

THE HASTINGS CENTER
ANNUAL REPORT 2010



Building...

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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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The Hastings Center

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WHAT DO WE BUILD?

We don't churn out widgets or erect skyscrapers. But the products of our labor are tangible, and they improve sight lines in meaningful ways.

What we build is knowledge. It is knowledge that informs the ways that patients and doctors talk to each other and think through the options for care. It helps policymakers to make sense of potential benefits and harms posed by emerging technologies. It is a trusted resource for journalists writing about complex and controversial topics, such as synthetic biology, the increased prescribing of psychiatric drugs to children, and genetics research. It enriches scholarship in the sciences and the humanities. It is knowledge about ethical issues in medicine, the life sciences, and the environment.

Our toolkit for building knowledge is The Hastings Center methodology, a highly effective technique developed by the Center's founders more than 40 years ago. It involves reaching out to people from different disciplines who have very different points of view and bringing them together for respectful discussions about pressing biomedical issues. These are the kinds of issues that spark heated opinions and too often have people talking past each other instead of listening to one another. The Hastings Center methodology breaks that logjam. Conversations flow, understanding improves, and debates move forward. Consensus is often reached.

"I marvel at all that happens at The Hastings Center," says David Roscoe, who completed his first year as chair of the Board. "Whether it is the energy and excitement around a new research project—and, having sat through a two-day synthetic biology meeting, I know firsthand the richness of the work—or a major contribution to the thornier questions surrounding health care costs, The Hastings Center is making a real difference. I am deeply proud of their work and my affiliation with this fine group of scholars."



WHO ARE THE BUILDERS?

The builders at The Hastings Center include an interdisciplinary group of research scholars who come from the fields of philosophy, social psychology, law, political science, theology, and English literature. The builders also include the worldwide network of Hastings Center Fellows, an elected association of 182 leading researchers in bioethics-related fields, nine of whom were welcomed in 2010. The following pages describe what the Center's research scholars built in the last year.

"This was a year of many accomplishments for The Hastings Center—no surprise given the tremendous talent and dedication of our research scholars, leadership team, Board, and Fellows," says Thomas Murray, president. "It was my 12th year as president, and each year we continue to build on past achievements and create new ways of fulfilling our mission."

In addition to its fine scholars, the Center has other kinds of builders. Experts in public affairs, publishing, and new media build the audiences for the new knowledge that is developed here. They produce the publications, blogs, videos, and other communications channels for disseminating it.

No knowledge-building enterprise would be complete without an expert development team and dedicated Board of Directors to build for its future. In December 2010, the Center publicly launched Facing Life: The Campaign for Bioethics, a comprehensive campaign to raise \$20 million. As the year drew to a close, a case statement neared completion that captured the intellectual and emotional force of the Center's work.

"Facing Life: Campaign for Bioethics is a defining moment in the Center's history," says Joshua Boger, the campaign chair and a Board member. "We strive to build a permanent culture of philanthropy to reinforce our existing strengths while providing the essential underpinnings critical for future projects. Every 'brick' in this 'building' program adds heft and weight to The Hastings Center."



MICHAEL GUSMANO

“The World Cities project looked at the extent to which different cities deliver care on the basis of need, rather than on how much money you have or where you live.”

Gusmano, a political scientist, joined The Hastings Center in January 2010, and the timing could not have been better. He arrived when the debate over health reform legislation in this country had become exceptionally heated and polarized. His research has provided much-needed perspective.

Gusmano has long been interested in distributive justice—ethical issues that come into play when institutions and governments must decide how to allocate scarce resources—in health care. He has focused on the consequences of different health policies for poor and vulnerable populations, including seniors. That interest has led him to travel the world doing detailed comparisons of health systems in Europe, Asia, and the United States, as part of the World Cities Project—a joint investigation of The Hastings Center, the International Longevity Center at Columbia University’s Mailman School of Public Health, and New York University’s Robert G. Wagner Graduate School of Public Service—which is comparing the health, social services, long-term care, and quality of care in Hong Kong, Tokyo, New York, London, and Paris. Gusmano is codirector of the project.

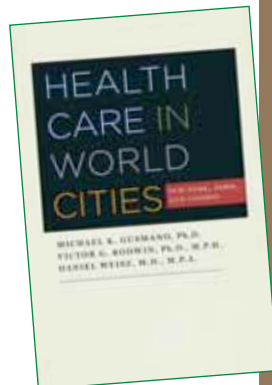
“The World Cities Project looked at the extent to which different cities deliver care on

the basis on need, rather than how much money you have or where you live” says Gusmano. A product of that effort is *Health Care in World Cities*, a book coauthored by Gusmano and published in 2010. It looked at access to primary care in three of the cities (New York, London and Paris) and concluded that poor access correlated with premature death from treatable conditions and avoidable hospitalizations. Disparities in access to health care are greater in New York than in the other cities, but Gusmano and his coauthors found large disparities in Paris and London, too. Although each of these cities has a wealth of resources, “they have shocking—some would say embarrassing—health inequalities,” the book states.

Gusmano has also been studying health care in China, including its nascent health reform effort. With the push to introduce a market economy in the 1970s, China cut government support for medical care, which reduced access to care among the poor. Now, the government is guaranteeing minimal insurance coverage for most citizens, but, like the U.S. government, it is struggling with rising health care costs. Gusmano spoke about these and other issues at a conference for the Yale-Hastings Program in Ethics and Health Policy in January that explored

the implementation of health reform in China and the U.S. “Interesting parallels came to light,” he says.

Gusmano was named deputy codirector of the Yale-Hastings program, with Daniel Callahan, cofounder of The Hastings Center, and David Smith, director of Yale’s Interdisciplinary Center for Bioethics. Gusmano also taught a course on health policy at the Yale School of Public Health, and he collaborated with other Hastings Center colleagues on research for the Open Society Institute that examined ethical dilemmas in the delivery of health care to political detainees.



2010 HIGHLIGHTS

- In London, Hong Kong, and Beijing, he gave talks on health care inequities, comparative effectiveness, care of the aging, and other health care issues.
- Elected Secretary of the American Political Science Association’s Organized Section on Health Politics and Policy.
- Conducted research (with Nancy Berlinger and Karen Maschke) for the Open Society Institute on ethical dilemmas in providing care in drug detention centers.
- *Health Care in World Cities* by Michael Gusmano, Victor G. Rodwin, and Daniel Weisz (Johns Hopkins University Press, 2010) was published.

GREGORY KAEBNICK

“Claims about ‘creating life’ touch a nerve for anybody who cares about the human relationship to nature. But once we articulate what synthetic biology actually achieves, it’s not clear that it changes that relationship after all.”



