

The Hastings Center



Making a Difference

ANNUAL REPORT 2009



The Hastings Center

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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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From the Chair of the Board



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The impact of The Hastings Center is felt every day in people's lives, in communities across our nation, and increasingly in communities around the world. Our 2009 annual report reflects on a year of ***Making a Difference*** in so many ways.

Take a look at the timeline that flows across the next thirteen pages of the book. It will give you a good feel for our deepening involvement with mainstream media and policy-makers. The Center has long prided itself on the broad scope, rich depth, and high quality of our research, and what shines through these pages are the many novel ways these ideas are now impacting the real world. It's become clear that many people care deeply about what we do and what we think, and we're intent on connecting with them in as many new and creative ways as possible.

As I begin my term as board chair, I'm especially proud of a few particular accomplishments in the past year.

We had aspired early on to play a major role in the national health care reform dialogue and debate, which took primary form through two key projects: an essay collection called *Connecting American Values with Health Reform*, and a blog, the Health Care Cost Monitor. In both our essay set and our blog, we were able to maintain our nonpartisan position, and yet, the national dialogue was elevated invaluablely as we brought together multidisciplinary thinking and a broad spectrum of philosophical and political perspectives—continuing hallmarks of The Hastings Center tradition.

We have established formal relationships with Yale's Interdisciplinary Center for Bioethics and with the National University of Singapore's Centre for Biomedical Ethics. Early progress gives us confidence that these two new alliances will allow us to leverage

our own talents and core capabilities, while providing networking opportunities to expand our reach and influence.

The year also saw the inaugural Hastings Center Cunniff-Dixon Physician Awards, offered in collaboration with the Cunniff-Dixon Foundation. The awards aimed to foster exemplary end-of-life care practices in the doctor-patient relationship by recognizing doctors with the essential skills and virtues that embody those practices. The recipients unquestionably deserved recognition, and the enthusiastic national and community reactions to this first set of awards exceeded our expectations.

In June we celebrated our fortieth anniversary at a tribute dinner for our esteemed founders Dan Callahan and Will Gaylin. Forged from their vision in 1969, the influence and reach of The Hastings Center remain unparalleled today.

Finally, I wish to acknowledge and thank my predecessor, Hal Edgar, who retired at the end of 2009 as board chair. Hal was a source of inspiration to both board and staff, his vision and leadership helped us keep pace with a fast-moving world, and his friendship with all of us will endure for many years.

I look forward to my partnership with all members of the Hastings family as we begin the fifth decade in our proud history of making a difference in people's lives.

DAVID L. ROSCOE

From the President



The little Center that could: Not a bad description of The Hastings Center's survival, against all odds, for four decades. The accolades, reminiscences, and hosannas drifted down like gentle spring rain at the celebrations of the Center's fortieth anniversary. Those celebrations included the bestowal of the first-ever Cornerstone Award from ASBH, the American Society for Bioethics and the Medical Humanities, for the Center's unparalleled pioneering role. Forty years ago—and continuing ever since—The Hastings Center has insisted that developments in health, medicine, and the life sciences raise important and complex ethical questions, and that the best answers to those questions are found at the intersection of multiple disciplines and professions.

The Fellows of The Hastings Center, barely a few dozen in the early years, now number 178 strong. A great many of them gathered at the Yale Club in New York City in June to honor the Center and each other's contributions. Listening to the praise for the Center's accomplishments, I felt both grateful and challenged. The challenge is to understand, in light of ever changing environments in scholarship, medicine, and public policy, the best way to keep faith with the Center's mission of creating knowledge and sharing knowledge. I'll mention just a few noteworthy developments in 2009.

Since our last Annual Report, we've begun a systematic exploration of how new media—such as podcasts, Web videos, and social media like Facebook and Twitter—might be used to further our mission. The early results are already visible in a vastly improved Web site, meant to be a superb resource for everyone interested in the issues we cover.

Our historically warm relationship with Yale University led this year to the establishment of the Yale-Hastings Program in Ethics and Health Policy. Center researchers are collaborating with colleagues at Yale on teaching and research. (Negotiations went smoothly once we were able to assure Yale that the Center had no intentions of attempting a hostile takeover.)

Our relationship with the National University of Singapore blossomed into an expanded visiting scholars program for scholars and clinicians affiliated with the NUS Centre for Biomedical Ethics. We've also worked closely with the Centre to help launch an excellent new journal, the *Asian Bioethics Review*, that rapidly established itself as the leading English-language bioethics publication focusing on that region. We continue to explore other possible collaborations, both in Asia and North America.

The little Center that could, far from merely struggling along, is racing ahead at full steam. The challenges for the future include assuring that there's enough fuel for the engine (as in, sufficient money to pay our bills), and always pushing ourselves to find new and more effective ways to fulfill our mission. We can never rest on our laurels, no matter how well deserved for these first four decades. We are eagerly entering the fifth decade running at full speed, full of gratitude to the donors, grantors, and colleagues who make our work possible.


THOMAS H. MURRAY



2009

A Year of Making a Difference

*H*health care reform, the H1N1 pandemic, the new federal policy on stem cell research—these were some of the major headline issues of 2009 in which The Hastings Center had an impact. Hastings Center staff advised policy-makers, informed journalists, and engaged in research whose ultimate aim was to improve people’s lives. A timeline of highlights below shows the ways in which The Hastings Center made a difference. On the pages that follow are descriptions of projects and activities, ranging from an exploration of synthetic biology to efforts to promote better end of life care.

January
February
March

HIGHLIGHTS

	OCTOMOM & ASSISTED REPRODUCTION TECHNOLOGIES	CHILDREN & PSYCHIATRIC DRUGS
 MEDIA	<p>Tom Murray interviewed on NPR <i>Talk of the Nation</i>; Josephine Johnston quoted on <i>am/New York</i>; NBC’s <i>Dateline</i> and CBS’s <i>Dr. Phil</i> show among the media outlets requesting information.</p> <p>“Are Eight More than Enough?” commentary by Tom Murray on CNN.com; Josephine Johnston quoted on MSNBC.com.</p>	<p><i>American Medical News</i> quotes Erik Parens and Josephine Johnston about “zone of ambiguity” in the diagnosis and treatment of ADHD.</p>
 OTHER		



Making a Difference in Research

Uses and Misuses of Neuroimaging

By looking inside the brain with fMRIs and other imaging devices, neuroscientists have made great strides in understanding how the brain works. They have begun to map which areas are active when someone thinks about something, feels an emotion, or tells a lie. But the findings are hyped in the media and exploited for commercial purposes. Companies sell MRIs as the ultimate lie detectors in hope that the evidence will be admissible in court. Today, a growing circle of people are encountering neuro-images, including judges, scholars, and journalists.

