

conversations

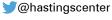
Director of Communications and Development: Bill Jeffway Writer: Susan Gilbert Art Director: Nora Porter Photography: Siofra Vizzi

The Hastings Center is an independent, nonpartisan, and nonprofit bioethics research institute founded in 1969. Hastings' mission is to address fundamental ethical issues in the areas of health, health care, life sciences research, and the environment as they affect individuals, communities, and societies.

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21 Malcolm Gordon Road Garrison, NY 10524 Tel 845-424-4040 Fax 845-424-4545 mail@thehastingscenter.org www.thehastingscenter.org



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Message from the President

Dear Friends and Colleagues,

Unparalleled scholarship is the heart of The Hastings Center's work. We identify compelling questions to which our society needs answers, based on facts, ethical considerations, and thoughtful reflection. To address those big questions, we purposely invite people with diverse views to our conversations. The result is unparalleled scholarly rigor and fiercely independent analysis.

Our conversations are not only with and among scholars. We invite stakeholders of every kind, including patients and families, clinicians, legislators, the elderly, students, and members of the public. We enable *conversations* literally over generations and all over the world.

Conversations are held within, and some times across, our five major program areas: Children and Families, Chronic Conditions and End-of-Life Care, Science and the Self, Humans and Nature, and Health and Health Care.

We enable dialogue on these topics among policy makers, legislators, and the judiciary. Among those with aging parents and those about to become parents. Among clinicians. With high school students, medical students, and scientists. We do so through conferences, domestic and international. At national commissions. Through lectures. Through our two journals, the *Hastings Center Report* and *IRB*. Through published articles. Guidelines. Press interviews on television and in print, and digital media. Through blogs. Global webcasts. Tweets. And Facebook postings!

The stimulus for these conversations comes not only from our staff scholars and senior advisers. There are also vital contributions from our visiting scholars, our 200 elected Hastings Fellows, our advisory council members, and our very intellectually curious and engaged board.

Life's most profound questions have been essentially unchanged for as long as humans have been able to consider what it means to be human and how best to lead a good life. The Hastings Center takes up these age-old questions with respect to brand-new realities—new scientific discoveries which offer newfound powers—and to troubling, persistent realities that need our constant vigilance, like injustice, poverty, and the tragedy of the commons.

Especially in 2014, we put a major emphasis on engaging with all our constituents through emerging digital media. Without any dilution to our traditional approach, we added a significant number of new ways to engage with Hastings.

We hope you will support these profound conversations both through your financial support *and* by joining in one or several of them yourself. Together, we can make a difference in the scholarly and public dialogue on matters of urgency to us all.





Mildred Z. Solomon President and CEO



▲ (I. to r.): Hastings Center board member Joshua Boger, Hastings Center scholar Erik Parens, and John Fallon of Massachusetts Blue Cross Blue Shield talk over dinner at a salon in Boston in May.

▼ Author Andrew Solomon (I.) and Hastings Center board chair David Roscoe at the LGBT Health and Human Rights symposium in New York in November





■ Geneticist Raju Kutcherlapati (I.) and Harvard professor and author Atul Gawande at the Boston salon



■ At The Hastings Center to discuss reproductive rights, bottom (I. to r.): Judy Norsigian, cofounder of Our Bodies Ourselves, and Shirley Shalev, a research fellow at the Center for Bioethics at Harvard Medical School; top (I. to r.): Hastings Center president Mildred Solomon; director of research Josephine Johnston; and Sally Whelan, cofounder of Our Bodies Ourselves.

CONVERSATIONS THAT MATTER



▲ Jordan Cohen (r.), the speaker at the "What Makes a Good Doctor" public event in New York in February, talks with an audience member.

▼ Students in Yale University's summer institute visit The Hastings Center in June as part of the Yale-Hastings Program in Ethics and Health Policy.

▼ Tia Powell, center, a speaker at the LGBT Health and Human Rights symposium in New York, in conversation with members of the audience.



- ▲ (I. to r.): Hastings Center Advisory Council members Peter Canellos, James Evans, and Gretchen Dykstra at a meeting in Garrison in September
- Hastings Center scholar Nancy Berlinger talks with Hon Lam Li, a professor in the philosophy department at Chinese University of Hong Kong, in July at the First Annual Summer Workshop of the university's new Center for Bioethics, which The Hastings Center helped establish with leadership from Hastings board member Edgar Cheng.





CHILDREN AND FAMILIES

uman beings have long sought to control their reproduction

and shape their children's futures. Today, through innovations in reproductive medicine and a growing understanding of the many factors that influence children's health and well-being, our power to do this is greater than ever before. But having this power prompts

Should we place limits on the decisions parents make for their children?

difficult questions about the obligations of individuals, families, and society. What, in

this new context, is responsible procreation? Which children do we consider "normal" and "healthy"? Should we place limits on the decisions parents make for their children? What are the ethics of creating families and caring for children in the twenty-first century?

The Hastings Center's major 2014 research project in this program area is examining the ethical, legal, and social implications of the use of wholegenome sequencing in newborns, possibly as part of state-mandated newborn screening programs. Currently, newborns are screened for between 29 and 60 conditions, depending on the state. But as the price of whole-genome sequencing falls, it could become a cost-effective method of testing newborns.

Below (I. to r.): Hastings Center scholars Josephine Johnston and Michael Gusmano receive an award from Resolve, the National Fertility Association, for their article on the risks of multiple births; Johnston speaks at Chinese University of Hong Kong's Center for Bioethics summer workshop; Kent Place School students make presentations on the theme, "What is the value of the human body?"







It would significantly increase the number of conditions screened for, as well as expand the type of information revealed, including the risk of late-onset disorders, incidental findings of potential relevance to the health of parents or other family members, findings pertinent to the parents' reproductive decision-making, and genetic variants whose significance is unknown.

