

THE HASTINGS CENTER
BLUEPRINT FOR THE FUTURE

Visioning Plan - 2012	
5 SUBJECT AREAS	ARCHITECT Hastings Center Scholar
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DATE: 12/30/12	



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

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View of the Hudson River from The Hastings Center looking north across Donnelley Lawn.

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From the President: A Blueprint for the Future



Mildred Z. Solomon
President and CEO

Dear Friends and Colleagues,

What are some of the most pressing societal challenges our nation and the global community face? What are the ethics questions at the heart of those challenges? These questions are ones that Hastings Center research scholars and senior staff asked themselves during a visioning process conducted during the summer and fall of 2012. Through a series of retreats, we identified challenges with pressing ethics questions which the Center was poised to address. Our goal was to say what we think matters, why, and what we are well-equipped to work on.

Five large challenge themes emerged, depicted in the figure on the next page and described on the following pages. In all five areas, The Hastings Center already has considerable expertise. Yet all five also represent open-ended challenges of great complexity, where there is much remaining work to be done. These challenges and the normative questions they raise are our blueprint for the future.

We also reaffirmed the Center's commitment to address these challenges through rigorous scholarship and to bring them into the public square, because for democracy to flourish, citizens must be engaged.

Since its founding, The Hastings Center has been a place where people with diverse views can talk about the most basic questions human beings can ask: How should we live? What is the right thing to do? The Center has asked these questions in the context of advances in the life sciences and the technologies they spawn, care of the sick and suffering, and protection of human and animal research participants.

Figuring out how to live and what to do are difficult questions in part because they conjure apparent irreconcilables: how best to balance personal liberty and community wellbeing? Whose interests to privilege, when resources are limited or when the manmade world imposes on nature? Grappling with these tensions is at the heart of what The Hastings Center is all about.

Now more than ever our society needs a calm oasis for considering these tensions and how best to resolve them. We should expect rational analysis, inclusion of all relevant stakeholders, a willingness to act dispassionately, without regard to self-interest and with respect for divergent views. The Hastings Center has reaffirmed its commitment to these values and identified the challenges to which we will devote our time and talent. There will be many opportunities for you to join with us, and we hope you will.

Sincerely,

A handwritten signature in cursive script that reads "Mildred Z. Solomon". The signature is written in dark ink on a light background.

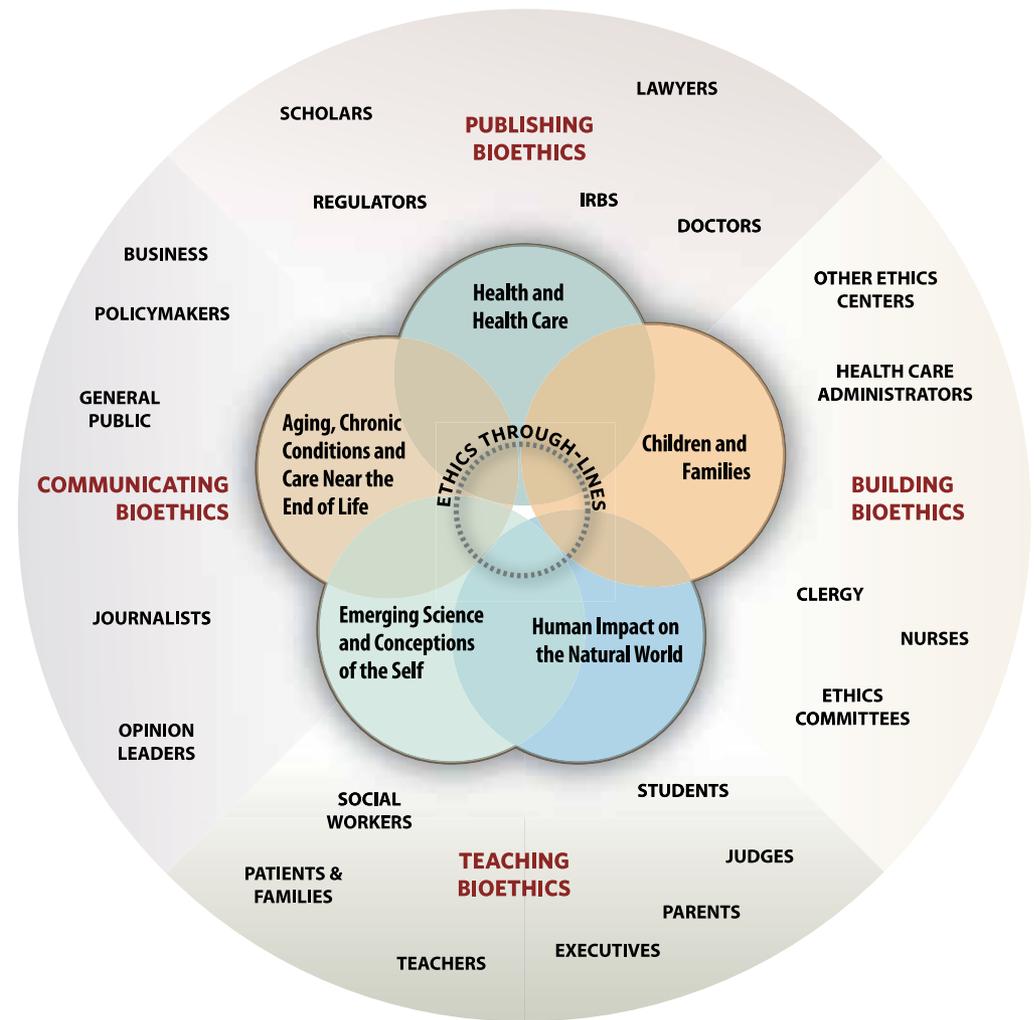
ENVISIONING THE HASTINGS CENTER'S WORK

Under President Millie Solomon's leadership, Hastings Center Scholars, with input from the Fellows, identified five broad areas where the nation and global community face serious challenges and where bioethics can help. The resulting vision creates the blueprint for The Hastings Center's work over the coming years:

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

Given the Center's dual mission of scholarship and public impact, these themes are stated in ways meant to be accessible to educated citizens as well as scholars. Clinical ethics, research ethics, public health ethics and other aspects of bioethics scholarly inquiry arise as through-lines within each of the themes.