Scanning the brain is easier than interpreting what the scans mean, leading many to believe that it is premature to use neuroimaging for commercial and legal purposes. Some critics call the practice “the new phrenology.” A Hastings Center project on the uses and misuses of neuroimaging technologies aims to help people understand what knowledge neuroimages can and cannot impart.

Hastings Center senior research scholar Erik Parens and research scholar Josephine Johnston are leading the project, which includes a working group of neuroscientists and scholars in law and ethics. Parens and Johnston are drawn to issues at the nexus of technology and the human yearning for enhancement. “Neuroimaging captivates people because it seems to uncover how humans think, reason, and experience the world,” Johnston says. “But in our enthusiasm, we may fail to appreciate the complexities of the technology and the human traits it seeks to illuminate. We hope our project can expose that complexity.” The first meeting of the three-year project, funded by the Dana Foundation, took place in January 2009 at the University of Pennsylvania. Topics included what nonexperts believe neuroimages can reveal and the ways that interpretations can be distorted.

“Neuroimaging captivates us because it seems to uncover how humans think, reason, and experience the world. But in our enthusiasm, we may fail to appreciate the complexities of the technology and the human traits it seeks to illuminate.” —JOSEPHINE JOHNSTON

INTERNATIONAL OUTREACH	EMBRYONIC STEM CELL RESEARCH POLICY	ENHANCEMENT
	<i>Slate</i> cites stem cell policy post on the Center’s blog, Bioethics Forum. <i>Washington Post</i> and <i>Boston Globe</i> interview Tom Murray about anticipated new federal stem cell research policy.	NPR’s <i>Radio Times</i> & XM Radio interview Erik Parens on use of memory-enhancing drugs in children; NPR’s <i>On Point</i> interviews Tom Murray on cognitive enhancement. Wired.com interviews Josephine Johnston about risks of popular wakefulness drug. Associated Press interviews Erik Parens on “brain drugs for healthy people.”
The Hastings Center is invited to participate in the Global Alliance of Biomedical Ethics Centers Project (GABEX), a new interdisciplinary international base for bioethics education and research.		



"I hope that our project helps people remember that . . . we know far less than any of us would wish. That shouldn't paralyze us, but it should make us humble as we seek to diagnose and treat."—ERIK PARENS

Psychiatric Drugs and Children: Engaging the Controversies

Concern has been building for years about the appropriateness of the diagnosis and treatment of children who are wild, inattentive, or have other behavioral problems. How accurate are the diagnoses? Are some populations of children overdiagnosed with conditions such as attention deficit hyperactivity disorder (ADHD), while others are underdiagnosed? Particular concern has focused on prescriptions for antipsychotic drugs, which have increased fivefold for children in the last decade and a half and have been linked to thirty-one deaths. Meanwhile, children and their families are suffering and are in need of sound, reliable help.

A Hastings Center project has been exploring the controversies around the use of drugs in treating children's behavioral and emotional disturbances. The project, funded by the National Institute of Mental Health and the Center's Fund for Children and Families, conducted its fifth and final workshop in June 2009. The workshop's objective was to achieve a consensus among a working group of clinicians, researchers, scholars, and patient advocates.

Among the findings was that more research is needed on the comparative advantages of medical, behavioral, and combination treatments. The group also concluded that parents' and physicians' decisions about how to treat childhood psychiatric disorders depend partly on their personal values. On a policy level, the group concluded that the pharmaceutical industry has too much influence over research and that alternatives to the pharmaceutical industry are needed to fund research. Topics of previous workshops included ADHD, bipolar disorder, and depression in children.

Erik Parens and Josephine Johnston, the project's leaders, published a report on ADHD in *Child and Adolescent Psychiatry and Mental Health* in January 2009. "I hope that our project helps people remember that we know far less than any of us would wish," says Parens, who investigates how we use new technologies—including medications—to shape ourselves and our children. "That shouldn't paralyze us, but it should make us humble as we seek to diagnose and treat."

SPORT DOPING

USA Today quotes Tom Murray on the prospect of gene doping and on steroids use in Major League Baseball.

Tom Murray addresses NCAA Convention in Washington on ethics and performance enhancement in college sports; Tom Murray chairs the ethics committee of the World Anti-Doping Agency; Tom Murray is appointed to a panel, "Drugs, Genes and the Future of Sports," at an American Enterprise Institute conference.

HEALTH CARE REFORM

"It Costs More to Treat Cancer" and "How to Control Rising Health Care Costs," commentaries by Daniel Callahan run in the *New York Times* Room for Debate.



Homeland Security and Individual Privacy

How can we protect innocent people from terrorist attacks without violating their privacy? That balancing act has posed a growing challenge since 9/11 and the resulting push for new and better security technology. Most recently, heightened airport security complete with full body scans has raised questions about how long scans of the naked body are kept, how widely they are shared, and whether people are identified. The Hastings Center is one of only two American organizations involved in an international effort called HIDE—Homeland Security, Biometric Identification and Personal Detection Ethics—to develop policy solutions to these and other questions. HIDE’s mission is to set up a platform devoted to the ethical and privacy issues in biometrics and personal detection technologies, which, in addition to full body scans, include digital fingerprinting, iris scanning, and smart cards. HIDE aims to become the world’s preeminent catalyst for innovative policy solutions to emerging ethical problems in the area of surveillance technologies.

Last year was the second of the three-year HIDE project, which is funded by the European Commission. Principle investigators from The Hastings Center are Tom Murray, president, and Karen Maschke, a research scholar. In June 2009, the Center hosted a meeting in Prague on privacy and biometrics. Participants included international experts from data protection organizations, academia, government agencies, and bioethics commissions. Harald Edgar, then-chairman of the board of The Hastings Center, delivered the keynote address on privacy. He noted that Europe is ahead of the United States in thinking about the regulation of data and information sharing, citing the patchwork of state and federal regulations and other obstacles in this country. Maschke moderated a session on DNA databanks for law enforcement. As part of its work with HIDE, The Hastings Center edits and publishes *Dialogue*, a quarterly newsletter that reports on international and local HIDE workshops and news related to biometrics. Maschke serves as editor.

HEALTH CARE REFORM

The Center launches the Health Care Cost Monitor, a blog on cost control in health reform; Health Care Cost Monitor cited as a recommended resource in *Slate* and the *New York Times*; *Connecting American Values with Health Reform*, a collection of essays by staff scholars and other leading experts in health reform, is published.

Daniel Callahan is a panelist on consumer choice in health care convened by the Alliance for Health Reform and Robert Wood Johnson Foundation at the National Press Club.

RED CROSS TORTURE REPORT

NPR’s *All Things Considered* interviews Nancy Berlinger on ethics violations of medics involved in torture.

SPORT DOPING

Tom Murray speaks on antidoping efforts at the American College of Sports Medicine’s annual meeting in Seattle.