The synthetic biology project meeting at The Hastings Center in May discussed ethical and policy issues.

In May 2010, The Hastings Center was in the midst of the third and final meeting of its project on the ethical issues of synthetic biology when major news broke: scientists had created the first self-replicating cell with a synthetic genome. President Obama soon called on the Presidential Commission for the Study of Bioethical Issues to examine the ramifications of a feat that appeared to move us closer to “playing God,” and the commission invited Gregory Kaebnick to speak at its first meeting. The House of Representatives called Kaebnick to testify at hearings on synthetic biology.

“A general moratorium on synthetic biology is not warranted,” said Kaebnick, a Hastings Center research scholar who managed the

two-year project on synthetic biology, when he spoke before the presidential commission in July. “But I’m not confident that we are assessing the outcomes appropriately and setting up the right regulatory structures.” Five Hastings Center Fellows serve on the commission: Amy Gutmann, the chair; Anita Allen, who is also a Hastings Center board member; John Arras; Christine Grady, a former board member; and Daniel Sulmasy.

Synthetic biology is a new science that uses genes and strands of DNA from different organisms to write genetic instructions for the purpose of creating desirable products, including medicines and inexpensive biofuels. The Center’s synthetic biology project, funded by the Alfred P. Sloan Foundation, held two meetings in 2010 that examined moral concerns about the science and their bearing on public discourse and policy. The meetings included a multidisciplinary working group—researchers in the field; a policy analyst from the J. Craig Venter Institute, which created the synthetic genome; philosophers; bioethicists; and political scientists. Other Hastings Center scholars working on the project were Tom Murray, president, who is principle investigator, and Erik Parens, senior research scholar.



Kaebnick gave a talk on synthetic biology at the Center’s Garrison Seminar in November.

In his testimony to the House of Representatives in May, Kaebnick said that

synthetic biology raises two types of moral concerns. There are intrinsic concerns, beliefs that there is something inherently wrong with synthesizing life forms. There are also concerns about consequences, such as risks of environmental contamination or bioterrorism, and worries about justice—that inequities in who owns and benefits from the technology could lead to long-term social and environmental harms. Kaebnick recommended continued attention to ethical issues and risks, as well as an analysis of whether our current regulatory framework is adequate.

Throughout the year, Kaebnick was interviewed by several news outlets about synthetic biology, including NPR’s “All Things Considered,” *Science*, Bloomberg News, and *Nature News*. He was also at work on two products of the synthetic biology project. He was editing a book of essays by members of the working group and writing a book about the human relationship to nature.



Kaebnick spoke about moral and regulatory questions posed by synthetic biology to the Presidential Commission for the Study of Biological Issues in July.

Aside from his inquiry into synthetic biology, Kaebnick served as editor of the *Hastings Center Report* and as editorial director of the Center, with responsibility for coordinating its publishing activities.



2010 HIGHLIGHTS

- Interviewed on NPR’s “All Things Considered” about the implications of creation of the first synthetic genome.
- Testified in the U.S. House of Representatives on ethical issues in synthetic biology. Quoted by Reuters, *Wired*, and *Science*.
- Spoke before the Presidential Commission for the Study of Bioethical Issues in Washington about synthetic biology.
- Quoted by *Nature News* and Bloomberg News about the report on synthetic biology by the Presidential Commission for the Study of Bioethical Issues.
- Gave talk on synthetic biology at The Hastings Center’s Garrison Seminar
- Delivered Earth Day talk on the concept of nature at the Garrison Institute



“What is the difference between tools that help us flourish and those that thwart that effort? Bioethics encourages us to ask the oldest of questions in the context of the newest technologies”

Technologies continuously come along that present us with new opportunities to enhance ourselves. There are medications that can sharpen concentration or improve mood. There are surgical procedures to improve appearance or merely to “normalize” it, such as limb-lengthening for dwarfs. Erik Parens, senior research scholar, investigates what it means to shape ourselves and our children with these and other technologies, asking some of the oldest, most fundamental questions: What is human flourishing? What is the difference between tools that help us flourish—fulfill our human

potential—and those that thwart that effort?

“Those questions have been around at least since Homer wondered about the effects of lotus flowers that could make people forget everything,” says Parens. “Bioethics encourages us to ask the oldest of questions in the context of the newest technologies.” Parens lectures internationally on this subject, and has begun work on a new book about it as the recipient of the Willard Gaylin Research Award, which supports theoretical work. He was also a co-investigator on the Center’s project on ethical issues in synthetic biology.

Parens and Josephine Johnston, a research scholar with a background in law and bioethics, led two major interdisciplinary projects. One project, supported by the Dana Foundation, is examining the controversies and complexities of using neuroimages to understand human behavior. Two of the project’s three meetings took place at the University of Pennsylvania in 2010. The first meeting explored basic assumptions at work in the use of fMRI and other neuroimaging technologies in psychiatric research and practice. The second one considered how neuroimaging-based findings do and should inform how we understand the mind, free will, and criminal and moral responsibility.

Parens’s and Johnston’s other project aimed to better understand the controversies surround-

2010 HIGHLIGHTS

Erik Parens

- Served on the International Advisory Board for the Responsible Innovation Program, helping the Dutch government allocate funding for ethics research.
- Received the Willard Gaylin Research Award, which supports theoretical work, to write a book on the use of technology to shape selves.
- Gave lecture, “On Good and Bad Forms of Medicalization,” at the University of Navarra, Barcelona.
- Delivered The Crosley Lecture, “The Ethics of Treating Children with Psychotropic Drugs,” at the University of New England, Portland, Maine.
- Published “The Ethics of Memory Blunting and the Narcissism of Small Differences” in *Neuroethics*.

- Gave presentation on bioethics and new technologies at a Center for Genetics and Society conference in Tarrytown, N.Y.

Josephine Johnston

- Served on the Tri-Institutional Embryonic Stem Cell Research Oversight committee for Weill Medical College of Cornell University, Memorial Sloan-Kettering Cancer Center, and The Rockefeller University.
- Collaborated with legal scholars at the University of Toronto (and Center scholars Karen Maschke and Nancy Berlinger) to develop curriculum on competency in human rights, public health, and health care ethics for the Open Society Institute’s Case Studies in Human Rights and Patient Care. The curriculum was presented in May at the University of Macedonia for medical and law faculty.

