professor of Bioethics, received The Hastings Center's 2019 Henry Knowles Beecher Award for lifetime achievement in bioethics at the annual meeting of the American Society for Bioethics and Society in Pittsburgh in October. Faden is also a Hastings Center fellow.

Launch of *Ethics & Human Research*

In January, The Hastings Center's longstanding journal, *IRB: Ethics & Human Research*, became *Ethics & Human Research*: revised, expanded, and launched through Wiley Online Library and featuring articles by leading scholars in research ethics. Karen J. Maschke, a Hastings Center research scholar who edited *IRB*, remains editor of the new journal. Maschke says that *E&HR* is positioned to publish from authors around the globe whose work broadens the approaches to analyzing the challenges that 21st century science and medicine bring to human biomedical and behavioral research.


Mildred Solomon at the **United States Military Academy at West Point** in November.


David Roscoe, with Stephanie Morain and Emily Largent, recipients of the inaugural David Roscoe Award for an Early-Career Essay on Science, Ethics, and Society, at the award ceremony in October.


Karen J. Maschke spoke on public engagement at the annual conference of the **Public Responsibility in Medicine & Research (PRIM&R)**.

■ **Supporting Early-Career Scholars** The Hastings Center launched the David Roscoe Award for an Early-Career Essay on Science, Ethics, and Society, which recognizes an essay on the social and ethical implications of advances in science and technology written in a style that is accessible and engaging to a general audience. The inaugural award went to Stephanie R. Morain, of Baylor College of Medicine, and Emily Largent, of the University of Pennsylvania's Perelman School of Medicine, for "Recruitment and Trial-Finding Apps: Time for Rules of the Road," which explores ethical questions raised by the use of mobile apps intended to reduce the critical shortage of people who volunteer for clinical trials. The award is named in honor of a recent past chair of The Hastings Center's board and current head of the advisory council.

■ **In Search of Authentic Public Engagement** Hastings Center research scholar Karen Maschke urged more careful thinking about and greater financial commitment to the design of feasible and effective public engagement on public policy choices regarding "technologies of concern," such brain interface devices, the use of machine-learning algorithms to analyze and decode brain activity, and human germline editing. Her remarks were part of a plenary session entitled "50 Years of Bioethics—Reflections from The Hastings Center" at the annual conference of the Public Responsibility in Medicine & Research (PRIM&R) in November. "Making the calls for public engagement is easy," Maschke said, "but doing it means disrupting existing centers of power, and requires hearing a multitude of voices that challenge the underpinnings of innovation—which requires will, time, and money." Mildred Solomon moderated the panel.

wisdom

TRUST

The 50 YEARS Hastings Center

Hastings Kicks off 50th Anniversary Celebrations

The Hastings Center marked its 50th anniversary with a party in September at its campus in Garrison, N.Y., kicking off a series of programs honoring the Center's work and looking ahead to the future. "We are facing a tsunami of innovation that is moving so fast individuals, institutions and governments cannot keep up," said Mildred Z. Solomon in remarks to more than 100 friends and colleagues, including cofounder Willard Gaylin, board chair Brad Gray, as well as present and former Hastings Center staff members, other ethics leaders, supporters, and researchers.

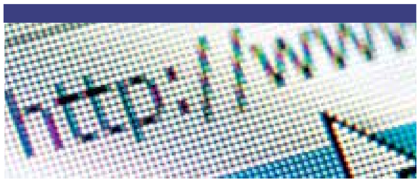
"Advances in genetics, assisted reproductive technologies, neuroscience, synthetic biology, nanotechnologies, and artificial intelligence are galloping forward," Solomon said. "But no technology is neutral. And in all these cases, it will be essential to consider how best to integrate these technologies."


(l. to r.) Eric Cassell, Jody Heyward, and Willard Gaylin at The Hastings Center's 50th anniversary party.

At "Belonging: On Disability, Technology, and Community": (far left) panelist Haben Girma, the first Deafblind graduate of Harvard Law School; (middle, l. to r.) Erik Parens, Haben Girma, Rachel Kolb, Teresa Blankmeyer Burke, and Rosemarie Garland-Thomson; (right) Erik Parens with the assistance of an interpreter and closed-captioning.