“How should we think about technology in sport, whether it be carbon fiber legs or other devices? Paralympians have had to think about these matters far more carefully than most of us.” —THOMAS MURRAY

Sport Doping

Athletes are constantly striving to improve their performance. Pick-up basketball players turn to sports drinks, Olympians to medically monitored dietary supplements. But some performance aids are considered “doping,” and others are not. What’s the difference between a special swimsuit that enables an athlete to slip through the water with less resistance and a drug that boosts endurance?

These and similar questions drive the work of Tom Murray, president of The Hastings Center. Murray’s research on ethical issues in sport goes back thirty years. For the last five years, he has served as chairman of the ethics committee of the World Anti-Doping Agency (WADA), which makes recommendations on the use of drugs and other means of improving athletic performance. Murray’s interest in ethical issues in sport enhancement has been informed by his experience as an amateur athlete—he played basketball for decades and today is an avid cyclist. He came to value the personal effort, practice, and dedication that are manifestations of excellence in sport, and that are undermined by relying on performance-enhancing drugs.

Performance Enhancing Technologies in Sports: Ethical, Conceptual, and Scientific Issues, a book edited by Murray and Karen Maschke, a research scholar at the Center, was published in September 2009 by Johns Hopkins University Press. The book, which is based on a Hastings Center research project completed in 2008, features contributions by scientists, ethicists, and athletes themselves. In 2009, Murray began work on a new book, which he describes as “a clear, forceful statement defending the meaning of sport.” The book, with funding from WADA, will explore ethical issues in sport through the experience of the Paralympics.

“I became interested in the Paralympics for what they can tell us about two central issues,” Murray says. “First, how should we think about fairness in sport when we face a huge variety of physical impairments? Second, how should we think about technology in sport, whether it be carbon fiber legs or other devices? Paralympians have had to think about these matters far more carefully than most of us, including most others involved in sport.”

OCTOMOM & ASSISTED REPRODUCTION TECHNOLOGIES	BIOETHICS LEADERSHIP	H1N1 PANDEMIC & INFECTIOUS DISEASE RISK
<i>Hastings Center Report</i> publishes “Judging Octomom,” essays examining the ethical, medical, and legal issues concerning assisted reproductive technologies; “At Issue: Should egg and sperm donors be paid? Yes,” commentary by Josephine Johnston in <i>CQ Researcher</i> .		<i>American Medical News</i> , <i>Medical Ethics Advisor</i> , and other media outlets interview Tom Murray and Nancy Berlinger; <i>Science</i> contacts the Center for pandemic planning resources.
	Center celebrates fortieth anniversary; Center presents Beecher Award to Alex Capron for lifetime achievements in bioethics; thirtieth annual U.S. Military Academy at West Point/Hastings Center bioethics meeting held.	Tom Murray appointed to the National Institutes of Health Blue Ribbon Panel on Risk Assessment of the National Emerging Infectious Diseases Laboratories at Boston University Medical Center; Hayden Rudy of the Senate HELP Committee contacts the Center for pandemic planning resources.

“Many feel that the organisms made by synthetic biology are unnatural—Frankensteinian—and that creating them amounts to ‘playing God.’” —GREGORY KAEBNICK



Synthetic Biology: Balancing Potential Breakthroughs and Harms

The term “synthetic biology” was probably unfamiliar to most people until the last year or so, when articles started appearing in publications like the *New York Times* and the *New Yorker*. But The Hastings Center was tracking developments in this new science and its potential to profoundly reshape medicine, our environment, and our concept of what is “natural.” Synthetic biology uses genes and strands of DNA from disparate organisms to write new genetic instructions and custom-make all sorts of products. The potential benefits include breakthrough medicines and cheap biofuels, but the risks include bioweapons and unintended ecological damage.

In 2009, as companies were selling DNA over the Internet, The Hastings Center began a two-year investigation, funded by the Alfred P. Sloan Foundation, on ethical issues in synthetic biology, including the concern that it could change the human relationship with nature in ways that are undesirable. Gregory Kaebnick, Tom Murray, and Erik Parens are the principal investigators. The first meeting, which took place at the Center last August, featured presentations by scientists, philosophers, social scientists, public policy experts, and theologians. Topics included public perceptions of synthetic biology and the relevance of moral arguments about nature.

“Many feel that the organisms made by synthetic biology are unnatural—Frankensteinian—and that creating them amounts to ‘playing God,’” says Kaebnick, whose scholarship focuses on appeals to nature and how they matter in public policy. “Our goal is to investigate concerns about synthetic biology and figure out which ones have a legitimate place in public policy.”

In addition, Center scholars’ lectures and publications brought ethical issues in synthetic biology to international audiences. Kaebnick gave a lecture at the University of Freiburg in Germany. Kaebnick and Parens made presentations at the Woodrow Wilson Center in Washington, D.C. Murray spoke at the Royal Society in London. A commentary by Kaebnick in *Nature Biotechnology* asked, “Should moral objections to synthetic biology affect public policy?” The Center’s blog, Bioethics Forum, covered pending guidelines on preventing the sale of DNA to bioterrorists.

EMBRYONIC STEM CELL RESEARCH POLICY

When President Obama lifts the ban on federal funding of embryonic stem cell research, Talk 1410 Radio, WDEL Radio, Wired.com, *Nature*, *Newsweek*, *Boston Globe*, *Washington Post*, Associated Press, *American Medical News*, *Genetic Engineering News*, *The Scientist*, and other media contact the Center for information and interviews.

Josephine Johnston appointed to an embryonic stem cell research oversight committee which oversees ethical use of embryonic stem cells in research. for Weill Medical College, Memorial Sloan Kettering Cancer Center, and The Rockefeller University.

CONFLICTS OF INTEREST

The *New York Times* quotes Josephine Johnston on investigations into financial conflicts of interest of a researcher on pediatric bipolar disorder; Josephine Johnston contributes to an Institute of Medicine report, *Conflict of Interest in Medical Research, Education, and Practice*.



“Research with human biospecimens raises complex ethical, social, and legal questions about access to and control of bodily material: individual autonomy versus public health imperatives, as well as governance of biobanks.” —KAREN MASCHKE

Ethical Use of Human Cells in Research

Henrietta Lacks was a black woman whose cells, taken in the 1950s while she was being treated for cervical cancer, were used in research around the world for decades without her or her family’s knowledge. While this story is now widely considered an example of the unethical use of human biospecimens, many ethical issues remain unresolved, and new ones have emerged. Demand for human cells and tissue is exploding, driven to a large extent by the initiative to achieve personalized medicine, which requires research on the genetic influences on human disease and behavior.

Informed consent is required when biospecimens are collected from people for research, but how effective is it? Can the donor revoke consent for certain types of research? Who has access to the genetic and other personal information that is gained? These and other questions drive the research of Karen Maschke, a research scholar at the Center who specializes in research ethics.