JOSEPHINE JOHNSTON

ing the diagnosis of mental disorders in children and recent increases in the use of medication to treat them. Funded by the National Institute of Mental Health and The Hastings Center's Fund for Children and Families, it involved five workshops over three years with a working group of clinicians, researchers, scholars, and patient advocates with diverse views. Parens and Johnston prepared a report on the working group's conclusions for publication with support from Eve Hart Rice and Timothy Mattison. Among the conclusions was over-diagnosis, underdiagnosis, and misdiagnosis are all real problems. Apart from those problems, the report found that there is reasonable disagreement about diagnosis and treatment in a "zone of ambiguity," which grows out of differences in personal values. The report's most disturbing conclusion was that many children with patently problematic moods and behaviors fail to receive the care recommended by experts.

Poor children are at especially high risk of getting inappropriate care—either being underdiagnosed or being overmedicated, the project found. To explore this disparity further, Parens and Johnston lead a symposium at Brooklyn Law School in October on treating mental disorders in poor and vulnerable children. Participants included psychiatrists, lawyers, and professionals in social services.



“Many people who work in social services express professional distress about children being medicated heavily with psychiatric drugs.”

In addition to her work with Parens, Johnston studies ethical issues around embryonic stem cell research, assisted human reproduction, and conflicts of interest in biomedical research. She also collaborated with Hastings Center colleagues Nancy Berlinger and Karen Maschke to develop a curriculum on competency in human rights, public health, and health care ethics for the Open Society Institute. A book that she edited with Tom Murray, president of The Hastings Center, *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest*, was published in by Johns Hopkins University Press 2010.

from seven nations in Eastern Europe and Central Asia.

- Published letter in *Nature* on guidelines for reviewing embryonic stem cell research.
- Quoted by Reuters about conflicts of interest in medical research. MSNBC and other media outlets picked up the story.
- Published commentary in *The Scientist* on a federal district judge's decision to suspend federal funding of embryonic stem cell research.
- Quoted by ProPublica's "Dollars for Doctors" investigative news report on drug companies hiring doctors who have been sanctioned for misconduct.
- *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest*, ed. Thomas H. Murray and Josephine Johnston, published; reviewed by *JAMA*.

Erik Parens and Josephine Johnston

- Lead seminar on controversies in the use of psychiatric drugs in children to Child Psychiatry Fellows at SUNY-Stony Brook Medical Center.
- Published report on controversies in the diagnosis and treatment of bipolar disorder in children in *Child and Adolescent Psychiatry and Mental Health*.
- Published Perspective in the *New England Journal of Medicine* about a prospective change in the updated Diagnostic and Statistical Manual of Mental Disorders on criteria for pediatric bipolar disorder.
- Lead symposium on treating mental disorders in poor and vulnerable children at Brooklyn Law School.



NANCY BERLINGER

“Doing health care ethics requires constant attention to human suffering: What are its causes? What do we know about how it can be relieved? And when is a system so flawed that it cannot protect those in it from being harmed?”

Much of Nancy Berlinger’s research occupies the space between patients and health care providers. What influences the decisions that they make? What considerations are at work when the patient is dying? Or is a seriously ill child? Or is a detainee? These were among the varied questions that Berlinger explored in 2010.

With funding from the Texas Children’s Hospital, Berlinger and investigators at Rush University Medical Center in Chicago and Brandeis University conducted a pilot study to understand how hospitals give spiritual care to seriously ill children and their families. Spiritual care is recognized as integral to interdisciplinary palliative care medicine, but little is known about how it is provided in pediatric settings. In a survey of 28 well-established pediatric palliative care programs, the study found that spiritual care is most often given by hospital chaplains who are members of palliative care teams. Interviews with physicians and chaplains serving

nurses cope with the enormous stress of treating very sick children. And when some patients suffered from psychological distress that was not alleviated by treating their physical symptoms, physicians reported that chaplains were sometimes able to provide relief. “They helped get at what’s known as existential suffering,” says Berlinger.

She has also been directing the first revision and updating of the Center’s ethics guidelines on treatment decision-making and care near the end of life. Originally published in 1987, it was the first set of ethics guidelines for clinicians caring for patients near death. The new guidelines were supported by the Sussman Charitable Trust and the Patrick and Catherine Weldon Donaghue Medical Research Foundation.

The nexus of health care and human rights was the focus of two research consultations for the Open Society Institute (OSI) conducted by Berlinger and Hastings Center colleagues. One project, with Michael Gusmano and Karen Maschke, focused on the drug detention centers that have proliferated over the last decade in Asia. Detainees may receive no effective drug treatment and be subjected to human rights violations. Nongovernmental organizations that seek to provide health services or humanitarian aid to these detainees often face ethical challenges: Are they doing more good than harm? Are they helping detainees, or legitimizing fundamentally unethical systems? The research produced a working paper for OSI and NGO representatives that analyzed the ethical conse-

on the teams in a random sampling of the programs revealed that chaplains facilitated communication among patients, parents, and clinicians. They helped doctors and



*Berlinger autographed her book, **After Harm**, at Brown University.*

quences of U.S. health-related foreign aid policies that supported drug detention centers. The paper also addressed the problem of moral complicity experienced by health workers on the ground.

For the other OSI project, Berlinger, Maschke, and Josephine Johnston, along with legal scholars at the University of Toronto, developed a case-based curriculum on human rights, public health, and health care ethics for medical and law faculties in Eastern Europe and Central Asia.

Berlinger also taught health care ethics in graduate programs at the Yale School of Nursing and at Lund University in Sweden.



2010 HIGHLIGHTS

- Appointed to the advisory panel for the Clinical Ethics Network for Training Research and Support at the National University of Singapore.
- Delivered lecture on care near the end of life at the second annual GABEX International Conference, University of Tokyo.
- Gave talk to the Open Society Institute in Washington, "Doing Good or Doing Harm? Toward an Organizational Ethics Framework for Donors to Health-Related Programs in Compulsory Drug Detention Centers."
- In Sweden, delivered talks on patient safety and medical error at Lund University and first Nordic Patient Safety Conference in Stockholm.
- Spoke on the chaplain's role in pediatric palliative care at the Association of Professional Chaplains meeting in Schaumburg, Illinois.
- Collaborated with legal scholars at the University of Toronto (and Hastings Center scholars Karen Maschke and Josephine Johnston) to develop curriculum on competency in human rights, public health, and health care ethics for the Open Society Institute's Case Studies in Human Rights and Patient Care. The curriculum was presented in May at the University of Macedonia for medical and law faculty from seven nations in Eastern Europe and Central Asia.
- Quoted by *USA Today* about a controversy in which a bishop

rebuked doctors at a Catholic hospital in Arizona for performing an abortion on a woman to save her life.