■ **What If Deaf Parents Were to Use Gene Editing to Produce a Deaf Child?** A Russian scientist wants to use Crispr gene editing on embryos to prevent deafness; what if deaf parents were to use Crispr on embryos to produce a deaf child? This was among the questions discussed at the lively inaugural event in The Hastings Center's series exploring how people with disabilities are using—or choosing not to use—technologies to promote their own flourishing. "Belonging: On Disability, Technology, and Community" took place in New York City in December before an audience of nearly 200 people in person and more on livestream. Supported by the National Endowment for the Humanities, the series is being organized by Erik Parens, a senior research scholar at The Hastings Center, with Joel Michael Reynolds, the inaugural Rice Family Fellow in Bioethics and the Humanities at The Hastings Center, and Rosemarie Garland-Thomson, a professor at Emory University and a Hastings Center Fellow. Five more public events will take place in 2020 and 2021.

■ **Hastings President Speaks at West Point** Mildred Solomon spoke at the United States Military Academy at West Point in November with a talk titled "What is Bioethics and Why Does it Matter?" All the cadets who attended the talk were interested in careers in medicine and the life sciences.



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AUTONOMY dignity

courage

Commemorative Events Across the U.S.

■ April/Wake Forest University • *Beyond Our Beginnings: 50 Years of Bioethics, a Celebration of the 50th Anniversary of The Hastings Center* • Symposium

■ October/Pittsburgh • American Society of Bioethics and the Humanities Annual Meeting
  • Hastings Center Fellows Annual Meeting—*Big Ideas in Bioethics: The Questions that Got the Field Started, and What Is Needed for the Future* • Presentations and discussion
  • *Remembering the Births of The Hastings Center and Bioethics* • Panel discussion
  • *Reflections on The Hastings Center on Its Fiftieth Anniversary* • Panel discussion

■ November/Boston • *Bioethics Turns Fifty* • *Symposium at PRIM&R conference* • Plenary session at PRIM&R Annual Meeting

■ December/NYC • Daniel Callahan Inaugural Lecture: *Safe Enough Spaces*, a talk by Michael Roth, President of Wesleyan University

Events will continue into 2020.

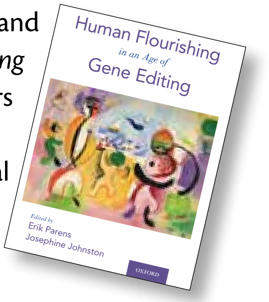
Michael Roth delivers the inaugural Daniel Callahan Lecture in New York City in December.

Visitors stop by The Hastings Center's booth at the American Society for Bioethics and Humanities annual meeting in October.

Wise Use of Genetic Technologies

The sheer volume of genetic information is exploding. Genetic testing—from doctors and from direct-to-consumer companies—can reveal our risks for cancer, Alzheimer's, and other illnesses. Gene editing is being done in humans and in the wild. Scientists are treading into hot-button areas such as whether genes can predict a person's potential for educational attainment. In original research and public engagement, Hastings Center scholars provide guidance on how to use genetic technologies, and other new biotechnologies, responsibly. This means evaluating the benefits and harms but also going deeper to explore the implications of a technology on the well-being of individuals, societies, and ecosystems.

■ **What Does It Mean to Flourish in the Age of Gene Editing?** International uproar followed the recent birth of the first babies created from embryos whose genomes had been edited with a breakthrough technology. The prospect of using gene editing to change ourselves, our children, and their offspring raises a host of difficult questions, and they are explored in *Human Flourishing in an Age of Gene Editing* (Oxford University Press, 2019), edited by Hastings Center scholars Erik Parens and Josephine Johnston. The book is one outcome of a three-year international project, supported by the John Templeton Foundation, that focused on the potential social and ethical implications of using gene editing on human germline cells, creating changes that could be inherited.



The book's aim is to stimulate a public conversation about ethical questions raised by gene editing, including: How might it change the relationship between parents and children? Could it exacerbate the gap between the haves and the have-nots—and how can we avoid this risk? Parens and Johnston wrote: "It is through this public conversation that citizens can influence laws and the distribution of funding for science and medicine; that professional leaders can shape understanding and use of gene editing and related technologies by scientists, patients, and practitioners; and that individuals can make decisions about their own lives and the lives of their families."

■ **How Can Behavioral Genetics Research Be Done Responsibly?** Scientists have high hopes for using new techniques to investigate the genetic influences on behaviors and capabilities. These techniques produce "polygenic risk scores" to assess social and behavioral characteristics such as intelligence and obesity. But much behavioral genetics research has an ugly history and contemporary research risks exacerbating health inequities. A new Hastings Center project is exploring how this research can be done responsibly, in ways that minimize harms and maximize benefits.