Dissemination of our work will reach many kinds of audiences and will be achieved through publishing, communicating bioethics in the public square, teaching bioethics, and building bioethics capacity upon request, such as the consultative work the Center did in helping to launch the first bioethics journal in Asia.



Ethics Through-Lines

- Clinical Ethics
- Cultural-Religious Diversity
- Genetics
- Global Ethics
- Research Ethics
- Professionalism
- Public Health
- Neuroethics



- What are the fairest, most compassionate and cost-effective ways to redesign the U.S. healthcare system?
- How much health care is enough?
- Are there marginally beneficial but extremely expensive treatments that should not be offered? Who should decide?
- How can we better balance investments in public health with investments in health care?

Health and Health Care

This thematic area examines the ethical issues that arise both in the course of enhancing health care delivery systems and improving population health. As health care costs rise worldwide, governments debate whether—and how—they can make health care more affordable, while also improving its quality and safety. At the same time, we know that health care accounts for only a small proportion of health outcomes. Social and economic factors like income and education, the availability of neighborhoods with safe access to the out-of-doors and affordable, healthy foods—as well as the personal choices we make—are far more consequential.

Due in large part to social and economic factors, there is a growing gap between the health of the most privileged and the most disadvantaged members of U.S. society. Yet the gaps between the health of the population in

wealthy nations and the populations of poorer countries are even larger. People live much longer in developed nations, while the populations of developing nations struggle to achieve even the most basic health-related goals—clean water, adequate nutrition, and emergency health care. What do the populations of the developed world owe to those of the developing world?

How we live our lives also affects our health. Obesity is now a problem in rich and poor countries alike. How can we change the unhealthy behaviors of large populations, particularly when education alone has made little difference? Where is the line between empowerment, persuasion and coercion? What role should regulations, environmental redesign and incentives play?

The U.S. health care system provides far greater financial rewards for treating illness than it does for keeping people healthy. In every other developed nation, about half of all physicians work

in primary care, where the focus is on preventing illness as well as treating it. In the U.S., only one third of physicians work in primary care, mainly because specialty care is more highly remunerated.

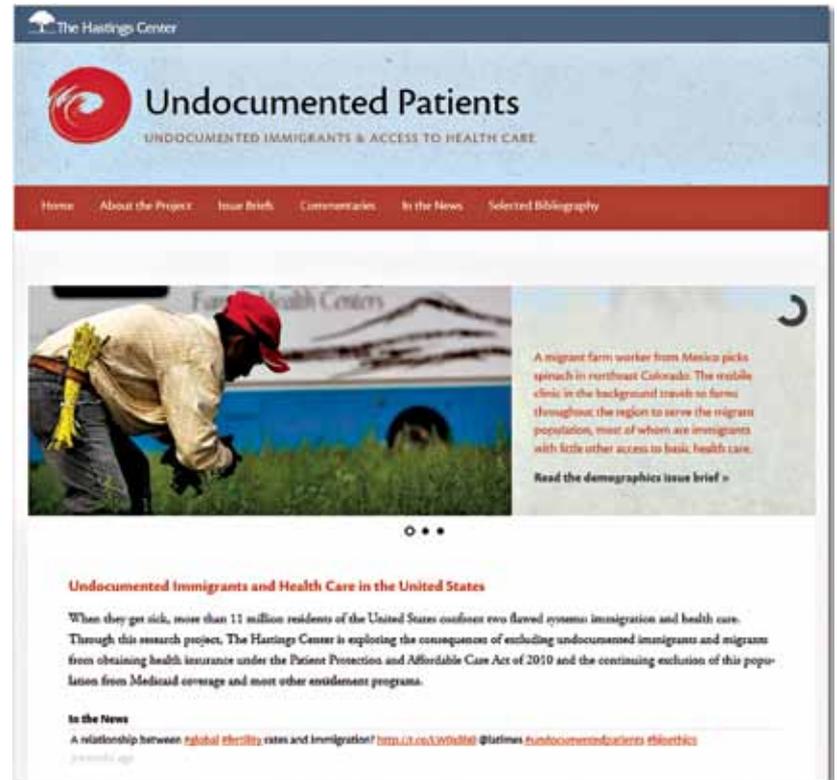
In addition to expanding its focus on prevention, the U.S. health care system must also improve quality and safety and rein in costs. The U.S. spends about double what other developed nations spend with health outcomes that are no better and often worse. Further, health care spending is crowding out other social goods, such as the ability to build a more sustainable environment or to provide effective education of the young, introducing intergenerational inequities. How much health care is necessary for human beings to flourish? To what extent should we pay for marginally beneficial treatments?

Advances in genetics and genomics and in our understanding of the needs

of our aging population will raise still more questions about how best to improve population health and our health care delivery systems. For example, as personalized medicine advances, how will new knowledge about what works best for individual patients affect health care costs, policies about coverage, and community health?

None of these problems is easy. However, all will benefit from careful reflection on how best to balance costs and benefits, safety and risks, competing notions of fairness, and individual rights versus community wellbeing.

The Undocumented Patients Web site (www.undocumentedpatients.org) is part of the Overbrook Foundation funded research project that explored ethical, legal, and policymaking challenges arising when undocumented immigrants living in the U.S. need medical care. It provides statistics, facts, and a wealth of resources geared to journalists, policymakers, advocates, and anyone interested in issues concerning undocumented patients.



