



SCHOLARSHIP

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ENGAGEMENT

ANNUAL REPORT 2013

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The Hastings Center

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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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# THE HASTINGS CENTER

## ANNUAL REPORT 2013

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*inside back cover* Current Staff of the Hastings Center

## Message from the President

Dear Friends and Colleagues,



Mildred Z. Solomon  
President and CEO

In 1969, when we were founded, The Hastings Center was the first bioethics research institute in the world. After nearly 45 years, we have maintained our nonpartisan independence and our unflagging commitment to identifying and illuminating life's toughest questions. We are committed to ensuring that new biomedical knowledge is used wisely and well, that its benefits are shared fairly, that health policies are just, and that all stakeholders, and particularly vulnerable populations, are respected.

Reasonable people often disagree about these matters. We intentionally bring people of many persuasions into the room, ensure that all voices are heard, and then offer recommendations and analyses not usually possible in our bitterly polarized world.

The Hastings Center performs three major roles:

- We do our own original scholarship in five key program areas
- We support the field of bioethics
- We engage the public

This year's annual report has been organized in terms of these three roles. I invite you to sit back and spend a few minutes reading about Hastings' accomplishments. You will see the wide-ranging scope of our scholars' expertise, the ways in which we support visiting scholars and collaborate with others to enhance the field, and our growing capacities in public engagement.

Our scholarship focuses on five key program areas with increasing global impact:

- Health and Health Care
- Children and Families
- Aging, Chronic Conditions and End-of-Life Care
- Emerging Science and Conceptions of the Self
- Human Impact on the Natural World

In this annual report, we have provided examples of our accomplishments in three of these program areas. Future annual reports will highlight examples from the other program areas.

None of this work would be possible without the generous and continued support of our donors each year. We are deeply grateful to the many people who contribute to The Hastings Center, and we dedicate this report to you. Thank you!

Sincerely,

A handwritten signature in blue ink that reads "Mildred Z. Solomon". The signature is fluid and cursive.

Mildred Z. Solomon, Ed.D  
President



# SCHOLARSHIP

## Genetics Hits the Clinic

In the little-over-a-decade since the human genome was mapped, we have gained a wealth of knowledge about the genetic influence on disease and hints of its contribution to personal characteristics such as aggression and intelligence. As this information makes its way from the lab to the clinic, genetic and genomic testing are forcing us to grapple with an array of questions—about privacy, personal responsibility, each individual’s potential, and

### Highlights

- Josephine Johnston helped oversee controversial research involving human embryos and stem cells by serving on one of the busiest committees in the U.S., the Tri-Institutional Embryonic Stem Cell Research Oversight Committee for Weill Medical College of Cornell University, Memorial Sloan-Kettering Cancer Center, and The Rockefeller University.
  - She brought attention to inconsistencies in the oversight of embryonic stem cell research in “The NIH Stem Cell Registry: An Absence of Gamete Donor Consent,” a co-authored paper in *Cell Stem Cell*.
- Karen Maschke’s focus group research with the Mayo Clinic Biobank’s Community Advisory Board provides evidence that patients are willing to have their genomic information in their electronic medical records, even though they remain concerned about who will have access to it and how it will be used.
  - Her role in the bioethics workgroup for the International Human Epigenome Consortium included clarifying for scientists around the world the ethical and policy issues related to sharing epigenomic research data and the privacy issues that need to be addressed.
- Erik Parens addressed the Presidential Commission for the Study of Bioethical Issues on the meaning of incidental findings from genetic testing and research. The Commission incorporated specific recommendations by Parens into its final report.
  - He addressed the March of Dimes leadership on ethical questions about non-invasive prenatal genetic testing.
- Mildred Solomon spoke on Nazi eugenics and its contemporary implications at the New York Genome Center.



Hastings Center scholar Erik Parens addressing the Presidential Commission for the Study of Bioethical Issues in Washington.

Hastings Center  
Program Area:  
Emerging Science  
and Conceptions  
of the Self



President Mildred Z. Solomon speaking at the New York Genome Center about Nazi eugenics and the need for scientists to be educated about the ethical implications of their work.

the very core of who we are. Hastings Center scholars are exploring many of these questions.

In 2013, Hastings began a five-year project on the genetic underpinnings of the brain—the genetic contribution to psychiatric and neurological conditions and to complex behaviors such as aggression and intelligence. This work is being done in collaboration with Columbia University Medical Center’s Center for Research on the Ethical, Legal and Social Implications of Psychiatric, Neurologic and Behavioral (PNB) Genetics. Research scholars Erik Parens and Josephine Johnston are leading the project’s investigation into the ethical implications of PNB genetics for medical practice and other applications, such as evidence in court cases. They will synthesize their findings into recommendations for policies and practices.

In the first year, The Hastings Center helped develop a website, [braingenethics.org](http://braingenethics.org), with news, commentaries, and other information, and created a free monthly e-newsletter with a roundup of new research. The project is funded by the National Human Genome Research Institute.

Other projects have been focusing on whole-genome analysis for two kinds of clinical applications, described below.