- Quoted by *Nature* and the *CMAJ* (Canadian Medical Association Journal) about the Physicians for Human Rights report that medical professionals working with the CIA conducted illegal human subjects research on political prisoners.
- Quoted by *The New York Times* about "comfort feeding," an innovation in palliative care for people with Alzheimer's disease.
- Served as a panelist on a roundtable discussion on the impact of biologic drugs on the health care system, convened in New York and moderated by *Health Affairs* editor.
- Gave lecture on the ethics of "hope" and care near the end of life, at Cold Spring Harbor Laboratory.
- Interviewed by *Medscape* about a *Hastings Center Report* survey of physician-assisted death in Oregon in an article about physician assisted death and palliative care.



DANIEL CALLAHAN

“How do we assess national priorities and compare health care versus defense versus environment versus education? Health care is so big that it affects spending in other areas.”

Medical progress is expensive. Should it be limited in some way? If so, how? By whom? These questions have been central to Daniel Callahan’s research and writing for decades, and they took on new urgency with the passage of health care reform in March 2010. The Patient Protection and Affordable Care Act (ACA) extends access to health care to millions of Americans, but it also carries the challenge, as its name states, of making health care affordable. “Many people think of health reform as a management problem,” says Callahan, cofounder and former president of The Hastings Center. “But the problem is at a deeper, philosophical level. Endless medical progress is out of control economically and is not curing people for the most part, but it is keeping sick people alive longer. We need to rethink the aims of health care.”

The Health Care Cost Monitor, a blog that Callahan started, continued to be an outlet for fresh thinking on medical progress and health reform. Leaders in medicine and health policy contributed commentaries, including Richard Saltman, a professor of health policy and management at Emory University, and Peter Ubel, the Jack O. Blackburn Professor of Marketing at Duke University’s Fuqua School of Business and a professor of public policy at Duke’s Sanford School of Public Policy.

In addition, shortly after ACA passed, *Science* magazine praised Callahan’s 2009 book, *Taming the Beloved Beast: How Medical Technology Costs are Destroying Our Health Care System*. In the book, Callahan presents a conundrum: medical technology saves lives and relieves suffering, and yet its costs are rising so much that they threaten to weaken our health care system, eventually harming everyone. “No one who comes to *Taming the Beloved Beast* with an open mind can deny the intellectual and ethical power of the questions he[Callahan] poses,” the *Science* reviewer wrote. “He probes issues central to resolving the enormous problems and inequities—not to mention the looming financial threats—that bedevil American medical care.”

In 2010, Callahan widened his scope and



Callahan delivered the baccalaureate address at Lehigh University in May after receiving an honorary doctorate.

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began a challenging project that aims to assess national priorities, including health care, education, economic security, defense, environment, and quality of life. “I got interested in this project since health care is one of the nation’s biggest expenses—so big that it affects spending in other areas,” he says. Callahan is directing the project with Michael Gusmano, a Hastings research scholar; David Roscoe, chair of The Hastings Center Board of Directors; Harold Edgar, past Hastings Board chair; and an interdisciplinary group of other participants. They began by mapping a list of about two dozen priorities, ranking them, and then posing questions about them. “How do we compare health care versus defense versus the environment versus education?” he says. “There are no experts, no literature, no conclusions.”

Callahan also serves as codirector of the Yale-Hastings Program in Ethics and Health Policy, which completed its first full year. He helped organize a conference in January on health care reform in China and the United States. In addition, under the program, Hastings scholars teach courses at Yale and mentor students from Yale Medical School who write their theses on bioethics topics. Callahan also serves on the executive committee of the Yale Bioethics Center.

Given the breadth of his research, Callahan is frequently asked to give talks and interviews. He received an honorary degree from Lehigh University, where he delivered the baccalaureate commencement address. He was interviewed on various topics by NPR’s “The Brian Lehrer Show,” *Time*, and *Forbes*, among other media outlets.



2010 HIGHLIGHTS

- *Science* praised Callahan’s 2009 book, *Taming the Beloved Beast*.
- Awarded an honorary Doctor of Humane Letters from Lehigh University; delivered the baccalaureate commencement address.
- Interviewed by *Forbes.com* about how the overuse of medical technology reduces the quality of health care and drives up costs.
- Interviewed by “The Brian Lehrer Show” on WNYC and “Air Talk” on Southern California Public Radio about President Obama’s decision to authorize Medicare funding for doctor-patient conversations about end-of-life planning and advance directives.

“Today, more and more people are being asked to donate tissue samples for genetic research. Yet several ethical, legal, and policy issues have not been resolved.”

A front-page news story in 2010 concerned a legal dispute over genetic research conducted with blood samples donated by members of the Havasupai Indian tribe in Arizona. The news brought to wide public attention a thicket of ethical issues that Karen Maschke has been working at the national level to resolve.

The dispute arose from a misunderstanding over the kind of research for which the blood samples would be used. Donors thought that it was only the genetic basis of diabetes, but the researchers also used the samples to study psychiatric disorders and ancestry. The tribe’s members said that these kinds of research violated their values. The ethical issues are these: How much information about the intended genetic research should the researchers have given the tribe’s members to get their informed consent to donate biospecimens? Was it necessary for the researchers to spell out all the possible research uses? Should the donors have been able to deny consent for certain types of research with their DNA?

These and related ethical questions are gaining urgency now that a growing number of human tissue samples are being donated for studies on the genetic basis of diseases such as cancer and Alzheimer’s disease. “Within the next 10 years, anyone being treated at medical center will likely be asked to donate a tissue sample for genetic research,” says Maschke. This research is essential for doctors to reach the long-sought goal of practicing personalized medicine—which

includes using genetic information to customize treatments to individual patient, ideally, making the treatments more effective (and cost-effective) and safer. Maschke, a political scientist, has been working on panels for the National Institutes of Health to help create policies on the ethical use of human tissues for research. She is also the editor of *IRB: Ethics & Human Research*, a Hastings Center journal that explores ethical issues in studies involving humans.

Maschke’s work aims to guide researchers on how to gain proper informed consent from prospective tissue donors, as well as several other important issues. For one thing, what steps are needed to protect the confidentiality of donors’ genetic information? And do donors have the right to learn what genetic information researchers find out about them? “Should genetic test information obtained in the research context be provided to individual tissue donors?” Maschke asks. Some say that donors should only have



Maschke, left, met with other members of the Tissue Banking Working Group of Yale University’s Interdisciplinary Center for Bioethics.

access to genetic results that meet the narrow definition of “clinical utility,” meaning that they pertain to a condition for which there are treatments or preventive measures. Others say that donors should have access to any genetic information about themselves obtained in research that they consider important. Maschke is a member of a project funded by the National Human Genome Research Institute that will make recommendations about whether and how to disclose genetic research results to individual tissue donors. “Things are moving very fast on this issue,” she says.



