



Working for Human Values in Policy and Practice

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FROM THE PRESIDENT



Mildred Z. Solomon President and CEO

Dear Friends and Colleagues,

In 2018, we reached a turning point. Anticipating the 50th anniversary of our founding in 1969, we began planning several major events to celebrate this milestone. We also looked ahead and made ambitious plans for the future.

The Hastings Center is the world's pioneering bioethics research center. We ensure that important values, like trustworthiness, compassion, and fairness, are designed into policy and practice in health, science, and biomedical technology. Throughout our history, we have been committed to producing original scholarship and to applying ideas from that scholarship to inform policymakers, health care practitioners, journalists, and the general public. In other words, public and policy engagement have always been core to our mission.

Toward the end of 2018, anticipating our 50th anniversary, we challenged ourselves to do even more to advance engagement. We set our sights on building The Hastings Center's Fund for Impact on Policy and Practice. The Impact Fund will enable us to develop new strategies to ensure the uptake of our ideas into health and science policy and practice, reaching public officials, opinion leaders, and the broader public on the most pressing ethical issues of our time.

We are enormously grateful to The Donaghue Foundation for believing in this vision and providing a generous anchoring gift of \$800,000 to launch the Fund. We now intend to build the Fund further, thereby securing the Center's impact on some of the world's most pressing questions.

In closing, I'll highlight some of our accomplishments in 2018. Here's a brief snapshot:

- With colleagues from around the country, we developed recommendations on the wise use of genome sequencing in newborns. In September, days after we published those recommendations, one of the world's leading medical journals, *The Lancet*, endorsed them in an editorial.
- We created and published a multidisciplinary examination of the ways to address the challenges of population aging. A consultant for World Health Organization told us: "The WHO has begun a project to develop an ethical framework for healthy aging policies. The Hastings Center's report is informing our initiative."
- We developed recommendations for industry leaders, government policymakers, and other stakeholders on the control and responsible use of artificial intelligence to help reap its benefits and productivity gains while minimizing its risks and undesirable social consequences.
- We launched a professional development workshop for high school science teachers to help them equip their students to recognize and analyze ethical dilemmas related to human gene editing and other emerging biotechnologies.
- In keeping with our commitment to public engagement, we closed the year by honoring three outstanding journalists with our Awards for Excellence in Journalism on Ethics and Reprogenetics. The awards recognized journalism that not only explained the science of technologies such as prenatal genetic testing but also engaged with broader philosophical questions—about how to use these technologies to promote human flourishing.

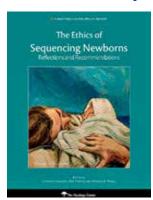
You can learn much more on the following pages about our research and our public engagement activities for 2018. For updates throughout the year, I invite you to visit our website, www.thehastingscenter.org, where you can sign up for our e-newsletter.

With great appreciation,

Mildred ZSolomon
Mildred Z. Solomon



Should We Sequence the Genome of Every Baby?



Gene editing is one thing. But what about sequencing the genome of every newborn? Many policymakers and clinicians are currently deliberating exactly that, asking whether we should offer full genome sequencing for all 4 million infants born annually in the United States. Should parents learn all that the genome has to tell? What if the information is highly uncertain? Is it right to identify risks for adult-onset diseases that may never materialize or that might arise decades later? Can newborn screening programs afford to integrate sequenc-

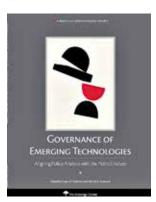
ing into their services? In response, the *Hastings Center Report* published recommendations which

grew out of a task force convened by Hastings Fellow Barbara Koenig at the University of California San Francisco and co-led by Koenig, Hastings director of research Josephine Johnston, and senior scholar Erik Parens. They and their co-authors concluded that sequencing the genomes of some infants may be appropriate in specific contexts—for example, for some newborns with unexplained symptoms, but they recommended that genome-wide sequencing of all newborns should not be pursued at this time. Furthermore, health professionals should advise against parents using direct-to-consumer genetic testing to diagnose or screen their newborns.

