

BRIDGING  
BIOETHICS  
AND THE  
PUBLIC  
INTEREST

The Hastings Center  
Activities Report 2007-2008

# bridging bioethics and

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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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\*\* Retired as of June 1, 2008

# the public interest

# AT 40 YEARS, A NEW EMPHASIS



The Hastings Center will celebrate its fortieth anniversary in June 2009 and will honor its founders, Daniel Callahan and Willard Gaylin. They remain integral parts of the Center's community. We approach this milestone knowing the Center has never been stronger. Our journals remain the gold standards among their audiences, the scope of our scholarly research ranges from the emerging science of synthetic biology to enduring issues about death, and our global outreach extends to Asia.

Sadly, one important figure in the Center's history will not be with us in June. Strachan Donnelley, our second president, passed away in July 2008. During his 16 years at the Center, Strachan was a powerful participant in its intellectual life, bringing to bear philosophical tradition and theory to the emerging problems of biology.

Our Board is very active at the Center and has contributed in many ways to the accomplishments presented here. The Committee on University Relations oversees the Yale-Hastings Program in Ethics and Health Policy. The International Committee is guiding our collaboration with the National University of Singapore. The Committee on Governance is refreshing policies and practices now standard for nonprofit organizations. The Development Committee is launching a campaign to help sustain our Bioethics and the Public Interest initiative.

We thank Steven Holtzman, Robert Murray, and Susan Nial, who reached the end of their Board terms. Each not only contributed to the governance of the Center but also participated in the interdisciplinary research projects that form the core of our mission.

Harold Edgar  
Chair of the Board

The challenge had been growing for years: issues dear to The Hastings Center's heart, from end of life care and health care reform to stem cell research and gene doping, long the province of scholars, were becoming prominent public controversies. How could the Center tap its unmatched resources—its network of research scholars, fellows, and working group participants, with credibility and trust built through nearly four decades of creating and sharing knowledge in a scrupulously nonpartisan manner—to enrich public understanding? How could we connect policymakers, journalists, and opinion leaders with our trustworthy expertise?

We created a plan for the Bioethics and the Public Interest initiative, and the Ford Foundation embraced our vision. Since the initiative began in early 2007, we established the Center's first public affairs and communications department, led most ably by Mary Crowley. We launched a vastly more useful Web site in mid-2008 focused on issues and offering a wide range of resources.

Last fall, the first ever *Bioethics Briefing Book* was published featuring crisp, clear essays on 36 vital issues with bullet-point summaries, lists of experts, and recommended readings. It is available free on our Web site, and the print version was distributed to lawmakers and journalists in early 2009.

The Center's research continues with ideas for projects on values and health care reform, ethics and public health, and emerging technologies such as synthetic biology.

None of this would be possible without the generosity of everyone who has supported The Hastings Center. On behalf of all of us who labor here in search of insight and wisdom, our many thanks.

Thomas H. Murray  
President

# HIGHLIGHTS OF 2007-2008

*In 2007 and 2008, The Hastings Center reached out to new constituencies—policymakers, the media, and opinion leaders. It conducted research projects focusing on health care, public health, and emerging technologies. And it published reports and books that shaped professional and public understanding of the most pressing bioethical issues facing us today.*

## **FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS**

The *Bioethics Briefing Book* provides concise, nonpartisan backgrounders on topics on which the Center has expertise, such as assisted reproduction, genetic testing and screening, health care reform, medical error, stem cells, sports enhancement, and synthetic biology. The essays give journalists, policymakers, and political campaigns the tools they need to best write about and respond to the challenges posed by advances in medicine and science.

## **CAPITOL HILL BRIEFINGS**

Teaming up with the American Association for the Advancement of Science (AAAS), the Center held two briefings for Congressional staff, members of the press, and other opinion leaders. One briefing focused on the policy implications of gene doping and genetic testing in sports; the other was on the changing landscape of clinical trials. These well-attended sessions showcased panels of Hastings Center and other experts.

## **THE ETHICS OF QUALITY IMPROVEMENT**

A project focusing on the ethical and safety issues raised by quality improvement activities in health care institutions concluded in 2008. With the publication of a volume of essays and a forthcoming article in a peer-reviewed journal on policy options to ensure ethical conduct in quality improvement (QI), the project has served as the definitive source for scholarly commentary on the subject.

## **AFTER MEDICAL ERROR: THE ROLE OF APOLOGY AND FORGIVENESS**

Nancy Berlinger, deputy director and research scholar, followed the publication of her book, *After Harm: Medical Error and the Ethics of Forgiveness*, with a series of lectures at hospitals and major conferences. Her book has become a must-read, and she is a requested speaker in the aftermath of fatal medical mistakes.

## **ENGAGING THE CONTROVERSIES: CHILDREN AND PSYCHIATRIC DRUGS**

An ongoing Center project is exploring the scientific and ethical complexities that are often ignored in the debate over the increasing use of psychotropic medications among children. With the publication of articles outlining the issues and focusing on ADHD, childhood bipolar disorder, and depression, the project promises to inform more productive public debates.



# BRIDGING BIOETHICS AND THE PUBLIC INTEREST

Good bioethics begins with good facts. For nearly four decades, The Hastings Center has set the standard for bioethical inquiry and research, fostering nonpartisan exploration and deepening understanding of critical issues among clinicians and scholars around the world. Its inclusive process invites individuals representing diverse professions and perspectives to join the conversation.

In 2005, a very different kind of conversation was taking place. Through the media, we witnessed the prolonged dying of Terri Schiavo, and the division it created in her family and the nation. As the very public and bitter arguments raged, it became clear that something important was missing—attention to the facts, and respect for different perspectives.