The screenshot shows the homepage of the 'Undocumented Patients' website. At the top, it features the logo for 'The Hastings Center' and the main title 'Undocumented Patients' with the subtitle 'UNDOCUMENTED IMMIGRANTS & ACCESS TO HEALTH CARE'. Below the title is a navigation menu with links for 'Home', 'About the Project', 'Issue Briefs', 'Commentaries', 'In the News', and 'Selected Bibliography'. The main content area includes a large image of a migrant farm worker in a red cap and yellow gloves picking spinach in a field. To the right of the image is a text box that reads: 'A migrant farm worker from Mexico picks spinach in northeast Colorado. The mobile clinic in the background travels to farms throughout the region to serve the migrant population, most of whom are immigrants with little other access to basic health care. Read the demographics issue brief >'. Below the image is a section titled 'Undocumented Immigrants and Health Care in the United States' with a paragraph of text: 'When they get sick, more than 11 million residents of the United States confront two flawed systems: immigration and health care. Through this research project, The Hastings Center is exploring the consequences of excluding undocumented immigrants and migrants from obtaining health insurance under the Patient Protection and Affordable Care Act of 2010 and the continuing exclusion of this population from Medicaid coverage and most other entitlement programs.' At the bottom, there is a section titled 'In the News' with a link: 'A relationship between global ethnicity rates and immigration? [@latimes #undocumentedpatients #ethnics](http://t.co/3V0e386)'.



- What are the ethics of creating and caring for children in the 21st century?
- Whose responsibility is it to protect children from the negative health impact of poverty, poor nutrition, violent homes and unsafe neighborhoods?
- If a parent and adolescent have different wishes about continuing in research or treatment for the adolescent's serious disease, should the teenager's wishes outweigh the parent's?

Children and Families

Human beings have long sought to control their reproduction and shape their children's futures. Our power to do this is greater than ever before, and prompts difficult questions about the obligations of individuals, families, and society. What is responsible procreation?

Using assisted reproductive technologies, people who not long ago could only dream of having biologically related children are doing so. There is also a growing global aspect to procreation with a sperm donor from one continent, an egg donor from another and a surrogate mother in still another. People can time and plan their families to a degree unimaginable even a year ago. Egg freezing, until recently an experimental procedure, allows women to preserve their eggs until they are ready to start families. A growing array of tests identifies medical and nonmedical traits in embryos

created through in vitro fertilization, affecting parents' decisions about which embryos to implant. Doctors screen fetuses early in pregnancy for Down's syndrome, other conditions, and for sex, potentially influencing judgments about whether to continue a pregnancy. In the near future, prenatal whole genome sequencing is expected to be less expensive and more available, dramatically increasing the amount of genetic information, ranging from disease risk to indicators of intelligence. How will this affect parenting? How will it add to the tension between parents' interests in learning as much as possible about their children and children's interests in shaping their own futures?

Complicating these questions is the reality that the meaning of much genetic information is unclear. Doctors may determine a child has a chance of developing a particular disease later in life, but they may not know with any certainty

this will happen or which environmental factors will have an impact. Even in rare cases when doctors know a child will fall ill with a particular condition, there is often no cure or effective treatments, raising questions about the value of having such information.

Most of society agrees parents have broad discretion in making decisions for their children. Some decisions are straightforward, and others are agonizing with long-term consequences. When should very premature infants or sick children be allowed to die? Which moods and behaviors in children are problematic and warrant altering with drugs or other interventions? What atypical or unwanted physical characteristics justify using surgery to change them? What role should children have in making their own medical decisions and at what age?

We know children's environments—the foods they eat, the air they

breathe, their neighborhoods, and their schools—dramatically influence their mental and physical health. Beginning before they are born, their environments may be as influential as their genes, often more. As we learn about the importance of these environments, we may ask whether all the responsibilities for raising healthy children should fall to parents alone. What is the role of society—on the local, national, or global level—in setting and implementing standards?

Reproduction and child rearing are fundamental human activities, and they have long been contested. New reproductive and genetic technologies, as well as new knowl-

edge about genetic and environmental influences, intensify the need for reasoned analysis of the challenges posed by creating and caring for children in the 21st century.

Hastings Center Research Scholar Josephine Johnston, speaking on *In Vitro Fertilization and Multiple Births* for a panel at the 2012 American Society for Bioethics and Humanities (ASBH) Conference in Washington, DC.





- What more can be done to ensure that people with chronic conditions, disabilities or in the final stage of life receive the best care possible?
- Should new tests, like ones that identify biomarkers for Alzheimer's disease years before symptoms arise, be broadly promoted, if nothing can be done to prevent or cure the illness?
- What special protections should be in place when we conduct research with aging patients who suffer from dementia and cannot give their consent?

Aging, Chronic Conditions, and Care Near the End of Life

Many ethical issues in medical care result from astounding leaps in life expectancy achieved during the 20th 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 nations—to live much longer. Often, part of a longer life is developing age-related chronic illnesses that people may live with for years.

These illnesses include familiar chronic diseases that are treatable such as diabetes and others that currently are not, such as Alzheimer's. They also include diseases that used to kill patients quickly, like cancer and HIV/AIDS, as well as many physical disabilities and mental health conditions. Low-cost whole genome sequencing may lengthen even further the time people live with chronic illnesses by raising the possibil-

ity of diagnosing some of these conditions decades before we develop them.

Individuals with chronic conditions, long-term injuries, and disabilities face decisions about which treatments to try, whom to involve in medical decision making, how to find the daily support they may need, and when to use or forego potentially life-sustaining technologies. Basic ethical questions—like whether a patient is still able to make health care decisions or live independently—go unaddressed. Those living with chronic conditions may also face profound questions of identity, meaning and uncertainty about goals, arising from aging, illness and impending mortality. Doctors, nurses, nurse practitioners, and physician assistants may be very good at battling disease, but in our current health care system, they struggle to coordinate patients' care over time, especially after a patient leaves the hospital. Patients and their caregivers, often family members, are left trying to manage and finance

increasingly complex care regimens at home. The burdens on family caregivers are enormous, impacting the caregivers' own health and the family's fiscal security.

What does our society owe to those living with chronic conditions? How can we build systems of care that are more responsive? How can we help people "age in place," remaining members of their community within familiar settings for as long as possible?

