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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As We Go To Press

March 2012 brought an historic moment to The Hastings Center: the announcement that Mildred Z. Solomon would become its fifth president in June, succeeding Thomas H. Murray, who has served in this role since 1999. This exciting news concluded an international search, chaired by Board member Michael Patterson. Other members of the search committee included former Board members and Hastings Fellows Harold Shapiro and Harold Edgar; current Board members Andrew Adelson, Anita Allen (Hastings Fellow), and Alan Fleischman (Hastings Fellow), and ex officio committee members David Roscoe, Hastings board chair; Josephine Johnston, research scholar; and Lyn Traverse, director of development.

Throughout 2011 there were bittersweet tributes to Tom. At the American Society for Bioethics and Humanities meeting in October, Hastings Center Fellows, colleagues, and friends feted him, celebrating his years of service to Hastings and to the field of bioethics. In addition, the Board of Directors has established the Thomas H. Murray Fund in his honor (please see Touching Lives through Philanthropy section), and over $700,000 has already been raised for this endowment.

Tom was a transformative president and leader in the field, enhancing the Center’s position as a pre-eminent research institution while expanding its capacity to reach a wider audience of journalists, policymakers, and the public. Tom remains a Hastings Center Fellow and will continue as a senior research scholar, working on several research projects. A Board resolution designated him President Emeritus.

Millie Solomon is no stranger to The Hastings Center. She is a Hastings Center Fellow and has worked on several research projects and published in the Hastings Center Report. She currently serves as the senior director for implementation science at the Association of American Medical Colleges and associate clinical professor of medical ethics in the Department of Global Health and Social Medicine at Harvard Medical School and the Department of Anesthesia at Children’s Hospital Boston. For the past 10 years, she has also served as director of the Fellowship in Medical Ethics in the Division of Medical Ethics at Harvard Medical School, a role that she will continue. In taking the reins, Millie will have the opportunity to build upon the past and take the Center into its next chapter of leadership in the field of bioethics.
By its very nature, bio (life) ethics touches lives. As the leading bioethics research institute, The Hastings Center takes on the big questions that people face at the beginning of life, the end of life, and turning points in between. It is a trusted resource on ethical issues posed by advances in medicine and technology.

Hastings scholars come from a wide range of disciplines, including philosophy, social psychology, law, political science, and theology. Their methodology involves bringing together people with different areas of expertise and points of view for respectful discussions about difficult bioethics problems. In stark contrast to the polarized state of much of public debate today, The Hastings Center’s inclusive approach, used successfully for more than 40 years, helps clear paths toward workable solutions.

In 2011, The Hastings Center’s work touched many lives. Among them were people contemplating genetic testing and wondering how private the information would be. There were also dying patients and their loved ones in search of caregiving options that would help their last days together be as full and rewarding as possible. And there were policymakers scrutinizing the ethical implications of synthetic biology, a science that could make humans the creators of new life forms. Through its publications and public affairs outreach, Hastings also touched doctors and other clinicians, biomedical researchers, journalists, and the general public—in short, anyone in need of reliable information of unsurpassed quality on fundamental ethical issues in the areas of health, medicine, and the environment as they affect individuals, communities, and societies.

You should only be interested in what Hastings does if you care about what happens at the beginning of life, at the end of life, and many of the most important moments in between.

—Nancy Gibbs, Deputy Managing Editor, TIME, member, Facing Life Campaign Council
Children

Children are not just small adults. When a bioethical dilemma affects a child, it takes on special significance because the person is young and vulnerable and because other people—parents and doctors—are often responsible for making decisions that are in the child’s interest. Knowing what those decisions should be is frequently far from clear. Several Hastings Center activities in 2011 touched on children’s lives and well-being.

A new project has begun to examine some of the ethical and policy issues around the creation of life through fertility treatments. In vitro fertilization, ovarian stimulation, and other fertility treatments significantly contribute to the tremendous increase in the number of multiple births. In the past three decades, the number of twin births has increased 50 percent and the number of triplets or higher-order multiples has increased by more than 400 percent. Rates of pregnancy complications, miscarriage, preterm delivery, infant death, and lifelong neurological and other impairments are markedly higher for pregnancies with multiples than with singletons. The project, funded by the March of Dimes, is being conducted jointly by The Hastings Center and the Yale Fertility Center. It has three goals: 1) to summarize what it is known about the determinants of multiple birth rates following fertility treatments, 2) to identify and critically analyze policy and education interventions that have lowered, or could plausibly lower the rate of multiple births following fertility treatments, and 3) recommend steps that U.S. policymakers and stakeholder leaders could take to lower the multiple birth rate. Hastings research scholars Josephine Johnston and Michael Gusmano are directing the project.