That controversy spurred soul searching at the Center. After a planning process in 2005, a new role for the Center emerged—that of a bridge between the scholarly world and the worlds of public policy and media. Making good facts more accessible to three audiences—policymakers, journalists, and opinion leaders—the Center agreed, would inform public policy and enhance public understanding of bioethics. With a generous \$2.1 million grant from the Ford Foundation, as well as individual gifts, the Bioethics and the Public Interest initiative was created.

Bridging the Center's work and the public interest would require the creation of a public affairs and communications department. In June 2007, the Center hired Mary Crowley, a seasoned journalist with expertise in health policy, medicine, and ethics, and a former consultant to the

Robert Wood Johnson Foundation's Cover the Uninsured campaign, to lead this new department. Crowley's experience includes reporting on medical ethics and public policy for the New York Academy of Sciences and for the Policy Research Institute for the Region at Princeton University's Woodrow Wilson School for International Affairs.

Rounding out the department, the Center hired Susan Gilbert as the staff writer and Michael Turton as the communications associate. Gilbert is a journalist and author who worked for *The New York Times* and Harvard Health Publications. Turton's background includes extensive experience in communications in the fields of environmental conservation, agriculture, and community development.

In a short time, the Center has taken on an increasingly visible role as a trusted bioethical resource for the media and policymakers.

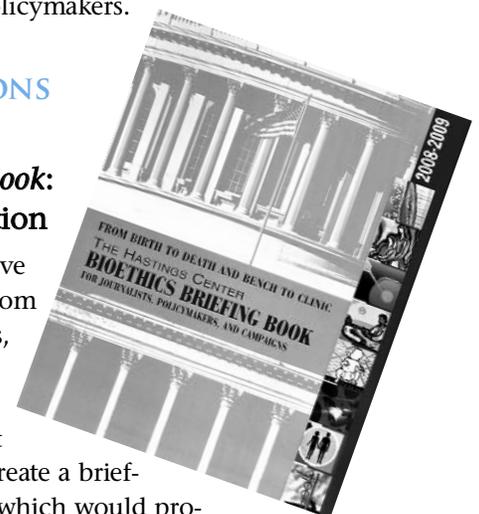
## NEW COMMUNICATIONS MATERIALS

### ■ *The Bioethics Briefing Book: A Universe of Information*

"The Public Interest initiative marks a shift for the Center from being reactive with journalists, policymakers, and opinion leaders to being proactive," said Crowley. "One of the first things I set out to do was to create a briefing book for these audiences, which would pro-

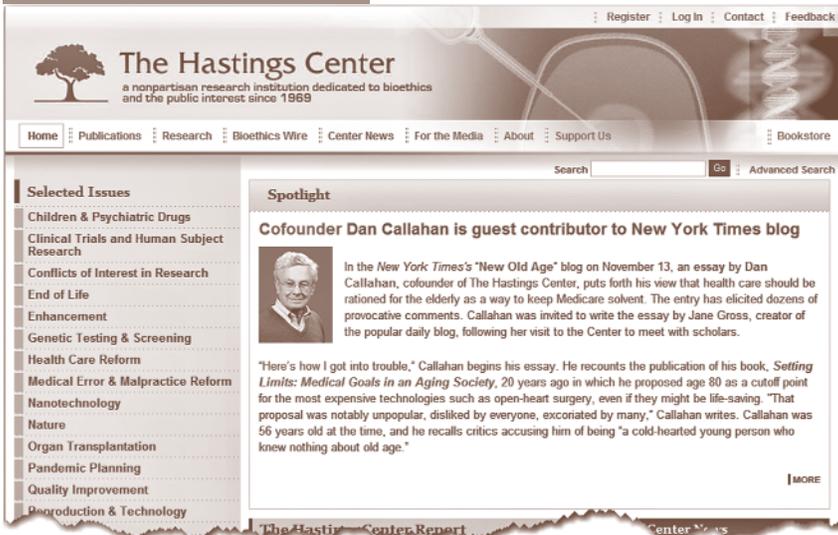


Mary Crowley,  
Director of Public Affairs  
and Communications



# public interest

## The Hastings Center's new homepage



vide a detailed grounding in the universe of projects that we are engaged in.”

The result was *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*. Timed for the presidential campaign, the book was published on the Center’s Web site in September 2008 and in print in October.

The 36 chapters provide concise, nonpartisan backgrounders on topics such as health care reform, stem cells, and synthetic biology. Each chapter outlines the science and the range of ethical concerns that are raised, providing journalists, policymakers, and political campaigns with the tools they need to best write about and respond to the challenges posed by advances in medicine and science.

The book was distributed to all members of Congress, and Crowley met with selected staff on both sides of the aisle about the book. It stirred strong interest and garnered positive response, particularly around issues of health care reform, end of life care, family caregiving, and health care costs. Crowley is planning events with journalists and a series of Congressional briefings based on the book.

The *Bioethics Briefing Book* was made possible by grants from The Greenwall Foundation and the Richard Lounsbery Foundation.

## ■ Bioethics Responders: Linking the Center’s Work to Breaking News

The Center developed another innovation for reaching out to journalists: bioethics responders, press releases that link major news in bioethics with expertise at the Center. Bioethics responders provide the media with the context, science, and ethical considerations relevant to these news events. With topics including the cloned primate embryos that generated embryonic stem cell lines, the Genetic Information Nondiscrimination Act, and human face transplants, the responders have connected the Center’s scholarship with journalists, resulting in increased media response and numerous placements.

## ■ The Center’s New Web Site: [www.thehastingscenter.org](http://www.thehastingscenter.org)

The overhaul of the Center’s Web site was completed in mid-2008. The upgraded Web site enables visitors to quickly access information about the Center, its researchers, and its activities. By clicking on selected issues, such as children and psychiatric drugs, genetic testing and screening, quality improvement, and synthetic biology, visitors can read an overview and get relevant materials, such as entries from the *Bioethics Briefing Book*, abstracts from the *Hastings Center Report*, summaries of books published by the Center, and information about its research projects.