### **Whole-Genome Sequencing for Cancer Treatment**

Many cancer centers have recently begun using genomic sequencing of patients to guide treatment decisions. But the meaning and utility of the data is not straightforward; the challenge for clinicians is to determine what results are potentially actionable or yield information about disease risk, prognosis, and other key factors. Sarah McGraw, a medical anthropologist and Hastings research scholar, is examining the process that a team of scientists and clinicians goes through to



Neurological findings, such as the brain images shown here, are becoming increasingly important in research and medicine, as well as in court cases. But they are subject to misinterpretation and other problems, which are being explored by The Hastings Center. fMRI scan courtesy of Geoffrey Aguirre



## Center for Research on Ethical, Legal & Social Implications of Psychiatric, Neurologic & Behavioral Genetics

RESEARCH PROJECTS & PUBLICATIONS

EDUCATION & TRAINING PROGRAMS

FOR THE COMMUNITY

make these decisions, including how their deliberations take into account patient preferences; potential impact on the patients, families, and clinicians; and the uncertainties or dilemmas encountered in the process. The project is a collaboration with Dana Farber Cancer Institute, funded by the National Institutes of Health.

### Whole-Genome Sequencing in Newborn Screening

With Hastings Center Fellow Barbara Koenig, of the University of California, San Francisco, Johnston and Parens are investigating whole-genome analysis in newborn screening. Whole-genome analysis is expected to become part of routine state-mandated hospital testing of newborns. It would significantly expand the data that comes out of this testing, from the childhood illnesses currently screened for to a vast array of additional conditions and traits. While some of this information could be extremely valuable, much of it would be unclear or ambiguous. Some of it might be unwelcome to parents: would they want to know, for example, if their new baby is at elevated risk for Alzheimer's disease or some other condition that doesn't show up until late in life? Johnston and Parens are identifying and examining the ethical, legal, and social implications of whole-genome analysis in newborn screening, focusing particularly on its potential to identify gene variants that would affect the response to specific medications. The project is a subcontract with the University of California, San Francisco, funded by the National Institutes of Health.

The homepage of [braingenetics.org](http://braingenetics.org), a website produced by The Hastings Center in collaboration with Columbia University Medical Center.



Research scholar Josephine Johnston is one of the lead investigators of a project on the genetic contribution to psychiatric and neurologic conditions and complex behaviors and a project on whole-genome analysis in newborn screening.

## Toward Better Health and Health Care

Helping people who are sick is a primary goal of medicine. Knowing how best to help can be a tremendous challenge. Throughout its history, The Hastings Center has been at the forefront of developing ways to improve doctor-patient communication and decision-making, particularly in difficult circumstances—when doctors, patients, and family members disagree, for example, or when a treatment for a dying patient seems futile or possibly even harmful.

Nearly 30 years ago, The Hastings Center published its first ethics guidelines to help health care professionals provide good care to patients nearing the end of life. This groundbreaking publication was instrumental in shaping the ethical and legal framework for medical decision-making and end-of-life care we rely on today, including the right to refuse treatment and the value of palliative care in relieving patients' pain and suffering. The Center revised and greatly expanded that essential resource into a book published in May 2013: *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life* (Oxford University Press).

The Hastings Center followed up with initiatives to put *Guidelines* into practice. With support from the Donaghue Foundation, research scholar Nancy Berlinger, the lead author, conducted interviews with medical and nursing societies and working clinicians to identify the needs and concerns of professionals who care for patients facing treatment decisions or nearing the end of life, but who may not be part of “end-of-life care” networks. Insights from these interviews have helped the Center develop educational partnerships with key professional societies. Berlinger also gave invited talks about *Guidelines* and related health policy topics to hospitals, clinical ethics networks, and professional societies around the world. She also co-authored an article for the journal *Pediatrics* summarizing key end-of-life issues affecting infants, children, and adolescents. Mildred Solomon, president of the Center, who served on the *Guidelines* project working group, gave



Obesity, Agency, and Ethics meeting participants: front row (l. to r.) Steve Latham, Daniel Callahan, Luc Bovens, Richard Reeves, Cathy Nonas, Mark Schlesinger, and P. Anne Scott; back row (l. to r.) Adam Oliver, Larry Brown, Michael Gusmano, Josephine Johnston, Naomi Scheinerman, Rebecca Kaebnick, and Cameron Waldman. Not pictured: Erik Parens.