When it comes to the final phase of life, there has been great progress. We now have good evidence of how best to relieve suffering, provide good palliative care, resolve conflicts, and honor the individual preferences of dying patients, but our health system is slow to incorporate this knowledge. Health care professionals are seldom reimbursed for discussing the end of life with patients, have limited time to address the subject, and often are poorly prepared to talk about such sensitive matters.

They may also be unaware of what is ethically and legally permissible or confused by continuing ethical debates on issues like physician-assisted suicide or determining death in the context of organ transplantation.

As the 21st century progresses and the massive Baby Boom generation ages, health care professionals, patients and families face unprecedented challenges. There will be hard choices to make requiring careful ethical analysis, balancing of stakeholder interests, health care professional accountability, the need for civil discourse in the public square, with wisdom and moral insight.

Hastings Center Scholars are collaborating with researchers at the Centre for Biomedical Ethics at the National University of Singapore to develop best practices in end-of-life care and an online teaching casebook. At a meeting in Singapore are (from right) Alastair Campbell, director of the Centre for Biomedical Ethics and a Hastings Center Fellow, and Hastings Center Research Scholars Nancy Berlinger and Michael Gusmano. Principal investigators from the Centre for Biomedical Ethics are (second from the right) Calvin Ho and (fourth from the right) Jacqueline Chin.





- How will advances in neuroscience and genetics affect our concepts of human agency and free will?
- If brain scans suggest a murderer has brain anomalies consistent with violent tendencies, does this lessen his responsibility for his crime?
- If we discovered a drug that could make us treat others better, should it be offered? Should everyone be required to take it?

Emerging Science and Conceptions of the Self

Advances in genetics, epigenetics, neuroscience, psychology, and computer science are contributing detailed explanations of the mechanisms that underlie human experience. This knowledge poses two related challenges: First, what do these advances tell us about ourselves? Second, if we could use them to better ourselves, should we?

Regarding the first challenge, perhaps no science offers more clues about who we are than neuroscience. It has begun to associate specific characteristics in the brain with inclinations for particular kinds of behavior, such as violence. Does this information suggest our behaviors are predetermined? How does this evidence change our notions of personal responsibility and our long-standing societal debate over free will?

Interpretation of the meaning of neuro-images is fraught with uncertainty, and yet it is increasingly likely that

they will be used as evidence in criminal cases to excuse defendants or reduce their sentences. Findings that link genetic traits with behaviors and emotions may revolutionize how we see ourselves, or prompt us to oversimplify complex relationships among our genes, our environment and how we act.

As for the second challenge, we have always used technology, from foot binding and body piercing to wigs and cosmetics, to change how we appear to others in the hope they will experience us differently and our notion of ourselves will be enhanced. We have enhanced our perceptions, emotions, and functioning more directly by using a variety of substances such as caffeine, alcohol, nicotine, and peyote. Over the last few decades, our arsenal of tools for personal enhancement has grown to include drugs like Prozac, Ritalin, and Viagra, as well as computer-based technologies such as cochlear implants to help the deaf to hear and, most recently, robotic limbs that

patients can move with their thoughts.

Each of these enhancers directly affects how we interact with each other, in school, in sports, and in life in general. Pressures to compete at elite universities, at the highest levels in sports, and in society, in general, where the odds of success are increasingly long are felt by people in the U.S. and the rest of the world. Is it fair to enhance ourselves to gain an edge? What about those who do not have access to enhancements?

We may also gain the power to transform ourselves not to compete, but to bring society together. Some of the most talked-about recent work in neuroscience suggests new drugs may enhance moral behaviors. There is some evidence we can increase trust in others with drugs such as the naturally occurring hormone oxytocin. Other work suggests we might make ourselves less prone to harm others by taking a drug that modulates the neurotransmit-

ter serotonin.

We have always aspired to make ourselves better people, and that's a noble goal. But does the way we achieve these goals matter? Does taking a drug to make ourselves "more moral" diminish or enhance our humanity?

The Hastings Center teamed up with WBGH to produce *Cracking Your Genetic Code*, a NOVA special on new frontiers on genetics and genomic-based medicine that aired in March 2012. The Center organized an advance screening of the show in Washington, followed by a panel discussion. On the panel, below, (from left): Sarah Holt, filmmaker of the show; Francis Collins, director of the National Institutes of Health; Paula Apsell, senior executive producer of NOVA; and Tom Murray, president of The Hastings Center.





- New technologies may help resolve major environmental challenges, but may also pose serious risks to the environment and to human health. How should we think about risk and benefit, especially when so little is known?
- As we consider how to mitigate the effects of global warming, whose interests—from future generations to non-human animals—should be weighed in our deliberations?
- How can scientists study the effects of toxic chemicals such as pesticides without putting healthy adults and children who enroll as subjects of this research in harm's way?

Human Impact on the Natural World

Humans exert great pressure on the natural world. Habitats and species suffer not only from environmental changes caused by industry and technology, but also from the strain caused by the world's massive human population, which has doubled in the past 50 years and is rising rapidly.

At the same time, human health and well-being face huge environmental challenges. Increasingly, these challenges are global in scale such as the relentless rise of greenhouse gases driving climate change, the acidification of the oceans, and shortages of fresh water, fuel, and other natural resources. Local environmental problems such as urban smog, pesticide-contaminated water, and industrial toxins also affect human health and are often sharpest among the most vulnerable in developing countries and disadvantaged populations.

Solutions to these problems must be

multifaceted involving political and institutional change at national and global levels, reduced human demands on the environment, and better technologies to provide water, fuel, and other resources. Genetic engineering (the modification of organisms to serve human ends) and non-genetic forms of synthetic biology (creating artificial and potentially nonorganic life forms) are technologies that may benefit humans and the planet, but they also may pose great risks. If, for example, we can alter a species of algae to produce gasoline, should we? Will introducing it into the environment lead to unforeseen consequences for ecosystems and human health?