Fully searchable, the Web site contains access to the Center’s journals and other print and online publications, news, press releases, a listing of staff and board members, and much more. Visit [www.thehastingscenter.org](http://www.thehastingscenter.org) to experience this helpful new resource.

## ■ WGBH TV Series

In 2008, The Hastings Center joined forces with WGBH Boston, the leading producer of national programming for PBS, to produce a primetime public television series and multiplatform initiative on bioethics. The four-part series, tentatively titled *Designing Life: Stories from the Bioethical Frontier*, will use powerful storytelling

to draw viewers into intimate, often wrenching moments of a person's life, in which decisions such as genetic screening, surrogate motherhood, or enhancement surgery may have a profound impact. The project will also include resources on the Web sites of The Hastings Center and PBS, as well as educational materials. The Greenwall Foundation provided a planning grant.

## ESTABLISHING A GREATER PRESENCE IN WASHINGTON, DC

Because national policy takes shape in Washington, and because the Public Interest Initiative aims to help inform policy decisions, the Center has stepped up its presence in the capitol. Partnering with the American Association for the Advancement of Science (AAAS), the Center initiated a series of Capitol Hill briefings. The briefings, which focus on areas where the Center has expertise, feature panels of experts from The Hastings Center and other institutions, such as government agencies and academia. AAAS has provided the Center with office space

Two briefings took place in 2007-2008: one on the policy implications of gene doping and gene testing in sports, and the other on the changing landscape of clinical trials. Both briefings were very well attended by Congressional staff and members of the press.

A dinner at the Cosmos Club in Washington in December 2007 called attention to a Center project on nanotechnology. The dinner featured Susan Dentzer, then the health correspondent and head of the health policy unit at PBS's *The News Hour with Jim Lehrer*, as host, along with a panel of experts, including Josephine Johnston, a Center research scholar, and David Rejeski, director of the Project on Emerging Nanotechnologies at the Woodrow Wilson International Center for Scholars. Dentzer, now editor of *Health Affairs*, has since become a Hastings Center Fellow.

In May 2008, the Center sponsored a Washington briefing called *Aging America: A Reform Agenda for Living Well and Dying Well*. Joanne Lynn, a Hastings Center Fellow and a bureau chief at the District of Columbia Department of Health's Community Health Administration, discussed the disconnect between



Joanne Lynn (center) received the Beecher Award at a Washington luncheon in 2008; shown here with Board member Christine Grady and Tom Murray.

how people die—after several years of chronic illness—and the fact that the health care system was designed to treat acute illness.

Along with fellow panelists Phillip Ellis, senior analyst at the Congressional Budget Office, and Gail Hunt, president and CEO of the National Alliance for Caregiving, Dr. Lynn outlined an agenda to reform end of life care. At a luncheon after the briefing, the Center awarded Dr. Lynn the prestigious Henry Knowles Beecher Award for lifetime achievement in bioethics.

## A GREATER PUBLIC GOOD

In just two years, the Public Interest Initiative has raised the profile of the Center's work and connected it with the worlds of media and public policy. "The Schiavo debate helped us realize that we needed to extend the Center's work beyond our traditional audiences of scholars and clinicians," Crowley said. "Now we've built relationships among journalists, policymakers, and opinion leaders, and the Center's accumulated knowledge is having a greater impact on the public interest than ever before."

# HASTINGS CENTER RESEARCH

*The Hastings Center provides an independent, nonpartisan forum where facts and values can be analyzed in an effort to find common ground. Its research projects engage interdisciplinary groups of experts, representing a diverse range of perspectives, to uncover the relevant facts, outline the issues, and explore the points of agreement. The Center conducts research in three broad categories:*

- Health care
- Public health
- Emerging technologies

*The following pages summarize the Center's research and other project activities for 2007-2008.*

## HEALTH CARE

### The Ethics of Improving Health Care Quality and Safety



Mary Ann Baily,  
Research Scholar

Quality improvement (QI) efforts in health care institutions provide valuable tools to make health care safer and more effective, but they can also pose a host of ethical issues. Sometimes they can constitute research, which then makes them subject to federal regulations that protect human research subjects. Not surprisingly, this intersection causes confusion, which can discourage the very quality improvement efforts that health care institutions—and patients—need.

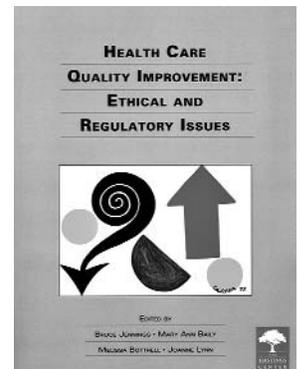
A multiyear project, the Ethics of Improving Health Care Quality and Safety, explored these issues and produced definitive resources to help clinicians, scholars, and policymakers navigate them. The project was led by Mary Ann Baily, research scholar, and Bruce Jennings, senior consultant. In January 2007, the project published a volume of essays, *Health Care Quality Improvement: Ethical and Regulatory Issues*, which explore how to conduct QI while protecting patients from harm or unfair treatment.

In February 2008, Baily published an essay on

QI in the *New England Journal of Medicine*.

Another paper by Baily, on the intersection between QI and research that explains the problem and evaluates policy options, is under review by a major policy journal.

The project received funding from the Agency for Healthcare Research and Quality, as well as from partner organizations and individuals. The Commonwealth Fund supported Baily's policy options paper.