A major long-standing Hastings Center project explored controversies in the diagnosis and treatment of mental health disorders in children and recent increases in the use of medications to treat them. Funded by the National Institute of Mental Health, it culminated in a special report, “Troubled Children: Diagnosing, Treating, and Attending to Context,” which was funded by Dr. Eve Hart Rice and Dr. Timothy D. Mattison and published in the March-April Hastings Center Report. Research scholars Erik Parens and Josephine Johnston were the lead authors of the report and leaders of the project. Among the report’s conclusions is that decisions about whether and how to diagnose and treat these children often lie within a “zone of ambiguity” in which there is no single right answer. In these cases, personal values can greatly influence people’s decisions. One of the report’s disturbing conclusions is that many children with patently problematic moods
Because bioethics issues are ethically complex and often contentious, it can be difficult for students and teachers to broach them in the classroom. And yet understanding and engaging in nuanced and civil discussion about complex, contentious issues is an important skill for informed, engaged citizens. The educational program we are developing aims to help high school students sharpen these skills.

—JOSEPHINE JOHNSTON, RESEARCH SCHOLAR

and behaviors fail to receive the care recommended by experts. Systemic and cultural pressures compromise the diagnostic process and constrain the treatment choices of clinicians and parents, making it increasingly likely that medication is the only treatment children receive, even if the combination of medication and psychosocial treatment is recommended by experts. An another product of the project is a Web page that contains the special report, as well as numerous searchable, updated resources.

In 2011, The Hastings Center began a novel venture that aims to touch children’s lives through education. Hastings teamed up with the Ethics Institute at Kent Place School to develop a student-centered educational program that employs a modified version of the Hastings methodology of interdisciplinary research. The program is designed to provide high school students with a model for civil engagement around a variety of complex and contested issues in bioethics. It is being piloted in 2012 with a group of students from Kent Place School, an independent girls’ school in New Jersey, who will investigate the ethical issues that arise when medicine is used to enhance performance and appearance. The yearlong pilot project, supported by an anonymous private donor, includes mentorship by Hastings Center research scholars, a workshop at Hastings, and a community symposium to be held at the school. The long-term goal is to create a program and resources that teachers and students in the United States and elsewhere can use to investigate bioethics issues. The principle investigators are research scholar Josephine Johnston and Jacob Moses, the new media director.

Finally, 2011 saw the courageous publication by Hastings Center Board member and Fellow Blair Sadler about a threat to hospitalized children that is almost unimaginable and rarely discussed. Sadler was planning for his retirement as chief executive officer at San Diego’s leading pediatric hospital when two employees were arrested and ultimately convicted on charges of child molestation and trafficking in child pornography. Sadler’s recounting of the experience, and the lessons learned, are featured in “How a Children’s Hospital Discovered Child Pornographers in Its Midst,” a Narrative Matters essay in Health Affairs (September 2011), a leading health policy journal. It offers important guidance for any child-focused institution.
Our Genes, Our Selves

Genetics is one of the most active and promising areas of medical research and, increasingly, also medical practice. Already, genetic testing is helping doctors and patients select treatments whose effectiveness depends on particular genetic traits. This personalized approach has the potential to save lives and transform the quality of life for people with diseases such as cancer and cystic fibrosis. And as the cost of whole-genome sequencing falls, new possibilities could be on the horizon for disease prevention and treatment, as well as for connecting our genetic traits to behavioral tendencies. But with these great possibilities come many questions for society.

Research scholar Erik Parens began working with Columbia University to help create a Center of Excellence in the Ethical, Legal, and Social Implications of Research Program (known as CEER, for Center of Excellence in ELSI Research). The center will focus on the implications of advances in our understanding of the genetic contribution to behavior, psychology, and neuroscience. Among the important emerging questions that need to be considered are: What if researchers identify particular genes that increase the odds of a person engaging in certain kinds of criminal behavior? How might that information influence judges and juries? How should it? The National Human Genome Research Institute is supporting this research. Parens, whose work has long focused on the intersection of genes and behavior, was invited to speak before the Presidential Commission for the Study of Bioethical Issues in February about ethical and social issues raised by research on behavioral genetics.

Ethical questions about genetic testing and interpretation of the results were the subject of a major public television program for NOVA produced by WGBH Boston in association with The Hastings Center. Production work took place in 2011, with considerable input from Hastings Center scholars and the public affairs and communications department. (See Being in Touch for more information.)

What is the genetic component of human behavior? As scientists look for answers, they revive ancient questions about the meaning of free will and morality. If genes exert significant control over behavior, for example, what do we mean when we say that people are free and responsible for their actions?

—Erik Parens, research scholar
As sharing personal information has become increasingly easy and routine, many people are asking what privacy means today. Often raised in the context of Facebook, Twitter, and other social media, this question is every bit as relevant to personal medical information and genetic research results. Concerns about the privacy and confidentiality of genetic information come up when scientists conduct genetic research with DNA samples of people who donated them to a biobank. Several Hastings Center research activities in 2011 were concerned with questions about sharing research participants’ genetic information.

Research scholar Karen Maschke is co-investigator of an empirical study of the policies and practices of institutional review boards around the country regarding how researchers share biobank participants’ DNA samples and genetic research results. The study, funded by the Ethical, Legal, and Social Implications (ELSI) Program of the National Human Genome Research Institute, will develop policy recommendations for these ethics review boards.