“Research with human biospecimens raises complex ethical, social, and legal questions about access to and control of bodily material: individual autonomy versus public health imperatives, as well as governance of biobanks,” says Maschke. She is involved with the following projects, which deal with the ethical use of human tissue in research, the practical applications of the information gained, and the policy implications.

Cancer Biomedical Informatics Grid (caBIG)TM

The cancer Biomedical Informatics Grid is an information network that enables everyone in the cancer community—researchers, physicians, and patients—to share what they know. Funded by the National Cancer Institute, this collaboration aims to accelerate breakthroughs in the detection, diagnosis, treatment, and prevention of cancer. The resources and infrastructure being developed by caBIG, which are applicable to other diseases, hold promise for improving patient outcomes and helping to make personalized medicine a reality. Maschke’s work involves facilitating data sharing by examining the legal, regulatory, ethical, and other barriers to it and working toward policy solutions. In September 2009, Maschke gave a talk on data sharing

ENHANCEMENT	END-OF-LIFE CARE	NEWBORN SCREENING
The <i>New Yorker</i> cites Hastings Center research on ethical issues in ADHD treatment; the <i>New Yorker</i> interviews Erik Parens on cognitive enhancement drugs; <i>USA Today</i> front-page article cites <i>Hastings Center Report</i> essays on cosmetic surgery in children.	Tom Murray talks on ethical and policy challenges in end-of-life care at the Cunliff-Dixon Foundation 2009 Symposium on Continuing Medical Education on End-of-Life Care at the New York Academy of Sciences.	<i>Ethics and Newborn Genetic Screening: New Technologies, New Challenges</i> , edited by Mary Ann Baily and Tom Murray, is published by Johns Hopkins University Press.

at an annual international conference in London that was organized jointly by the National Cancer Institute and the U.K. National Cancer Research Institute’s Informatics Initiative.

National Cancer Institute Biobank

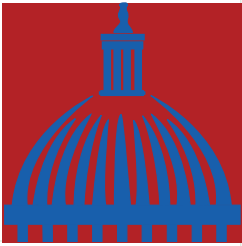
There is a critical shortage of high-quality biospecimens for cancer research. To remedy this problem, the National Cancer Institute is developing the first national, standardized human biospecimen resource in the United States, called the cancer Human Biobank, or caHUB. In the fall of 2009, Maschke was named cochair of the Ethical, Legal, and Social Implications Work Group, charged with developing the ethical, legal, and social foundation for establishing the biobank. The goal is for caHUB to serve as an ongoing source of high-quality human biospecimens and associated data for cancer researchers who are developing new diagnostic tests and therapies.

Law and Ethics of Drug Addiction Genetics Research

What can genetic testing reveal about someone’s risk of drug addiction and abuse? Scientists are just beginning to learn about the genetic basis for addiction. Understandably, drug court judges, corrections officials, and others in the criminal justice system are eager for this information. But this use of the genetic information raises many questions. What is the potential for misinterpretation or misuse? To what extent should genetic information help determine which criminal offenders to test for drug use and subject to drug treatment? Who should have access to this information? What legal protections exist to safeguard individual privacy and help assure that the information is used responsibly?

These questions are the focus of Law and Ethics of Drug Addiction Genetics Research (LEDGER), a joint project of The Hastings Center and several other academic and research institutes. The project, funded by the National Institute of Drug Addiction, aims to produce an educational resource and reference materials for people interested in the ethical, legal, and social implications of genetic information about drug addiction. The target audience includes researchers on drug addiction or genetics, institutional review boards, drug treatment professionals, and criminal justice officials.

EMERGING BIOTECHNOLOGY	GENETIC TESTING	INTERNATIONAL OUTREACH
	NPR’s <i>All Things Considered</i> interviews Nancy Berlinger about a new genetic test on the risk of developing smoking-related lung cancer.	
Gregory Kaebnick and Erik Parens give presentations on synthetic biology at the Woodrow Wilson Center in Washington, D.C.; Tom Murray speaks on controversies in synthetic biology at the Royal Society in London.		Karen Maschke moderates a panel on privacy and security surveillance at the Homeland Security, Biometric Identification and Personal Detection Ethics (HIDE) policy forum in Prague; Tom Murray speaks on democracy, security, and surveillance at the forum.



Health Care Reform

When President Obama made health care reform a national priority, Hastings Center staff discussed how to bring the Center’s expertise with health care issues to bear on the debates taking place in Congress and discussions in the media. Being non-partisan, the Center did not advocate for particular positions or plans, but it identified two areas where it could make significant contributions.

First, Mary Crowley, director of public affairs and communications, proposed an in-depth exploration of the values that Americans appeal to when they talk about their health care system and what changes they would or would not want. People on both sides of the political aisle were invoking values such as liberty and fairness, but they often did so superficially, and only to support their own viewpoints. Crowley wanted to promote a full and honest discussion that did not have a partisan agenda and that could help policy-makers and journalists as they wrestled with the complicated issues on health care reform.

Second, Daniel Callahan, cofounder of The Hastings Center, wanted to take a hard look at health care costs and critically examine the ideas being floated to control them. Callahan has spent decades writing about the dilemmas involved in allocating limited health care dollars for a seemingly unlimited appetite for medical innovation. He had written several books on the subject, and his latest book, on medical technology as a driver of health cost increases—*Taming the Beloved Beast: How Medical Technology Costs Are Destroying Our Health Care System*—was scheduled for publication in fall 2009.

Both of these ideas led to high-impact Hastings Center projects in 2009.

Connecting American Values with Health Reform

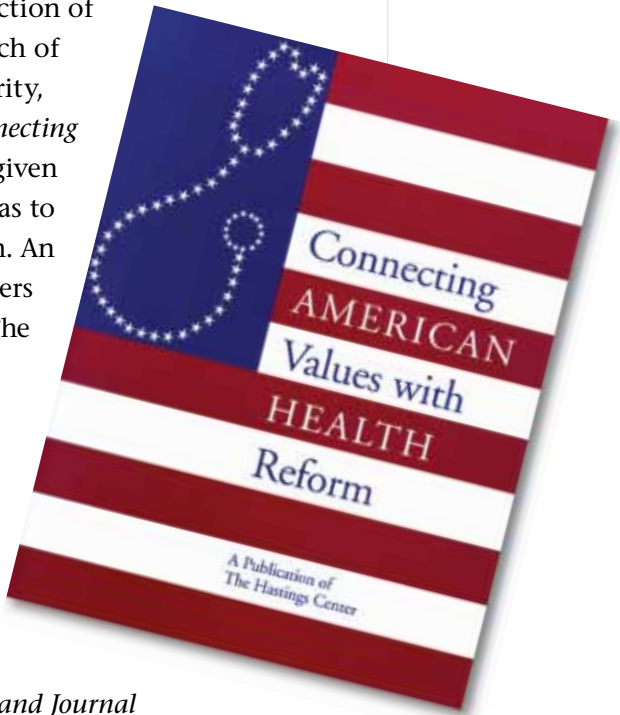
In January, as the debate over health care reform was building and becoming increasingly polarized, The Hastings Center launched a public affairs effort to focus