Hastings Center  
Program Area:  
Health and  
Health Care



## Highlights

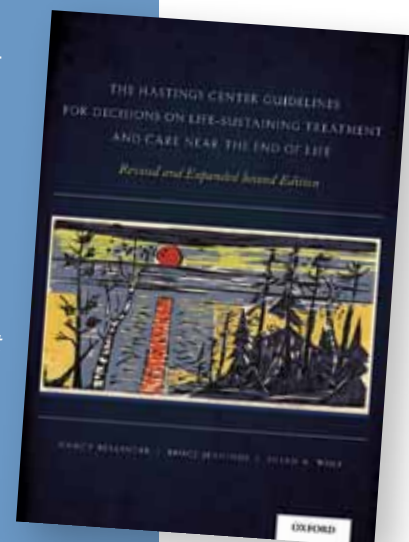
- Nancy Berlinger and Mildred Solomon spoke on ethics and evidence at the National Institutes of Health.
- Berlinger gave the keynote address on improving care near the end of life at the Japan Association for Bioethics annual meeting in Tokyo.
- She was a member of the expert panel on palliative care for the American Heart Association/American Stroke Association.
- She co-authored an article on pediatric palliative care in *Pediatrics*.
- She co-authored (with Michael Gusmano) an article in *Health Economics Policy and Law* on the consequences of the ACA for safety-net health care providers.
- Daniel Callahan published a commentary on physician-assisted suicide in *Congressional Quarterly*.
- He wrote a commentary on childhood obesity for *JAMA Pediatrics*.
- Michael Gusmano published an article on patients' voices in Food and Drug Administration decisions in *Public Administration Review*.
- He co-authored an article in *Publius: The Journal of Federalism* on the ACA's Medicaid expansion and health insurance marketplaces.
- He co-authored an article in the *Journal of Health Services Research and Policy* comparing re-hospitalization rates among elderly patients in the U.S. and France, with policy recommendations.
- *Hastings Center Report* special report on learning healthcare systems became the subject of an Institute of Medicine meeting.
- Karen Maschke was named a member of the NIH Chimpanzee Research Use Panel, helping to inform national policies on the use of chimpanzees in federally-funded research.
- Thomas Murray addressed the Presidential Commission for the Study of Bioethical Issues on ethical oversight of the BRAIN initiative.
- Mildred Solomon was a panelist at a public event on dilemmas on prolonging life at The New York Academy of Sciences.
- She co-authored an article on patient engagement in *Health Affairs*.
- She addressed the Presidential Commission for the Study of Bioethical Issues on bioethics education and the BRAIN initiative.



Mildred Solomon addressing the Presidential Commission for the Study of Bioethical Issues in Washington

## BOOKS

- *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life: Revised and Expanded Second Edition* by Nancy Berlinger, Bruce Jennings, and Susan M. Wolf (Oxford University Press) is an updated and expanded edition of a classic work.
- *Medicare Meltdown* by Rosemary Gibson and Janardan Prasad Singh (Rowman & Littlefield Publishers) examines how financial ties between Medicare and Wall Street cause wasteful spending.



## 2013 Hastings Center Cunniff-Dixon Physician Award



Recipients (l. to r.): Charles G. Sasser, Conway Medical Center, Conway, S.C. (senior award); Daniel C. Johnson, Kaiser Permanente's Care Management Institute, Denver (mid-career award); Jane deLima Thomas, Dana-Farber Cancer Institute, Boston (early career award); Drew Rosielle, University of Minnesota Medical Center, Minneapolis (early career award); Alen Voskanian, VITAS Innovative Hospice Care, Torrance, Calif. (early career award)

talks on related topics to audiences at the National Institutes of Health and The New York Academy of Sciences.

Medical dilemmas can arise with patients of all ages and in a wide range of circumstances. Making difficult decisions with patients and families was the focus of a Hastings Center collaboration with the Centre for Biomedical Ethics at the Yong Loo Lin School of Medicine at the National University of Singapore and the Ethox Centre at Oxford University. Hastings Center scholars Nancy Berlinger and Michael Gusmano worked with more than 50 clinicians and other professionals in Singapore to produce an online ethics teaching casebook on decision-making with patients and families facing critical illnesses. The casebook, launched in January 2014, is available for free.

### Addressing Controversies in Response to Obesity

Responding to the obesity epidemic and the low success rate of efforts to curb it, Daniel Callahan, cofounder of the Center, published prominent commentaries in the *Hastings Center Report* and *JAMA Pediatrics* calling for fresh approaches, including the recommendation for more discussion between pediatricians and parents about children's weight. To give voice to diverse views, the Center convened a two-day meeting of international health policy experts. They discussed ethics, personal responsibility, and health policy in addressing obesity, including the tension between individual choice and public health policies aimed at restricting individual's choices of food and beverages that promote obesity. Hastings Center research scholar Michael Gusmano, who led the meeting, said there was clear disagreement among the participants about the extent to which policy ought to focus on individual responsibility, but there was broad agreement that more attention should be paid to corporate responsibility.

In addition, Hastings Center scholars published several articles about the Affordable Care Act (ACA) implementation and lessons that the U.S. might draw from health care systems in other countries.



A packed house: The Center hosts a Hastings Seminar on legal and ethical questions about end-of-life care presented by Hastings Center President Mildred Z. Solomon and Tia Powell, director of the Montefiore Einstein Center for Bioethics in New York.

## Engineering Life

Biotechnology sometimes bridges the genetics revolution with the natural world. Synthetic biology, for example, uses genetic manipulation to design organisms that serve human interests. It holds promise for great benefit, including the production of inexpensive biofuels from algae and bacteria modified to serve as vaccines. It might also pose risks to public health and the environment. And it raises moral questions about nature and the extent to which humans should strive to preserve it.