2010 HIGHLIGHTS

- Served on the Tissue Banking Working Group, Interdisciplinary Center for Bioethics, Yale University.
- Cochaired Ethics Subgroup, National Cancer Institute’s Cancer Human Biobank.
- Served as panelist at National Cancer Institute’s Cancer Biomedical Informatics Grid’s annual conference in Washington.
- Gave presentation on policy issues and emerging technologies at a Center for Genetics and Society conference in Tarrytown, N.Y.
- Participated in National Cancer Institute workshop on the release of research results to people who have donated tissue for scientific study.
- Delivered lecture on genetic testing and personalized medicine at University of Texas Southwestern Medical Center’s ethics grand rounds.
- Spoke on genetic research to New York School of Medicine.
- Collaborated with legal scholars at the University of Toronto (and Hastings Center scholars Nancy Berlinger and Josephine Johnston) to develop curriculum on competency in human rights, public health, and health care ethics for the Open Society Institute’s Case Studies in Human Rights and Patient Care. The curriculum was presented in May at the University of Macedonia for medical and law faculty from seven nations in Eastern Europe and Central Asia.
- Conducted research (with Michael Gusmano and Nancy Berlinger) for the Open Society Institute on ethical dilemmas in providing care in drug detention centers.


 THOMAS MURRAY

“The kinds of problems, like synthetic biology, that involve attentiveness to different worldviews have always fascinated me. It’s not just what different people believe, but also how they arrive at and reconcile their beliefs.”

As president of The Hastings Center and one of its research scholars, Tom Murray divides his time between building the organization’s capacity and building its knowledge base. Murray’s knowledge-building in 2010 was focused on two areas of strong interest to policymakers and the general public. He was the principal investiga-



Murray, left, with David Rejeski, of the Woodrow Wilson International Center for Scholars, spoke at a meeting on synthetic biology at the Woodrow Wilson Center in November.

tor on the Center’s project on ethical questions about synthetic biology. He also worked on an issue that has occupied him for three decades: questions about fairness in sport that arise from the use of performance-enhancing drugs and other technologies.

Murray was invited to give several lectures about synthetic biology, including a talk at the Woodrow Wilson International Center and the AAAS-Hitachi Lecture, both in Washington. Synthetic biology is “both a mind-set and a marketing term,” Murray said in the AAAS-Hitachi Lecture. He proposed that public policy

debates about synthetic biology may hinge on two different mind-sets: one that sees the issue as a dispute over interests, in which compromises and trade-offs can be made, and one that sees the issue as one that reaches to identities, in which core beliefs about oneself and one’s place in the world are at stake. If the debate proves to be over interests, public policy can strike reasonable balances. If the debate is about identities—if synthetic biology threatens beliefs about the sacredness of life, humans’ relationship with nature, or similarly fraught matters—then going forward will be harder. But he concluded that the current state of research, dealing with microbes, does not appear to threaten beliefs that turn on identity. That could change as synthetic biology turns its attention to the human body.

Near the year’s end, Murray met with the Presidential Commission on the Study of Bioethical Issues to provide guidance on its draft of policy recommendations on synthetic biology. “I batted cleanup,” he says, alluding to fellow scholar Gregory Kaebnick, who led off the commission’s discussions on ethics and synthetic biology. Murray’s recommendations included the importance of taking into account the diversity of innovators at work in synthetic biology. “The commission had biomedical scientists in mind, but the field also includes engineers, whose training and worldviews are different,” he says. “I hope my comments helped to make the final recommendations more encompassing and inclusive.”

Murray was also engaged in a variety of ac-

tivities concerned with ethical issues in sport. He cochaired a committee of the United States Anti-Doping Agency that oversaw a survey of 9,000 Americans about their beliefs and values about sport, especially its impact on young people. He continued to chair the ethical issues panel of the World Anti-Doping Agency. And he was at work on a book that asks the basic question: why do we play? “Discerning what’s fair and what is not requires an inquiry into the meaning of sport, its structure, and the values it embodies,” he says.

Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest, a book co-edited by Murray and Josephine Johnston, was published in 2010 by Johns Hopkins University Press. An earlier book co-edited by Murray and Mary Ann Baily, *Ethics of Newborn Screening: New Technologies, New Challenges*, received a “highly recommended” commendation in the British Medical Association’s 2010 book award competition.



2010 HIGHLIGHTS

- Served on the National Institutes of Health’s Blue Ribbon Panel of the National Emerging Infectious Diseases Laboratories at Boston University Medical Center.
- Quoted by *Washington Post* about a Canadian doctor arrested for giving banned performance-enhancing drugs to athletes.
- Quoted by *Time* on the BP oil spill in the Gulf of Mexico and the prospects for synthetic biology to remediate such an environmental hazard.
- British Medical Association’s 2010 book awards competition cites as “highly recommended” *Ethics of Newborn Screening: New Technologies, New Challenges*, edited by Tom Murray and Mary Ann Baily.
- Quoted by Bloomberg News about the U.S. district judge ruling that stopped federal funding of embryonic stem cell research.
- Delivered the AAAS-Hitachi Lecture on synthetic biology in Washington; talk cited by *Science*.
- Tweet from William Saletan, of *Slate*, about AAAS-Hitachi lecture: “If Aristotle were alive today, he’d be Tom Murray. Nimbleness, insight and common sense informed by modern science.”
- Gave talk on societal issues in synthetic biology at the Woodrow Wilson International Center.
- Addressed the Presidential Commission for the Study of Bioethical Issues on synthetic biology in response to a draft of the commission’s recommendations to President Obama.
- *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest*, ed. Thomas H. Murray and Josephine Johnston (Johns Hopkins University Press, 2010); reviewed by *JAMA*.
- Chaired the World Anti-Doping Agency’s ethics committee.
- Cochaired a United States Anti-Doping Agency committee that planned a major national survey of Americans’ beliefs and values about sport.

● 2010 HASTINGS CENTER BOARD OF DIRECTORS



Left to right, back row: Joshua Boger, Francis Geer, Michael Patterson, Alan Fleishman, Thomas Murray, Patricia Klingenstein, David Roscoe, Thomas Hakes, Blair Sadler, John Wong, Sherwin Nuland; front row: Joseph Fins, Harriet Rabb, Andrew Adelson, Michele Moody-Adams, Robert Michels, Willard Gaylin, and Daniel Callahan



Anita Allen



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● NEW BOARD MEMBERS & FELLOWS

BOARD



Michele Moody-Adams, Ph.D., is Dean of Columbia College and Henry L. and Lucy G. Moses Professor. She is also Vice President for Undergraduate Education and Joseph Straus Professor of Political Philosophy and Legal Theory in Columbia's Philosophy Department.