HEALTH CARE REFORM		GENETIC PATENTING	SPORT DOPING
The Center launches The Values Connection, a blog on values underlying health reform proposals. “Cost Control: Time to Get Serious,” commentary by Daniel Callahan in <i>New England Journal of Medicine</i> ; “Should Government Ration Health Care,” a commentary by Daniel Callahan in <i>Congressional Quarterly</i> ; <i>Newsweek</i> , in two articles, quotes Tom Murray on health care reform.		<i>Scientific American</i> quotes Josephine Johnston on the ethics of patenting genes.	<i>Performance Enhancing Technologies in Sports</i> , edited by Thomas Murray and Karen Maschke, is published by Johns Hopkins University Press.
<i>Taming the Beloved Beast: How Medical Technology Costs Are Destroying Our Health Care System</i> , by Daniel Callahan, is published by Princeton University Press.			

on the values that Americans hold dear in health care. The aim was to get beyond the nuts and bolts of the various reform plans and examine the fundamental and sometimes competing values that underlie any significant social change—and to inject these values into the public debate with a robust outreach strategy. The project was supported by the Adelson Family Foundation and the Cranaleith Foundation.

Crowley, along with Gregory Kaebnick, a research scholar and the Center’s editorial director, and Tom Murray, president, planned a collection of eleven essays by prominent writers and thinkers on health care, each of whom considered a particular value, such as liberty, choice, solidarity, physician integrity, fairness, and affordability. The collection, *Connecting American Values with Health Reform*, was published in June. It was given to key staff on Capitol Hill involved in health care reform, as well as to journalists and foundations, such as the Alliance for Health Reform. An accompanying blog, The Values Connection, drew other stakeholders into the discussion and helped the collection get traction online. The blog was launched in partnership with *Health Affairs*, the leading journal of health policy.

The Values project left its mark. “Values, Health Care Reform, and Universal Participation,” a commentary by Mary Crowley, appeared in the *New England Journal of Medicine*’s September 3 issue. On November 6, NPR’s *Science Friday* radio show aired an interview with Tom Murray on values and health reform, and on the same day, PBS’s *Religion and Ethics Weekly* TV show interviewed Daniel Callahan on the topic. Soon after, the *New England Journal of Medicine* invited Murray to write a Perspective essay on values and health reform; it appeared online on December 23. On the eve of the Senate’s vote on its health reform bill, Crowley sent the essay with personalized letters to Capitol Hill staffers.

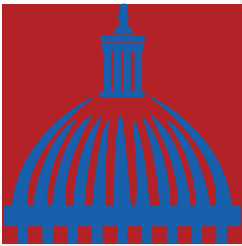


CONSCIENCE CLAUSES	END OF LIFE CARE	EMERGING BIOTECHNOLOGY
<p>NPR’s <i>All Things Considered</i> interviews Nancy Berlinger on repeal of Bush-era regulations allowing health care workers to refuse to assist in abortion.</p>	<p>The <i>New York Times</i> quotes Tom Murray and Daniel Callahan on issues in care of dying patients.</p>	<p>“Should moral objections to synthetic biology affect public policy?” a commentary by Gregory Kaebnick, appears in <i>Nature Biotechnology</i>.</p>
		<p>Gregory Kaebnick is invited to give a lecture on synthetic biology at the University of Freiburg in Germany.</p>

October

November

December



“As the only blog in the country devoted to cost control, the Health Care Cost Monitor provided comprehensive coverage of the main issues, and touched on topics . . . that did not get much thoughtful attention in the reform debate.” —DANIEL CALLAHAN

The Health Care Cost Monitor

Amid the fierce disputes about health care reform, there was one point of bipartisan agreement: something had to be done about health care costs. Daniel Callahan was disappointed in the largely uncritical coverage in the press of the cost control proposals. He searched the health care blogs—increasingly influential sources of information—and was surprised to find none devoted entirely to curbing health care costs. So he decided to start one.

The Health Care Cost Monitor was launched in May as a public affairs and communications project. Leading health policy experts wrote posts. *Slate* named it one of the best online information sources on health care reform, and the Association of Health Care Journalists called it “nuanced and deliberative.” The *New York Times* cited it several times as recommended reading. “As the only blog in the country devoted to cost control, the Health Care Cost Monitor provided comprehensive coverage of the main issues, and touched on topics, such as rationing and cost control efforts in Europe, that did not get much thoughtful attention in the reform debate,” says Callahan.



healthcarecostmonitor.thehastingscenter.org

HEALTH CARE REFORM

NPR's *Science Friday* interviews Tom Murray on values in health reform; PBS Television's *Religion and Ethics Weekly* interviews Daniel Callahan.

“How to Control Rising Health Care Costs,” a commentary by Daniel Callahan, appears in the *New York Times* Room for Debate.

“American Values in Health Care Reform,” a commentary by Tom Murray, appears in *New England Journal of Medicine*; *Health Affairs* quotes Tom Murray on values and cites The Values Connection blog.

The Hastings Center and the American Association for the Advancement of Science convene a Capitol Hill briefing on comparative effectiveness research. On the eve of the Senate's historic vote on health care reform, public affairs staff sent personal emails to Capitol Hill staffers with Tom Murray's *New England Journal of Medicine* commentary on values in health care reform.

NEW MAMMOGRAPHY GUIDELINES

Bioethics Forum post exposes conflicts of interest among the critics of the new guidelines; *Health Reform Watch* and *Prevention Matters* cite Bioethics Forum post.

Los Angeles Times and other publications interview Nancy Berlinger.



Improving Care of Seriously Ill Patients

Since its beginning, The Hastings Center has been a pioneer in efforts to improve care of the dying, and its influence continues to be recognized. “Its thinking underlies the momentum of the recent growth in the palliative care continuum,” write the authors of *Palliative Care: Transforming the Care of Serious Illness*, a new book by leaders in the field, referring to a 2003 Hastings Center report on access to hospice care.

In 2009, the Center continued its work in end-of-life care with a focus on previously unrecognized populations and new issues. It undertook a project aimed at improving palliative care for a population that many people are uncomfortable thinking about but who are in great need: dying children. The Center also neared the completion of an ambitious update of its landmark *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*. Finally, it launched an annual award to recognize doctors who deliver exceptional care to terminally ill patients.

Palliative Care for Children

Over the last few years, pediatric palliative care has become a distinct specialty. Professional chaplains are pediatric palliative care providers. They give solace to seriously ill children and their families. They also collaborate with physicians and nurses to care for children coping with pain or the side effects of treatment. Chaplains’ insights, therefore, may help improve the quality of pediatric palliative care. In March 2009, The Hastings Center and Rush University Medical Center began a project that aims to help chaplains learn how to improve the quality of the care they provide. Nancy Berlinger, deputy director of The Hastings Center, is the investigator on the project, which is funded by Texas Children’s Hospital.