Making good decisions about new technologies requires thinking 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?

Considering our deepest philosophical beliefs also will help to clarify our goals and our priorities. Does the concept of nature carry moral weight? What is the proper relationship between humans and nature? Should humans strive to affect nature less, or try to use it for their benefit? Should animals be used to benefit human medical research?

It should be no surprise that harm to nature often results in harm to humans. Pollutants cause health problems, ocean acidification affects the food supply, and climate change may cause unnecessary deaths and widespread social disruptions. Environmental impacts that range from the small-scale (such as patient-friendly design of hospitals or removal of toxic chemicals in our homes) to the large-scale (such as food production and water supply) may benefit or harm our health, sometimes in surprisingly dramatic ways.

Paying attention to human health

and well-being is crucial as we contemplate how to help our environment. An environmental ethic that does not take human health seriously will itself not be taken seriously. There are tradeoffs between protecting the environment and advancing human well-being. Social injustices may arise when certain populations are affected more acutely by harm to the environment. Where do we draw the line between concepts of individual liberty and the common good? How much do we owe to future generations who will inherit the planet we leave them?

The Hastings Center has been studying ethical issues in synthetic biology, a science that seeks to develop organisms and other biological systems that are not found in nature but can serve desired human purposes. At a project meeting at the Center were the project leaders (top row, far left) Tom Murray, President Emeritus and senior research scholar, and Gregory Kaebnick, research scholar; (bottom row, third from left) Michael Gusmano, research scholar; and (top row, third from right) Erik Parens, senior research scholar. Top row, second from right, is Mildred Solomon, Hastings Center President.



Scholarship: Scholars and Research Projects

Nancy Berlinger



Daniel Callahan



Michael Gusmano



Josephine Johnston



Gregory Kaebnick



Sarah McGraw



Karen Maschke



Thomas Murray



Erik Parens



Mildred Solomon



Undocumented Patients: Human Rights, Access to Health Care, and the Ethics of the Safety Net

Nancy Berlinger, Michael Gusmano (Human Rights Program of the Overbrook Foundation)

Ethics of Medical Research with Animals: Science, Values, and Alternatives

Susan Gilbert, Greg Kaebnick, Thomas Murray (The Esther A. and Joseph Klingenstein Fund)

Role of Patients in Drug Regulation

Michael Gusmano, Thomas Murray, and Mary Crowley (California Institute for Regenerative Medicine, Food and Drug Administration; CONNECT, Domain, and the Wireless Health Institute)

Hastings Center Report Special Report: Ethical Oversight of Learning Health Care Systems, Mildred Solomon (AAMC)

Research Methods for Evaluating Patient Health Outcomes in Rare Diseases: Symposium and Special Report

Sarah McGraw (Agency for Healthcare Research and Quality under subcontract from Brigham and Women's Hospital)

The Use of Whole-Exome Sequencing to Guide the Care of Cancer Patients

Sarah McGraw (National Institutes of Health/National Human Genome Research Institute under subcontract from Dana-Farber Cancer Institute)

Accountability and the Role of the Principal Investigator in Multicenter Trials

Sarah McGraw (National Institutes of Health/National Human Genome Research Institute under subcontract from Dana-Farber Cancer Institute)

The Bioethics Project: The Medically Modified Human, Josephine Johnston, Jacob Moses (anonymous donor)

Fertility Treatment and Multiple Births: Ethical and Policy Issues on the Path to a Healthy Singleton

Josephine Johnston, Michael Gusmano, with the Yale Fertility Center (March of Dimes 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 and the Patrick and Catherine Weldon Donaghue Medical Research Foundation; additional support was provided by the donors to The Anika Papanek Memorial Fund)

Development of Best Practices in End-of-Life Care and an Online Teaching Casebook

Nancy Berlinger, Michael Gusmano, Jacob Moses (Lien Foundation under a subcontract from the National University of Singapore)

Challenges of Informed Consent in Return of Data from Genomic Research

Erik Parens (National Human Genome Research Institute under a subcontract from Columbia University)

Center for ELSI Research on Psychiatric, Neurologic, and Behavioral Genetics

Erik Parens (National Human Genome Research Institute under a subcontract from Columbia University)

Advancing Collaborative Genetic Research: Ethical and Policy Challenges

Karen Maschke, Tom Murray (National Human Genome Research Institute under a subcontract from Case Western Reserve University)

Ethical Issues in Synthetic Biology: Four Case Studies

Greg Kaebnick, Thomas Murray, Michael Gusmano, Erik Parens (Alfred P. Sloan Foundation)

Ethics Consultant to the Mayo Clinic Biobank, Karen Maschke (under a subcontract from the Mayo Biomedical Research Ethics Unit)

Returning Individual Genetic Results to Participants in Cohort Studies, Sarah McGraw (National Institutes of Health/National Human Genome Research Institute under subcontract to Dana-Farber Cancer Institute)

Cracking Your Genetic Code: A WGBH/NOVA Production in Association with The Hastings Center

Mary Crowley (Greenwall Foundation; National Institutes of Health under a subcontract from WGBH)

Scholarship: Our Journals, Special Reports, and Books

Our Journals. The Hastings Center publishes two leading journals in bioethics: *Hastings Center Report* and *IRB: Ethics & Human Research*. The *Report*, the Center's flagship journal, is read by a diverse audience, including doctors, nurses, lawyers, and bioethics scholars. *IRB* has a specialized readership of members of institutional review boards that oversee research protocols involving human subjects and research ethics scholars.

Special Reports. Many of the Center's special reports grow directly out of the Center's research projects. For example, The Hastings Center collaborated with the Yale Interdisciplinary Center in Bioethics on a 2011 project on the use of animals in research. Funded by the Esther A. and Joseph Klingenstein Fund, the project investigated alternatives to animal models in biomedical research and resulted in a 2012 special report: *Animal Research Ethics: Evolving Views and Practices*. This report describes arguments for and against using animals in particular kinds of studies, alternative models that might replace animals in some research, and the ways U.S. laws governing animal experimentation can be amended to reduce unnecessary animal suffering.