Maschke, who is also editor of The Hastings Center journal *IRB: Ethics & Human Research*, was on a project supported by the National Cancer Institute that developed ethical, legal, and policy recommendations for researchers and institutional review boards on sharing cancer research participants’ genetic samples and information. In 2011 she gave major talks about the ethical and privacy issues concerning genetic research at a meeting of the National Academy of Science’s Committee on Science, Technology, and Law in Washington, DC and at the Third Global Alliance for Biomedical Ethics Centers (GABEX) International Conference in Tokyo.

Another simmering national debate about genetic research results has implications for the privacy and confidentiality of the people who donate their biospecimens for research. What should happen when the results show that some participants have an increased risk for an illness—do researchers have an ethical obligation to share that information with the participants? What if no treatments are available to manage the illness? Should participants’ family members have access to their relative’s genetic research results? Who should have access to genetic research results from studies with children’s DNA samples?

Hastings researchers addressed these questions in two other projects of the ELSI Program. Maschke was involved in one of the projects, led by Hastings...
Center Fellow Susan Wolf, of the University of Minnesota, which issued recommendations on the ethical obligations of biobanks and researchers to share genetic research results with study participants. Hastings scholar Erik Parens is working on the other project, led by Hastings Center Fellow Paul Appelbaum, of Columbia University, to conduct an empirical study of the attitudes of researchers and biobank participants about informing participants of their genetic information. Many researchers think that they should only be obligated to share such genetic information when some medical action can be taken to prevent or treat genetic-related illness. But research participants may want all of their genetic research results, even if no medical remedies are available. The aim is to understand the range of opinions as a first step to refining policies for researchers and biobanks.

New privacy issues are coming up now that some genetic research results have begun to be inserted into participants’ medical records. Maschke worked with the Mayo Clinic Biobank’s Data Access Committee and Community Advisory Board to examine these issues. Although the federal Genetic Information Nondiscrimination Act (GINA) of 2008 prohibits discrimination in health coverage and employment based on genetic information, there are gaps in the law’s coverage. Thus, many people remain concerned about their genetic research information going into their medical records.
How well are patients’ health care needs being met? How clearly are their voices being heard by clinicians and the health care system as a whole? These basic questions have been central to The Hastings Center since its founding more than 40 years ago, but new developments prompted a close look at specific issues.

Hastings scholars Nancy Berlinger and Michael Gusmano began a project that explores the health-related rights and needs of the 11 million undocumented residents in the U.S., most of whom have no health insurance. They are excluded from obtaining health insurance under the Affordable Care Act of 2010, and they have long been excluded under Medicaid and most other entitlement programs. And yet, they get sick and seek care in hospital emergency departments and other health care facilities. As federal and state policymakers face hard budgetary choices, this project is exploring the values that can sustain or imperil the domestic health care safety net. The Overbrook Foundation Domestic Human Rights Program is supporting the project, which included a research meeting in September with experts in health policy, ethicists, and clinicians who treat undocumented patients. The meeting resulted in a series of policy briefs about undocumented patients: their access to care, health care needs, and socioeconomic status.

Part of the challenge of meeting patients’ needs is understanding what those needs are. Another Hastings project examined the role of patients in the regulation of drugs by the U.S. Food and Drug Administration. Including patients on advisory boards is certainly helpful, but far from sufficient. Are there more effective mechanisms? Hastings organized a two-day meeting in Washington to discuss these questions with an interdisciplinary group that included patient advocates, industry representatives, FDA officials, bioethicists, and policy scholars. The meeting, which took place in January 2012, was funded by the California Institute for Regenerative Medicine, the FDA, CONNECT, Domain, and the Wireless Health Institute. Michael Gusmano directed the project, which also included Tom Murray, Hastings Center president, and Mary Crowley, director of public affairs and communications.

Other activities included commentaries on medical advances and their potential impact on patients. Following the major news about tests becoming available that can predict Alzheimer’s disease before symptoms emerge, Hastings scholars Erik Parens and Josephine Johnston wrote a commentary for TIME.com in June that encouraged clinicians, policymakers, and others to discuss the prospect that people with this knowledge may seek assisted suicide. The commentary coincided with the death of Jack Kevorkian.
We look to technology to help solve human and societal problems. But the process is rarely straightforward. It often involves balancing benefits against harms and it challenges us to ask bioethical questions: Just because something can be done, should it? And how can it be done responsibly?

For several years The Hastings Center has been exploring these bioethical questions in relation to synthetic biology, a technology that may design new life forms by cutting and assembling genetic material from disparate species. The purpose is to solve a wide range of problems, from producing inexpensive biofuels from algae to creating vaccines from modified bacteria. But these initiatives risk causing environmental damage and changing the human relationship to nature in fundamental ways. The Alfred P. Sloan Foundation has funded Hastings work on ethical issues in synthetic biology all along and in 2011 it supported a major new project that focuses on case studies to illuminate the examine the moral and social questions. The cases serve as anchor points to expand and deepen the discussion of how to move forward with the technology in a responsible way. The principal investigators are Gregory Kaebnick, Tom Murray, Erik Parens, and Michael Gusmano. Meanwhile, a set of essays from the Center’s first project on synthetic biology, “Synthetic Biology and the Ethics of Human Ingenuity,” was published in the Hastings Center Report (July-August 2011).