FELLOWS

Hastings Center Fellows are an elected association of leading researchers influential in fields in which the Center is engaged. Nine new Fellows were elected in 2010.



Nicholas Agar, Ph.D, is a philosopher and an associate professor in the School of History, Philosophy, Political Science, and International Relations at Victoria University in Wellington, New Zealand. He is the author of four books, including *Liberal Eugenics* and, most recently, *Humanity's End: Why We Should Reject Radical Enhancement*.



Dame Silvia Cartwright, L.L.B., was the first woman appointed to the High Court of New Zealand. She served as Governor General of that nation from 2001 to 2006. In 1988 she presided over an inquiry into ethics violations in cervical cancer research. The investigation resulted in reform of New Zealand's system for protecting human research subjects. She serves as a judge in the Extraordinary Chambers in Cambodia, overseeing the war crimes trials of former Khmer Rouge.



Tod Chambers, Ph.D., is director of the Medical Humanities and Bioethics Program at Northwestern University's Feinberg School of Medicine. He is a leader in the development of narrative ethics approaches to biomedical problems. Other projects have included studies of enhancement technologies and personal identity.



Leslie Pickering Francis, J.D., Ph.D., is chair of the department of philosophy and Alfred C. Emery Professor of Law at the University of Utah. She has written and edited numerous books and journal publications on many topics, including infectious disease, end-of-life treatments, autonomy and disability, and discrimination.



Vanessa Northington Gamble, M.D., Ph.D., is an historian of medicine, a physician, and a bioethicist at George Washington University. She chaired the Tuskegee Syphilis Study Legacy Committee in 1997 and is the author of groundbreaking work on race and racism in the history of American medicine and public health, including *Making a Place for Ourselves: The Black Hospital Movement, 1920-1945*.



Mark A. Hall, J.D., is the Turnage Professor of Law and Public Health at Wake Forest University School of Law and School of Medicine. His work focuses mainly on health care law and policy. He has written or edited 15 books, including *Making Medical Spending Decisions and Health Care Law and Ethics*.



Edison Liu, M.D., is chairman of the Governing Board of the Health Sciences Authority of Singapore and president of HUGO, the Human Genome Organization. He received Singapore's Public Service Medal in 2003 for his work in controlling SARS. Previously, Dr. Liu was director of the Division of Clinical Sciences at the National Cancer Institute.



Bettina Schöne-Seifert, M.D., M.A., is a physician and philosopher who chairs the Biomedical Ethics section of the Institute for Medical Ethics, History, and Philosophy of Medicine at the University of Münster in Germany. A leader in European bioethics, she has served on both the influential German National Ethics Council and its successor, the German Ethics Council.



Benjamin S. Wilfond, M.D., is director of the Treuman Katz Center for Pediatric Bioethics at Seattle Children's Hospital and chief of the Division of Bioethics in the Department of Pediatrics at the University of Washington School of Medicine. He is also a member of the Ethics Subcommittee of the Food and Drug Administration's Pediatric Advisory Committee and the National Children's Study Federal Advisory Committee.

● 2010 HASTINGS CENTER STAFF



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Christine Zouzias
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BUILDING OUR AUDIENCE

The Hastings Center disseminates bioethics knowledge to multiple audiences using a variety of media. We publish two of the leading journals in bioethics. We also connect with broader audiences of journalists, policymakers, and the general public with two blogs, a vibrant public affairs and communications department, and new media activities.

Hastings Center Report, the Center's flagship journal, is read by scholars, physicians, lawyers, and other professionals. Among the 2010 highlights was a study on payments offered to potential egg donors who are students at elite colleges, an essay contest for early-career bioethics scholars, and a collection of essays on ethical issues in personalized medicine. Selected articles from the *Hastings Center Report* were reprinted in the *Asian Bioethics Review*, a bimonthly online journal that the Center helped launch and that is published by the National University of Singapore. **IRB: Ethics & Human Research** is geared to members of institutional ethics boards that review research involving human subjects. Articles in 2010 included an examination of efforts to improve informed consent and the challenges of guarding the confidentiality of individuals who donate tissue samples for genetic research.

Bioethics Forum is a blog of weekly commentaries on topical bioethics issues. It received 200,000 page views from 116,000 unique visitors. Selected pieces were reposted on a new Hastings Center blog for *Psychology Today*. Another blog, **Health Care Cost Monitor**, provides weekly commentary on cost control as part of the implementation of health care reform. It received 27,000 page views from 14,000 unique visitors.

The **Public Affairs and Communications department** connected the Center's work with journalists and policymakers. The department partnered with producers at WGBH Boston and NOVA to create a major public television show on personalized medicine, funded by the National Institutes of Health. The show will air in 2012 and reach 4 million viewers.

New media activities expanded in 2010 with the production of videos of Hastings Center scholars and events, a Google Grant to promote the Center in Google searches, and the creation of Web pages dedicated to research projects. The Center's online presence—including its Web site, blogs, and social media pages—attracted an international audience with 900,000 views from 179 countries and territories.

2010 HIGHLIGHTS

Hastings Center Report

- Article on payments for egg donors at elite colleges (March-April issue) prompts widespread coverage in the media, including *Wall Street Journal*, *Washington Post*, *Los Angeles Times*, *Boston Globe*, MSNBC, and Kaiser Health News.
- *New York Times* science section publishes article on payments for egg donors, linking to *Hastings Center Report* article; a companion article is posted on the *Times'* Well blog.
- *Chronicle of Higher Education* praises the literature and bioethics essays in the July-August issue.
- *Consumer Reports* health blog cites personalized medicine essay set in the September-October issue.
- NPR's "Science Friday" interviews Leonard Fleck, author of an essay on personalized medicine.

Bioethics Forum

- *Science* cites a *Bioethics Forum* post on alleged misconduct in tuberculosis and HIV treatment trial.
- Post on controversial surgery to shorten large clitorises of infant girls gets coverage, in *Time* and *Nature's* Spoonful of Medicine blog.
- Post on prenatal medical treatment aiming to prevent homosexuality is subject of articles in *Newsweek*, *Nature Genetics*, and *Washington Times*.
- Susan Reverby, the medical historian whose revelations about unethical U.S. studies on syphilis in Guatemala in the 1940's lead to an apology from the Obama administration, writes a follow-up commentary for *Bioethics Forum*.