### Professional Chaplaincy and Health Care Quality Improvement

Chaplains provide spiritual support in many health care settings, frequently caring for extremely ill patients and navigating complex family dynamics. What role can and do chaplains play in improving the quality of health care in the United States? This is among the questions that formed the basis for the Professional Chaplaincy and Quality Improvement project. Launched in 2007 as a collaboration with The

# PROJECTS AND PUBLICATIONS



*“Human responses to human mistakes can be part of patient safety systems. They may be essential to meeting the needs of all parties affected by medical harm.”*

—Nancy Berlinger, RESEARCH SCHOLAR

HealthCare Chaplaincy and funded by The Arthur Vining Davis Foundations, the project engaged chaplains, bioethicists, researchers, and clinicians. Nancy Berlinger, deputy director and research scholar, was a principal investigator with Martha Jacobs of The HealthCare Chaplaincy.

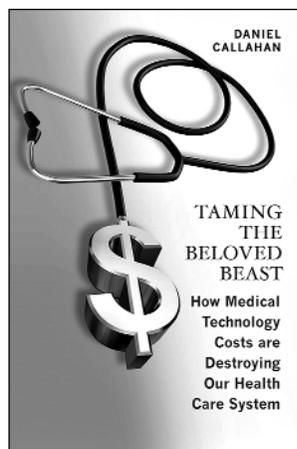
In 2007, the project conducted a study in four states on chaplains’ involvement in and attitudes toward QI in their institutions. A working group was convened at the Center in October 2007 to report the findings and explore the project’s research questions. A set of essays on the project’s findings was published in the November-December 2008 *Hastings Center Report*. Additional articles based on the project are being prepared for submission to scholarly journals.

## FORTHCOMING BOOK

### *Taming the Beloved Beast: How Medical Technology Costs Are Destroying Our Health Care System*

“Medicine has given us longer, and in many ways healthier lives,” says Daniel Callahan, cofounder of The Hastings Center. “But we operate on the ‘infinity’ model: no matter how long we live, it’s never enough.”

The very technologies that have extended our lives, Callahan says, are set to bankrupt Medicare and double health care costs in less than a decade. This is the provocative premise behind Callahan’s forthcoming book



from the Princeton University Press, *Taming the Beloved Beast: How Medical Technology Costs Are Destroying Our Health Care System*. Because medical technology is the main driver of these rising costs, it must be controlled, he says—a cause that he admits will be unpopular. Callahan lays out options to tame the beloved beast. His book is scheduled for publication in August 2009.

## The Harm Is Done. What Next?

*To Err Is Human* is the title of the well-known 1999 report by the Institute of Medicine on the high incidence of medical error in the U.S. “But what about forgiveness?” asks Nancy Berlinger.

Berlinger has forged new directions in inquiry about patient safety, medical errors, and the aftermath of medical harm. Her 2005 book, *After Harm: Medical Error and the Ethics of Forgiveness*, emphasizes the importance of acknowledging fallibility, telling the truth, confronting feelings of guilt and shame, and providing just compensation. An outgrowth of a Center project, the book has become a must-read among clinicians, administrators, researchers, and others concerned with patient safety, especially in hospitals where serious medical errors have occurred. Berlinger is a requested speaker at hospital lectures and grand rounds and at major conferences. She is often invited to speak in the aftermath of a fatal medical mistake.

Apologizing to injured patients and families plays a critical role in ethical responses to medical error, Berlinger points out, but it also provokes clinicians’ well-founded fears of lawsuits. However, 35 states have passed or drafted “apology laws,” which protect apologies from being used as evidence in court. The book’s reverberations have been felt in Canada, where it played a

# health care



CHARLES PORTER

The plenary meeting of the Guidelines II project in New York in June 2007; Nancy Berlinger, far right.

role in helping the Winnipeg Regional Health Authority develop a process to identify cases that warrant an apology and discussions about restitution and compensation. An article in *Healthcare Quarterly* in 2008 discussed the influence of Berlinger's book in Winnipeg.

## The Hastings Center Guidelines on End of Life Care

The Hastings Center is completing the three-year research phase of a project to revise and expand its guidelines. First published in 1987, the Hastings Center's *Guidelines on the Termination of*

*Life-Sustaining Treatment and the Care of the Dying* was the first ethical guide for professionals and institutions providing end of life care. It influenced the development of subsequent guidelines and was cited in the Supreme Court ruling in the landmark Cruzan case.

The new guidelines will reflect changes in end of life care over the past two decades, and in how clinical ethics identifies and addresses moral dilemmas in such care. The publication will include a major section on treatment

decision-making involving infants, children, and adolescents, and recommendations on how to support bedside discussions among patients, families, and clinicians. To be published in print and in a searchable Web-based format, it will be a major contribution to the field of clinical ethics, as moral dilemmas at the end of life constitute the majority of requests for ethics consults in health care institutions.

The three-year project is led by Nancy Berlinger, with funding from The Donaghue Foundation and the Phyllis and Albert Sussman Charitable Trust.

## Impact beyond the Funding: Deploying the Center's Expertise in Stem Cell Research

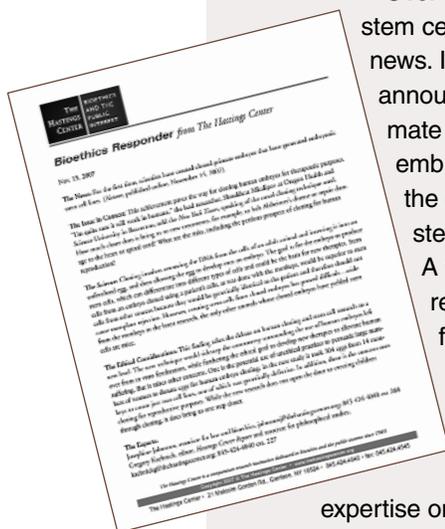
Over the last two years, advances in stem cell research have made big news. In November 2007, scientists announced that they had cloned primate embryos that had generated embryonic stem cell lines, bringing the debate on human cloning and stem cell research to a new level. A week later, *Science* online reported that scientists for the first time had generated human stem cells from adult cells.