In 2012, the Center also began publishing special reports as supplements to the *Hastings Center Report*, on topics for which we did not already have a funded project. The goal of these special reports is to provide an opportunity for thought leaders, drawn from Hastings fellows, staff scholars and other national

experts, to serve as guest editors on topics they want to bring to national attention. The Center launched the first of these: *Ethical Oversight of Learning Health Care Systems* to catalyze a national debate on advancing quality improvement research. Co-guest editors Mildred Solomon, Hastings Center President, and Ann Bonham, Chief Science Officer at the Association of American Medical Colleges, invited commentaries to "provoke a national conversation. The challenge is to design oversight that adequately protects patients without impeding the kinds of data collection activities we need to improve health care quality, reduce disparities, and bring down our rate of medical errors."

Books. The year would not be complete without another new book from Hastings Center co-founder, Daniel Callahan, and 2012 saw two new ones: his memoir *In Search of the Good: A Life in Bioethics* (MIT Press) and a collection of his writing, *The Roots of Bioethics: Health, Progress, Technology, Death* (Oxford University Press). These works encompass a half century of Callahan's observations of, and influence on, how we are born, live and die, through the prism of the impact of advances in science and medicine. His achievements have "earned him recognition as one of a handful of thinkers who shaped the second half of the 20th century," writes Jonathan E. Moreno, David and Lyn Silfen University Professor at the University of Pennsylvania.



Scholarship: Visiting Scholars



RUTH HORN

Wellcome Trust Ethics and Society Fellow, Ethox Centre of the University of Oxford - May 2012

Ruth Horn came to The Hastings Center in May

2012 to work on a bi-national comparative research project that explored ethical issues in end-of-life care in France and England. Her review of arguments and legislation on this topic suggested that the English perspective on advance directives was more concerned with the risk that the documents could be misinterpreted, whereas the French concerns focused more on the fear that doctors would become mere instruments for fulfilling patient demands. To gain deeper insight on these perspectives, Horn conducted twenty eight interviews with physicians in each country. She spent her time at Hastings analyzing the data she gathered from her interviews and preparing a paper based on her findings. Horn's research led to a Wellcome Trust Ethics and Society fellowship at the University of Oxford where she continues to explore ethical implications of advance directives in European countries.



WENDELL WALLACH

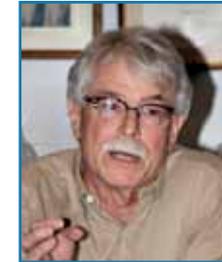
Yale Interdisciplinary Center for Bioethics, Yale University - Recurring Visitor 2012

Wendell Wallach, a scholar at the Yale Interdisciplinary Center

for Bioethics, visited The Hastings Center regularly in 2012. Wallach's research centers on the ethical issues that arise in emerging technologies, for which he is recognized as a leading figure in the developing field of "Machine Ethics." Also known as "Artificial Morality," the study of Machine Ethics aims to incorporate morality into the decision making processes of machines and systems of artificial intelligence. Recently, Wallach created a project proposal related to an executive order from President Barack Obama to limit the creation of machines with the capacity for killing human beings. According to Wallach, this proposal would be "a first step" in pursuing a standard in international law that would prohibit robots from "making decisions" that result in human deaths. Wallach also used his time at the Center to complete a proposal for a book titled, *Navigating the Future*.

On his time visiting with Hastings scholars, including Daniel Callahan and Millie Solomon, Wallach noted, "we began

discussing the prospect of future Hastings Projects that would focus more on the governance of emerging technologies."



BARRY HOFFMASTER

Department of Philosophy, University of Western Ontario - October 2012

Most visiting scholars come to The Hastings Center to explore

moral questions related to specific bioethical issues. However, some scholars pursue their philosophical underpinnings, such as about how we ought to reason on moral and bioethical issues more generally. Barry Hoffmaster, former president of the Canadian Bioethics Society, visited The Hastings Center in October with broader philosophical projects in mind. In his co-written book project with Cliff Hooker, *Re-Reasoning Ethics*, Hoffmaster attempts to bridge the divide between traditional—often highly logical—philosophical approaches to morality with more realistic and common understandings of moral reasoning. In Hoffmaster's presentations at the Center, he described how traditional moral philosophy resists normally experienced concepts such as moral compromise. "Compromise," Hoffmaster explained, "has no place in moral philoso-

phy because it preserves inconsistencies between principles.” Hoffmaster critiques this understanding and argues for a broader, less formal conception of rationality, one that can account for real-life experiences such as moral compromise. In a concurrent project while at Hastings, Hoffmaster also presented his work on the nature of human suffering for an article “Understanding Suffering,” which will appear in an upcoming anthology on suffering and bioethical decision making.



KATIE WATSON

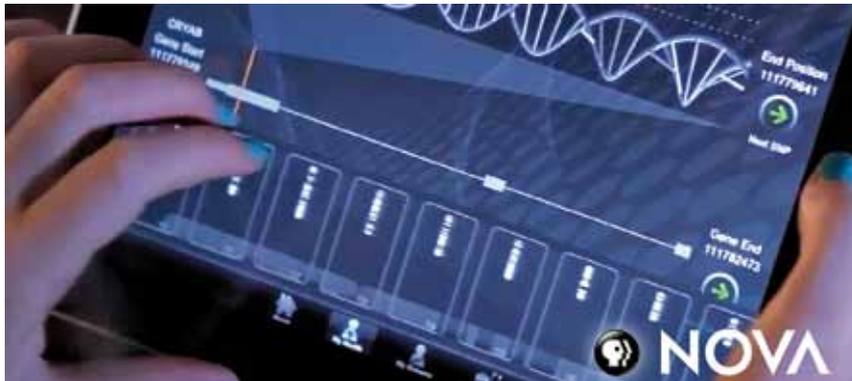
Feinberg School of Medicine, University of Chicago - December 2012