Their recommendations were heard around the world. The Lancet, a leading medical journal, supported them in an editorial. Politico said: "A consortium of NIH-funded bioethicists has produced a report calling for doctor and scientists to be careful about knee-jerk genetic sequencing of all newborns." Their special report grew out of a project supported by the Eunice Kennedy Shriver National Institute of Child Health and Human Development and the National Human Genome Research Institute.

IMPACT Director of research Josephine Johnston was appointed by New York Governor Andrew Cuomo to the ethics committee of the Empire State Stem Cell Board. The board advises the New York State Stem Cell Science program, which has awarded hundreds of millions of dollars for stem cell research to dozens of New York institutions. The ethics committee advises the stem cell board funding committee on clinical, ethical, and regulatory issues associated with stem cell research.

Aligning the Use of Emerging Biotechnologies with Public Values

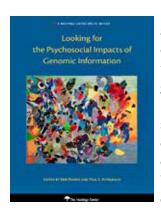


How to implement human gene editing and sequencing are two examples of a set of larger questions science policymakers and the public must face: How can we make wise policy decisions about emerging technologies—decisions that are grounded in facts yet anticipate unknowns and promote the public's preferences and values? A *Hastings Center Report* special report on the governance of emerging technologies, edited by research scholars Gregory Kaebnick and Michael Gusmano, proposed some answers. Among the takeaways: cost-benefit analysis, the primary tool policymakers use to evaluate technologies, may seem to be based on "hard facts," but it is laden with hidden

value judgments that ought to be examined carefully and transparently. Kaebnick argues for a precautionary approach in implementing new technologies—which doesn't mean a moratorium on their use, but rather a "pause or slowdown in a decision about technology so that we have time to reflect" and "a broad view of the values that should be reflected in policy."

Cost-benefit analysis, the primary tool policymakers use to evaluate technologies, may seem to be based on 'hard facts,' but it is laden with hidden value judgments that ought to be examined carefully and transparently.

—Governance of Emerging Technologies special report



Do Genomic Test Results Cause Distress?

Questions about how to proceed with genomic testing extend beyond their utility and effectiveness: learning disturbing or uncertain genetic test results about yourself, your child, or your fetus can also impact your identity, plans, and overall well-being. When information is highly uncertain, as it often is (because we simply don't yet know what many genetic variants mean), we may make parents over-anxious or cause undue stress with no clear benefits. "Looking for the Psychosocial Effects of Genomic Test Results," a public symposium in February organized by The Hastings Center and Columbia University as part of a joint project, explored what we know and don't know about the emotional impacts of genomic information and proposed next steps for research, clinical practice, and policy. While depression, anxiety, and other serious negative effects may be transient, more subtle effects are longer lasting, such as feelings of hypervigilance and worry. The conference was livestreamed worldwide.

Genomic Knowledge: A Gift and a Weight

With the significant popularity of direct-to-consumer genetic testing, genetic knowledge is assuming a growing role in our lives. On the one hand, this knowledge is a gift, offering insights into the genetic drivers of disease. But it is also a weight, presenting new obligations, new forms of social classification, and new forms of surveillance. How can we live well in the face of knowledge that can change the criteria, conditions, and experience of life?

To address that fundamental question, The Hastings Center organized a public symposium, "The Gift and Weight of Genomic Knowledge," at Brooklyn Law School in October as part of the Humanities Research Initiative, which The Hastings Center launched with funds

made available by the National Endowment for the Humanities, the Rice Family Foundation, and numerous generous donors. Senior research scholar Erik Parens and Rice Family Fellow in Bioethics and the Humanities Joel Michael Reynolds led the convening, which brought together leading experts from around the country in fields such as disability studies, race and gender studies, and ethics of data. A takeaway from the conference is that the benefits of genomic knowledge are a given, but many of the risks come down to questions of justice: Who is



Erik Parens, Hastings Senior Research Scholar

helped or hurt by genomic knowledge? How? How can the injustices to vulnerable groups such as people with disabilities be reduced? The conference was livestreamed worldwide.