The project will identify programs that can serve as models for the involvement of chaplains in pediatric palliative care. The investigators will use Web-based and print methods to disseminate practical recommendations that chaplains can use to improve the quality of their work with children and their families. Berlinger gave a preliminary report on the project’s findings at the Conference on Spirituality in Pediatrics: Transforming Care for Children, held in Houston in October.

END-OF-LIFE CARE	RESEARCH ETHICS	CONFLICTS OF INTEREST
Southern California Public Radio interviews Daniel Callahan on end of life care, rationing, and health care reform; CBS’s <i>60 Minutes</i> contacts the Center for information on ethical issues.	“Biobanks: Questioning Distinctions,” a letter by Karen Maschke, appears in <i>Science</i> ; the <i>New York Times</i> cites the Center’s <i>IRB: Ethics & Human Research</i> on bending the rules in clinical trials.	The <i>Chronicle of Higher Education</i> quotes Tom Murray on conflicts of interest in medical research.
The Hastings Center Cunniff-Dixon Physician Awards launched to honor doctors for exemplary care at the end of life.	Karen Maschke named cochair of the National Cancer Institute’s Ethical, Legal, and Social Implications Work Group, charged with helping to develop the ethical and legal basis for the first national human biobank for cancer research.	



Guidelines on Decision-Making Near the End of Life

The ethical issues in end-of-life care have grown far more complex since 1987, when The Hastings Center published the first clinical guidelines on end-of-life care,

Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. Back then, the overarching concerns were getting terminally ill patients to make their wishes about life-prolonging treatment known, getting doctors to honor those wishes, and establishing an ethical and legal foundation for withholding or withdrawing futile care. The Center's *Guidelines* helped start the widespread establishment of advance directives and the movement for better palliative care. The Center is updating and expanding its historic *Guidelines* with funding from the Donaghue Foundation and Sussman Charitable Trust. It will include new information on decision-making for terminally ill children and teenagers, the psychological dimensions of decision-making at the end of life, and discussion of specific life-sustaining treatments. Nancy Berlinger conducted the final meeting of the project staff and working group in 2009. The guidelines are scheduled for publication in 2011.

Journalist in Residence: Jane Gross



In June 2009, Jane Gross was named the first journalist in residence at The Hastings Center. A longtime award-winning reporter for the *New York Times*, Gross launched the *Times*'s popular New Old Age blog, which focuses on the elderly and their adult children who care for them. During her three months at the Center, Gross was completing a book on caregiving at the end of life, in part a memoir of her experience caring for her mother and in part a journalistic investigation into the state of end-of-life care in America today. As part of her residency, she gave a public talk on end-of-life care and advised on some posts for the Health Care Cost Monitor.

GARDISIL APPROVED FOR BOYS

Wall Street Journal and other media interview Nancy Berlinger on controversies around the use of this vaccine for cervical cancer.

BIOETHICS LEADERSHIP

The Hastings Center receives the inaugural Cornerstone Award from the American Society for Bioethics and Humanities for helping to shape the field of bioethics and medical humanities.

CHILDHOOD OBESITY

Los Angeles Times quotes Erika Blacksher on social determinants of childhood obesity.

ASSISTED REPRODUCTION TECHNOLOGIES

"The Trouble with Twin Births," commentary by Josephine Johnston, appears in the *New York Times* Room for Debate.

The Hastings Center Cunniff-Dixon Physician Awards

While strides have been made in palliative care, all too many people still suffer physical and emotional pain as death approaches. Patients and their families often feel abandoned by their doctors, who are at a loss for how to talk to or help them. And yet, there are doctors with an awe-inspiring gift for compassionate care—listening to patients and their families, honoring their wishes, and providing great comfort. The Hastings Center and the Cunniff-Dixon Foundation joined forces in 2009 and created the Hastings Center Cunniff-Dixon Physician Awards to recognize those doctors and to advance their skills and virtues. The Cunniff-Dixon Foundation was founded by Matthew A. Baxter in honor of his wife, Carley Cunniff, who died of breast cancer, and her attending physician, Peter S. Dixon.

To select the recipients of the inaugural award, The Hastings Center convened a committee of four physicians who are themselves leaders in end-of-life care, including Richard Payne, Esther Colliflower Director of the Duke Institute on Care at the End of Life and a Hastings Center board member. From more than one hundred nominees, the committee selected five winners. The awards were made in two categories: an established physician category for leadership in end-of-life care, and an early career physician category for serious commitment to the field and contribution through practical research or clinical work. The winners were selected in December. The Hastings Center announced the winners in January 2010 and participated in local awards ceremonies for each of them.

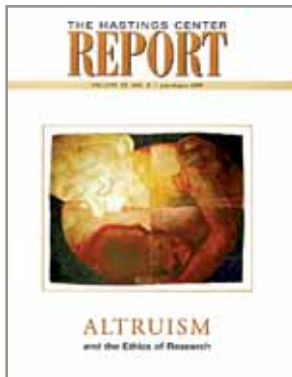
“The awards not only honor the achievements of these fine doctors, but also advance the reach and prestige of the field of palliative and end-of-life care and its power to achieve true holistic, high-quality, patient-centered care,” says Payne. The awards will be given again in 2010.



“The (Cunniff-Dixon) awards not only honor the achievements of fine doctors, but also advance the reach and prestige of the field of palliative and end-of-life care and its power to achieve true holistic, high-quality, patient-centered care.” —RICHARD PAYNE

Making a Difference through Words

Leading Bioethics Publications



The Hastings Center publishes two of the leading bioethics journals: the *Hastings Center Report* and *IRB: Ethics & Human Research*. Thousands of subscribers paid for full access to the journals, and select content reached more than 500,000 readers around the world in 2009. Also in 2009, the *Asian Bioethics Review*, a bimonthly online journal published by the National University of Singapore with the Center's editorial guidance, completed its first year. The *Asian Bioethics Review* features original articles, as well as select articles from the *Hastings Center Report*, and is part of a broader collaboration between The Hastings Center and the National University of Singapore's Centre for Biomedical Ethics to expand bioethics scholarship in Asia.

The *Hastings Center Report*, published since 1970, is read by physicians, lawyers, and other professionals drawn to its mix of clinical case studies, research reports, and essays on issues in medicine, health care, public health, and the life sciences. Highlights of 2009 included “Judging Octomom,” a collection of essays on the ethical controversies in assisted reproduction exposed by the birth of octuplets earlier in the year. Three other essay sets were published around newsworthy subjects: cosmetic surgery and other medical enhancements in children, comparative effectiveness research, and The Hastings Center's fortieth anniversary.