Abortion is one of the most controversial and emotionally charged topics in bioethics. Katie Watson came to The Hastings Center with a project meant to engage with the nuances of abortion practices and to ultimately move the conversation forward to what Watson described as a “next step in its maturity.” According to Watson, the current discussion has, for too long, been a matter of all or nothing—abortion is framed as either “good” or “bad.” In response to this, Watson developed a book project that endeavors

to address the shortcomings in the current discourse on abortion. She argues for a greater effort among bioethicists to move beyond the controversy to explore ethical questions existing within the provision of abortion that have gone largely unnoticed. In other words, Watson signals a need for more ethical conversation on a clinical level that would address the on-the-ground dilemmas that abortion providers and their patients face. “I’ve learned that many abortion providers feel abandoned by ethicists,” said Watson. “My book will demonstrate that a robust ethics discussion needn’t cast doubt on abortion services; instead it supports patients, doctors, and the ethical practice of medicine.”

2012 Visiting Scholars

Kiararash Aramesh	Tehran University of Medical Science, Iran
Joseph Balog	The College of Brockport, NY
Daniel Brauer	University of Gottingen, Germany
Catherine Caldicott	Cazenovia, NY
Stephen Campbell	University of Michigan
Betsy Campbell	Altoona, PA
John Coggon	University of Manchester, UK
Lisa Forsberg	King’s College, UK
Anne-Marie Greaney	Institute of Technology, Ireland
Melinda Hall	Vanderbilt University
Scott Ijaz	Ohio State University
Elizabeth Kitsis	Albert Einstein College of Medicine, NY
Tamara Mann	Columbia University
Sheelagh McGuinness	Keele University, UK
Neil Messer	University of Winchester, UK
Jade (Hyojung) Mo	Arizona State University
Nicolae Morar	University of Oregon
Kieran Owens	New South Wales, Australia
Andrew Peterson	University of Western Ontario, Canada
Henrique Moraes Prata	University of San Paulo, Brazil
David Rodrigues	Instuto de Filosofia, Madrid, Spain
Barbra Rothschild	University of North Carolina, Chapel Hill
Jitka Rusova	Charles University, Czech Republic
Heikki Saxon	University of Tampere, Finland
Rosana Trivano	Instuto de Filosofia, Spain
Yvette van der Eijk	National University of Singapore
Ayesha Verrall	National University of Singapore
Mark Julian Wells	Vanderbilt University
Robert Whiteman	Attorney, Mount Kisco, NY
Kirk Zachary	SUNY Health Science Center



Cracking Your Genetic Code Research Evaluation

The NOVA show significantly increased the general public's awareness of bioethics. A survey assessed changes in awareness and understanding of bioethics, biotechnology, and related issues among several hundred people from the general population and regular PBS viewers before and after watching the show. The number of people from the general population who were "very or somewhat familiar" with bioethics jumped from 40 percent to 67 percent. The number of regular PBS viewers with this much familiarity with bioethics increased from 52 percent to 73 percent. The survey also found that before the show both groups were far more aware of biotechnology than of bioethics, but that after the show that gap disappeared.

As part of its ongoing commitment to bioethics in the public interest, The Hastings Center expanded its channels for engaging varied audiences, including journalists, policymakers, and the general public. Those channels included major events, new publications, and an award-winning television show viewed by millions.

A significant initiative was a collaboration with TEDMED, a vast, multi-disciplinary community of innovators and leaders who share a common determination to create a better future in health and medicine. The Hastings Center worked with TEDMED on its 20 Great

Challenges in Health and Medicine, a year-long imitative that explored America's most confounding health and medical problems by incorporating multiple perspectives to set the stage for effective action. Center co-founder Daniel Callahan, Thomas Murray, then Hastings president, along with Hastings Center board members Alan Fleischman, Richard Payne and Blair Sadler, and Hastings Fellows Bruce Jennings and Carol Levine, were designated experts in the challenges, which

included end-of-life care, the caregiving crisis, and the obesity crisis. The effort culminated in events at TEDMED 2013.

Journalists regularly write about Hastings Center research and interview staff Scholars, but in March 2012 the Center employed a new way to engage journalists: it organized a "bioethics boot camp," a one-day workshop at CUNY Graduate School of Journalism in New York, funded by a grant from the National Association of Science Writers. Hastings Center staff held panel discussion on topics such as conflicts of interest in research and medicine, genetic testing and personalized medicine, and emerging biotechnology. Prominent journalists also participated, including Ivan Oransky, executive editor of Reuters Health and Charles Ornstein, senior reporter at ProPublica. The workshop attracted a capacity group of journalists and journalism students, as well as clinicians. A post-workshop survey of attendees showed a very positive response, with several people expressing the desire for a longer bioethics boot camp in the future.

In addition, the Center launched a new blog, *Over 65*, to give voice to ongoing concerns of an aging population: health, economic well-being, family needs, and values about illness and mortality. It was created by Daniel Callahan with James Sabin, a psychia-

trist and clinical professor of population medicine and of psychiatry at Harvard, and Sherwin Nuland, professor emeritus of surgery at Yale and bestselling author. Over 65 has dozens of contributors, including Nobel laureate David Baltimore and two MacArthur Award Fellows, Hastings Fellow Carol Levine, director of the Families and Health Project of the New York Hospital Fund, and Diane Meier, director of the Center for Palliative Care at Mount Sinai Medical Center in New York.

A major public television program produced by WGBH in association with The Hastings Center aired on March 28, 2012. *Cracking Your Genetic Code*, a NOVA special on new frontiers in personalized genetic and genomic-based medicine, received major funding from the National Institutes of Health and support from The Greenwall Foundation. NOVA is the nation's most watched science series, reaching four million viewers weekly. Partnering with the American Association for the Advancement of Science, a leading professional organization dedicated to advancing science around the world, the Center organized an advance screening of the show in Washington. The screening was followed by a panel discussion that included Thomas Murray, then president of The Hastings Center; Francis Collins, director of the National Institutes of Health; the

filmmaker, and the senior executive producer of NOVA. In November, the NOVA show was awarded the AAAS Kavli Science Journalism Award in the television category.