A takeaway from The Hastings Center's symposium on genomic knowledge: the benefits of genomic information are a given, but many of the risks come down to questions of justice: Who is helped or hurt by genomic knowledge? How? How can the injustices to vulnerable groups such as people with disabilities be reduced?

How Should We Guide the Responsible Innovation of Artificial Intelligence?

Artificial intelligence poses innumerable opportunities, but reconciling innovation with values including privacy, autonomy, and justice is of paramount importance. A major international project at The Hastings Center released policy recommendations for the development of AI to help reap the benefits and minimize the risks and undesirable social consequences. The project was funded by the Future of Life Institute and led by Hastings senior advisor Wendell Wallach. David Roscoe, former chair of The Hastings Center's board of directors and current chair of the advisory council, was a participant.

There were three core recommendations:

• An international congress should convene to create a global mechanism for monitoring AI development and oversight.



Hastings Senior Advisor Wendell Wallach



Good Sport: Why Our Games Matter—and How Doping Undermines Them: A book by Thomas Murray, Hastings Center President Emeritus, published just before the Winter Games in

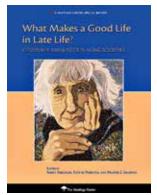
Pyeongchang, drew on research Murray undertook while at The Hastings Center. Murray identifies three fundamental qualities that make sport matter: natural talents, the dedication and discipline to perfect those talents, and the courage to test yourself and risk failure. All these reasons are undermined by doping in ways his volume explains. Murray discussed the book in several media interviews and at public events.

- Colleges and universities should include ethics education for AI and robotics students.
- Foundation and government funders should help establish in-depth and comprehensive analyses of the benefits and risks of particular applications of AI, beginning with AI in health care.

The Hastings Center's special report, What Makes a Good Life Late in Life, is a stupendous achievement. The WHO has begun a project to develop an ethical framework for healthy aging policies. The Hastings Center's report is informing our initiative.

—Sridhar Venkapapuram, consultant, global health ethics, World Health Organization

What do aging societies like the U.S.—where more people are over 65 than under 15—need now?



In aging societies, people live longer due to advances in medicine and public health, but they often lack the means to pay for the care and housing they need. This societal challenge cannot be solved solely by health care systems and with financing. A two-year Hastings Center project on ethical challenges arising from population aging convened experts from gerontology, housing policy, urban design, and other fields to consider how bioethics should respond to support good lives for older adults and for caregivers. Hastings Center president Mildred Z. Solomon and research scholar Nancy Berlinger led the project, which was funded by the Robert W. Wilson Charitable Trust

and the Center's Boger, Callahan, and Gaylin Funds. In 2018, a Hastings Center special report, What Makes a Good Life in Late Life?, aimed to "support greater understanding of late life and more just and humane public policy in aging societies." The report was widely shared in the U.S. and internationally; numerous groups, including the World Health Organization, are now discussing and integrating ideas from our publication into their own thinking.

Hastings Center President calls for "moral leadership" to improve end-of-life care



Are caregivers helping patients and families to make fully informed decisions about the treatments they want and that are in their best interest? Or are patients simply being conveyed along a pathway of default choices, leading them to more and more procedures without the benefit of real discussion? These were among the challenges that Hastings Center President Mildred Z. Solomon posed

in May at the Joseph N. Muschel Medical House Staff Award Lecture at Medicine Grand Rounds at Columbia University and the Wilhelm S. Albrink Lecture in Bioethics at West Virginia University. "In many cases, patients are not actually making decisions but rather simply yielding to what seems expected of them," she said. Noting that current financial incentives are "terribly skewed," with Medicare paying for high-tech medicine, "but none of the low-tech, high-touch supports that people need so desperately," Solomon called on everyone with a voice in our health care system—including health care executives,



Eric Kandel takes questions from the audience

payers, policymakers, and patient advocates—to be "willing to build new systems of medical care and social support that will challenge the status quo."