Much of this information will undoubtedly be useful to parents in making decisions about their babies' health. But some of it could cause tremendous anxiety, especially findings that are unclear or that indicate increased risk of a devastating condition for which there is no treatment. Some parents

might not want to know about risks that their children may face in adulthood. Can their wishes be respected without sacrificing the potential benefits of whole-genome sequencing? Hastings Center scholars Josephine Johnston and Erik Parens are leading the project's Ethics and Policy Advisory Board, which will develop and disseminate policy recommendations for using whole-genome sequencing in newborns. They are working with Hastings Center Fellow Barbara Koenig of the University of California, San Francisco. The project is a subcontract with the University of California, San Francisco funded by the National Institutes of Health.

After their presentations, Kent Place students step outside and celebrate

Safeguarding the Next Generation

- Reducing risk of multiples. The Hastings Center was recognized for research on fertility treatment risks with an award from Resolve, the National Fertility Association. The award was for an article published in the journal Fertility & Sterility, co-authored by Hastings Center scholars Josephine Johnston and Michael Gusmano, that identified six changes in policy and practice that can reduce the odds of multiple births and prematurity from certain fertility treatments, including expanding insurance coverage for in vitro fertilization and improving doctor-patient communication about the risks associated with multiple births, including twins.
- Making sense of "repro-genetics." In talks around the world,
 Josephine Johnston discussed "repro-genetics"—the application of advances in genetics to reproductive medicine—and how
 prospective parents can use them well. She spoke at the University of Otago in New Zealand, Chinese University of Hong Kong,
 and Occidental College in California.
- theme of the third year of The Bioethics Project, a research program for high school students developed jointly by The Hastings Center and the Ethics Institute of Kent Place School in New Jersey. It includes instruction on ethical decision-making and bioethics and an in-depth bioethics research project. In 2014, students explored themes of fairness, quality of life, and safety while delving into topics such as adoption of frozen embryos, organ donation of infants who have died, and legalizing the sale of kidneys as a way to reduce the critical shortage of life-saving organs. Josephine Johnston leads the Center's contribution to this project.

CHRONIC CONDITIONS AND END

any ethical issues in medical care result from astounding leaps in life expectancy achieved during the twentieth century. Effective public health measures, treatment of once-fatal infectious diseases, and a wide range of life-sustaining technologies allow people in developed nations—and increasingly, in developing na-

tions—to live much longer. A common consequence of a longer life

How can we ensure that people with chronic conditions or disabilities receive the best care possible?

is the development of agerelated chronic, often progressive, illnesses. Individuals with chronic conditions, long-term injuries, and disabilities face decisions about which therapies to try, whom to involve in medical decision mak-

ing, how to secure and pay for the services they may need, and when to use or forgo potentially life-sustaining interventions. What does our society owe to people living with chronic conditions? How can we build systems of care that correspond to the foreseeable medical and social needs of chronically ill people? What are the social values needed in aging societies to keep aging from being narrowly perceived as a problem of individual patients and their families?

Below (I. to r): Hastings Center research scholar Nancy Berlinger speaks at the The Hastings Center's bootcamp on covering endof-life care at the Association of Health Care Journalists annual meeting in Denver in March; journalists fill the ballroom for the bootcamp; Hastings Center president Mildred Solomon moderates a debate about legalizing aid in dying between Marcia Angell (center) and Kathleen Foley (right) at a public event in New York in April.



-OF-LIFE CARE

Questions such as these formed the basis of a bootcamp for journalists that The Hastings Center organized as a preconference workshop at the annual meeting of the Association for Health Care Journalists, the premier professional organization of health journalists, in Denver in March 2014. This three-hour bootcamp helped journalists separate fact from fiction in their coverage of end-of-life care, especially in addressing persistent misconceptions about what is legally and ethically permissible in the use of life-sustaining treatment. The sessions were led by Mildred Solomon, president of The Hastings Center, and Nancy Berlinger, a research scholar and lead author of *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* (Oxford University Press, 2013), an updated and expanded edition of a groundbreaking publication that was instrumental in

shaping the ethical and legal framework for medical decision-making and end-of-life care. Attending the sessions were roughly 100 journalists who then produced articles and broadcasts for media outlets such as Cleveland Public Radio, *The Boston Globe*, and Reuters.

The journalists bootcamp, supported by the Donaghue Foundation and the Adelson family, was part of The Hastings Center's effort to put *Guidelines* into practice. Another such effort, also funded by Donaghue, involved interviews with medical and nursing societies and working clinicians to identify the needs and concerns of professionals who care for patients nearing the end of life, but who may not be part of "end-of-life care" networks. Insights from these interviews helped the Center develop educational partnerships with key professional societies.

Recipients of the 2014 Hastings Center Cunniff-Dixon Physician Awards

(I. to r.): Catherine D. Deamant, Cook County Health and Hospitals System, Chicago (senior award); Chris Feudtner, The Children's Hospital of Philadelphia (mid-career award); Elise C. Carey, Mayo Clinic, Rochester, Minn. (early career award); Jeanette S. Ross, South Texas Veterans Health Care System, San Antonio (early career award); Nadia Tremonti, Children's Hospital of Michigan (early career award).





Making Difficult Decisions Near the End of Life

- Should aid in dying be legal? The Hasting Center hosted a public event in New York in April 2014 with two of the nation's leading physicians debating whether state laws should allow doctors to prescribe lethal medication for terminally ill patients who request it. Marcia Angel, M.D., former editor of the New England Journal of Medicine, argued why she supports legalization and Kathleen Foley, M.D., a palliative care specialist at Memorial-Sloan Kettering Cancer Center, outlined her reasons for opposing it.
- Improving end-of-life care in the hospital. At the end of 2014, the Center began a project with the Society of Hospital Medicine to improve end-of-life care in hospitals. The project, funded by the Milbank Foundation, involves building institutional support for this goal among hospital leaders and developing educational resources for hospital clinicians, drawing on content from
- Recognizing exemplary care of dying patients. The Hastings Center Cunniff-Dixon Physician Awards are given annually to five doctors in the United States who have distinguished themselves in advancing the practice of palliative care and modeling outstanding skill and compassion at the bedside of people nearing the end of life. The 2014 recipients are shown above.