In 2013 The Hastings Center completed a two-year project on ethical issues of synthetic biology. The project took up four case studies that capture the range of work in synthetic biology: the production of biofuels; do-it-yourself efforts; field release of syn bio products into the environment; and engineering the human microbiome—microbes in and on the human body. The investigators were research scholars Gregory Kaebnick, Erik Parens, and Michael Gusmano, and President Emeritus Thomas Murray. The project wrapped up with the publication of two books in 2013 and the development of a final report to be published in 2014.

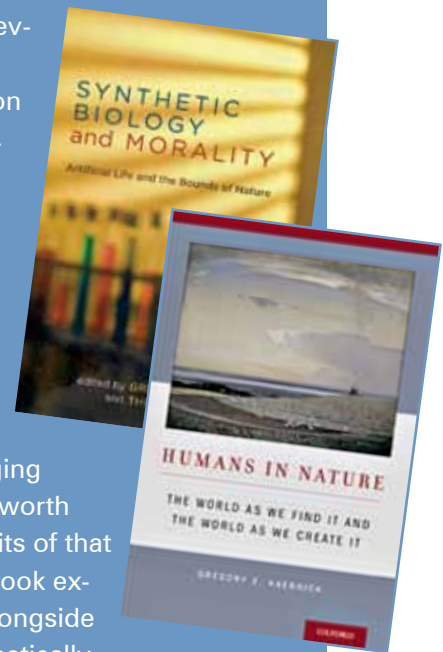
Earlier Hastings work on synthetic biology included testimony to the U.S. House of Representatives and presentations before the Presidential Commission for the Study of Bioethical Issues.

### Highlights

- Michael Gusmano identified challenges in achieving meaningful public engagement in policy-making about synthetic biology in a presentation at Governance of Emerging Technologies: Law, Policy, and Ethics conference, a conference at the University of Arizona co-sponsored by The Hastings Center and Yale University.

#### BOOKS

- *Humans in Nature: The World as We Find It and the World as We Create It*, by Gregory E. Kaebnick (Oxford University Press) articulates a careful middle ground for the ethics of emerging technologies—defending the idea that nature is worth caring about morally while pointing out the limits of that concern in public policy and other areas. The book examines foundational philosophical problems alongside debates about environmental preservation, genetically modified crops and livestock, synthetic biology, and the biotechnological enhancement of human nature.
- *Synthetic Biology and Morality: Artificial Life and the Bounds of Nature*, edited by Gregory E. Kaebnick and Thomas H. Murray (MIT Press) offers a range of perspectives on whether synthetic organisms detract from or enhance the inherent value of nature.



## Our Work with Institutions around the World

The Hastings Center collaborates with major academic and medical institutions in the United States and abroad. These collaborations include projects on ethical issues in genomics, such as guarding individual privacy in an age of Big Data, and educational initiatives for students and professionals.

With the Dana-Farber Cancer Institute, an affiliate of Harvard Medical School, research scholar Sarah McGraw has been working on a project concerning the use of genetic testing in the prevention and treatment of cancer. Deciding which genetic results are actionable—and, therefore, are worth disclosing to doctors and patients—is not straightforward. The project aims to come up with a paradigm to help guide those decisions and incorporate genetic information into the care of patients with cancer (see p.4). Another Harvard-related collaboration, begun in early 2014 with the Petrie-Flom Center, looks at ethical issues in Harvard’s Football Players Health Study.

Genomic research is the focus of collaborations with the Mayo Clinic and University of California, San Francisco. Hastings Center scholar Karen Maschke has been working with Mayo’s Biomedical Ethics Program on an empirical study that examines the hopes, concerns, and expectations of Mayo patients enrolled in a study that examines how genes affect a person’s response to medications. Some participants’ genomic research data will be inserted into their electronic medical records, raising questions about who has access to their genetic information and

related issues of confidentiality and privacy. Our collaboration with University of California, San Francisco, involves whole-genome analysis in newborn



Students from Kent Place School participating in The Bioethics Project listen to Hastings Center scholars discuss their work.



Students in Yale University’s summer institute attend a symposium on bioethics at The Hastings Center as part of the Yale-Hastings Program in Ethics and Health Policy.



At National University of Singapore (l. to r.): Hastings Center scholars Michael Gusmano and Nancy Berlinger, and John Wong, of the National University of Singapore.



screening and is described on page 5. A project with Columbia University Medical Center, described on page 4, is examining genetic contributions to brain function and illnesses.

With other collaborators, we are helping to educate the next generation. The Bioethics Project is a bioethics research program for high school students jointly developed by Hastings and the Ethics Institute at Kent Place School in New Jersey. A pilot project that completed is second year in 2013, it includes instruction on ethical decision-making and bioethics and an in-depth bioethics research project for the students. It culminates in a community symposium in which the students present their research. For middle school students, Hastings has teamed up with i2 camps, a new series of science, engineering, and math summer camps. Hastings produced eight bioethics modules on responsible innovation. "Bioethics is full of rich and relevant debates that fascinate students of all ages. By helping students engage deeply with these debates, we are not just teaching them about how science and medicine work, we are also helping them sharpen their critical thinking, argumentation, and communication skills, which are all crucial skills for the next generation of citizens," says Josephine Johnston, the research scholar who leads the Center's work in this area.