Nobel Prize winner Eric Kandel, who has done groundbreaking work on the molecular mechanisms of memory, spoke at The Hastings Center's advisory council meeting in May about the differences between normal age-related memory loss and Alzheimer's disease. Hastings Center fellow Tia Powell followed with a talk about the "substantial ethical challenges" posed by dementia. How do caregivers determine

when a person with dementia should no longer drive? "How do you protect the safety of that person, the safety of those around them, without unnecessarily curtailing the rights and dignity of that person?" she asked.

How should health systems counter the rising threats to immigrant health?

The Hastings Center's ongoing work on justice and immigrant health has expanded in response to federal policy changes threatening immigrants and asylum seekers. In October 2018 the Center convened a two-day meeting in New York City to explore how practitioners and health care systems can counter threats and harms to the health of immigrant populations in the U.S. The convening, supported by a rapid-response grant from the Open Society Foundations, generated consensus around priority issues and has supported

collaboration among health, law, and community-based practitioners in metropolitan areas, and on needed guidance for practitioners in border-region hospitals.

continuing conversations on how to foster

IMPACT In early 2019, New York City launched NYC Care, a program based on recommendations by Hastings scholars and others, that guarantees access to health care for all New Yorkers regardless of their immigration status. The program was convening of The Hastings Center in partnership with the New York Immigration Coalition for an approach that provides preventive health care, and specialty care and other services. In most of the U.S., uncare, a situation rife with ethical questions, said Nancy Berlinger, who co-authored The Hastings Center recommendations and good care to a patient who is or is presumed to be undocumented? How could their actions have harmful consequences for the patient? Which actions on the part What should providers do when their practice is constrained by a policy that is



Naromie Hilaire, MPH student, City University of New York, and Hastings Center intern, with Nancy Berlinger, Hastings Center scholar, at the Creating Systems of Safety for Immigrant Health Convening

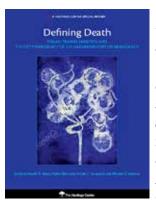


(I. to r.): Gregg VandeKieft, Providence St. Peter Hospital, Olympia, Wa. (senior award); John M. Saroyan, BAYADA Home Health Care, Vermont and New Hampshire (mid-career award); Erin Denney-Koelsch, University of Rochester Medical Center (early-career award); Jolion McGreevy, Boston Medical Center (early-career award); Jane Schell, University of Pittsburgh School of Medicine and UPMC Health System (early-career award)

Recognizing the Importance of Palliative Care

The Hastings Center Cunniff-Dixon Physician Awards recognize doctors in the United States who give exemplary care to patients near the end of life. In 2018, awards totaling \$95,000 were given to five physicians who advance the practice of palliative care, improve doctor-patient communication, and reduce cultural disparities in care.

What does "dead" mean?



Should death be defined in strictly biological terms, when the heart stops beating, breathing stops, or brain function ceases? Or is it essentially a social construct that can be defined in different ways? When is it ethical to extract organs from a donor? These are among the wide-ranging questions explored at Defining Death: Organ Transplantation and the 50-Year Legacy of the Harvard Report on Brain Death, the 2018 Harvard Medical

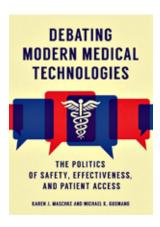
School's Annual Bioethics Conference, cosponsored by The Hastings Center in April. In December, a Hastings Center special report published commentaries

from the conference. The report included a close examination of the case of Jahi McMath, an African-American teenager declared brain dead in a California hospital in 2013 but whose family rejected this determination and moved her to New Jersey, whose brain death statute includes a religious exemption. Essays on McMath explored the medical, ethical, and social questions that the case raised and reconsidered the situation of McMath and her family in light of findings on the health consequences of implicit bias. The special report was a collaboration between The Hastings Center and the Center for Bioethics at Harvard Medical School. It was funded by the Boger Initiative for the Wise Use of Emerging Technologies at The Hastings Center.