Though the Center has no grant-funded project on stem cell research, it deployed its expertise on the subject.

as resources on the issue. Reporters from the *Washington Post* and other news outlets interviewed Tom Murray and other scholars.

Center staff applied their expertise in other ways, as well. Murray gave talks at research conferences in Singapore and Spain. Josephine Johnston served on the Tri-Institutional Embryonic Stem Cell Research Oversight Committee, which includes Weill Medical College of Cornell University, Memorial Sloan-Kettering Cancer Center, and The Rockefeller University.

The Center's effort to advance understanding of the ethical issues surrounding stem cells and other important topics demonstrates one of many ways that it leverages its resources to have an impact, even beyond the scope of its funded projects.



The Center distributed bioethics responders to members of the media, citing the Center's scholars



*“Social inequalities in health persist in the U.S. population, and yet typical approaches to health promotion may exacerbate these inequalities.”*

—ERIKA BLACKSHER, RESEARCH SCHOLAR

## PUBLIC HEALTH

### Increasing the Center’s Public Health Research Capacity

While the Center has long engaged in research on ethics and public health policy, the planning process for the Public Interest Initiative clarified the need for a greater investment in this area. The Ford Foundation’s \$2.1 million grant helped the Center make this aim a reality.

In October 2008, the Center hired Erika Blacksher, formerly a Robert Wood Johnson Foundation Health and Society Scholar at Columbia University and the vice president for research and programs at the Center for Practical Bioethics. Blacksher brings ambitious research interests that promise to yield fresh perspectives on intractable public health challenges.

Blacksher’s research agenda is driven by the well-documented and persistent social inequalities that characterize the health of the U.S. population. Typical approaches to health policy and health promotion do little to reduce, and may even exacerbate, these inequalities because they tend to benefit better off Americans with the resources and opportunities to avail themselves of health enhancing treatments and lifestyles. More promising approaches attend to the social, economic, and environmental barriers to health, but raise ethical questions that demand more attention. From bans on trans fats to incentives for healthy behaviors, the nation is flush with experiments in health policy. Research projects that explore these interventions, and the ethical

questions they raise, will become part of the Center’s expanded public health capacity.

### Incorporating Ethics into Emergency Plans for an Influenza Pandemic

Scientists almost universally agree that a new influenza pandemic, potentially triggered by a mutated flu, is inevitable. The question is not *if* but *when*.

In 2007, state public health directors submitted their pandemic influenza plans to the Centers for Disease Control and Prevention. A subsequent survey in the *American Journal of Public Health* found that few of these plans contained concrete guidance on how officials and first responders can make ethical and fair decisions under the immense pressure of a sustained crisis.

In response, in 2007 the Center, partnering with The Providence Center for Health Care Ethics in Oregon, produced a special report, *The Five People You Meet in a Pandemic—and What They Need from You Today*. Exploring the ethical issues that five groups of officials and first responders will face, the report provides guidance to regional planners for developing ethically sound pandemic plans and ensuring that front-line responders can do their jobs well during a disaster. A grant from the Providence St. Vincent Medical Foundation made the report possible.

*public health*

# emerging technology

## EMERGING TECHNOLOGY



AAAS PHOTO

Washington briefing on gene doping in 2007; from left, Theodore Friedmann, Tom Murray, Mark Rothstein, and John Feinstein

### Ethics, Genetics, and the Future of Sport: The Implications of Genetic Modification and Genetic Selection

The day hasn't arrived yet, but it soon will—when genetic manipulation can give athletes an edge over their competition. Science has already produced a few successful gene therapies for diseases, but grave risks can accompany them. At the same time, interest in genetic testing, which could help predict athletic aptitude, is growing.

In advance of the coming sea change, the Center conducted a research project, *Ethics, Genetics, and the Future of Sport: The Implications of Genetic Modification and Genetic Selection*. The project was headed by Tom Murray, who also chairs the Ethics Issues Review Panel of the World Anti-Doping Agency (WADA). It received funding from the United States Anti-Doping Agency.

The project, which included an interdisciplinary group of experts, held three meetings to pursue its four basic aims: (1) assessing the likely timeframe and ways in which gene transfer may be used in sport; (2) providing a conceptual and ethical analysis of gene transfer in sport; (3) exploring possible strategies for preventing and/or detecting prohibited gene transfer; and (4) considering the implications of genetic testing for Olympic sport.

In October 2007, the Center held a Capitol Hill briefing with the American Association for the Advancement of Science on gene doping and genetic testing in sports. Before a packed room of

Congressional staff and the press, Murray and his panelists warned of the potential dangers and ethical deficiencies of genetic treatment for nonmedical purposes, and the troubling issues that genetic testing for athletic aptitude raises.

The project garnered many articles in high-profile newspapers and magazines and interviews on television and radio. Murray and the project team gave presentations at conferences, hospitals, universities, and other institutions throughout the U.S. and internationally. They also published articles in peer-reviewed journals. Murray contributed to WADA's magazine, *Play True*, and he wrote an entry in *The Oxford Handbook of Bioethics* titled, "Enhancement." A book on the project's findings is being prepared for submission to Johns Hopkins University Press.