IRB: Ethics & Human Research covers topics in research with human subjects, including informed consent and financial conflicts of interest between industry and researchers. Its readership includes administrators and members of institutional review boards, as well as researchers and scholars. Several articles in 2009 attracted wider attention. For example, a report on how researchers bend the rules in clinical trials to favor certain human subjects—and how this practice may compromise the scientific results—was cited in the *New York Times*.

Bioethics Forum, the Center's online publication covering topical issues in bioethics, marked its third year in 2009 with a readership of 50,000 unique visitors (and 200,000 page views). “Lavish Dwarf Entertainment,” an essay about a dwarf who has sparked controversy by running a company that hires out dwarfs for entertainment, was selected for *Best Creative Nonfiction 2009*.

New Media

The Hastings Center firmly established its capacity to use new media to enhance its ability to engage its target audiences of friends, scholars, journalists, and policy-makers. In August 2009, Jacob Moses was named new media director. Moses, formerly a research assistant, made technical upgrades that have drawn the Center's audiences into rich conversations on its blogs. Moses also began producing videos of Hastings Center activities and events and podcasts by the journals' editors. He has used social networking tools such as Twitter to communicate news about the Center's scholars and publications. Further enhancements are planned for 2010.



Making a Difference through Partnerships

Yale-Hastings Program in Ethics and Health Policy

The Hastings Center and Yale University have a long history of collaboration. Hastings Center scholars have taught courses at Yale, and Yale scholars have participated in Hastings Center research. In January 2009, the two institutions formally joined forces, creating the Yale-Hastings Program in Ethics and Health Policy. The collaboration is designed to increase the range, depth, and impact of both bioethics programs. Daniel Callahan, who earned a bachelor's degree from Yale, is codirector of the Yale-Hastings Program, along with David Smith, director of Yale's Interdisciplinary Center for Bioethics. Michael Gusmano, a Hastings Center research scholar, is the deputy codirector.

The Yale-Hastings program's inaugural event, which took place at the Yale School of Public Health in April, explored health care reform in the United States from the perspectives of history, politics, economics, and values. In addition, Hastings Center research scholar Nancy Berlinger taught a course on health care ethics in Yale's program in Nursing Management, Policy, and Leadership. Hastings Center and Yale scholars are working together on two research projects: one on post-traumatic stress syndrome and the other on human subjects research involving food and nutrition.



Top: Audience members at the first Yale-Hastings Program meeting. *Bottom:* Nancy Berlinger, Hastings Center deputy director (left), converses with David Smith, Yale Bioethics Center director (right).

People Making a Difference

HASTINGS CENTER BOARD AND STAFF—2009

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Administrative Assistant

Working lunch. Hastings Center board and staff members discuss health care reform.





Michael Gusmano



Lyn Traverse



David Roscoe

New Staff and Board Leadership

As 2009 drew to a close, The Hastings Center hired two staff members and approved changes to its board of directors. Michael Gusmano joined the Center as a research scholar. A political scientist, Gusmano investigates health equity in the United States and abroad. His work at the Center will focus on health policy. Lyn Traverse became director of development early in 2010. Previously, she was campaign director for the Friends Seminary, a Quaker school in New York, and did fundraising and development work for New York University, University of Hartford, Saint Joseph College, and Long Wharf Theater.

In December 2009, Harold Edgar stepped down from The Hastings Center board after fifteen years of service, the last five years as its chairman. Edgar, the Julius Silver Professor in Law, Science, and Technology at Columbia University, had worked with the Center for decades and was elected a Fellow in 1972. David Roscoe was named the new chairman of the board. Roscoe is a retired executive from RiskMetrics Group, which he joined in 2003. Previously, he was a chief executive officer of Bridge Information Systems and a managing director of J.P. Morgan. Roscoe joined The Hastings Center board in 2004 after becoming increasingly interested in the many perplexing ethical questions surrounding advances in science, medicine, and technology.

New Hastings Center Fellows

Hastings Center Fellows are an elected association of scholars who have made major contributions to health, medicine, and the life sciences. Eight new fellows were elected in 2009.

Abdallah Daar is a professor of public health sciences and of surgery at the University of Toronto. He is also a senior scientist and director of the Program on Ethics and Commercialization of the McLaughlin-Rotman Centre for Global Health and director of ethics and policy at the McLaughlin Centre for Molecular Medicine.

Christopher H. Evans is an internationally known chemist and molecular biologist at Harvard Medical School. His research broadly relates to biotechnology, with special emphases in genetics and gene therapy. He has a deep commitment to the work of The Hastings Center.

Atul Gawande is a Harvard surgeon and staff writer at the *New Yorker*. He is a nationally recognized commentator on error and performance in clinical medicine and on policy issues related to health care services. A MacArthur Award recipient, Gawande is the author of two recent bestselling books, *Complications* and *Better*.

Diego Gracia is a professor of the history of medicine and bioethics at the Complutense University in Madrid. Trained in psychiatry and history, Gracia is a prolific author and is widely recognized as “dean” of the field of medical history and ethics in Spain and Latin America.

Mats G. Hansson is the director of the Centre for Research Ethics & Bioethics at Uppsala Universitet in Sweden. He has conducted extensive research in bioethics as principal investigator in several multidisciplinary research projects dealing with issues such as the ethical, social, and legal aspects of genetic diagnosis in clinical practice, the use of human tissue materials in research, and empowerment in outpatient care as a means to achieving systemic efficiency.

Karla Holloway is the James B. Duke Professor of English and a professor of law at Duke University, with appointments in the law school and in the departments of women’s studies and African and African American studies. A former cochair of the Black Faculty Caucus at Duke, she is widely recognized as a leader in bioethics at the intersection of law and the humanities, and for her talents as a writer, mentor, and an advocate.

Lainie Ross is a general pediatrician and a medical ethicist in the MacLean Center for Clinical Medical Ethics at the University of Chicago. She serves on the American Academy of Pediatrics Committee on Bioethics and the Section of Bioethics. Her interests are research ethics, genetics and ethics, transplant ethics, and pediatric ethics. She is the author of *Children in Medical Research: Access Versus Protection* and is working on a book about ethical issues in newborn screening.

Paul Root Wolpe is the Asa Griggs Candler Professor of Bioethics, the Raymond F. Schinazi Distinguished Research Chair in Jewish Bioethics, a professor in the departments of medicine, pediatrics, and sociology; and director of the Center for Ethics at Emory University. He serves as the first chief of bioethics for NASA, is coeditor of the *American Journal of Bioethics* and sits on numerous editorial boards for journals of medicine and ethics. Wolpe’s scholarship focuses on the social, religious, and ideological impact of technology on the human condition and has had a particular impact on the field of neuroethics.