SCIENCE AND THE SELF

Advances in genetics, epigenetics, neuroscience, psychology, and computer science are contributing increasingly detailed explanations of the mechanisms that underlie human experience. This new knowledge poses two related challenges: First, what do these

We have always aspired to make But does the way we achieve this goal matter?

ourselves better people.

Second. if we could use them to better ourselves, should we? We have always aspired to make ourselves better people, and that's a noble goal. But does the way we achieve these goals matter?

advances tell us about ourselves?

One of the most controversial areas of inquiry in this area concerns the genetics of intelligence. While geneticists

have long argued that genetics can help explain why different people exhibit different levels of intelligence, new technologies are making it possible to attempt to specify which genetic variants can help explain those differences. In 2014 The Hastings Center began a project called "Responsible Research and the Genetics of Intelligence." It is cosponsored with the Columbia University's Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurologic and Behavioral Genetics. Leading the project are Erik Parens, a Hastings Center research scholar, and Paul Appelbaum, a Hastings Center Fellow who is at Columbia University College of Physicians

Below (I. to r.): Paul Appelbaum, a Hastings Center Fellow and coleader of the genetics of intelligence project; a presentation at the genetics of intelligence project meeting at The Hastings Center in November; Gail Geller, a Hastings Center Fellow and participant in the meeting; Elaine Tuttle Hansen, executive director of the Johns Hopkins Center for Talented Youth, at the meeting. Next page (I. to r.): James Evans, a Hastings Center advisory council member talks, with Hastings Center board member Frank Geer and Hastings Center research scholar Erik Parens at a public event on genetics in New York in December at which Evans was the speaker.







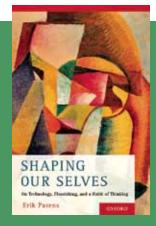
James Evans speaks on new genetic technologies at a Hastings Center public event in New York.

and Surgeons. An interdisciplinary working group of experts from education, law, psychology, sociology, and other areas met for two days in November to discuss questions such as: What are the prospects and problems with this research? Can it be socially neutral? What are the implications for education might findings on the genes that influence intelligence improve education for all by making it more personalized? Or does it risk stigmatizing some individuals or groups? The project, which is funded by the Johns Hopkins Center for Talented Youth and a Gaylin Award, will produce a special report with recommendations on the responsible conduct of research on the genetics of intelligence.



What Technologies Can, and Can't, Tell Us about Ourselves

• Enhancing ourselves. In his book,
Shaping Our Selves: On Technology,
Flourishing, and a Habit of Thinking
(Oxford University Press), research
scholar Erik Parens examines polarized
debates about the use of medical and
surgical technologies for human enhancement. While enthusiasts promise



that such technologies will promote human happiness, critics fear they will thwart it. Parens outlines a way beyond this standoff.

- Becoming a savvy consumer of new genetic technologies. James Evans, a member of The Hastings Center advisory council who is editor-in-chief of *Genetics in Medicine* and Bryson Distinguished Professor of Genetics and Medicine at the University of North Carolina, gave two talks on the state of the art of genetic and genomic testing, explaining how it canand cannot-help with the diagnosis and treatment of illnesses. He spoke at The Hastings Center advisory council meeting in September in Garrison, N.Y., and at a public event in December in New York.
- Uses and misuses of neuroimages. A special report of the Hastings Center Report published in March 2014 examined

the growing use of brain images in biomedical research, medicine, courtrooms, and everyday discussions about what it means to be a person. Interpreting Neuroimages:

An Introduction to the Technology and Its
Limits was the product of a project funded by the Dana Foundation. The guest editors were Josephine Johnston, The Hastings
Center's director of research, and Erik
Parens, a research scholar.

HUMANS AND NATURE

umans exert great pressure on the natural world. Habitats and species suffer not just from environmental changes caused by human industry and technology, but also from the strain caused by the world's massive human population, which has doubled in the last fifty years and is still rising rapidly. Many believe we have come to the end of nature. Ironically, better technologies may be effective tools to counteract the harm-

ful effects to our planet caused by our pursuit of technology. Genetic engineering (the modification of organisms to serve human ends) and "synthetic biology" (research aimed at creating artificial and potentially nonorganic life forms) are

How should we think about the risk and benefit that new technologies pose to the environment and to human health?

Below (I. to r.): Hastings Center research scholar Gregory Kaebnick gives a presentation on the moral value of nature at a Hastings Seminar in Garrison in January; online commentaries on efforts to revive extinct animals, produced in partnership with the Center for Humans and Nature.

Next page: A series of meetings for the project on synthetic biology, such as the one shown here, resulted in a Hastings Center special report published in November.

cutting-edge technologies that may pose risks but may also promise great benefit to humans and the planet. If, for example, we can alter a species of algae to produce ethanol, should we? Would that be a greener, safer way of producing fuel? If it escaped into the environment, would it have unforeseen consequences for ecosystems and human health?

Making good decisions about new technologies requires that we think more deeply about how we judge them. What counts as a risk, and what

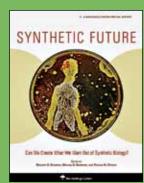


counts as a benefit? How heavily should each be weighed? Will we be better off in the long run if we promote action or caution? A project begun in 2014, funded by the National Science Foundation, is examining the role of values in the assessment of new technologies. Risk assessment and cost-benefit analysis are sometimes represented as being objective, even "value free." But they are also sometimes viewed as supporting special interests under the cloak of "objectivity"; in particular, they are sometimes seen as favoring science and industry. Focusing specifically on synthetic biology, the project aims to im-

prove the understanding and use of impact assessment mechanisms and, ultimately, to contribute to the growing effort to develop strategies that ensure that the governance of emerging technologies aligns appropriately with the public's values. Research scholars Gregory Kaebnick and Michael Gusmano are leading the project, and Karen Maschke is an investigator.