Synthetic biology is but one development that asks that we consider moral concerns about the human relationship to nature. A comprehensive look at these concerns was the subject of The Ideal of Nature, edited by Gregory Kaebnick and published by Johns Hopkins University Press in 2011. The book was the product of a project on the topic that was funded by the National Endowment for the Humanities.

Another project that began in 2011 investigated a different area of technology: alternatives to animal models in biomedical research. Ethical concerns over research involving animals are long-standing, but the debate usually comes down to weighing animal suffering against the potential to reduce human suffering with research that points the way to new knowledge and therapies. The Hastings Center’s project reframes the debate by examining the prospects for replacing animals with alternative models, such as tissue culture and computer simulations, without hampering the quality of biomedical research—and possibly even enhancing it.
We have been through one industrial revolution and we are about to enter a second, characterized by synthetic biology. An overarching question for us now is, How can we avoid some of the mistakes we made the first time around?
—Gregory Kaebnick, research scholar

Funded by the Esther A. and Joseph Klingenstein Fund, the project is being coordinated by The Hastings Center using the resources of the Yale-Hastings Program in Ethics and Health Policy, a partnership between the Yale Interdisciplinary Center for Bioethics and The Hastings Center. An interdisciplinary workshop took place at Yale in November, and a set of print and electronic educational resources are in development for use by a diverse audience: biomedical researchers, ethical oversight committees for animal research, students in medical research and law, and policymakers. Principal investigators are Gregory Kaebnick, Tom Murray, and public affairs editor Susan Gilbert.

A field of biomedical research that does not involve animals—and, in fact, could help replace them—uses neuroimaging technology to study the human brain. A wealth of new information has emerged from this research, linking particular brain structures and functions to particular behaviors and thoughts, and to psychiatric and neurological illnesses. But determining what these associations mean is far from clear. Controversy in the interpretation of neuroimaging was the subject of a three-year Hastings Center project funded by the Dana Foundation. The third and final workshop for the project took place in September 2011. Principal investigators Josephine Johnston and Erik Parens are preparing a special report on the findings of the project, which will take up questions such as the prospects for using neuroimages as evidence for guilt or innocence in legal cases and for classifying or diagnosing psychiatric disorders. The latter possibility was the topic of a paper co-authored by Parens with Seth Gillihan, of the University of Pennsylvania, “Should We Expect ‘Neural Signatures’ for DMS Diagnoses,” in the Journal of Clinical Psychiatry in March 2011.

Some of the most persistent questions involving technology and society land on the sports pages—they are about athletes using performance-enhancing drugs and other questionable means of gaining a competitive advantage. Hastings Center president Tom Murray was co-chair of a task force of the U.S. Anti-Doping Agency that published a report in March 2011, What Sport Means in America: A Survey of Sport’s Role in Society. Based on a survey of nearly 9,000 Americans, the report sought to understand what we believe about the role and significance of sport in society and to assess our views on sport ethics and values, role models, and aspirations. Among the key findings is that we rank the use of performance-enhancing drugs as the most serious problem facing sport today and that well-known athletes have a responsibility to be positive role models for young people. Murray has been writing a book on the meaning of sport that examines these and other ethical issues, funded in part by a grant from the World Anti-Doping Agency.
Throughout its 43-year history, The Hastings Center has been a driving force in framing health care choices in light of the values that shape them. These choices include those made by doctors and patients about options for care, as well as health policy choices about resource allocation and controlling health care costs.

A Hastings project led by cofounder Daniel Callahan and research scholar Michael Gusmano stepped back and looked at health policy choices in relation to the array of other national priorities vying for attention, ranging from education to environmental protection to national defense. Timed with the debate over the Affordable Care Act, the project, funded by individual donors, brought together a diverse group from law, business, and academia for a number of meetings in which they discussed national priorities in terms of underlying ideals and values. Participants ranked these priorities in a detailed survey. The ultimate question was arguably the most ambitious one that Hastings has ever taken on: What kind of country should the U.S. be?

Of course, individuals face health care choices, too, and many of these choices require working through ethical dilemmas. A new Hastings effort, supported by individual donors, aims for the first time to help people in the general public think through hard ethical questions posed by advances in medicine and technology. This initiative, called Help with Hard Questions, produced two booklets in 2011—*Patients and Care Partners: Ethical Questions about Sharing Information* and *Troubled Children: Ethical Questions about Diagnosing and Treating Pediatric Psychiatric Disorders*. Planning began for a Help with Hard Questions Web site geared to the general public. Mary Crowley, director of public affairs and communications, is leading the initiative. (For more information, see Public Affairs and Communications, page 18.)