Erik Parens is co-leading this project, which is supported by the Russell Sage Foundation, the Robert Wood Johnson Foundation, and the JPB Foundation. "Bringing researchers and scholars together to speak over time about ethically fraught and scientifically complex questions is at the heart of The Hastings Center's mission," Parens told the journal *Nature* in an interview about the project.

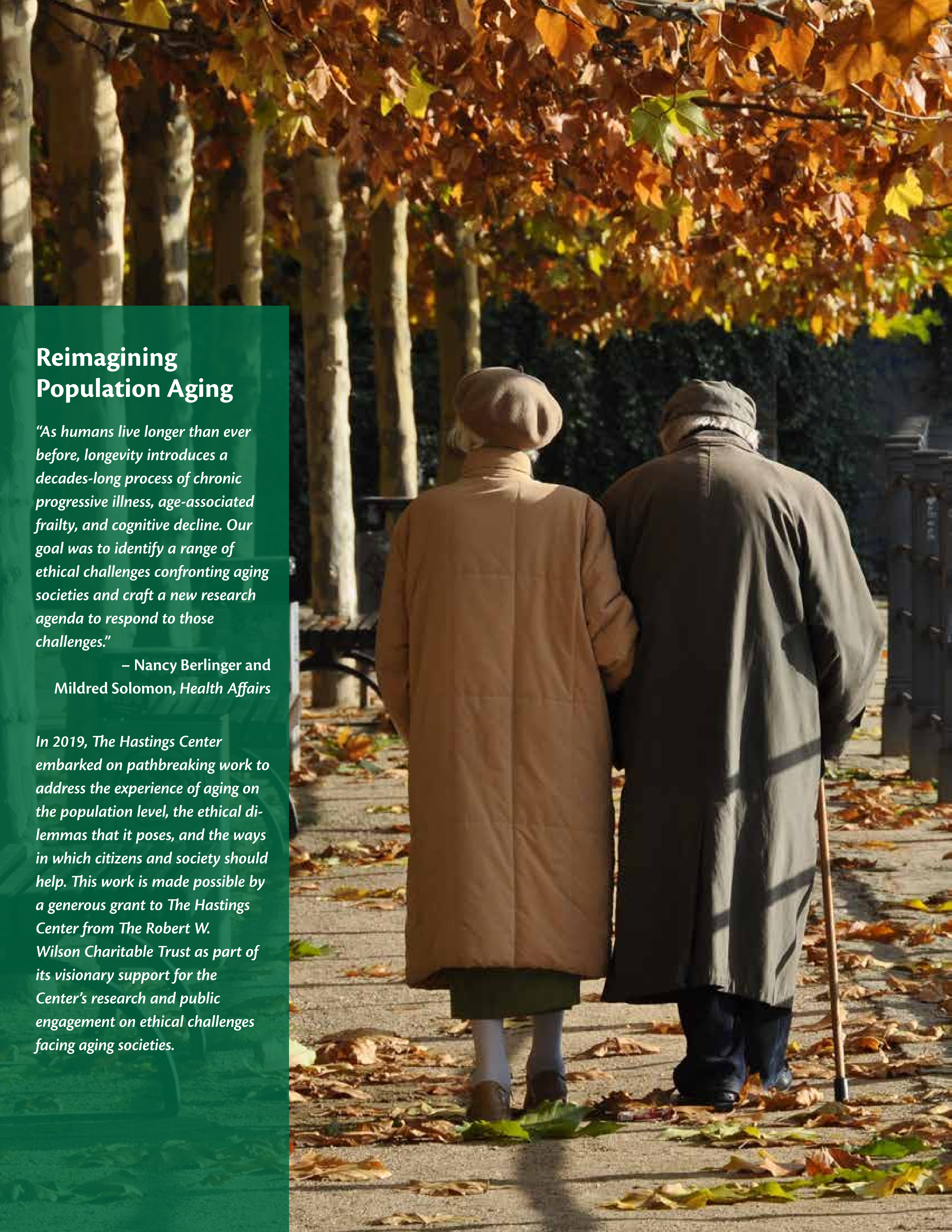
■ **Hastings Partners on Unprecedented Genetics Resource Hub** The Hastings Center is a collaborator on a major new federally funded center—the Center for ELSI Resources and Analysis—that will fill a void in genetics research by collecting and sharing information about its ethical, legal, and social (ELSI) implications. This resource hub, the first of its kind, will enable people grappling with these issues to easily find ethical or policy guidance or published research, and to connect with experts who can help them. The project is supported by the National Human Genome Research Institute. Lead Hastings investigators, Josephine Johnston and Carolyn Neuhaus, are engaging in a range of activities aimed at policymakers, educators, and journalists.