Exploring Human Impact on the Natural World

- Does nature have moral value? Research scholar Gregory Kaebnick took up questions such as this one in talks at a Hastings Seminar in Garrison, N.Y. and Fordham University in Bronx, N.Y. He built on philosophical and policy debates examined in his book, *Humans in Nature: The World as We Find It and the World as We Create It* (Oxford University Press, 2013).
- Promise of synthetic biology. A special report, Synthetic Future: Can We Create What We Want from Synthetic Biology, was published in November with
 - the Hastings Center Report. Editors were Kaebnick and Michael Gusmano and president emeritus Thomas Murray. The lead article considered whether or how we should move forward with synthetic biology, and nine commentaries expanded on and argued with those views. It was the product of a project funded by the Alfred P. Sloan Foundation.



Partnering with the Center for Humans and Nature and the American Museum of Natural History. The Hastings Center teamed up with the Center for Humans and Nature, a research institute, and the American Museum of Natural History in New York on a public event at the museum that explored the implications of efforts to revive extinct animals such as the passenger pigeon and the wooly mammoth. What ethical guidelines should scientists follow? Participants included Gregory Kaebnick, Hastings Center president Mildred Solomon, and Hastings Center Fellow Bruce Jennings. The event was part of a project that involved a series of online commentaries written by Kaebnick and other experts.



HEALTH AND HEALTH CARE

hen we think about health care, many of us have in mind what we need as individuals: readily available doctors and nurses, accessible hospitals and clinics, and affordable treatments. But another feature of health care is just as important: our health as a community. This includes public health measures to prevent illness and ward off epidemics, as well as the economic and social facets of life that promote, or harm, our health. There is a gap between

the health of the most privileged

and the most disadvantaged members of U.S. society. Are inequalities in health and access to health care unfair? Should health care be distributed equally, or should it be distributed according to greatest need? How much health is necessary for human beings to

Should health care be distributed equally or according to the greatest need?

Below (I. to r.): Hastings Center research scholar Nancy Berlinger speaks at the Chinese University of Hong Kong bioethics center's summer workshop, which The Hastings Center helped organize, in July; author Andrew Solomon, a speaker at the LGBT Health and Human Rights symposium in New York in November; a packed audience at the LGBT symposium.

Next page: Hastings Center presi-

dent Mildred Solomon moderates

the LGBT symposium.

Hastings Center scholars Nancy Berlinger and Michael Gusmano have been examining these questions they relate to undocumented immigrants. This population includes more than 11 million U.S. residents, all of whom are excluded from obtaining health insurance under the Affordable Care Act (ACA) and through government entitlement programs, with some exceptions for emergency treatment. When they get sick, therefore, they often seek care at hospital emergency rooms and public clinics. Berlinger and Gusmano,

flourish?





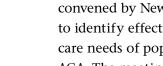


About 200 clinicians and clinical educators attended the Chinese University of Hong Kong Center for Bioethics First Annual Summer Workshop, which The Hastings Center helped organize, in July; second row (l. to r.): Hastings Center scholars Nancy Berlinger, Michael Gusmano, and Josephine Johnston.

partnering with the New York Immigration Coalition, organized a meeting in December 2014 in New York City of policymakers, clinicians, and advocates to identify gaps in access to health care for undocumented and uninsured New York City residents and to explore proven or promising local solutions to closing these gaps. The meeting was a response to a task force

convened by New York mayor Bill de Blasio, to identify effective ways to meet the health care needs of populations left out of the ACA. The meeting produced recommenda-

tions presented to the de Blasio administration in 2015. This project was supported by the Robert Sterling Clark Foundation and New York Immigration Coalition.





Providing Health Care to Diverse Populations

- LGBT health and human rights. LGBT people experience

Nancy Berlinger



Daniel Callahan



Michael Gusmano



Josephine Johnston



Gregory Kaebnick



Sarah McGraw



Karen Maschke



Thomas Murray



Erik Parens



Mildred Solomon



Our Scholars and Their Projects at a Glance

Children and Families

- Next-Generation Prenatal Testing Josephine Johnston (Gaylin Fund)
- Sequencing of Newborn Blood Spot DNA to Improve and Expand Newborn Screening Josephine Johnston and Erik Parens (National Institutes of Health, subcontract from University of California, San Francisco)

Chronic Conditions and End-of-Life Care

- Hastings Center Guidelines Teaching Tools Development Nancy Berlinger (Institute for Ethics, Memorial University Medical Center, Savannah, Ga.)
- Improving End-of-Life Care in the Hospital Nancy Berlinger and Mildred Solomon (Milbank Foundation)
- Making Difficult Decisions with Patients and Families: A Singapore Casebook Nancy Berlinger and Michael Gusmano (Lien Foundation under subcontract from National University of Singapore)
- Reaching Non-Self-Identifiers: Marketing The Hastings Center Guidelines for Health Care Professionals Outside End-of-Life Networks Nancy Berlinger (Donaghue Foundation)
- The Use of Whole-Exome Sequencing to Guide the Care of Cancer Patients Sarah McGraw (National Institutes of Health under subcontract from University of Pennsylvania)

Science and the Self

- Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurologic and Behavioral (PNB)
 Genetics Erik Parens and Josephine Johnston (National Institutes of Health under subcontract from Columbia University
 Medical Center)
- . Genetics of Intelligence Erik Parens (Johns Hopkins Center for Talented Youth and Gaylin Award)

Humans and Nature

- Ethical Issues in Synthetic Biology: Four Case Studies Gregory Kaebnick, Thomas Murray, Michael Gusmano, and Erik Parens (Alfred P. Sloan Foundation)
- · Values in Impact Assessment Gregory Kaebnick, Michael Gusmano, and Karen Maschke (National Science Foundation)

Health and Health Care

- Capacity-Building Collaboration with Chinese University of Hong Kong Nancy Berlinger and Michael Gusmano (Chinese University of Hong Kong)
- Financing Health Reform in Vermont Michael Gusmano (Blue Cross Blue Shield of Vermont)
- Kavod ha'adam in Patient Care in Israel, Phase 1 Nancy Berlinger and Michael Gusmano (Rabin Medical Center, Israel)
- The Football Players Health Study at Harvard University, Law and Ethics Initiative, Michael Gusmano, Karen Maschke, and Sarah McGraw (National Football League Players Association under subcontract from Harvard Medical School)
- The Selfhelp Virtual Senior Center Initiative Michael Gusmano (Selfhelp Community Services, Inc.)
- Undocumented Immigrants and Access to Health Care in New York City: Identifying Fair, Effective, and Sustainable Local Policy Solutions Nancy Berlinger and Michael Gusmano (The Robert Sterling Clark Foundation and New York Immigration Coalition)