IMPAC Should medical aid-in-dying be legal? Hastings Center research scholar Nancy Berlinger was on the planning committee of a public workshop of the National Academies of Science, Engineering, and Medicine that examined whether, and under what circumstances, terminally ill patients should be legally able to take life-ending medications prescribed by a physician. This workshop, held in February, aimed not to debate the pros and cons of physician-assisted death, but to understand the current landscape and to identify areas where more data and research would help inform

Debating Modern Medical Technologies: The Politics of Safety, Effectiveness, and Patient Access

Does a new medicine or diagnostic test work? Is it safe? How much of evidence, and what kind, should the government have before approving it and should insurers have before paying for it? The answers are not as straightforward as they may seem—and the reasons are the subject of *Debating Modern Medical Technologies: The Politics of Safety, Effectiveness, and Patient Access,* a book by research scholars Karen J. Maschke and Michael K. Gusmano, published in September 2018. The book reveals how competing ideas about science, as well as interest groups and political ideology, frame debates about the risks and benefits of new medical interventions, including brain imaging for signs of Alzheimer's disease and stem cell therapies. The fight over medical technology "is often a fight among competing interests about the meaning of the public interest," the authors write. Maschke and Gusmano end with three recommendations to help policy-makers muddle through difficult choices: increase public engagement in debates about evidence, provide public access to accurate information from the Food and Drug Administration about the safety and effectiveness of new medical technologies, and facilitate transparency about public and private payer coverage decision-making.





Hastings president calls attention to public engagement in setting science policy

Nearly every report or commission that seeks to inform the responsible use of novel technologies ends with the same recommendation: we must involve the public. But what does "public engagement" mean in practice? Who should count as a stakeholder? What happens when they disagree, and what is an appropriate response when large numbers of the public deny scientific evidence? Hastings Center president Mildred Z. Solomon addressed these questions in a plenary talk at the 2018 Harvard Clinical Bioethics Course. While scientists and other experts can inform how technologies can be used, publics must be involved in deliberation about how

WHAT ROLE
SHOULD PUBLIC ENGAGEMENT PLAY
IN SCIENCE POLICY? WHY?

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they ought to be used, she said. She identified three essential elements of public deliberation: provision of balanced, factual information about an issue; inclusion of diverse perspectives; and the opportunity for participants to freely discuss a wide spectrum of viewpoints and to challenge competing views and claims.

Mildred Solomon speaking on public engagement in a plenary address at Harvard

The Code: Documentary Film Premier Features Hastings Scholars

Hastings Center president Mildred Z. Solomon and director of research Josephine Johnston were featured speakers at the premiere screening of *The Code*, a series of documentaries on the origins of genetic medicine and what its successes and failures mean for the future. The series was produced by Retro Report in partnership with *STAT* news. Following the screening, which took place in New York City in April, Solomon and Johnston participated in a discussion of the films and the ethi-



Josephine Johnston, filmmaker Jill Rosenbaum, and Millie Solomon

cal questions that they explore. How should prospective patients separate the hope from the hype of new genetic technologies and make informed choices about whether to use them? Should gene editing be used for human enhancement? If so, under what circumstances, and who decides?

Has conscientious objection gone too far?

When is it acceptable for health care professionals to refuse to provide a treatment because it violates their conscience? The implications of recent developments in federal and state governments that increase protections for conscientious objection were the focus of a panel discussion at Fordham University New York City in April with Hastings Center research scholar Nancy Berlinger and Pulitzer prize-winning journalist Linda Greenhouse. Berlinger said that the central duty of health care providers is to care for patients, and

The Center for Ethics Educa

Nancy Berlinger and Linda Greenhouse

conscience in health care work always exists in relation to that duty. Blocking health care access or discriminating against patients is unethical, and invoking "conscience" doesn't make it right.