The homepage of the online casebook that The Hastings Center helped develop for the National University of Singapore.

Bioethics education of undergraduates and recent college graduates is a focus of the Yale-Hastings Program in Ethics and Health Policy, a collaboration with Yale's Interdisciplinary Center for Bioethics that involves joint research and symposiums. A key annual event is a daylong symposium at The Hastings Center for Yale's summer institute of college students to learn about bioethics topics from Hastings Center scholars.

Hastings collaborations have become increasingly global. They include a major project with National University of Singapore to help doctors make difficult decisions with patients and their families (see p. 8) and work begun in early 2014 with Chinese University of Hong Kong and Rabin Medical Center in Israel.

## Highlights

### BOOK

- *Taking Sides: Clashing Views on Bioethical Issues*, 15th ed., Gregory E. Kaebnick, ed. (McGraw-Hill) features essays on a wide range of bioethics issues for use in classrooms.

## Our Scholars and Projects

### Health and Health Care

**Capacity-Building Collaboration with Chinese University of Hong Kong** • Nancy Berlinger and Michael Gusmano (Chinese University of Hong Kong)

**Ethical Problems in Health Care (book)** • Nancy Berlinger (Gaylin Fund)

**Financing Health Reform in Vermont** • Michael Gusmano (Blue Cross/Blue Shield of Vermont)

**Improving Treatment for Black Lung Cancer Patients: Perspectives of the Providers** • Sarah McGraw (National Institutes of Health under subcontract from Massachusetts General Hospital)

**Obesity, Agency, and Ethics** • Michael Gusmano (Callahan Exploratory Fund)

**Perceptions about Orphan Drug Efficacy and Risk by Patients with Rare Diseases** • Sarah McGraw (Agency for Healthcare Research and Quality under subcontract from Brigham and Women's Hospital)

**Smoking and Persons of African Ancestry** • Sarah McGraw (National Institutes of Health under subcontract from Massachusetts General Hospital)

**The Selfhelp Virtual Senior Center Initiative** • Michael Gusmano (Selfhelp Community Services, Inc.)

**Undocumented Patients after Health Reform: Human Rights, Access to Health Care, and the Ethics of the Safety Net** • Nancy Berlinger and Michael Gusmano (Overbrook Foundation)

### Children and Families

**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)

### Aging, Chronic Conditions, and Care near the End of Life

**Journalists' Bootcamp on Covering End-of-Life Care** • Susan Gilbert (Andrew and Nancy Adelson and The Donaghue 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 to Health Care Professionals Outside End-of-Life Networks** • Nancy Berlinger (The Donaghue Foundation)

**The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life** • Nancy Berlinger (The Albert Sussman Charitable Remainder Annuity Trust, the Patrick & Catherine Weldon Donaghue Medical Research Foundation, and donors to The Anika Papanek Memorial Fund)

**The Hastings Center Guidelines Teaching Tools Development** • Nancy Berlinger (Institute for Ethics, Memorial University Medical Center, Savannah, Ga.)

**Use of Whole-Exome Sequencing to Guide the Care of Cancer Patients** • Sarah McGraw (National Institutes of Health under subcontract from University of Pennsylvania)

### Emerging Science and Conceptions of the Self

**Advancing Collaborative Genetic Research: Ethical and Policy Challenges** • Karen Maschke (National Institutes of Health under subcontract from Case Western Reserve University)

**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)

**Challenges of Informed Consent in Return of Data from Genomic Research** • Erik Parens (National Institutes of Health under subcontract from Columbia University Medical Center)

**Human Subject Protection and Genomic Research at Mayo Clinic** • Karen Maschke (Mayo Clinic)

### Human Impact on the Natural World

**Ethical Issues in Synthetic Biology: Four Case Studies** • Gregory Kaebnick, Thomas Murray, Michael Gusmano, Erik Parens (Alfred P. Sloan Foundation)

### 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)

### Education

**i2Camps: Responsible Innovation Modules** • Josephine Johnston (Ethan Berman)

**The Bioethics Project: What is the Value of the Human Body?** • Josephine Johnston (anonymous donor)



Nancy Berlinger



Daniel Callahan



Michael Gusmano



Josephine Johnston



Gregory Kaebnick



Sarah McGraw



Karen Maschke



Thomas Murray



Erik Parens



Mildred Solomon



# SERVICE TO THE FIELD OF BIOETHICS

As the longest-serving independent nonpartisan bioethics research institute in the world, The Hastings Center has been a leader in the field since its inception more than 40 years ago. Today, a prime example of the Center's continuing leadership is its commitment to supporting bioethics. It does this in several ways: publishing journals and blogs, recognizing distinguished scholars and clinicians with awards, and hosting an international visiting scholars program to share knowledge and build bridges around the globe.

## Publishing

The Hastings Center publishes two journals: *Hastings Center Report* and *IRB: Ethics & Human Research*. The *Report*, the oldest bioethics journal, contains articles and commentaries on the full breadth of bioethics topics. It also periodically publishes special reports on new and emerging issues of significant impact. A special report called *Interpreting Neuroimages: An Introduction to the Technology and its Limits*, the product of a research project, was in production in 2013 for publication with the March-April 2014 issue. The readership of the *Report* includes clinicians, lawyers, and bioethics scholars. *IRB* is focused on ethical issues in research with human subjects. It is read by research ethics scholars and members of institutional review boards that oversee the ethics of human subjects research.