Conduct of Research

- Accountability and the Role of the Principal Investigator in Multicenter Trials Sarah McGraw (National Institutes of Health under subcontract from Dana Farber Cancer Institute)
- Advancing Collaborative Genetic Research: Ethical and Policy Challenges Karen Maschke (National Institutes of Health under subcontract from Case Western Reserve University)
- Human Subject Protection and Genomic Research at the Mayo Clinic Karen Maschke (Mayo Clinic)
- Patient and Physician Knowledge about FDA Drug Safety Alerts Sarah McGraw (FDA under subcontract from Brigham and Women's Hospital)
- Returning Individual Genetic Results to Participants in Cohort Studies Sarah McGraw (National Institutes of Health under subcontract from Dana Farber Cancer Institute)

Education

- i2Camps: Responsible Innovation Modules Josephine Johnston (Ethan Berman)
- Journalists' Bootcamp on Covering End-of-Life Care Susan Gilbert (Adelson family and the Donaghue Foundation)
- The Bioethics Project 2014: "What is the Value of the Human Body?" Josephine Johnston (Kent Place School)

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Welcoming 2014 Hastings Center Fellows

The Hastings Center Fellows are individuals of outstanding accomplishment, whose work has informed scholarship and/or public understanding of complex ethical issues in health, health care, life sciences research, and the environment. Hastings Center Fellows may be academic bioethicists, scholars from other disciplines, scientists, journalists, lawyers, novelists, artists, or highly accomplished persons from other spheres. Their common distinguishing feature is uncommon insight and impact in areas of critical concern to the Center-how best to understand and manage the inevitable values questions, moral uncertainties, and societal effects that arise as a consequence 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. The following Fellows were elected in 2014:

- Robert Baker Union College
- Martha Farah University of Pennsylvania
- Chris Feudtner University of Pennsylvania and Children's Hospital of Philadelphia
- · Susan Dorr Goold University of Michigan
- Lori Gruen Wesleyan University
- Robert Klitzman Columbia University
- Tia Powell Albert Einstein College of Medicine
- Rosamond Rhodes Icahn School of Medicine at Mount Sinai
- Cynda Rushton Johns Hopkins University



The Hastings Center is committed to strengthening the field of bioethics nationally and globally. We accomplish this goal by publishing journals, special reports, and blogs; convening groups of distinguished scholars and societal leaders; hosting visiting scholars from around the world; and recognizing excellence in bioethics scholarship and medical care with major awards.

Journals and Blogs. The Hastings Center publishes two bimonthly journals: *Hastings Center Report*, the first bioethics journal, and *IRB: Ethics & Human Research*, a leading publication on research ethics involving human subjects. The *Report*, which has a diverse audience that includes clinicians, lawyers, philosophers, and journalists, covers the full range of bioethics topics concerning health and health care, emerging technology, clinical ethics, law, and education. *IRB* is read by members of institutional review boards that oversee human subjects research and by research ethics scholars.

The *Report* also periodically publishes special reports. Some of them emerge from funded projects and others are independent reports. In both cases the goal of the reports is to provide an opportunity for thought leaders, drawn from Hastings Center Fellows, staff scholar, and other national experts, to serve as guest editors on topics that deserve attention. Five special reports came out in 2014. They included *Interpreting Neuroimages: An Introduction to the Technology and its Limits*, the product of a research project funded by the Dana Foundation, published in April and edited by research scholars Erik Parens and Josephine Johnston; *LGBT Bioethics: Visibility, Disparities, and Dialogue*, published in September (see Health and Health Care, pp. 12-13); and *Can We Create What We Want Out of Synthetic Biology?*, the product of a research project funded by the Alfred P. Sloan Foundation, published in November and edited by research scholars Gregory Kaebnick and Michael Gusmano and president emeritus Thomas Murray.

In 2014 The Hastings Center also published two blogs: Bioethics Forum, the blog of the *Hastings Center Report*, and Over 65. Bioethics Forum posts commentaries with a range of perspectives on bioethics issues in the news. It has an audience of over 75,000 people, including scholars, clinicians, students, and journalists. Bioethics Forum commentaries were cited by leading journalists including Michael Pollan and publications such as the *New York Times*. Over 65, a blog of personal essays about issues facing seniors, reaches about 30,000 people.

Visiting Scholars Program. The Center's Visiting Scholars Program offers scholars from all over the world a unique opportunity to conduct independent research on issues in or related to bioethics, as well as to meet with Hastings Center research scholars. Visiting scholars include professors and students, clinicians, lawyers, and policy-makers. Many of the visiting scholars also spend time at the Yale Interdisciplinary Center for Bioethics, under the Yale-Hastings Program in Ethics and Health Policy, which organizes research projects and symposiums. In 2014, we hosted 39 scholars from 10 countries, including Australia, Czech Republic, Italy, Ireland, Spain, Poland, and the U.K.

Awards. The Hastings Center's Henry Knowles Beecher Award recognizes lifetime achievement in bioethics. The award was named for the first recipient, an American anesthesiologist who, in the 1960's, courageously exposed unethical practices in research with human subjects. The 2014 award recipient was Ruth Macklin, a professor in the Department of Epidemiology & Population Health at Albert Einstein College of Medicine in New York, the Dr. Shoshanah Trachtenberg Frackman Faculty Scholar in Biomedical Ethics, and a Hastings Center Fellow. Her work has focused on research involving human subjects, global health, women's health, and human rights.

The Hastings Center Cunniff-Dixon Physician Awards are given annually to five physicians who demonstrate exemplary compassion and skill in caring for patients near the end of life. There are three categories: a senior award and a mid-career award of \$25,000 each and three early-career awards of \$15,000 each. (See details on page 7.)