The Hastings Center Teams up with the New York Academy of Sciences

Powerful technologies could enable us to redesign ourselves in permanent and heritable ways. But is it wise to edit our genes in the hope of creating faster, stronger, or



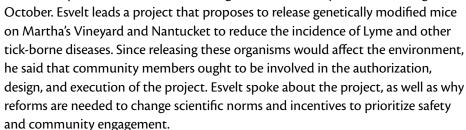
L. to r. Hastings president Mildred Solomon, George Church (MIT), Jamie Metzl (Atlantic Council), director of research Josephine Johnston, Meredith Whittaker (Al Now Institute at NYU), and Glenda Greenwald (Aspen Brain Institute)

smarter humans? Or to use artificial intelligence to "read" our thoughts? "The Enhanced Human: Risks and Opportunities," a public event cosponsored by The Hastings Center, the New York Academy of Sciences, and the Aspen Brain Institute, took place at the New York Academy of Sciences in May. Hastings Center President Mildred Z. Solomon served as moderator and director of research and research scholar Josephine Johnston was a panelist. "I find some enhancements laudable and nec-

essary, such as helping our children to be kinder and smarter than their parents," Johnston told an audience of more than 200 people and many more via livestream, "but these are likely solved with social, political, and economic advances, as opposed to biotechnological enhancement."

Gene Editing in the Wild: What Does Responsible Community Guided Science Look Like?

That's one question addressed by Kevin Esvelt, an evolutionary biologist at the MIT Media Lab, in an impassioned talk at The Hastings Center's advisory council meeting in





Kevin Esvelt

In July, Hastings research scholar Carolyn Neuhaus participated in a community forum with Esvelt on Martha's Vineyard to discuss a proposal to release genetically modified mice to curb the spread of Lyme disease and other tick-borne illnesses. Michael Specter, a staff writer for *The New Yorker*, was the moderator.

Honoring Journalists

The Hastings Center concluded the year by honoring three outstanding journalists with its Awards for Excellence in Journalism on Ethics and Reprogenetics. The awards recognized journalism that not only explained the science of reprogenetic technologies and



Journalists Andrew Joseph, Antonio Regalado, and Amber Dance

concerns about their safety and efficacy, but that also engaged broader philosophical questions. The first-place award went to Antonio Regalado, senior editor for biomedicine at *MIT Technology Review*; two runner-up awards went to Amber Dance, a freelance science writer; and Andrew Joseph, a general assignment reporter for *STAT*. The awards were presented at an event in New York City in December—just a week after news of the first gene-edited babies was announced. Regalado broke that

major worldwide story. Carl Zimmer, a *New York Times* columnist and book author, gave the keynote address. The awards and the event were supported by the John Templeton Foundation.

Preparing Teachers to Prepare Students for the Age of Crispr

The Hastings Center held a professional development workshop for secondary

school science teachers to help them equip their students to recognize and analyze ethical dilemmas posed by gene editing and other emerging technologies. Twenty-one teachers from the U.S. and Canada attended the workshop, which was held on July 31 to August 3 at The Hastings Center. It was part of The Hastings Center's project on gene editing and human flourishing, supported by the John Templeton Foundation. Hastings Center president Mildred Solomon and Jeanne Chowning, of the Fred Hutchinson Cancer Center, led the development of the workshop with Hastings research scholar Carolyn Neuhaus and director of research Josephine Johnston. Some of the participating teachers provided ideas that shaped the agenda. Teachers explored the science of

gene editing and the social, ethical, and legal implications of its use, including possible use for human enhancement and the implications for people with disabilities.



Teachers at the Hastings professional development workshop

What Can *Frankenstein* Teach Us About Living in the Genomics Age?

The Hastings Center marked the 200th anniversary of the publication of *Frankenstein* with a public event at the Center in October, which explored the novel from the perspectives of bioethics, literary criticism, and science fiction. Speakers were Victor Lavalle, associate professor of writing at Columbia University and author of *Destroyer*, a graphic novel adaptation of *Frankenstein* that explores contemporary issues of race, violence, and alienation; Charlotte Gordon, distinguished professor of the humanities at Endicott College and author of *Romantic Outlaws: The Extraordinary Lives of Mary Wollstonecraft and Mary Shelley*; and Hastings Center director

of research Josephine Johnston. The event was supported by the John Templeton

Foundation.