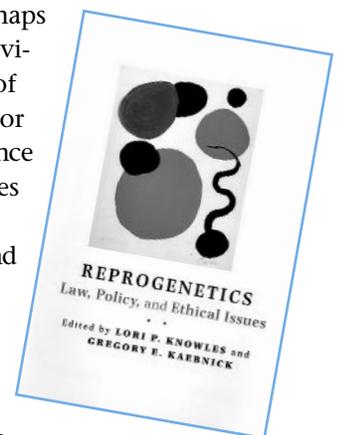
### NEW BOOK

#### Reprogenetics: Law, Policy, and Ethical Issues

New genetic technologies often spur polemical, ill-informed debates. Consider the cloning of Dolly the sheep and, more recently, embryonic stem cell research. Perhaps nowhere is this more evident than in the field of reproductive genetics, or "reprogenetics," a science that employs techniques to create, use, and manipulate gametes and embryos.

*Reprogenetics: Law, Policy, and Ethical Issues*, published in 2007 by Johns Hopkins

University Press, brings together an international group of bioethicists to examine the ethical and policy quandaries created by new genetic technologies. Edited by Lori Knowles, formerly of The Hastings Center, and Gregory E. Kaebnick, research scholar and editor of the *Hastings Center Report*, it features an overview of the field's history, com-





*“Our project revealed that there is a zone of ambiguity in the diagnosis and treatment of ADHD in children.”*

—ERIK PARENS, SENIOR RESEARCH SCHOLAR

## Children and Psychiatric Drugs

The U.S. Surgeon General estimates that as many as one in ten American children and adolescents has a “significant functional impairment” as a result of a mental health disorder. The number of children in the United States who are taking psychotropic medications—drugs that affect mood and behavior—is increasing dramatically, and is outpacing use in other countries. This trend has given rise to multiple controversies:

- Are children being overmedicated?
- Is normal childhood behavior being medicalized?
- What is the long-term safety of psychotropic drugs?
- How effective are these drugs?

The Center’s project, *Pharmacological Treatment of Emotional and Behavioral Disturbances in Children: Engaging the Controversies*, brings together thoughtful advocates of pharmacological treatment with thoughtful critics to illuminate the scientific and ethical complexities that are too often ignored in the heat of public debate. Headed by Erik Parens, senior research scholar, and Josephine Johnston, research scholar, this three-year project is supported by the National Institute of Mental Health and the Center’s Fund for Children and Families.

The project includes a series of five two-day workshops, which gather a diverse and distinguished group from fields such as child psychiatry, neurobiology, epidemiology, philosophy, anthropology, and sociology. The workshop presentations are designed to build upon each other and are followed by a sustained hour of debate. Research by the scholars and communication with the interdisciplinary group are ongoing between the workshops.

By the close of 2008, four workshops had taken place at Rockefeller University in New York: an introductory session that gave an overview of the major controversies, and sessions focused on attention deficit-hyperactivity disorder (ADHD), childhood bipolar disorder, and depression. The first workshop produced widespread agreement on eight major points and resulted in the publication of an article, “Understanding the Agreements and Controversies Surrounding Childhood Psychopharmacology,” in *Child and Adolescent Psychiatry and Mental Health* in February 2008. An article on the findings of the ADHD workshop appeared in the same journal in January 2009.

In 2009, the principal investigators are preparing an article on childhood bipolar disorder and planning the fifth workshop, which will synthesize the findings of the first four workshops and identify emerging issues for further study. In addition, a one-day free public symposium will take place at the New York Academy of Sciences, accompanied by a briefing on the Academy’s Web site. Plans also include the publication of an article in the *Hastings Center Report* and a book of essays.

# emerging technology

parisons of international and domestic government regulations, and discussions of how the market and public opinion affect research. It considers both the risks and the benefits of combining genetic and reproductive technologies.

## On the Uses and Misuses of Neuroimaging Technologies

Brain imaging technologies such as SPECT, PET, and MRI play an increasingly important role in the study of human psychology, from normal cognition to neuropsychiatric illnesses. They have already expanded basic knowledge of disease processes, and it is hoped that they will facilitate diagnosis and treatment. Clinicians, researchers, and others are concerned, however, that neuroimages will be misinterpreted and misapplied in the scientific, clinical, and lay communities.

A new Center project, *On the Uses and Misuses of Neuroimaging Technologies*, aims to shed light

on what knowledge neuroimages can—and cannot—impart. Such knowledge is especially critical for the scientists, clinicians, judges, scholars, journalists, and members of the public who encounter these images but may not possess expertise in interpreting them.

In 2008, Erik Parens and Josephine Johnston, the principal investigators, began planning the first meeting, which was held in January 2009. Funding for the project comes from The Dana Foundation.

## Homeland Security and Biometric Identification

Digital fingerprinting and iris scanning are already in use, and many other identification technologies are under development for security, criminal background checks, and identifying suspected terrorists. To create an international dialogue on the ethics and oversight of these tech-

## The Hastings Center's Journals: Informing and Advancing Bioethics Debate

The Hastings Center produces the two most influential and respected bioethics journals: the *Hastings Center Report* and *IRB: Ethics and Human Research*. As the Center's flagship journal, the *Report* attracts a broad readership of professionals and scholars with articles on ethical, legal, and social issues in medicine, health care, public health, and the life sciences.

The *Report* has a major influence on public bioethics debate. A September-October 2008 essay set on physician assistance in dying was the subject of *The New York*

*Times* blog, "The New Old Age." An essay set in the March-April 2008 issue explored the changing landscape of clinical research and the failure of the oversight system to keep pace, and it formed the basis of a Congressional briefing. An article in the May-June 2008 issue, "Ethics, Evidence, and Cost in Newborn Screening," along with a companion piece written on behalf of the U.S. Preventive Services Task Force, prompted a meeting of the March of Dimes Bioethics Advisory Committee.

With a more focused audience and purpose, *IRB* explores topics in research with human subjects, drawing a readership that includes administrators and members of institutional review boards, scholars, and researchers. In 2008, *IRB* celebrated its thirtieth anniversary.