■ **Building Diverse Participation on Precision Medicine Research** The Hastings Center is co-leading a project to examine recruitment and retention of participants in the National Institutes of Health's All of Us Research Program, an unprecedented initiative to collect genetic and other health-related data from at least one million people living in the United States, most of whom are from underrepresented groups. Carolyn Neuhaus is the Hastings Center lead on the project, which is funded by the National Human Genome Research Institute of the National Institutes of Health. The project is identifying strategies for meaningfully engaging underrepresented populations in health research—in ways that match their values and expectations. The project is an example of The Hastings Center's commitment to creating more informed and more meaningful dialogue in the public square.

compassion

beneficence

diversity



Reimagining Population Aging

"As humans live longer than ever before, longevity introduces a decades-long process of chronic progressive illness, age-associated frailty, and cognitive decline. Our goal was to identify a range of ethical challenges confronting aging societies and craft a new research agenda to respond to those challenges."

– Nancy Berlinger and Mildred Solomon, *Health Affairs*

In 2019, The Hastings Center embarked on pathbreaking work to address the experience of aging on the population level, the ethical dilemmas that it poses, and the ways in which citizens and society should help. This work is made possible by a generous grant to The Hastings Center from The Robert W. Wilson Charitable Trust as part of its visionary support for the Center's research and public engagement on ethical challenges facing aging societies.

■ **Aging and Inequality** Like many other facets of life in the U.S., aging is plagued by inequality. Studies show that lifelong social determinants of health shape the experience of older adults and family caregivers. These social factors demand social solutions, which is why we are examining how community values and processes of deliberation, including biases against affordable housing and competing priorities in local building, may limit who can age in place, whether this is at home or in another desired location. Hastings Center research scholar Nancy Berlinger is leading this effort, which is engaging health policymakers; practitioners in fields such as community planning, housing, and urban design; and community members on ways to promote inclusion and equity for older adults and caregivers.

■ **Who Should Get to Age in Place?** Public discussion and policy often cite “aging in place” as a way to improve quality of life for older people and reduce costs. But not all older adults can live in age-supportive communities, neighborhoods, or homes. Millions of people are in the “forgotten middle,” neither rich nor poor, whose housing and care needs in the last stage of life cannot be met through publicly funded health insurance or personal savings alone. The challenges raised by these inequalities were the focus of a public event cosponsored by The Hastings Center and the Harvard Joint Center for Housing Studies in October. Mildred Solomon and Hastings research scholar Nancy Berlinger spoke at the event, which was made possible by a generous grant to The Hastings Center from The Robert W. Wilson Charitable Trust. The meeting attracted nearly 1,000 people in person and watching the livestream, including age-focused policymakers practitioners and researchers. As an outgrowth of the meeting, many of these experts formed a network in the U.S. and Canada that meets regularly to analyze policies and practices with long-term promise.

■ **Dementia and the Ethics of Choosing When to Die** Dementia is on the rise. An estimated 12 million people will be at risk for developing it over the next 30 years. But the legal and ethical framework that gives other people choices about limiting their lives—for example, by refusing life-sustaining treatment or requesting medical aid-in-dying in the U.S. jurisdictions where it is legal—does not apply to people with dementia.

As part of our new work on aging, The Hastings Center is putting dementia in the foreground, asking which choices matter most to someone who is facing dementia.

“Should these choices include a way to say ‘enough’ in a way similar to—but not the same as—stopping cancer treatment or refusing mechanical ventilation? What would these choices look like?” ask Mildred Solomon and Nancy Berlinger, who are leading the project, made possible by a generous grant to The Hastings Center from The Robert W. Wilson Charitable Trust.