The Hastings Center also publishes two blogs. Bioethics Forum, the blog of the *Hastings Center Report*, posts commentaries on bioethics issues in the news. It is a platform for voicing diverse perspectives on controversial developments, with 75,000 unique visitors and 200,000 page views each year. Bioethics Forum posts have been cited in leading news outlets, including *Slate* and *Scientific American*, and by policymakers and government agencies, such as Department of Health and Human Services.

Over 65, with an audience of 22,000 unique visitors and 30,000 page views a year, is a blog of personal essays about issues facing seniors. Contributors include leaders in medicine and health policy, such as Carol Levine, a MacArthur Fellow; Sissela Bok, of the Harvard Center for Population and Development Studies and the School of Public Health; and James Sabin, a clinical professor of population medicine and psychiatry at Harvard Medical School. All are Hastings Center Fellows. Posts have been cited in the *New York Times* New Old Age blog.

## Awards

The Hastings Center's Henry Knowles Beecher Award recognizes individuals

Jane deLima Thomas (center), a physician at the Dana-Farber Cancer Institute, receives one of the 2013 Hastings Center Cunniff-Dixon Physician Awards from Mildred Solomon, president of The Hastings Center, and Andy Baxter, founder of the Cunniff-Dixon Foundation.



Robert M. Veatch, 2013 recipient of The Hastings Center's Henry Knowles Beecher Award, delivers a lecture in a Hastings Center-sponsored session at the annual meeting of the American Society for Bioethics and Humanities in Washington.

## Hastings Global Footprint: Visiting Scholars, Fellows, and Collaborations



Mildred Solomon, front center, enjoying an evening with a group of visiting scholars: front row, Ramona Fernandez, left, and Mihaela Matei; back row (l. to r.): Cristina Pardini, Daniel Livendahl, Wei Zhu

who have made a lifetime contribution to ethics and the life sciences and whose careers have been devoted to excellence in scholarship, research, and ethical inquiry. The award was named for the first recipient, a distinguished anesthesiologist who, in the 1960's, courageously exposed unethical practices in human subjects research in the United States. The 2013 award recipient was Robert Veatch, professor of medical ethics at the Kennedy Institute of Ethics and a Hastings Center Fellow.

The Hastings Center Cunniff-Dixon Physician Awards are given annually to five physicians for exemplary care of patients nearing the end of life. They are made in three categories: a senior award and a mid-career award of \$25,000 each and three early-career awards of \$15,000 apiece. The awards were given for the fourth time in 2013 (see p. 8).

### Visiting Scholars Program

The Hastings Center's Visiting Scholars Program serves scholars from all over the world who come to the Center to conduct research on issues in or related to bioethics. Visitors include scholars and practitioners from academia, medicine, law, and the media, as well as students pursuing degrees in the humanities, the sciences, and the professions. Many of the visitors also spend time at the Yale Interdisciplinary Center for Bioethics, under the Yale-Hastings Program in Ethics and Health Policy (see p. 11). In 2013, The Hastings Center welcomed 32 scholars from 15 countries in North America, Europe, Asia, Australia, and New Zealand.

**32** number of visiting scholars  
**15** countries represented  
**10** states represented





# PUBLIC ENGAGEMENT

## Connecting with the Press and the Public

The Hastings Center has a mission-driven commitment to public engagement. Hastings Center scholarship addresses many of society's greatest challenges, as well as difficult decisions that individuals face about their health and well-being. The public engagement effort has long involved building relationships with journalists and advising policymakers. But the Center has recently broadened its public engagement to include communicating with the general public. It has done this by developing public events on topical, and controversial, issues in bioethics.

### Public Events

In 2013, the Center greatly increased the number of its public events from roughly two a year held in Garrison to eight events that took place in Man-

*New York Times Magazine* contributor Robin Marantz Henig (r.) interviews bioethicist Peggy Battin at the kickoff "What Makes a Good Doctor" event in November at the Yale Club in New York.



◀ An attendee asks a question at a Hastings Center seminar on ethical dilemmas in end-of-life care led by Mildred Solomon, president of The Hastings Center, and Tia Powell, director of the Center for Bioethics at Montefiore Medical Center and Albert Einstein College of Medicine.



▶ Ezekiel Emanuel (r.) with Hastings Center board member Kim Kamdar and board chairman David Roscoe following Emanuel's talk in New York in December on challenges in the implementation of the Affordable Care Act.



◀ (l. to r.) Bob and Mandy Tschirki, Frank Trainer, a Hastings Center board member, and Jeanne Trainer.



Hastings Events 2013



hattan and elsewhere in the New York area. The events were organized around the themes of aging and care near the end of life, and they drew attention to *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*. Some of these events were intimate salons in private homes where Hastings research scholars and Fellows led discussions. At one of these gatherings, the topic of discussion was “Confronting the Aging of American Society,” with remarks by Daniel Callahan, cofounder and President Emeritus of The Hastings Center, and Sherwin Nuland, an award-winning author and surgeon. Among those attending was Nobel Laureate James Watson.