IRB: Ethics & Human Research

- *Science* writes about a report in the July-August issue concerning the value of shortened, simplified consent forms.

AWARDS

- The Hastings Center wins a 2011 American Inhouse Design Award for the 2009 Annual Report.



●● BUILDING BRIDGES

In our endeavor to build knowledge, The Hastings Center also builds bridges to individuals and groups whose work draws on bioethics to expand horizons and improve lives. The Center and the ethics faculty at the United States

Military Academy at West Point hold an annual meeting to explore issues in military and medical ethics. The Yale-Hastings Program in Ethics and Health Policy fosters research collaborations and visiting scholarship and presents symposiums on health policy. The Hastings Center Cunniff-Dixon



WEST POINT

The annual Hastings Center-West Point meeting in April centered on end-of life care. Hastings Center cofounder and president emeritus Daniel Callahan (left); Lyn Traverse, director of development; and Major Tim Knoth.

HASTINGS CENTER CUNNIFF-DIXON PHYSICIAN AWARD

On January 21, Dr. Robert Milch received the inaugural \$50,000 Hastings Center Cunniff-Dixon Physician Award for leadership in end-of-life care. Dr. Milch gave up a successful surgical practice to devote his career to improving treatment for the dying, and, in 1978, helped found Hospice Buffalo, one of the nation's first hospices. Hastings Center President Thomas Murray, left, with Dr. Milch, center, and Matthew A. Baxter, who established the award.



YALE-HASTINGS PROGRAM

Yale students visited The Hastings Center for a day-long discussion on July 7th.



CITY COLLEGE OF NEW YORK

Hastings Center president Thomas Murray delivered the Third Annual City College of New York President's Lecture on February 23, titled "Why We Play: Ethics, Drugs and the Future of Sport."

Physician Awards recognize doctors who give exemplary care to patients at the end of life. The Center regularly hosts visiting scholars from throughout the world who come to conduct independent research on issues related to bioethics. And

we build connections to our local community with periodic Garrison Seminars, engaging talks by writers, artists, and scholars who work on diverse topics, ranging from synthetic biology to neuroethics.



SINGAPORE COLLABORATION AND VISITING SCHOLARS

Photos clockwise from top left: From Singapore, Roy Joseph, associate professor, National University Health System and visiting scholar; Hastings Center Fellow Alastair V. Campbell, director, Centre for Biomedical Ethics, National University of Singapore, and Fellow Tony Hope, psychiatrist and professor of medical ethics, Oxford University, and a visiting scholar; visiting scholar Tereza Hendlova, Ph.D. student at the First Faculty of Medicine, Charles University, Prague; visiting scholar Mirko Daniel Garasic from Italy's Centre for Ethics and Global Politics.



On May 5, British designer James King presented "Design and Synthetic Biology."



GARRISON SEMINARS

On June 21, science writer Stephen S. Hall discussed his new book, Wisdom: From Philosophy to Neuroscience.

THE HOUSE THAT DAN BUILT

Celebrating Daniel Callahan's 80th Birthday



December 2, 2010 saw the celebration of a major milestone and many accomplishments for Hastings Center cofounder and president emeritus Daniel Callahan. Dan was honored for his 80th birthday and for his role in building the Center and the field of bioethics. Thomas Murray, Hastings Center president, acknowledged Dan's many contributions with the benefit of anecdotes from those who had served with Dan. In addition, Tom announced that the newly created Callahan Scholars Fund had already reached almost \$500,000 with support from Fellows, Board members, and other friends of Dan and his work.



Board member Pat Klingenstein, also a birthday celebrant.



Daniel Callahan blows out the candle as former Board member Irene Crowe looks on.



Board members John Wong and Tom Hakes

Will Gaylin, cofounder and Board member, and Harold Edgar, immediate past Board chair



Alexander Capron (right, with Board member Robert Michels) was the 2009 recipient of the **Henry Knowles Beecher Award**, which recognizes individuals who have made an outstanding lifetime contribution to scholarship in ethics and the life sciences. A founding Fellow of The Hastings Center and former Board member, Capron occupies the Scott H. Bice Chair in Healthcare Law, Policy and Ethics at Gould School of Law of the University of Southern California. His Beecher Award talk, delivered at the December 2nd event, was on rethinking informed consent in research.

Daniel Callahan envisions new horizons for bioethics.



Board members Michele Moody-Adams and Sherwin (Shep) Nuland, who was also celebrating a milestone birthday.

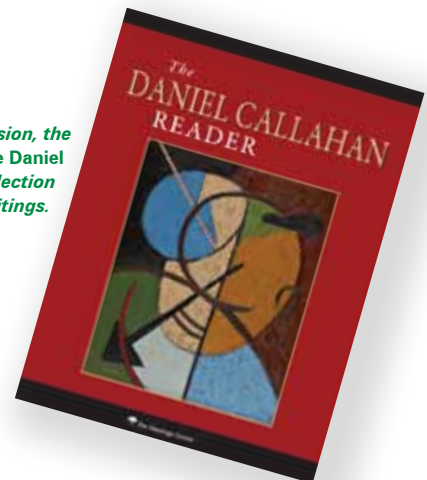


Tom Beauchamp, also celebrated a birthday.



Hastings Center staff, from left: Josephine Johnston, research scholar; Siofra Vizzi, development assistant; and Jacob Moses, new media director.

To mark the occasion, the Center published The Daniel Callahan Reader, a collection of Dan's best writings.



●● BUILDING FOR THE FUTURE

*Enabling good dialogue is one of the hallmarks of The Hastings Center, and one way we accomplish this is by listening to people outside our immediate orbit. On May 4, we were honored to present New York Times columnist **David Brooks** speaking on “The Cognitive Revolution and Civic Life Today” in New York City. His talk was insightful and engaging, and it stimulated a very lively question-and-answer session.*



Photos clockwise from top left: Dr. Susan Kaye and Jeffrey Levine; David Brooks; David Keller, Sue Keller, and Board Chair David Roscoe; G. G. Michelson and Marcia Warner; Bevis Longstreth and John Pritchard; Dennis and Terry Turko; former Board member Nobel Laureate James Watson; Sidney Callahan and Elizabeth Watson.

*Spring 2010 was ushered in with a warm and welcoming reception hosted by Hastings Center Board member and Fellow **Shep Nuland and his wife, Sarah**, at their lovely Hamden, CT home. The event afforded the opportunity to introduce the greater New Haven community to the new Yale-Hastings collaboration: the Yale-Hastings Program in Ethics and Health Policy.*



Photos left to right: Deputy Director, Yale Interdisciplinary Center for Bioethics Stephen Latham and Lisa Totman; Toddie Getman and Sarah Nuland; Hastings Center President Thomas Murray, Hastings Center research scholar Michael Gusmano, Michael Vlock, and Karen Pritzker.