Seated, I. to r.: Josephine Johnston, director of research, Victor Lavalle, and Charlotte Gordon; back, I. to r.: Liz Deitz, former research assistant, and Mildred Solomon, president



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Top: the audience at *The Code* premiere; above: journalism awards panel discussion; right: Sidney Callahan, Tia Powell, and Dan Callahan at the "What Makes a Good Life Late in Life?" event





Above: Hastings teachers workshop; right: Frankenstein panel discussion



2018 HASTINGS CENTER EVENTS AND MEETINGS

David Roscoe Tribute • Private dinner • March 20 • New York City

Looking for the Psychosocial Impact of Genomic Information • Conference • February 26-27 • Columbia University

Meet the Hastings Center President and Board Chair Private dinner • March 25, Washington, D.C.

Control and Responsible Innovation in the Development of Autonomous Systems • Project Meeting • March 29-30, The Hastings Center

The Code, Retro Report film premiere • April 2, New York City

Defining Death: Organ Transplantation and the 50-Year Legacy of the Harvard Report on Brain Death • Symposium • April 11-13, Harvard University

The Enhanced Human: Risks and Opportunities

Panel discussion • May 21, New York Academy of Sciences, New York City

What Makes a Good Life Late in Life? Eric Kandel and Tia Powell Advisory Council meeting • May 22, The Hastings Center

The Sherwin B. Nuland Summer Institute in Bioethics Program June 8, The Hastings Center

Expert Discussion About Artificial Intelligence • Private dinner • July 25, New York City

Bioethics Workshop for Secondary School TeachersJuly 31-August 3, The Hastings Center

Caregiving 2018, with Nancy Berlinger and Michael Gusmano Symposium • August 23, National University of Singapore

Creating Systems of Safety for Immigrant Health

Project convening • October 2 - 3, New York City

The Gift and Weight of Genomic Knowledge: In Search of the Good Biocitizen Symposium • October 4, Brooklyn Law School

Technology, Ethics, and Consequences, with Kevin EsveltAdvisory Council meeting • October 11, The Hastings Center

Frankenstein in the Age of Gene Editing • Panel discussion • October 27, The Hastings Center

Why Doping Matters in Sports • Lecture • November 7, New York University

How Should the Public Learn? • Project Meeting • November 16-18, The Hastings Center

Immigrant Health • Project Meeting • October 2-3, New York City

Control and Responsible Innovation of Artificial Intelligence

Panel discussion • December 4, New York City and Yale University

Public Understanding of Genetics and Why It Matters

Journalism awards ceremony and panel discussion • December 6, New York City





Daniel Callahan



Michael Gusmano









Thomas Murray











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)
- Ethical Issues in Prescription Drug Access Under Restricted Distribution Programs · Sarah McGraw (Greenwall Foundation under subcontract from Brigham & Women's Hospital)
- Governance of Learning Activities in Learning Healthcare Systems · Sarah McGraw and Mildred Solomon (Patient Centered Outcomes Research Institute under subcontract from the University of Pennsylvania)
- Harvard Integrated Program to Protect and Improve the Health of NFL Members · Sarah McGraw (National Football League Players Association under subcontract with Harvard Medical School)
- New Harms to Immigrant Health: A National Convening to Clarify Threats, Share Strategies, and Consolidate Guidance · Nancy Berlinger (Open Society Foundations)
- · Patient-Centered Cancer Genome Sequencing Education and Decision Support · Sarah McGraw (American Cancer Society under subcontract from City of Hope)

CHILDREN AND FAMILIES

- · Goals and Practices for Next Generation Prenatal Testing Systems · Josephine Johnston (National Institutes of Health/National Human Genome Research Institute)
- Sequencing of Newborn Blood Spot DNA to Improve and Expand Newborn Screening · Josephine Johnston and Erik Parens (National Institutes of Health under subcontract from University of California, San Francisco)

CHRONIC CONDITIONS AND CARE NEAR THE END OF LIFE

• Chronic Conditions, Aging, and the End of Life: Program Planning Process · Nancy Berlinger and Mildred Solomon (The Robert Wilson Charitable Trust and the Boger, Callahan and Gaylin Funds)