Solomon, Berlinger, and the work group are identifying areas where further research or policymaking is needed, with the goal of contributing to policy solutions and public understanding to improve the experiences of living with dementia and caring for people with the condition.

balance

JUSTICE

HONESTY

global stewardship

accountability

responsibility

2019 SCHOLARS AND PROJECTS

HEALTH AND HEALTH CARE

- Empowering Cancer Patients Through Innovations in Information Technology-Based Reporting of Precision Medicine
  Sarah McGraw (Agency for Healthcare Research and Quality under subcontract from City of Hope)
- Governance of Learning Activities in Learning Healthcare Systems
  Sarah McGraw and Mildred Solomon (Patient-Centered Outcomes Research Institute under subcontract from University of Pennsylvania)
- Harvard Integrated Program to Protect and Improve the Health of NFL Members
  Sarah McGraw (National Football League Players Association under subcontract from Harvard Medical School)
- Patient-Centered Cancer Genome Sequencing Education and Decision Support
  Sarah McGraw (American Cancer Society under subcontract from City of Hope)
- Scalable Tools to Effectively Translate Genomic Discoveries into the Clinic
  Sarah McGraw (National Institutes of Health under subcontract from City of Hope)
- Understanding "Engagement" in the All of Us Research Program
  Carolyn P. Neuhaus (National Institutes of Health/National Human Genomic Research Institute)

CHILDREN AND FAMILIES

- Goals and Practices for Next Generation Prenatal Testing Systems
  Josephine Johnston (National Institutes of Health/National Human Genome Research Institute)

CHRONIC CONDITIONS AND CARE NEAR THE END OF LIFE

- Aging at Home Alone with Alzheimer's and Related Dementias: Ethical Considerations for Inclusion
  Nancy Berlinger (National Institutes of Health under subcontract from University of Maryland)
- Bioethics for Aging Societies: Informing Policies and Practice
  Nancy Berlinger (Robert W. Wilson Charitable Trust)
- Dementia and the Ethics of Assisted Dying
  Nancy Berlinger and Mildred Solomon (Robert W. Wilson Charitable Trust)

SCIENCE AND THE SELF

- Actionable Ethics Oversight for Human-Animal Chimera Research
  Josephine Johnston and Karen Maschke (National Institutes of Health/National Human Genome Research Institute)
- Center for ELSI Resources and Analysis (CERA)
  Josephine Johnston (National Institutes of Health / National Human Genome Research Institute under subcontract with Stanford University and Columbia University Medical Center)
- Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurologic and Behavioral Genetics (Renewal)
  Erik Parens and Josephine Johnston (National Institutes of Health under subcontract from Columbia University Medical Center)
- Development of Recommendations and Policies for Genetic Variant Reclassification
  Erik Parens (National Institutes of Health under subcontract from Columbia University)
- Shaping Humans: A Discussion Series on Technology, Disability, and Human Flourishing
  Erik Parens (National Endowment for the Humanities)
- The Boger Initiative for the Wise Use of Emerging Technologies
  Mildred Solomon (Joshua Boger)
- Wrestling with Social and Behavioral Genomics: Risks, Potential Benefits and Ethical Responsibility
  Erik Parens (Russell Sage Foundation and Robert Wood Johnson Foundation)

HUMANS AND NATURE

- Public Deliberation on Gene Editing in the Wild
  Gregory Kaebnick (National Science Foundation)

EDUCATION

- Chinese University of Hong Kong-Hastings Center Scholarly Exchange
  Nancy Berlinger (Edgar Cheng)
- How Should the Public Learn? Reconstructing Common Purpose for a Democracy in Crisis
  Mildred Solomon, Bruce Jennings, and Gregory Kaebnick (John S. and James L. Knight Foundation)
- The Hastings Center Bioethics Briefings
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Jennifer Herbst

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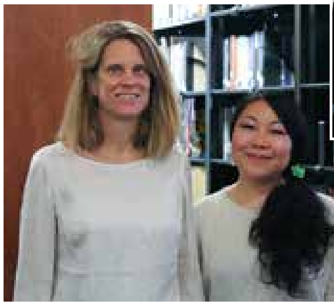

Kathrin Maurer and Ning Wang

Participants in an early-career scholar workshop

Melanie Challenger

2019 VISITORS

People from around the world visit The Hastings Center each year to do research on bioethics issues, make presentations, and meet with Hastings research scholars. In 2019, we welcomed 41 postgraduate, faculty, and other professional visiting scholars, a 58 percent increase from 2018. They came from 10 countries (see graphic). Their research topics included regulation of assisted dying and euthanasia, ethical and regulatory issues related to genomic medicine, ethics of representing transgender patient experiences in medical education, and privacy and informed consent in biobanking.

In addition, The Hastings Center welcomed early-career scholars by supporting one-week residencies for five undergraduates and organizing workshops with Macaulay Honors College of the City University of New York, the Sherwin B. Nuland Summer Institute in Bioethics at Yale, and the Montefiore-Einstein Center for Bioethics.