Whether they are made by individuals or policymakers, health care choices are made in the context of our medical system. While there is wide disagreement over how to fix our medical system, there is widespread agreement that fixes are needed to improve access to care, provide care that is effective and appropriate for individual patients, and, all the while, control health care costs. Much has been written on this issue, but one commentary in particular touched a nerve in 2011:
What kind of country does the U.S. want to be? A leading economic or military power? Where does health care fit? We asked participants in our project to assess and then rank national priorities—but not in the context of government budgets. No other organization that we could find had tried to do that.

—Daniel Callahan, cofounder and President Emeritus

“The Quagmire: How American Medicine is Destroying Itself,” in The New Republic in June, written by Daniel Callahan and Sherwin Nuland, Hastings Center Fellow, Yale surgeon, and best-selling author. They proposed a radical reinvention of medicine, requiring new goals and an understanding of death as part of medicine and of life. They argued that a sustainable—and more humane—medical system in the U.S. will have to reprioritize to emphasize public health and prevention for the young and care, not cure, for the elderly. The commentary elicited significant response from the press, as well as doctors. (For more information on the press response, see Touching off Controversy, right.)

Hastings Center scholars frequently write for influential publications, but one bold article captured an exceptional amount of attention in 2011. Writing in The New Republic, Daniel Callahan (top left) and Sherwin Nuland called for nothing less than a reformation of American medicine: “a top-down, bottom-up study of the entire U.S. health system, with a view toward taking it apart and reconstructing it in a manner adapted to our nation’s needs.”

One goal would be to bring everyone’s life expectancy up to an average age of 80 but give highest priority for medical treatment to those under 80. An interesting twist to their argument is that Callahan and Nuland were themselves 80 when the article appeared.

“The real problem is that we have medicine excessively driven by progress, which aims to rid us of death and disease and treats them as the targets of unlimited medical warfare,” wrote Callahan and Nuland. “That warfare, however, has come to look like the trench warfare of World War I: great human and economic cost for little progress.”

“We need to change our priorities for the elderly. Death is not the only bad thing that can happen to an elderly person,” they continued, noting that “disability, economic insecurity, and social isolation are also great evils.” They endorsed a culture of care, not cure, for the elderly, with a stronger Social Security program and a Medicare program weighted toward primary care that supports preventative measures and independent living.

For months after its publication in June, “The Quagmire: How American Medicine is Destroying Itself,” was cited and praised by major media outlets, including a column by David Brooks in The New York Times, as well as NPR, Washington Post, Boston Globe, Huffington Post, and CNN.
End-of-Life Care

A dying patient and his or her loved ones have physical, emotional, and spiritual needs. What are they? How can they best be met by doctors and other caregivers? What obstacles stand in the way of a peaceful death, and what can be done about them?

The Hastings Center has long been a leader in establishing standards for good end-of-life care, and in 2011 it reached a new milestone: completion of the first revision of its landmark ethics guidelines on treatment decision-making at the end of life. Originally published in 1987, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* was the first set of guidelines on the ethical management of end-of-life care. The new volume is updated for the current generation of health care professionals on the decisions dying patients, their families, and other caregivers may face. It describes the practices, policies, and other systems that support communication and decision-making and promote access to palliative care, hospice care, and other services. Research scholar Nancy Berlinger was the project director. Coauthors were Hastings Center Fellows Bruce Jennings, of the Center for Humans and Nature, and Susan M. Wolf, of the University of Minnesota Law School. The project was funded by a distribution from The Albert Sussman Charitable Remainder Annuity Trust and a major grant from The Patrick and Catherine Weldon Donaghue Medical Research Foundation. Additional support was provided by donors to the Center’s Anika Papanek Memorial Fund and by unrestricted donations to the Center. The book will be published in 2012 by Oxford University Press.

Toward the end of 2011, The Hastings Center received funding from the Lien Foundation in Singapore to work with colleagues at the National University of Singapore to support clinician education on the care of seriously ill patients. The project involves creating a Web-based casebook with special attention to effective communication around family, religious, and cultural values and practices related to end-of-life care. The Hastings team consists of research scholars Nancy Berlinger and Michael Gusmano and new media director Jacob Moses.

Berlinger and Gusmano together gave a major talk in February 2011, “Taking
There is broad consensus in bioethics that medical professionals should avoid futility. But it is often difficult for clinicians and families to have conversations about the issues. Policies that create incentives to provide intensive care and discourage the use of palliative care make these conversations even harder.

—Michael Gusmano, Research Scholar

Seriously Ill People Seriously: Ethics and Policy Dimensions of the Chronic Disease/End-of-Life Care,” at the Third Global Alliance for Biomedical Ethics Centers (GABEX) International Conference in Tokyo.

Comparing end-of-life care internationally, Gusmano completed a project that examined aging and health in Hong Kong, London, and New York. Funded by the Hong Kong Jockey Club, this research was done in connection with Gusmano’s work as codirector of the World Cities Project, the first effort to compare the performance of health, social, and long-term care systems in New York, London, Paris and Tokyo, the four largest cities among the wealthy nations of the world.