40th Anniversary Celebration

JUNE 10, 2009 • YALE CLUB OF NEW YORK



Cofounder and honoree Daniel Callahan with former board member Sissela Bok



Cofounder and honoree Willard Gaylin with Peachy and Robert Murray, a Hastings Center Fellow



Board member Patricia Klingenstein, honoree Daniel Callahan, and Frank Gump

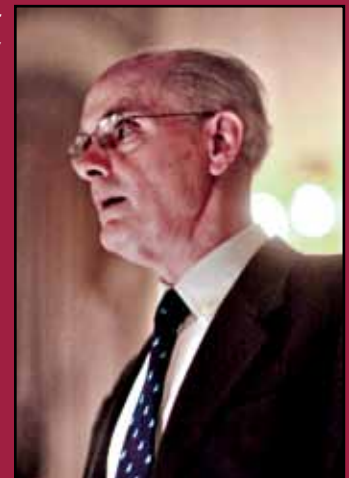


Chair of the Board Harold Edgar with Jacqueline Weld, Rodman Drake, and Annalu Ponti



Board members Joshua Boger (left) and David Roscoe (right) with Frank Gump

Hastings Center President Thomas Murray



Hastings Center Distinguished Scholar Sidney Callahan and former board member Irene Crowe



*Gratitude is not only the greatest of virtues,
but the parent of all the others. —Cicero*

Considering a Bequest for The Hastings Center

If you value the work of The Hastings Center, you can help provide for its future through a charitable bequest. The decision to include The Hastings Center in your will can be a meaningful way to support the Center's unparalleled mission.

Whether your interest is in end-of-life care, clinical trials, or emerging technologies that aren't even yet on the radar screen, you can choose *now* to ensure that the world of bioethics remains fertile in the *future*, through a bequest.

What Is a Charitable Bequest?

A bequest is a gift made through a will, testamentary trust, or codicil to a will or trust. Bequests may include cash, marketable securities, closely held stock, real estate, or tangible personal property.

Why Are Bequests So Popular?

- Bequests enable donors to maintain ultimate control of their assets. A bequest does not affect your assets or cash flow during your lifetime. It is revocable, allowing you to change the provisions in your will or trust at any time. It is private and will not be filed or made public until your death.
- A bequest can allow donors to make much larger gifts than they could during their lifetimes. This is particularly appealing to donors who want their gifts to “amount to something” but haven't the means to make a substantial current donation.
- Bequests also provide the opportunity to honor or memorialize a loved one through the establishment of a testamentary named fund. They enable donors to avoid federal and state estate taxes. As with other financial decisions, it is important to consult legal counsel to maximize the benefits of your estate planning.
- A bequest increases your giving options.
Your bequest can be for a **specific gift** to The Hastings Center (“I give and bequeath the sum of _____ dollars.”) or it can be for a **percentage** of the balance remaining in your estate after taxes, expenses, and specific bequests have been paid—what's known as the residue (“I give, devise, and bequeath ____% of the rest, residue, and remainder of my estate.”).
- And finally, bequests allow you to decide what your legacy will be and the kind of impact you will have on the future. Whether you choose to make your bequest unrestricted or earmark it for endowment or a specific program, you will have the comfort of knowing that your gift will be carefully stewarded and that it will live on, providing support for years to come.

Your decision to provide for a bequest now will make a *real* difference for the future of The Hastings Center and the future of bioethics. To learn more about how to take advantage of this gift opportunity, please contact Lyn Traverse, director of development at traversel@thehastingscenter.org or 845-424-4040, ext. 230.

STATEMENT OF FINANCIAL POSITION

As of December 31, 2009

	Audited 2009
Assets	
Cash and Equivalents	264,006
Investments, at Fair Value	3,618,703
Receivables (Grants and Other)	944,610
Other Assets	40,717
Furniture and Equipment (Net of Accumulated Dep)	51,834
Leasehold Improvements (Net of Accumulated Amort)	<u>1,294,831</u>
Total Assets	<u>6,214,701</u>
Liabilities and Net Assets	
Payables and Accruals	70,114
Deferred Revenue	162,416
Total Liabilities	232,530
Net Assets	<u>5,982,171</u>
Total Liabilities and Net Assets	<u>6,214,701</u>

STATEMENT OF UNRESTRICTED ACTIVITIES AND CHANGES IN NET ASSETS

Unrestricted Operating Support and Revenue:

Grants, Gifts, and Contributions	2,680,280
Government Grants	176,699
Publication Revenue	615,550
Other Income	<u>194,907</u>
Total Unrestricted Operating Support and Revenue	<u>3,667,436</u>

Operating Expenses

Program Services	2,372,442
Management and General	391,502
Fundraising	<u>367,970</u>
Total Operating Expense	<u>3,131,914</u>

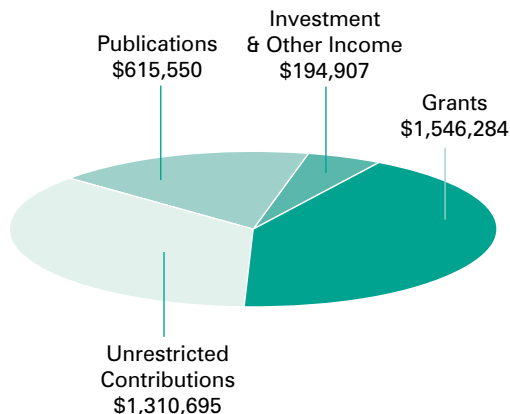
Changes in Unrestricted Net Assets from Operations	535,522
Changes in Unrestricted Nonoperating Income	<u>237,782</u>
Changes in Unrestricted Net Assets	<u>773,304</u>

Changes in Temporarily and Permanently Restricted Net Assets	<u>(785,901)</u>
Changes in All Net Assets	<u>(12,597)</u>

Net Assets, Beginning of Year	<u>5,994,768</u>
Net Assets, End of Year	<u>5,982,171</u>

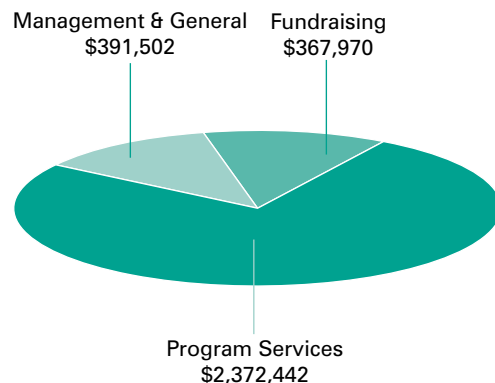
UNRESTRICTED OPERATING SUPPORT AND REVENUE

For the year ended 12/31/09 = \$3,667,436



OPERATING EXPENSES

For the year ended 12/31/09 = \$3,131,914



2009 Annual Report

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To obtain a copy of The Hastings Center's complete financial statement for 2009, please write to the Development Department, The Hastings Center, 21 Malcolm Gordon Rd., Garrison, NY 10524.