Global Capacity Building. The Hastings Center is committed to strengthening the global bioethics community. We collaborate with institutions and scholars around the world. Leading these international initiatives in 2014 were research scholars Michael Gusmano and Nancy Berlinger.

- Chinese University of Hong Kong. With the leadership of Hastings Center board member Edgar Cheng, we helped develop a bioethics center for Chinese University of Hong Kong, a major regional institution in medical research and education. In July, The Hastings Center provided major programming for a two-day workshop at the university for clinicians and clinical educators on ethical challenges at the beginning and end of life. Josephine Johnston, director of research, spoke on assisted human reproduction, preimplantation genetic diagnosis, and prenatal genetic testing. Berlinger discussed decision-making at the end of life.
- National University of Singapore. Berlinger and Gusmano worked with the National University of Singapore (NUS) to produce a free online ethics teaching casebook on decision-making with patients and families facing critical illnesses. The casebook launched in January and has been used by thousands of people in Singapore, the U.S., and more than 50 other countries. It was also incorporated into a postgraduate education curriculum at University of Oxford and was the subject of talks to clinicians around the world. The project was supported by the Lien Foundation under subcontract from NUS.
- Rabin Medical Center, Israel. After spending time at The Hastings Center as a visiting scholar, an oncologist at Rabin Medical Center asked for our help in improving doctor-patient communication. Berlinger and Gusmano consulted with doctors at the medical center to explore the educational needs of clinicians in meeting the challenges to upholding the moral concept of kavod ha'adam (respecting other people) in the care of patients, families, staff, and members of minority communities in Israel.



Students from Yale University's summer institute at the annual symposium on bioethics at The Hastings Center in June



Ruth Macklin, of Albert Einstein College of Medicine in New York, was the 2014 recipient of The Hastings Center's Henry Knowles Beecher Award for lifetime achievement in bioethics.



Board member Edgar Cheng provided leadership for The Hastings Center's work in helping to establish a bioethics center at Chinese University of Hong Kong.

Since its inception, The Hastings Center has steadily enlarged its commitment to creating more informed, more meaningful conversations in the public square.

Several important factors have accelerated and increased this effort: In 2007 the Ford Foundation awarded Hastings a major gift to help improve our outreach. In 2014 a major gift from board members Andy Adelson and Frank Trainer enabled





Board members Andy Adelson (left) and Frank Trainer provided major support for communication to the general public, especially through digital marketing.

Hastings to expand its reach to the general public, especially through digital marketing. Thanks to this gift, Hastings has achieved broader and deeper public engagement through its website, blogs, global video webcasting, video archiving, Twitter, and Facebook—all outreach that

relies on and amplifies Hastings scholarship.

Our goal relative to the public is to ensure better understanding of what is at stake in debates as changes in technology, medicine, and the environment reshape the landscape of human possibilities. Such changes raise profound questions that become potential sources of conflict or indecision. Ultimately, we aim to identify common ground from which solutions can emerge.

The Hastings Center is a physical and virtual forum whose energetic intellectual life informs conversations and shapes major decisions. We are a constant and independent resource to the media, while our own in-person events and web-based strategies give us more direct routes to the public.

Helping journalists has always been an important way that the Center contributes to educating the public. In 2014, we conducted a ballroom-packed journalist boot camp at the Association of Health Care Journalists conference, in Denver, that focused on end-of-life care (see photos and more on pp. 6-7).

Research scholar Erik Parens spoke there about ethical issues in neuroscience. Journalists from this meeting subsequently interviewed Hastings President Mildred Solomon and Nancy Berlinger and other Hastings scholars for stories in Reuters, Crains News Pro, Pew Charitable Trusts Stateline, Modern Healthcare, Interlochen Public Radio (Cleveland), and additional publications and broadcast media.

Hastings handled about 200 media calls in 2014, offering

Hastings Center Events: Across

January 28 • Garrison, N.Y.

Hastings Seminar, research scholar Gregory Kaebnick discusses his book, *Humans In Nature: The World As We Find It and The World As We Create It.*

February 26 • New York, N.Y.

What Makes a Good Doctor? Series, "How will your relationship with your doctors fare in this era of reform?" A talk by Jordan J. Cohen, president emeritus of the American Association of Medical Colleges.

March 26 • Denver Salon

"Decisions Near the End of Life, What's Ethically and Legally Permissible?" A discussion with the Honorable Richard Lamm, former governor of Colorado; physician Charles Hamlin; Hastings Center president Mildred Solomon; and Hastings Center Fellow and legal scholar Alan Meisel.

April 8 • New York, N.Y.

"Should New York Endorse Aid In Dying"? A debate between Marcia Angell, senior lecturer in social medicine at Harvard Medical School and former editor-in-chief of *The New England Journal of Medicine*, and Kathleen Foley, a neurologist at Memorial Sloan Kettering and a global leader in palliative care.

April 23 • New York, N.Y. Salon

"Advances in Genetics," a conversation with Hastings Center president Mildred Solomon and Hastings Center scholars Greg Kaebnick, Josephine Johnston, and Erik Parens.

May 20 • Boston Salon

Hosted by Joshua Boger, former Hastings Board member, and Ragu Kucherlapati, a Harvard geneticist, with talks by Hastings Center president Mildred Solomon and Hastings Center scholars Michael Gusmano, Josephine Johnston, Gregory Kaebnick, Karen Maschke, and Erik Parens.

May 22 • Irvington, N.Y. Salon

"What Would She Want? Protecting Our Loved Ones When Life's End Nears," a conversation with Hastings Center president Mildred Solomon and Tia Powell, a Hastings Center Fellow who is psychiatrist-bioethicist at Montefiore Medical Center and Albert Einstein Medical School.

June 10 • Garrison, N.Y.

Hastings Seminar and Open House, Barron Lerner discusses his new book, *The Good Doctor, A Father, a Son, and the Evolution of Medical Ethics*.

November 17 • New York, N.Y.