Rewarding Outstanding End-of-Life Care

The Hastings Center Cunniff-Dixon Physician Awards were given for the second year in 2011 to physicians who have demonstrated exemplary care of patients at the end of life (see page 21). Winners of the award report that it is having a considerable impact on the lives of people who are seriously ill.

“We’ve started a palliative care program for children at North Carolina Children’s Hospital. We’ve been involved in the care of many seriously ill children and their families, and I feel strongly that our presence is helpful to them. The Hastings Center Cunniff-Dixon Physician Award gave me the jump start—both financial and with regard to energy and inspiration—that I needed to make this happen.”

—Elizabeth Dellon, M.D.

Recipient of a 2009 Hastings Center Cunniff-Dixon Physicians Award in the early career category.

Winners of the 2011 Hastings Center Cunniff-Dixon Physician Awards, left to right: Ann Allegre, Anthony N. Galanos, Savithri Nageswaran, Stefan J. Friedrichsdorf, and Eric W. Widera
**Selected Hastings Center Staff Publications, Presentations, and Public Service, and Hastings Center Media Citations**

**ENHANCEMENT**
- Erik Parens, “From ‘for’ or ‘against’ to ‘about’ Enhancement,” European Molecular Biology Organization/European Molecular Biology Laboratory, Heidelberg, Germany
- Erik Parens, “What’s the Ethical Difference between Using ‘Drugs’ and ‘Words’ to Treat Psychopathology?” Clinical Neuroscience and Society CME Course, University of Pennsylvania
- Erik Parens, “For ‘for’ or ‘against’ to ‘about’ Enhancement,” European Molecular Biology Organization/European Molecular Biology Laboratory, Heidelberg, Germany

**MEDICINE**
- Nancy Berlinger and Benjamin Boltin, “Health Politics: The Politics of Ethics,” Medical Decision Making, October 26, 2011
- Daniel Callahan, “Health Care Reform: Can a Communitarian Perspective Be Salvaged?” Theoretical Medicine and Bioethics, October 2011
- Daniel Callahan, “Rationing Cancer Care: The Emerging Debate” (interview), Advances in Hematology and Oncology, April 2011
- NPR’s “The Diane Rehm Show” interviews Daniel Callahan on health care costs.
- Michael Gusmano and Daniel Callahan, “Value for Money: Use with Care,” Annals of Internal Medicine, February 1, 2011
- Michael Gusmano, “Do We Really Want to Control Health Care Spending?” Journal of Health Politics, Policy and Law, June 2011
- Michael Gusmano, “Hard and Harder: The path to eradicating malaria in Africa involves much more than just a vaccine,” The Scientist, May 30, 2011
- Michael Gusmano, “Hospital Cost Control: Lessons from the OECD,” presented at Renmin University, Beijing
- NPR’s Washington, DC affiliate interviews Michael Gusmano about the graying of the world population.
- AMA News and O: The Oprah Magazine write about essays in the Hastings Center Report on the “Fable hospital.”
- MSNBC and Huffington Post cite article in Hastings Center Report on ethics of gallows humor in medicine.

**END OF LIFE CARE**
- Nancy Berlinger, “Treatment Decision-Making and Care Near the End of Life: Ethics Guidance for Pediatric Care Settings,” National Research Institute for Child Health & Development, Setagaya, Tokyo
- Nancy Berlinger, member, ad hoc Evaluation Advisory Committee, Needs Assessment of NIH-Funded End of Life and Palliative Care Science, National Institute of Nursing Research
- Daniel Callahan, “End of Life Care: A Philosophical or Management Problem?” The Journal of Law, Medicine and Ethics, May 11, 2011
- Michael Gusmano and Nancy Berlinger, “Taking seriously ill people seriously: ethics and policy dimensions of the chronic disease/end-of-life care,” Third Global Alliance for Biomedical Ethics Centers (GABEX) International Conference, Tokyo
- Michael Gusmano, “End-of-Life Care in the US: Overview and Policy Challenges,” presented at the International Longevity Center-Japan Symposium on End of Life Care, Tokyo

**AWARDS**
- The Hastings Center wins a 2012 American Inhouse Design Award for the 2010 Annual Report. This is the second year in a row that the Center has won this award.
Publications

With its two leading journals and increasing new media activity, The Hastings Center is regularly in touch with a diverse audience, which includes doctors and other clinicians, health care industry leaders, scholars, policymakers, and journalists. New developments augmented our capacity to engage these groups and reach new audiences.

The Hastings Center Report, our flagship journal, is a leading journal in bioethics. After more than 40 years of self-publishing it, the Center turned to Wiley-Blackwell, an international scientific, technical, medical, and scholarly publisher. It began publishing the Hastings Center Report with the January-February 2012 issue. Our more specialized journal, IRB: Ethics & Human Research, is read by members of institutional ethics boards that review research protocols involving human subjects.