● WHAT WILL YOUR LEGACY BE?

Many of us would like to leave a lasting legacy to show that our lives have made a difference. Through The Hastings Center bequest program, you can leave a permanent reflection of your personal values and commitment to important issues. No other planned gift is as simple to implement. You can include a bequest provision in your will that specifies an amount or a percentage of your estate that you wish to benefit The Hastings Center.

Benefits:

- This gift does not affect you financially during your lifetime.
- You may make adjustments to your will as circumstances change.
- Your loved ones will not be overlooked because you can specify the amount given to each party.
- A charitable bequest is deductible from federal estate taxes. It may also be exempt from state inheritance taxes.

PROFILES: BLAIR AND GEORGIA SADLER



Blair Sadler's connection with The Hastings Center dates back to 1968, when it was just a gleam in the eyes of Daniel Callahan and Will Gaylin. He and Alfred, his physician twin brother, were heavily involved in drafting the Uniform Anatomical Gift Act, the landmark legislation that established the legal power for individuals to donate organs, eyes, and tissue for life-saving transplants. Drafting the law demanded that the Sadlers confront many ethical issues, which inevitably led them to meet Dan and Will. The Sadlers soon became Founding Fellows of The Hastings Center.

Today, Blair, an attorney, serves on the Board of the Center. He is past president of Rady Children's Hospital in San Diego and teaches at the University of California, San Diego Schools of Medicine and Management. He is also a senior fellow at the Institute for Healthcare Improvement in Boston. Georgia, Blair's wife, is a cancer researcher at UCSD.

In 2010 Blair and Georgia made known their intention to provide a generous bequest to the Center. "The Hastings mission is vitally important, particularly in these polarized, partisan times," said Blair. "Hastings has established a well-deserved international reputation for excellence and thoughtful involvement in many important issues—it is the go to place for balanced and compelling scholarship and opinion. It needs to continue to develop a deep and broad philanthropic base in order to continue its noble work. Georgia and I are pleased to play a tiny part in helping to make that happen."

STATEMENT OF FINANCIAL POSITION

as of December 31, 2010*

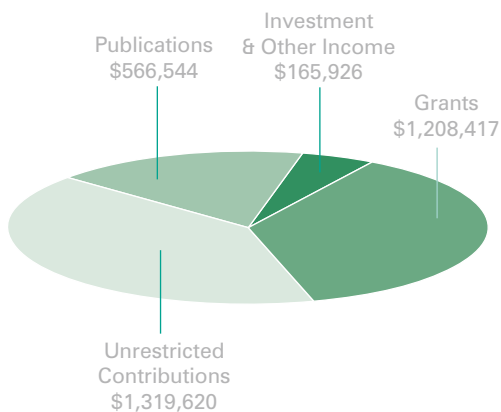
Assets	
Cash and Equivalents	395,764
Investments, at fair value	3,683,376
Receivables (grants and other)	238,844
Other Assets	45,223
Furniture and Equipment (net of accumulated dep)	44,498
Leasehold Improvements (net of accumulated amort)	<u>1,259,121</u>
Total Assets	<u>5,666,826</u>
Liabilities and Net Assets	
Payables and Accruals	113,600
Deferred Revenue	210,096
Total Liabilities	323,696
Net Assets	<u>5,343,130</u>
Total Liabilities and Net Assets	<u>5,666,826</u>

STATEMENT OF UNRESTRICTED ACTIVITIES AND CHANGES IN NET ASSETS

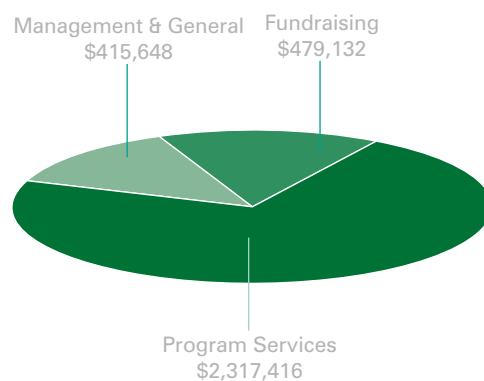
Unrestricted Operating Support and Revenue	
Grants, Gifts, and Contributions	2,428,319
Government Grants	99,719
Publication Revenue	566,544
Other income	<u>165,926</u>
Total Unrestricted Operating Support and Revenue	<u>3,260,508</u>
Operating Expenses	
Program Services	2,317,416
Management and General	415,648
Fund Raising	<u>479,132</u>
Total Operating Expense	<u>3,212,196</u>
Changes in Unrestricted Net Assets from Operations	48,312
Changes in Unrestricted Nonoperating Income	<u>72,953</u>
Change in Unrestricted Net Assets	<u>121,265</u>
Changes in Temporarily and Permanently Restricted Net Assets	<u>(760,306)</u>
Change in All Net Assets	<u>(639,041)</u>
Net Assets, Beginning of year	<u>5,982,171</u>
Net Assets, End of year	<u>5,343,130</u>

* Audited 2010

OPERATING UNRESTRICTED SUPPORT & REVENUE
for the year ended 12/31/10 = \$3,260,508



OPERATING EXPENSES
for the year ended 12/31/10 = \$3,212,196





● OUR HISTORIC BUILDING

The home of The Hastings Center in Garrison, N.Y., was built in 1854 by New York banker William Moore as a summer home on the Hudson. The family of Moore's wife, Margaret Philipse Gouverneur, had been awarded a vast tract of land by King William III of England in 1697, which included most of present Westchester, Dutchess, and Putnam counties. The site of the Moore's summer place was designed by architect Richard Upjohn and called Woodlawn.



Sledding hill, ca. 1936

Among its many iterations, this grand building at one time served as a rooming house with sheep kept on the first floor. In 1927 it became the home of The Malcolm Gordon School, a pre-preparatory school for boys, founded by Malcolm and Amy Gordon. With the closing of the school in 1990, this Garrison jewel—the last piece of land remaining in the Philipse inheritance—saw the end of its time as home to four generations of Gordons.

Enter The Hastings Center, which, in exchange for capital improvements, was afforded a long-term lease from the Open Space Institute, the owner, and has made this piece of history its home. In addition to its incredible charm and beauty, attractions include the Morison Library with over 9,000 volumes and two apartments that can accommodate four guests. Scholars from around the world can join The Hastings Center community for research and collegial camaraderie.





The Hastings Center
21 Malcolm Gordon Road
Garrison, NY 10524