Other events were larger. They included the launching of a series called “What Makes a Good Doctor,” which explored different facets of the doctor-patient relationship. One event was a discussion between *New York Times Magazine* contributor Robin Marantz Henig and bioethicist Peggy Batten about



Hastings Center president Mildred Solomon, Hastings board member Patricia Klingenstein, and Nobel Laureate James Watson at “Confronting the Aging of American Society,” a salon in New York in April.

The audience pays close attention at “Confronting the Aging of American Society.”



Bill Sadler and Anne Sidamon-Eristoff at “Confronting the Aging of American Society.”



Nancy and Andy Adelson, a Hastings Center board member, at the first “What Makes a Good Doctor” event.



Hastings Center board member Liza Bailey (l.) with Jan and Suzanne Baker at The Hastings Center’s open house in Garrison.

► Herve Gouraige (l.) and Nora and Raymond Wong at a salon in May at the home of Hastings Center board member Tom Hakes in New Jersey.



the experience of Batten's husband, who asked for aid in dying after having been gravely injured in a biking accident. The discussion built on a prominent article that Henig had written for the *Times Magazine*. Another public event featured a talk by Ezekiel Emanuel, an architect of the Affordable Care Act, about the implementation of the act and prospects for the future.

The Center also had a significant presence at the TEDMED conference in Washington in April 2013, which was attended by thousands of innovators and leaders in medicine and other areas. Hastings Center board member Richard Payne spoke at the conference. The Center organized a "bioethics breakfast" to discuss ideas for improving end-of-life care, featuring information from *Guidelines*. Leading the discussion were Mildred Solomon, president of The Hastings Center; Blair Sadler, a Hastings board member; and Susan Gilbert, public affairs and communications manager.

David Foster (l.), Sidney Babcock, and Michael Musgrave at a salon in April at the Bailey-Musgrave home in New York.



Ray Philips with Hastings Center board member Liza Bailey at the Bailey-Musgrave home.



▲ Board member Joshua Boger

Peter Hoffman (l.) and William Burbank talk with research scholar Michael Gusmano at The Hastings Center's open house in July.



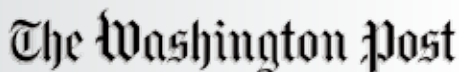
▲ Kevin Brine, Victor Linell, and David Ferry at a salon in October at the home of Hastings Center board member Andy Adelson in New York.



Bill Keller, former columnist and executive editor of the *New York Times*, and Emma G. Keller, an author and host of *The Guardian's* series on lifestyle and well-being, at "Confronting the Aging of American Society."



Karen Rezach (l.), Kathy Hugin, and Herve and Carla Gouraige at the Hakes home.



THE CHRONICLE OF HIGHER EDUCATION



THE HUFFINGTON POST



### Media Highlights

The Hastings Center has longstanding relationships with journalists at leading media outlets. The *New York Times*, NPR, the *Atlantic*, ProPublica, Slate, and BBC are among those that covered the Center and interviewed its scholars in 2013. Topics that received considerable attention were the publication of *Guidelines* and controversial articles in the *Hastings Center Report*. One of those articles was a case study on the ethical propriety of doctors Googling their patients. Another was a commentary on New York Mayor Michael Bloomberg’s attempt to ban large sodas and his other public health policies.

In addition, reporters from around the country sought accurate, trustworthy information from Hastings Center scholars when major news broke with questions about medical ethics. In May, the families of two children in need of lung transplants took legal action to challenge prevailing organ transplantation policy and enable the children to receive adult lungs. Hastings Center President Mildred Solomon was interviewed by *Huffington Post Live* and *Politico*, among other news outlets. In December, reporters from AP and NPR interviewed Hastings Center scholar Nancy Berlinger for a story dominating the news that questioned the meaning of “brain death” and the appropriate use of life-sustaining medical technology. The story involved Jahi McMath, a child who died by neurological criteria, but whose family did not believe she had died and insisted that she remain on machines that artificially sustained her circulation and respiration. Berlinger was able to clarify the meaning of brain death and other points of confusion about the tragedy.

The Hastings Center has recently added another dimension to its press outreach by organizing educational “bootcamps” for journalists. These are workshops about bioethics issues in the news. In 2013 the Center worked with the Association of Health Care Journalists, the premier professional organization of health journalists, to develop three one-hour sessions on end-of-life care and one talk on ethical issues in neuroscience to be presented at the 2014 annual meeting of the association. The need for sessions such as these was underscored by an expert review of 1,889 health stories in the U.S. media that found most of them were unsatisfactory on five or more criteria, including the quality of the evidence and explaining the benefits and harms of particular interventions.

## The Hastings Center 2013 Board of Directors

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Harriet S. Rabb  
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*Wesleyan University*  
Blair L. Sadler  
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### New Fellows

Hastings Center Fellows are an elected group of 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. The following Fellows were elected in 2013.