"LGBT Health and Human Rights: New Ideas for Dynamic Times," a symposium with talks by awardwinning author Andrew Solomon and Tia Powell, a Hastings Center Fellow who is a psychiatrist-bioethicist at Montefiore Medical Center and Albert Einstein Medical School.

December 12 • New York, N.Y.

"Navigating a Science-Dominated World: From Poetry to Genomics," a talk by James Evans, a Hastings Center advisory council member who is editor-inchief of the journal *Genetics in Medicine* and Bryson Distinguished Professor of Genetics & Medicine at University of North Carolina.

the U.S. and throughout the Year



From top: Research scholar Gregory Kaebnick speaks with audience members following his Hastings Seminar book talk in Garrison in January; former Colorado governor Richard Lamm and President Mildred Solomon at a salon in Denver on end-of-life decision-making; James Evans answers questions during his talk on genetics at a public event in New York in December; Suzanne Baker (I.) and Jan Baker (r.), members of The Hastings Center advisory council, and Peter Hofmann (center) at the Hastings Center Open House in June; Andrew Solomon signs copies of his bestselling book, Far from the Tree, after speaking at the LGBT event in New York in November.

everything from background information to quotes. We were mentioned in the press more than 150 times in this year, in sources including the *New York Times*, the *Washington Post*, the *Wall Street Journal*, public radio, and public television. Not only are our resident scholars consulted and quoted, but many of our 200 elected Hastings Fellows are leading commentators in the media.

We continue to focus on a broad geographic reach, and so, in addition to those in New York State, we held live events in Boston and Denver.

We hosted a highly respectful debate, moderated by Mildred Solomon, on physician aid-in-dying, with leaders of each view laying out their positions. And, using webcast technology, we have hosted simultaneous multiple-city events; a group in Denver, for example, participated in real time in a New York-based lecture and panel discussion. Webcasts like this remain in our online video library as fodder for discussion, sometimes for years!

Simultaneous webcasting and new, more active digital distribution have allowed us to enlarge an event's audience by a factor of ten. Over time, social media and our website and webcasts will enable us to reach hundreds of thousands of individuals around the world.

Over 12,000 individuals have signed up for our regular email communications. In 2014 we created a concise monthly analysis of current events called News in Context. Emailed to this group, News in Context draws on The Hastings Center's expertise to explain a major news topic.

Hundreds of thousands of visitors come to our website and blogs annually. Our *Bioethics Briefing Book*, providing background on 36 topics, remains the most popular destination. Among the most sought-out topics in 2014 were aid-in-dying, health care costs and medical technology, and organ transplantation.

Both our Facebook and Twitter communities grew by 25 percent in 2014—and did so with much more engaged audiences. Conversations through these channels reach into the hundreds of thousands of individuals worldwide!

The Hastings Center's unique dual commitment to the bioethics professional community and to the general public remains one of its most distinguishing and prized features.

2014: An Active Year for Board Members





▲ Hastings Center board member Alan Fleischman (I.), who hosted the Irvington salon, with Robert Brugger

▲ Hastings Center president Mildred Solomon (I.) and Hastings Center Fellow Tia Powell lead a discussion on end-of-life decision-making at a salon in Irvington, N.Y. in May

► At the Irvington salon, Robert Klein (I.) and Fran Greenberg talk with Bruce Jennings, a Hastings Center senior advisor and Fellow.



▼ Joshua Boger (r.) talks with John Fallon at the Boston salon.



Tia Powell (I.) with Michael and Lynn Reichgott at the Irvington salon



▲ (I. to r.): Robert Coughlin, Hastings Center research scholar Gregory Kaebnick, and Harvard professor and author Atul Gawande at the Boston salon



■ Josephine Johnston, The Hastings Center's director of research (I.), with Julia Byers at the Boston salon

▼ Joshua Boger (I.), Tony Colos, and Susan Windham-Bannister at the Boston salon



Special Thanks to Joshua Boger



The Hastings Center board and staff give Joshua Boger a standing ovation for his years of service.

After nine years of service, Joshua Boger stepped down from The Hastings Center board in June. Boger, the founder, president, and chief executive officer of Vertex Pharmaceuticals, was firmly committed to the Center's mission and a generous supporter of our work.







▲ (I. to r.): Jon Mann, Nancy Adelson, and Rick Reiss at a salon in New York in April on advances in genetics hosted by Nancy and Andy Adelson, a Hastings Center board member



James Evans, a Hastings Center advisory council member, and Liza Bailey, a Hastings Center board member, at a dinner for the advisory council in Garrison in September, one of many Hastings Center events that Bailey has generously hosted



Raju Kutcherlapati (I.) and Doug Cole at the Boston salon

The Hastings Center is fortunate to have an exceptionally active and engaged board of directors. It is a diverse group of leaders in academia, medicine, law, and business who recognize the vital role of the Center in identifying and illuminating life's toughest questions. At a time of polarization and spin, The Hastings Center is a nonpartisan trustworthy resource for individuals, journalists, and policy-makers.

Introducing The Hastings Center Advisory Council

We invited 24 distinguished leaders in medicine, law, economics, and business, including two Nobel Laureates, to join The Hastings Center's first advisory council. The advisory council's purpose is to provide guidance about how best to ensure the impact of our work, particularly our impact in the public square. Unlike other bioethics centers in the country, public engagement is a core part of our mission. The inaugural meeting of the advisory council took place at the Center in September, with the theme "Making Good on the Genetics Revolution." Advisory council member James Evans, editor-inchief of the journal Genetics in Medicine and Bryson Distinguished Professor of Genetics & Medicine at University of North Carolina at Chapel Hill, gave a talk, "Navigating the Genome: Progress and Hyperbole." Prenatal testing was the topic of a talk by advisory council Wendy Chung, Herbert Irving Associate Professor of Pediatrics and Medicine at Columbia University College of Physicians and Surgeons, and discussions led by Josephine Johnston, Hastings director of research, and Alan Fleischman, professor of pediatrics at Albert Einstein College of Medicine who is a Hastings Center board member and Fellow.