Bioethics Forum, our blog of commentaries on topical bioethics issues, reaches a broad audience of scholars, clinicians, students, and journalists. It received 122,207 page views from 47,102 unique visitors in 2011. It was the focus of a Hastings marketing campaign at the annual meeting of the American Society for Bioethics and Humanities, the major bioethics conference, in October. The campaign was a contest that asked for answers to two bioethics-related questions and a caption for a cartoon by Hastings Center Fellow Eric Juengst (here, with finalist captions). The contest generated nearly 500 responses and met its goal of attracting enthusiastic attention to the Center and Bioethics Forum.

BEING IN TOUCH
Public Affairs and Communications

The major public affairs initiative for 2011 was the production of “Cracking Your Genetic Code,” a public television special on personalized genetic and genomic-based medicine for NOVA produced by WGBH in association with The Hastings Center. NOVA is the nation’s most watched science series, reaching four million viewers weekly. The show, which received major funding from the National Institutes of Health and support from The Greenwall Foundation, aired on March 28, 2012. NOVA’s accompanying Web site, which reaches 1.5 million people, includes Hastings resources.

With the NOVA show, The Hastings Center saw an opportunity to engage with a new audience: the general public. It began a series of booklets to help people think through ethical dilemmas that arise with health care decision-making. Two were published in 2011: Patients and Care Partners: Ethical Questions about Sharing Information and Troubled Children: Ethical Questions about Diagnosing and Treating Pediatric Psychiatric Disorders. The Center also created the Help with Hard Questions Web site (hastingshardquestions.org), intended to serve as an online community for discussion about ethical dilemmas raised by genetics, advanced illness, and other topics. It went live just before the NOVA show aired.

We expanded our new media efforts to make them a core component in disseminating our research to target audiences. Web pages were created for two projects: Troubled Children (childpsychiatry.thehastingscenter.org) and Undocumented Patients (undocumentedpatients.org). These multimedia sites, accessible to all, contain resources, social media features, and continuous news updates.

The Center has been working with federal policymakers since 2007 as part of the Bioethics and the Public Interest initiative. We augmented that outreach in 2011 by hiring a part-time public policy associate in Washington. The associate meets with Congressional staff to discuss Hastings Center issues, attends important Congressional hearings and other events, and keeps the Center informed about legislation and other developments in Washington that are vital to our work. In short, the policy associate has enhanced and opened new lines of communication between The Hastings Center and the political leadership and other stakeholders in the nation’s capitol.
Visiting Scholars

Each year, scholars from around the world come to The Hastings Center through our visiting scholar program to do research for books, dissertations, and other projects. They become part of the daily intellectual and social life at Hastings, and many maintain lasting ties. Here are three of the scholars who visited in 2011.

**RON PATERSON**

Concern for patient justice and health care quality brought Ron Patterson to The Hastings Center in July 2011. Paterson, a professor of health law and policy at the University of Auckland, was formerly the New Zealand Health and Disability Commissioner. He came to Hastings to work on a book about how patients might best come to know whether their doctors are, in fact, good doctors. Paterson used the Morrison Library’s resources on the doctor-patient relationship and the history of medicine and he met with research scholars to discuss issues such as the disclosure of harm to patients. “The Hastings Center staff has a communal lunch and discussion of current work on most days, providing useful opportunities to discuss my ideas,” he said. Paterson’s book, *The Good Doctor: What Patients Want*, will be published in June 2012.

**DAVID RODRÍGUEZ-ARIA**

David Rodríguez-Arias spent the summer of 2011 at Hastings studying new questions about how to determine death in organ donors. For decades, most organs were procured following brain death, the irreversible cessation of all brain function. But new criteria permit organs to be taken from patients who have not irreversibly lost brain function. These patients are declared dead when blood circulation stops following withdrawal of life support. “During my time at The Hastings Center, I tried to understand the interrelationship between circulatory and neurological death in the new protocols,” said Rodríguez-Arias, a research fellow at the Institute of Philosophy of the Spanish National Research Council. His work at the Center enabled him to write a commentary for *The Lancet* about the ethical challenges of the new protocols.

**TAYLOR PURVIS**

Research for her undergraduate senior thesis on Islamic perspectives on reproductive medicine led Taylor Purvis to become a visiting scholar in December 2011. Her research built on work begun the previous summer when she traveled to Indonesia to conduct interviews with fertility clinicians and read government documents on reproductive policy. At the Center, Purvis read the library’s collection of books and journal articles on Islamic bioethics and ethnographic reflections on assisted reproduction and she talked with Hastings scholars to develop a theoretical and contextual basis for her research. “My work at The Hastings Center allowed me to place the empirical results and experiences from my interviews and site visits into a broader religious, cultural, and political context,” said Purvis, a 2012 graduate of Yale.
STAYING IN TOUCH

Events & Visitors

With almost nonstop visitors from around the world and frequent meetings on and off site, we stay in touch with leaders in health care, policy, communications, and bioethics-related scholarship, as well as the next generation in these fields. Visiting scholars spend time doing research. Authors give talks on topical issues. Yale summer interns come to learn. And, through our awards, we recognize people whose outstanding work touches and improves lives.

In late November, TEDMED’s curator Jay Walker, right, visited with Hastings staff and Board members for a lively exchange on health care issues.