- Marion Danis, National Institutes of Health
- Steve Joffe, University of Pennsylvania
- Jason Karlawish, University of Pennsylvania
- Eric Kodish, Cleveland Clinic
- Madison Powers, Georgetown University
- James Sabin, Harvard Medical School
- Julian Savulescu, University of Oxford
- Ilina Singh, Kings College London

## Statement of Financial Position *as of December 31, 2013*

*Audited 2013*

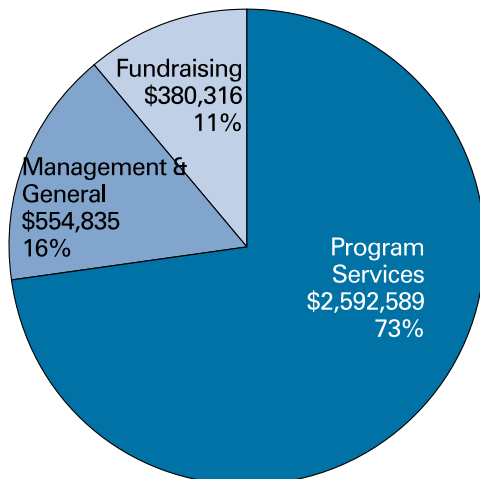
Assets	
Cash and Equivalents	662,177
Investments, at fair value	4,546,073
Receivables (grants and other)	753,514
Other Assets	162,478
Furniture and Equipment (net of accumulated dep)	38,781
Leasehold Improvements (net of accumulated amort)	1,113,778
Total Assets	7,276,801
Liabilities and Net Assets	
Payables and Accruals	82,965
Deferred Revenue	45,886
Total Liabilities	128,851
Net Assets	7,147,950
Total Liabilities and Net Assets	7,276,801

## Statement of Activities and Changes in Net Assets

Operating revenues and other support:	
Grants, Gifts, and Contributions	2,317,880
Government Grants	367,601
Publication Revenue	493,508
Other income	<u>126,894</u>
Total Unrestricted Operating Support and Revenue	<u>3,305,883</u>
Operating Expenses	
Program Services	2,592,589
Management and General	554,835
Fundraising	<u>380,316</u>
Total Operating Expense	<u>3,527,740</u>
Changes in Unrestricted Net Assets from Operations	(221,857)
Changes in Restricted Net Assets from Operations	748,140
Non-operating Income	<u>516,913</u>
Change in Net Assets	<u>1,043,196</u>
Net Assets, Beginning of year	<u>6,104,754</u>
Net Assets, End of year	<u>7,147,950</u>

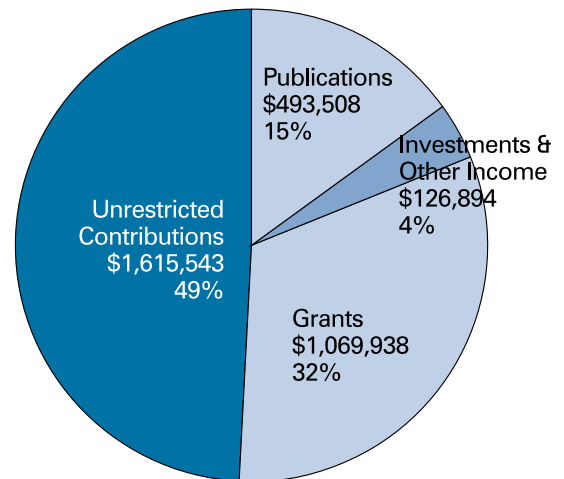
### Operating Expenses

*for the year ended 12/31/13*



### Operating Revenue and Support

*for the year ended 12/31/13*





## Current Staff of The Hastings Center

Mohini Banerjee  
*Research Assistant*

Nancy Berlinger  
*Research Scholar*

Noel Crotona  
*Annual Fund and Marketing Technology  
Manager*

Jodi Fernandes  
*Executive Assistant to the President*

Susan Gilbert  
*Public Affairs and Communications Manager*

Deborah Giordano  
*Accounting Manager*

Michael Gusmano  
*Research Scholar*

Laura Haupt  
*Managing Editor*

Chelsea Jack  
*Research Assistant*

Bill Jeffway  
*Director of Development  
Director of Marketing and Communications*

Josephine Johnston  
*Director of Research  
Research Scholar*

Gregory Kaebnick  
*Editor, Hastings Center Report  
Director, Editorial Department  
Research Scholar*

Karen Maschke  
*Research Scholar  
Editor, IRB: Ethics & Human Research*

Sarah McGraw  
*Director of Program Development  
Research Scholar*

Cathy Meisterich  
*COO/CFO*

Erik Parens  
*Research Scholar*

Vicki Peyton  
*Administrative Assistant to the Research  
Department*

Nora Porter  
*Art Director*

Anne Marie Schoonhoven  
*Circulation Marketing Manager*

Mildred Solomon  
*President & CEO*

Lin Tarrant  
*Finance Assistant*

Siofra Vizzi  
*Assistant to the Director of Development*

Carol Wood-Nutter  
*Director of Grants Management*

Christine Zouzias  
*Administrative Assistant,  
Website Coordinator*



The Hastings Center

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