On the Center's Web site, *Bioethics Forum* features engaging commentaries on topical issues in bioethics. In 2007-2008, more than 240,000 readers visited the *Forum*.





*“Values such as human dignity, self-determination, and nondiscrimination are challenged by technology for personal detection, authentication, and identification.”*

—KAREN MASCHKE, RESEARCH SCHOLAR

nologies, the Center joined a consortium of 11 organizations to launch the HIDE (Homeland Security, Biometric Identification, and Personal Detection Ethics) project, a three-year effort that began in January 2008.

The Center is initiating three policy forums related to personal privacy—the tradeoffs between privacy and public security, concern over the exposure of highly personal details from body scans, and the risks of outsourcing personal information processing and storage. Hastings Center principal investigators are Karen Maschke, research scholar and editor of *IRB: Ethics & Human Research*, and Tom Murray.



## Cancer Biomedical Informatics Grid (caBIG)

Cancer research produces a vast and ever-increasing amount of data. In an effort to promote collaboration and speed basic and clinical research, the National Cancer Institute has created a mechanism through which designated cancer centers and community cancer centers can share data.

The initiative, called the Cancer Biomedical Informatics Grid (caBIG), reached out to Karen Maschke at the Center for assistance. Maschke provided advisory and programmatic support to help overcome the legal, regulatory, policy, ethical, proprietary, contractual, and socio-cultural barriers that data exchange among caBIG participants faces.

In June 2008 Maschke chaired a session at the caBIG annual meeting in Washington, DC. In November 2008, she participated in a workshop at Harvard University. Maschke completed her involvement with the project in January 2009.

## The Ideal of Nature: Appeals to Nature in Debates about Biotechnology and the Environment

From genetically modified foods to assisted reproduction, an increasing number of social debates feature claims that leaving a naturally occurring state of affairs alone has moral value. What is meant by “natural?” What is valued about nature and natural states? And should appeals to nature affect public policy?

These are some of the questions considered by *The Ideal of Nature: Appeals to Nature in Debates about Biotechnology and the Environment*. Led by Gregory Kaebnick, the project explored debates on moral views about nature surrounding medical biotechnology, agricultural biotechnology, and the environment.

The project convened two meetings, one in 2006 and another in November 2007, and its members produced articles and chapters in peer-reviewed publications, including an essay set in the *Hastings Center Report* in January-February 2009 and a forthcoming book from the Georgetown University Press. Funded by the National Endowment for the Humanities, the project concluded in 2008.



*Gregory Kaebnick, Research Scholar and Editor of the Hastings Center Report*

## Nanotechnology

Considered by many to be the next Industrial Revolution, nanotechnology is engineering on the minuscule scale of atoms and molecules. While nanoproductions can be designed for great good, such as targeted cancer therapies, they can also be used for great evil.

In July 2007 Josephine Johnston, Erik Parens, and Tom Murray wrote a report for the Director’s



*“A picture of the brain with areas that are ‘lit up’ may actually tell us very little about an individual's personality, capacities, or inclinations.”*

—JOSEPHINE JOHNSTON, RESEARCH SCHOLAR

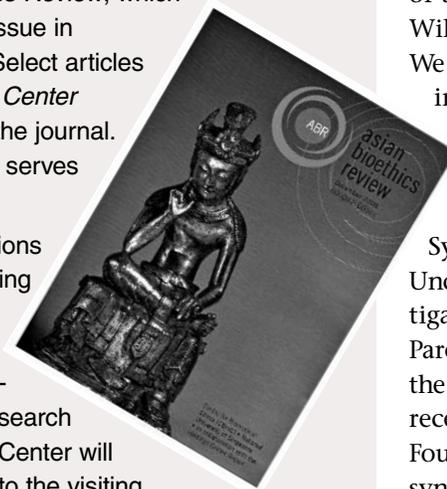
### Collaborating With Universities

Building research capacity at The Hastings Center also means forging partnerships with universities to enhance intellectual exchanges between scholars and broaden the impact of research and publications.

Yale University and The Hastings Center have longstanding ties, with Center scholars teaching at Yale and Yale scholars participating in Center research. Last year, these ties were strengthened to create the Yale-Hastings Program in Ethics and Health Policy, which was formalized at a ceremony at Yale in January 2009. New activities will include the development of joint research with Yale's Interdisciplinary Center for Bioethics, jointly sponsored educational seminars and student programs, and an exchange of library privileges.

In November 2008, The Hastings Center and the Centre for Biomedical Ethics (CBmE) at the Yong Loo Lin School of Medicine, National University of Singapore launched a collaboration aimed at expanding bioethics scholarship in Asia. The Center helped CBmE create a new online journal, *Asian Bioethics Review*, which produced its first issue in December 2008. Select articles from the *Hastings Center Report* appear in the journal. Gregory Kaebnick serves as liaison editor.

Both collaborations will bring new visiting scholars to The Hastings Center for periods of independent study. Research scholars from the Center will serve as mentors to the visiting scholars, discussing ideas and readings and critiquing drafts of their work. Visitors from Singapore will also be able to spend time at Yale.



Office of the National Institutes of Health on the subject. As previously mentioned, in December 2007 the Center organized a dinner discussion on nanotechnology at the Cosmos Club in Washington, DC, as part of the Public Interest initiative (see page 5).

### Ethical Issues in Synthetic Biology

Often described as “designing organisms from scratch,” synthetic biology uses molecular biology, computer science, and engineering principles to better understand the biological world and design useful products. More effective medicines, intelligent tumor-seeking bacteria, and cheap bio-fuels are some of the applications being promised today. However, synthetic biology raises ethical questions about benefit and harms.