To strengthen communications with Hastings Center Fellows, the Center began publishing *Currents*, a newsletter featuring new books by Fellows and other news, as well as updates on Hastings Center projects and visiting scholars.

Visitors to the Over65 blog (www.over65.thehastingscenter.org) have found a Web site rife with entries and discussion on topics ranging from end-of-life health decisions and caregiving for the elderly to global aging and ageism, and much more.



To inform the U.S. electorate prior to the 2012 Presidential election, The Hastings Center launched Bioethics 2012 (www.thehastingscenter.org/bioethics2012), a Web site that tracked where President Barack Obama and Governor Mitt Romney, as well as the Democratic and Republican parties, stood on key issues in bioethics. The site contained summary statements on issues such as caregiving; cloning; climate change, health care costs; health care reform, stem cell research, and undocumented immigrants' access to health care. We also used social media to foster conversation on these issues.

The "Next Chapter" Event: Celebrating Tom Murray

Hastings Center Board members enjoying a light moment. L-R, Joseph Fins, Robert Michels, and Willard Gaylin



L-R, Hastings co-founder and president emeritus, Dan Callahan, Board member Pat Klingenstein, and Sidney Callahan



L-R, Research Assistant Colleen Farrell, Barbra and Andy Rothschild and Bill Peace



Hastings Center Board member Gilbert Omenn with president-elect Mildred Solomon



L-R, President-elect Mildred Solomon, Board Chair, David Roscoe, Ethan Berman, and Fiona Hollands



Board members Michele Moody-Adams (l) and Anita Allen (r) with Paul Castellitto



Hastings Fellow Adrienne Asch with Bruce Levin



Guests join in recognizing and celebrating Tom Murray's years of service, with Tom somewhat challenged at being in the spotlight!



Roasting and toasting Tom Murray's Hastings Center career, Center Co-founder Will Gaylin got a very big laugh from Tom in the audience (and Tom's mother Terry in the background)



Campaign Council member Aimee Mullins offers a congratulatory hug to Tom Murray



Board member and campaign chair Joshua Boger announced that the Facing Life Campaign had surpassed \$13 million and that the Thomas H. Murray Fund had reached over \$1 million.

The proud Murray family gathers for the June 7 event: Front Row: Terry Murray, Tom Murray, Cynthia Murray; Back Row: Nicky Turco, Andy Murray, Pete Murray, and Kate Murray



Tom Murray with Hastings Center staff, L-R Research scholar Greg Kaebnick, Director of Public Affairs and Communications, Mary Crowley, Development Assistant, Siofra Vizzi, former Research Assistant, Polo Black Golde, and New Media Director, Jacob Moses

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Yong Loo Lin School of Medicine, National University of Singapore

New Board Members

Liza Bailey



Rebecca Dresser
Washington University School of Law



Kim Kamdar
Domain Associates



Barbra Rothschild
Columbia University



STATEMENT OF FINANCIAL POSITION *as of December 31, 2012*

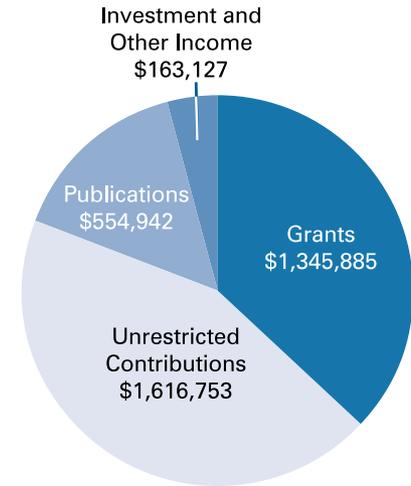
Audited 2012

Assets	
Cash and Equivalents	456,616
Investments, at fair value	3,587,674
Receivables (grants and other)	941,635
Other Assets	88,998
Furniture and Equipment (net of accumulated dep)	51,582
Leasehold Improvements (net of accumulated amort)	<u>1,156,286</u>
Total Assets	<u>6,282,791</u>
Liabilities and Net Assets	
Payables and Accruals	132,662
Deferred Revenue	45,375
Total Liabilities	178,037
Net Assets	<u>6,104,754</u>
Total Liabilities and Net Assets	<u>6,282,791</u>

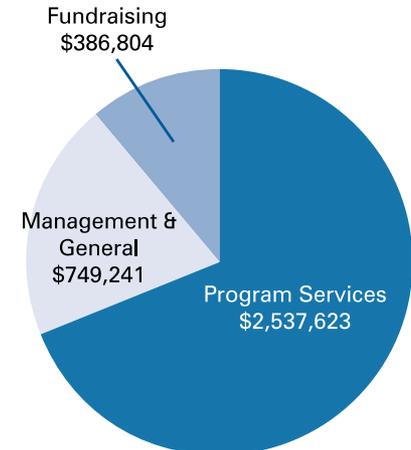
STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

Operating Revenues and Other Support	
Grants, Gifts, and Contributions	2,630,434
Government Grants	332,204
Publication Revenue	554,942
Other income	<u>163,127</u>
Total Operating Support and Revenue	3,680,707
Operating Expenses	
Program Services	2,537,623
Management and General	749,241
Fundraising	<u>386,804</u>
Total Operating Expense	<u>3,673,668</u>
Changes in Unrestricted Net Assets from Operations	7,039
Changes in Nonoperating Income	<u>196,004</u>
Change in Net Assets	<u>203,043</u>
Net Assets, Beginning of year	<u>5,901,711</u>
Net Assets, End of year	<u>6,104,754</u>

OPERATING REVENUE & SUPPORT
for the year ended 12/31/12 = \$3,680,707



OPERATING EXPENSES
for the year ended 12/31/12 = \$3,673,668





The Hastings Center

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Garrison, NY 10524