WHERE THEY CAME FROM

Argentina
Australia
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Korea
Netherlands
Switzerland
Taiwan
United Kingdom

Derek So

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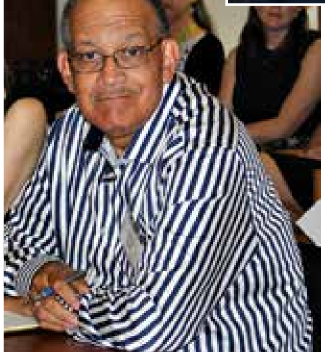
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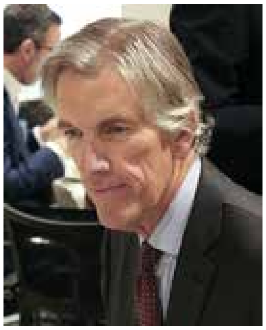
Arthur Caplan gave a talk titled “Recycling Our Parts: Ethical Challenges in the Rapidly Evolving World of Organ Transplantation” on May 10 in New York. Caplan is the founding director of the Division of Medical Ethics at the NYU Grossman School and a Hastings Center fellow. He joined the Advisory Council later in 2019.

Robert Cook-Deegan spoke about “Governance of 21st Century Technologies” on October 3 in New York. Cook-Deegan is a professor at Arizona State University’s School for the Future of Innovation in Society and a Hastings Center fellow.

David Roscoe, Robert Cook-Deegan, and Brad Gray

Al Glowasky and Robert Huffines



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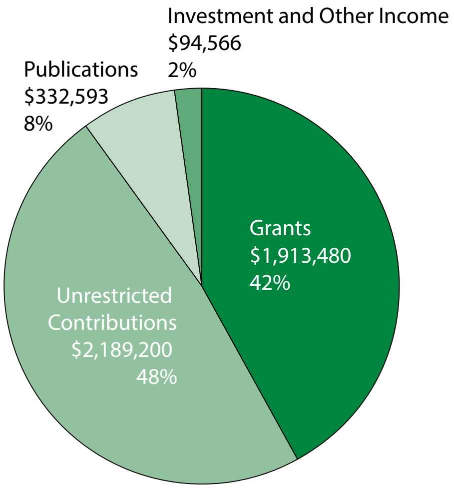
	Audited 2019
Assets	
Cash and Equivalents	1,077,166
Investments, at fair value	7,909,793
Receivables (grants and other)	4,249,282
Other Assets	87,141
Furniture and Equipment (net of accumulated dep)	20,989
Leasehold Improvements (net of accumulated amort)	906,152
Total Assets	14,250,523
Liabilities and Net Assets	
Payables and Accruals	69,067
Deferred Compensation Payable	170,599
Deferred Revenue	101,855
Total Liabilities	341,521
Net Net Assets	13,909,002
Total Liabilities and Net Assets	14,250,523

Statement of Activities and Changes in Net Assets

Operating revenues and other support:	
Grants, Gifts, and Contributions	7,032,198
Government Grants	1,095,188
Publication Revenue	332,593
Other income	94,626
Total Unrestricted Operating Support and Revenue	8,554,605
Operating Expenses:	
Program Services	3,011,701
Management and General	496,735
Fund Raising	432,889
Total Operating Expense	3,941,325
Changes in Net Assets from Operations	4,613,280
Non-operating Income	1,055,720
Change in Net Assets	5,669,000
Net Assets, Beginning of year	8,240,002
Net Assets, End of year	13,909,002

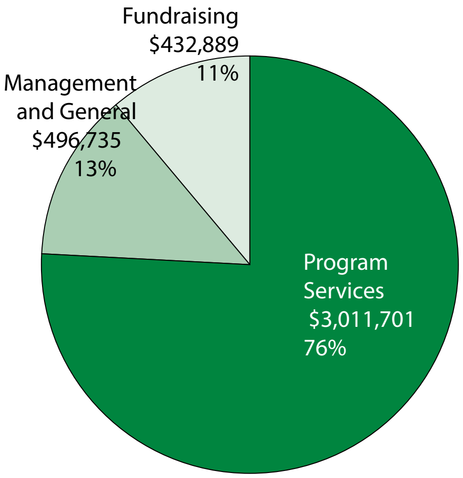
Unrestricted Operating Revenue and Support

For the year ended 12/31/19 = $4,529,839



Operating Expenses

For the year ended 12/31/19 = $3,941,325



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