Hastings Center board member Liza Bailey (I.), Hastings Center president Mildred Solomon, and advisory council member Sissela Bok

Advisory council members Stephen Oxman (I.) and Frederic Rich



Lunch on the Hastings Center's lawn at the advisory council meeting



Bradford Gray (I.) and Hastings Center research scholar Michael Gusmano



Peter Canellos, Sisela Bok, and Wendy Chung



The Hastings Center advisory council meeting, front row (I. to r.): Hastings Center president Mildred Solomon, Sissela Bok, Helen Darling, Wendy Chung, Shonni Silverberg, Hastings Center board member Liza Bailey; Middle row (I. to r.): James Evans, Jean Margo Reid. Gretchen Dykstra, Hastings Center board member Alan Fleischman, Harold Shapiro; Back row (I. to r.): Peter Canellos, Stephen Oxman, John Usdan, Thomas Schelling, Alexander (Sandy) Kemper, Hastings Center board chair David Roscoe, Bradford Gray, James Stahl, Frederic Rich



▲ Hastings Center board member Alan Fleischman (I.) and Thomas Schelling at an advisory council reception

◀ Hastings Center president Mildred Solomon and Harold Shapiro at the advisory council meeting

▶ (I. to r.): Jean Margo Reid, Hastings Center director of research Josephine Johnston, Frederic Rich, Hastings Center research scholar Sarah McGraw, and Gretchen Dykstra at the advisory council meeting

2014 Advisory Council Members

D. J. (Jan) Baker, JD • Partner and Global Co-Chair, Restructuring Practice Group

Suzanne Baker, JD • Partner and Head of Appellate Group (retired), Beirne, Maynard & Parsons

Sissela Bok, PhD • Senior Visiting Fellow, Harvard Center for Population and Development Studies

Peter Canellos, LLB • Wachtell Lipton Rosen + Katz

Wendy Chung, MD, PhD • Herbert Irving Associate Professor of Pediatrics and Medicine, Columbia University College of Physicians and Surgeons

Helen Darling • Strategic Advisor, Former President and CEO National Business Group on Health

Gretchen Dykstra • Writer-in-Residence, New York Public Library; Founding President, National 9/11 Memorial Foundation; Former NYC Commissioner of Consumer Affairs

Harold S. H. Edgar, LLB • Julius Silver Professor in Law, Science, and Technology, Columbia Law School

James P. Evans MD, PhD • Bryson Distinguished Professor of Genetics & Medicine, University of North Carolina at Chapel Hill; Editor-in-Chief, *Genetics in Medicine*; Member of the U.S. Secretary of Health and Human Services' Advisory Committee on Genetics, Health

Bradford H. Gray, PhD • Editor Emeritus, *The Milbank Quarterly*; Senior Fellow, The Urban Institute

Carol Greider, PhD • 2009 Nobel Laureate for Physiology or Medicine for discovery of the role of the enzyme telomerase; Daniel Nathans Professor and Director of Molecular Biology and Genetics, Johns Hopkins University

Alexander (Sandy) Kemper • Founder and Chairman of the Board, C2FO; Chairman, The Collectors Fund

Stacey Lane, JD, MS, MBE • Member, Board of Directors, The Familial Hypercholesterolemia Foundation

Marc Nivet, EdD • Chief Diversity Officer, Association of American Medical Colleges

Stephen A. Oxman, DPhil • Senior Advisor, Morgan Stanley; Former Assistant Secretary of State for European and Canadian Affairs

Jean Margo Reid, JD • General Counsel and CCO, Sanders Capital

Frederic C. Rich, JD • Partner and Head of Global Project Development and Finance, Sullivan & Cromwell, LLP (New York)

Thomas C. Schelling, PhD • 2005 Nobel Laureate in Economics, for enhancing understanding of conflict and cooperation through game-theory analysis; Distinguished Professor of Economics, University of Maryland

Harold T. Shapiro, PhD • President Emeritus and Professor of Economics and Public Affairs, Princeton University

Shonni J. Silverberg, MD • Professor of Medicine, Columbia University College of Physicians & Surgeons

Andrew Solomon, PhD • Author and lecturer on psychology, politics, and the arts; professor of clinical psychology at Columbia University Medical Center

James E. Stahl, MD, CM, MPH • Internist, Massachusetts General Hospital (MGH); Senior scientist, MGH Institute for Technology Assessment

Theodore J. Stahl, MD • Clinical Professor of Radiology and Medicine; Former Chief of Nuclear Medicine, Robert Wood Johnson University Hospital-Rutgers University Medical School, St. Peter's University Hospital

John Usdan • President, Midwood Investment & Development

STATEMENT OF FINANCIAL POSITION

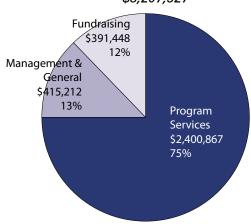
as of December 31, 2014

do of December 01, 2014	
	Audited 2014
Assets	
Cash and Equivalents	883,595
Investments, at fair value	4,640,072
Receivables (grants and other)	712,962
Other Assets	45,489
Furniture and Equipment (net of accumulated dep)	24,854
Leasehold Improvements (net of accumulated amort)	1,073,434
Total Assets	7,380,406
Liabilities and Net Assets	
Payables and Accruals	97,096
Deferred Revenue	41,657
Total Liabilities	138,753
Net Assets	7,241,653
Total Liabilities and Net Assets	7,380,406

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

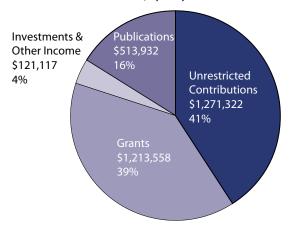
1 1 1 1 7 100
2,101,752
383,129
513,932
121,116
<u>3,119,929</u>
2,400,867
415,212
391,448
<u>3,207,527</u>
(87,598)
(47,856)
229,157_
93,703
7,147,950
7,241,653

Operating Expenses for the year ended 12/31/14 \$3,207,527



Operating Revenue and Support

for the year ended 12/31/14 \$3,119,929



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Nancy Berlinger Research Scholar

Noel Crotone

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