Beecher Award event at the Cosmos Club, Washington, D.C., in May 2011. Left to right: Tom Murray, Hastings Center president; David Roscoe, Board chair; 2010 Beecher Award recipients James Childress and Tom Beauchamp; and Daniel Callahan, Hastings cofounder and President Emeritus.

Celia Kitsinger, left, of the University of York, discussed her recent book, Coma, Consciousness, Culture, at a visit to the Center in October. Seen here with Board member Blair Sadler and research scholar Karen Maschke.

Beecher Award attendees: Irene Crowe and Andy Klingensteint (above) and Luann Van Campen and Robert Murray (left).
Matthew “Andy” Baxter, right, founder of The Hastings Center Cunniff-Dixon Physician Awards, presents a 2011 award to Dr. Eric W. Widera.

Annual Hastings Center-West Point meeting and dinner, hosted in April at West Point. Speaker David L. Perry, director of the Vann Center for Ethics at Davidson College, left, with Daniel Callahan, who began the conference with West Point more than 30 years ago.


Yale Interns luncheon, hosted at The Hastings Center in June.

Priorities project meeting held at Yale’s Interdisciplinary Center for Bioethics in May 2011.
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Hastings Center president Tom Murray reads the Board resolution to departing Board member and Hastings Center Fellow Anita Allen. During her Board tenure, from 2008-2011, she chaired the External Review Planning Committee and served as a member of the 40th Anniversary Advisory Committee and the Presidential Search Committee.
New Board Members

Gilbert S. Omenn, M.D., Ph.D., is a professor of internal medicine, human genetics, and public health and director of the Center for Computational Medicine and Bioinformatics at the University of Michigan. A leading cancer and translational science researcher and science policy expert, Omenn is principal investigator in the university’s Proteomics Alliance for Cancer Research.

Eve Hart Rice, M.D., is a clinical assistant professor of psychiatry at Weill Medical College of Cornell University. She also serves as vice president, treasurer, and a director of the Rice Family Foundation, which supports endeavors in health, education, and the environment. Rice returned to the Hastings Board, having served previously from 2003 to 2010.

Michael S. Roth, Ph.D., is the president of Wesleyan University. He is the author of five books, most recently Memory, Trauma and History: Essays on Living with the Past. Roth was founding director of the Scripps College Humanities Institute and associate director of the Getty Research Institute in Los Angeles. He publishes essays in a wide variety of venues, ranging from scholarly journals to the Huffington Post.

New Fellows

Hastings Center Fellows are an elected association of leading researchers influential in fields in which the Center is engaged. Ten new Fellows were elected in 2011.

Paul Appelbaum, M.D., is the Elizabeth K. Dollard Professor of Psychiatry, Medicine, and Law and director of the Division of Law, Ethics, and Psychiatry in the Department of Psychiatry at Columbia University. He is a member of the Institute of Medicine.

Gail Geller, Sc.D., M.H.S., is a professor of medicine in the Berman Institute of Bioethics at Johns Hopkins with affiliations in the Department of Pediatrics in the School of Medicine and Departments of Health Policy and Management and Health, Behavior and Society in the School of Public Health.

Susan Lederer, Ph.D., chairs the Department of Medical History and Bioethics at the University of Wisconsin, where she is the Robert Turell Professor of Medical History and Bioethics. Her work focuses on the history of medical research and the use (and abuse) of the body in medicine and medical research.

Alex London, Ph.D., is director of the Center for Ethics and Policy at Carnegie Mellon University and an associate professor of philosophy. He received the Distinguished Service Award from the American Society for Bioethics and Humanities in 2007.

Florence Luna, Ph.D., directs the Bioethics Program at FLACSO (Latin American University of Social Sciences in Argentina) and at the University of Buenos Aires. She is a former president and board member of the International Association of Bioethics.

Patricia Marshall, Ph.D., is a professor of bioethics and an associate professor of anthropology at Case Western University. She is a member of the team that is developing a haplotype map for the human genome at project sites in Nigeria, Kenya, and South Africa.

Jing-Bao Nie, Ph.D., is an associate professor in the Division of Health Sciences in the Bioethics Centre of the University of Otego in New Zealand. His books include Behind the Silence: Chinese Voices on Abortion, the first in-depth work to explore the perspectives of the people in mainland China on abortion.

Jan Payne, Ph.D., directs the project in bioethics at Charles University in Prague. He is a leader in the bioethics community in the Czech Republic and influential in Eastern Europe more generally, having founded a bioethics journal for the region.

Dorothy Roberts, J.D., is Kirkland & Ellis Professor of Northwestern University School of Law with a joint appointment as a faculty fellow at the Institute for Policy Research. Her work concerns issues related to race, gender, and the law.

Xiaomei Zhai, Ph.D., is executive director of the Centre for Bioethics, Chinese Academy of Medical Sciences, and professor and director of the Department of Social Sciences and the Humanities, Peking Union Medical College. She has led several national bioethics societies.
STAYING IN TOUCH

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