In 2008, the Center engaged in two projects involving synthetic biology. Under a contract with the Woodrow Wilson International Center for Scholars, Erik Parens, Josephine Johnston, and Jacob Moses, a research assistant, wrote a paper, “Ethical Issues in Synthetic Biology: An Overview of the Debates” to be posted on Woodrow Wilson's Web site. They also wrote an article, “Do We Need ‘Synthetic Bioethics?’” which appeared in *Science* in September 2008.

With funding from the Alfred P. Sloan Foundation, the Center explored the topic in more depth with a project, Ethical Issues in Synthetic Biology: Toward Clearer Understanding and Better Policy. Principal investigators Gregory Kaebnick, Tom Murray, and Erik Parens invited a panel of experts to a meeting at the Center in July 2008. In late 2008, the Center received a second, major grant from the Sloan Foundation for a three-year research project on synthetic biology. Principal investigators are Kaebnick, Murray, and Parens.

# STATEMENT OF FINANCIAL POSITION

As of December 31, 2008

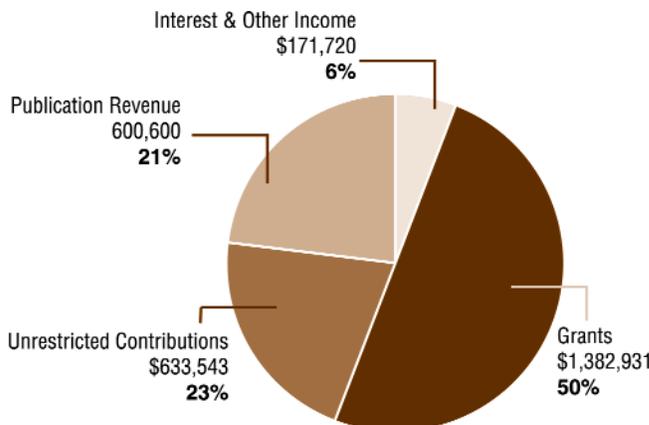
	Audited 2007	Audited 2008
<b>Assets</b>		
Cash and Equivalents	139,417	393,088
Investments, at fair value	4,876,140	3,457,087
Receivables (grants and other)	598,230	1,088,099
Other Assets	4,009	15,199
Furniture and Equipment (net of accumulated dep)	64,710	54,667
Leasehold Improvements (net of accumulated amort)	<u>1,288,053</u>	<u>1,314,977</u>
<b>Total Assets</b>	<b><u>6,970,559</u></b>	<b><u>6,323,117</u></b>
<b>Liabilities and Net Assets</b>		
Payables and Accruals	106,256	97,626
Deferred Revenue	233,244	230,724
<b>Total Liabilities</b>	<b>339,500</b>	<b>328,350</b>
<b>Net Assets</b>	<b><u>6,631,059</u></b>	<b><u>5,994,767</u></b>
<b>Total Liabilities and Net Assets</b>	<b><u>6,970,559</u></b>	<b><u>6,323,117</u></b>

# STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

<b>Operating Support and Revenue</b>		
Grants, Gifts, and Contributions	3,032,726	1,786,623
Government Grants	370,783	229,851
Publication Revenue	558,763	600,600
Other income	<u>208,354</u>	<u>171,720</u>
<b>Total operating support and rev</b>	<b><u>4,170,626</u></b>	<b><u>2,788,794</u></b>
<b>Operating Expenses</b>		
Program Services	2,161,052	2,472,473
Management and General	379,630	426,343
Fund Raising	<u>206,277</u>	<u>248,669</u>
<b>Total Operating Expenses</b>	<b><u>2,746,959</u></b>	<b><u>3,147,485</u></b>
Changes in Net Assets from Operations	1,423,667	(358,691)
Contributions-Campaign for Bioethics and the Public Interest	390,129	683,171
Changes in Non-Operating Income	<u>211,995</u>	<u>(960,771)</u>
<b>Change in Net Assets</b>	<b><u>2,025,791</u></b>	<b><u>(636,291)</u></b>
<b>Net Assets, Beginning of year</b>	<b><u>4,605,268</u></b>	<b><u>6,631,059</u></b>
<b>Net Assets, End of year</b>	<b><u>6,631,059</u></b>	<b><u>5,994,768</u></b>

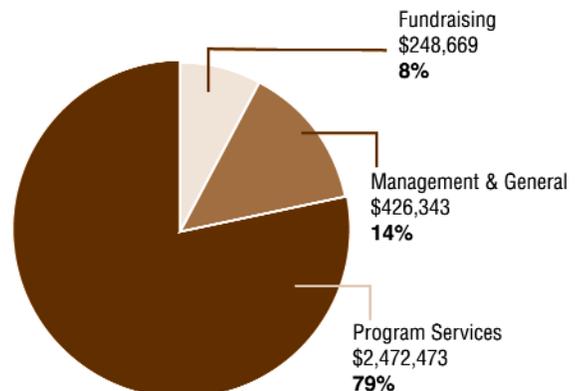
## SUPPORT AND REVENUE

Year ended 31 December 2008 - \$2,788,794



## EXPENSES

Year ended 31 December 2008 - \$3,147,485





**THE HASTINGS CENTER STAFF** As of December 31, 2008

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Nancy Berlinger  
*Research Scholar  
Deputy Director*

Polo Black Golde  
*Research Assistant*

Erika Blacksher  
*Research Scholar*

Daniel Callahan  
*President Emeritus  
Director, International Program*

Sidney Callahan  
*Distinguished Scholar  
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*Assistant to the President*

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*Staff Writer*

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Research and the Hastings Center Report*

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Director of Research Operations*

Alison Jost  
*Program Coordinator*

Gregory Kaebnick  
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**2007-2008 ACTIVITIES REPORT**

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**The Hastings Center**

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