SCIENCE AND THE SELF

- Actionable Ethics Oversight for Human-Animal Chimera Research · Josephine Johnston and Karen Maschke (National Institutes of Health and the National Human Genome Research Institute)
- Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurologic and Behavioral (PNB) Genetics (Renewal) · Erik Parens and Josephine Johnston (National Institutes of Health under subcontract from Columbia University Medical Center)
- Control and Responsible Innovation in the Development of Autonomous Machines · Wendell Wallach (Future of Life Institute)
- Development of Recommendations and Policies for Genetic Variant Reclassification · Erik Parens (National Institutes of Health under subcontract from Columbia University)
- Gene Editing and Human Flourishing · Erik Parens and Josephine Johnston (John Templeton Foundation)
- The Boger Initiative for the Wise Use of Emerging Technologies · Mildred Solomon (Joshua Boger)

HUMANS AND NATURE

- Public Deliberation on Gene Editing in the Wild · Gregory Kaebnick (National Science Foundation)
- Values in Impact Assessment · Gregory Kaebnick, Michael Gusmano, and Karen Maschke (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 (The Knight Foundation)
- The Hastings Center Bioethics Briefings · Susan Gilbert (Private Donor)

Anna Lewis



Bryn Esplin



Crane

Johanna

C cholars from around the world come to The Hastings Center each year to do independent research on topics with a bioethics component. They include professors, students, doctors, lawyers, and journalists. In 2018, there were 26 visiting scholars from 11 countries. Their research topics included: an ethical framework for use of big data in genomics, the ethics of end-of-life care in resource-poor countries, framework to assess methods to facilitate clinical research participation of vulnerable groups, and ethical and legal protections for hospital patients in ICE custody.



Alexandra Krstic



Students and teachers from the Macaulay **Honors College** at CUNY

Daphne Martschenko



Aleksandra Glos



Martha Finnegan with research assistant Liz Dietz





Tomasz Zuradzki



Noel Pingoy



Australia Canada Germany Hong Kong Ireland Philippines Poland Slovak Republic Spain **United Kingdom** USA





Richard Payne



Blair Sadler



Alan Fleischman and Gil Omenn



Former board chair David Roscoe and Liza Bailey



Shonni Silverberg



Eve Hart Rice and Joe Fins



Brad Gray



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Liza Bailey (Treasurer)

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| As of December 31, 2018 | Audited 2018 |
|---|--------------|
| Assets | |
| Cash and Equivalents | 627,312 |
| Investments, at fair value | 6,561,671 |
| Receivables (grants and other) | 416,867 |
| Other Assets | 52,185 |
| Furniture and Equipment (net of accumulated dep) | 23,775 |
| Leasehold Improvements (net of accumulated amort) | 975,039 |
| Total Assets | 8,656,849 |
| Liabilities and Net Assets | |
| Payables and Accruals | 107,303 |
| Deferred Compensation Payable | 170,599 |
| Deferred Revenue | 138,945 |
| Total Liabilities | 416,847 |
| Net Assets | 8,240,002 |
| Total Liabilities and Net Assets | 8,656,849 |

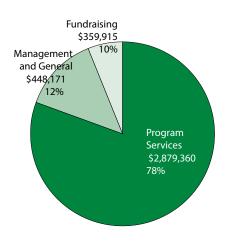
Statement of Activities and Changes in Net Assets Audited 2018

| Operating revenues and other support: Grants, Gifts, and Contributions Government Grants Publication Revenue Other income Total Unrestricted Operating Support and Revenue | 1,953,395 604,600 318,709 92,619 2,969,323 |
|--|--|
| Operating Expenses Program Services Management and General Fund Raising Total Operating Expense | 2,879,360 448,171 359,915 3,687,446 |
| Changes in Net Assets from Operations Non-operating Income Change in Net Assets | (718,123) (363,436) (1,081,559) |
| Net Assets, Beginning of year | 9,321,561 |
| Net Assets, End of year | 8,240,002 |

Unrestricted Operating Revenue and Support For the year ended 12/31/18 = \$3,799,070

Investment and Other Income \$92,619 Publications 2% \$318,709 9% Grants

Operating ExpensesFor the year ended 12/31/18 = \$3,687,446



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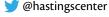
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