# Investing in People: The Greenwall Foundation's Bioethics Programs

A Report to The Greenwall Foundation May 2012

James Colgrove, PhD, MPH
Center for the History and Ethics of Public Health
Department of Sociomedical Sciences
Mailman School of Public Health
Columbia University

#### Introduction

In May of 1991, William Stubing addressed a group of senior staff members at the New York Academy of Medicine on the topic of "Biomedical Ethics: Critical Questions as We Confront the 21<sup>st</sup> Century." Stubing, who had been appointed the previous year as president of The Greenwall Foundation, described the process he had undertaken to determine how the foundation might implement a grant program to fund work on moral and philosophical issues in medicine and the life sciences. The foundation had a longstanding involvement in medical research, so addressing ethical topics such as end-of-life decision-making, genetic testing, and organ donation seemed an apt fit. But it was far from clear how the foundation should expand its giving in a still-evolving field that had acquired a name—bioethics—only two decades earlier.

Reflecting Stubing's background as a seminary graduate, his speech was evocative, with allusions ranging from the serious to the lighthearted: he quoted the priest and social activist Thomas Merton ("Our vocation is not simply to be, but to work together with God in the creation of our own life, our own identity, our own destiny") and the Broadway songwriter Johnny Mercer ("Oh happy day when miracles take place/And scientists control the human race"). What united the diverse issues grouped under the rubric of bioethics, Stubing argued, was that they all hinged on perhaps the most fundamental of questions: What does it mean to be human? That such a weighty existential matter was linked to very practical decisions in clinical care and public policy made the prospect of grant-making in bioethics both exciting and challenging. Stubing and the Greenwall board members had not yet defined the structure or direction of the foundation's bioethics giving. A program would soon take shape, however, and over the next two decades, the foundation would go on to fund work that would transform the field of bioethics in the United States.

A new program of grant-making in bioethics could hardly have been more timely, and the social backdrop more contentious. Less than a year before Stubing's talk, the U.S. Supreme Court had handed down a landmark decision in *Cruzan v. Missouri*, the first "right to die" case to reach the nation's highest court. The Human Genome Project, formally launched by the federal government a few months after the *Cruzan* decision, promised to unlock the secrets of life and alter fundamental notions of biology and even destiny. In the decade since the first test-tube baby had been born in the U.S., assisted reproductive technologies and novel surrogacy arrangements had opened up brave new worlds of parenthood. All these issues were prompting vigorous, sometimes acrimonious, debates among physicians, researchers, patients, and policy makers.

This report examines the evolution of The Greenwall Foundation's bioethics giving from the 1980s to the present. Some facets of this history can be expressed quantitatively. By 2011, the Interdisciplinary Program in Bioethics had awarded some 400 grants totaling more than \$43 million to 255 principal investigators in 30 states of the United States. Grants under the program ranged in amount from \$4,000 to \$2.4 million. This history can also be told in terms of products and outcomes: seminal and widely cited articles in scholarly journals; reports, books, and chapters for professional and lay audiences; conferences and workshops; guidelines for clinical practice; laws and public policies; educational films and videos. Finally, this history can be told in terms of a uniquely effective approach to grant-making. It shows the power of relatively small, carefully selected grants to produce large effects across many domains of policy and practice; the importance of a committed group of board members; and, most of all, the value of investing in people—of giving talented scholars the support they needed to do their best work.

This report will proceed in four parts. First, it traces the events that led to the establishment of bioethics as a focus area of The Greenwall Foundation. Next, it examines the

implementation and evolution of the foundation's Interdisciplinary Program in Bioethics and its longest-standing element, the project awards. Third, it describes the two most well-known Greenwall initiatives, the Fellowship Program in Bioethics and Health Policy and the Faculty Scholars Program in Bioethics. The report concludes with reflections on this history and suggests lessons learned as the foundation moves into the next generation of its efforts, with an exclusive focus on supporting talented and innovative scholars, especially those at an early stage of their career. This report seeks to situate the internal decision-making of the foundation within its historical context—the often contentious social and political environment that framed the issues addressed by Greenwall-funded investigators.

# I. Laying the Groundwork

The Greenwall Foundation, a small family philanthropy created in 1949, had its origins in medicine and a family tragedy. Frank Greenwall, who had built a successful company that produced industrial chemicals, established the foundation after his teenage daughter died of bone cancer. In its early years, it remained a "mom and pop" philanthropy awarding grants in loosely organized areas; one consistent emphasis was the prevention and treatment of children's diseases. In the 1960s and 1970s, the foundation expanded its medical focus to include diabetes research and gerontology and geriatric medicine, especially the care and treatment of Alzheimer's disease. Over the years, it developed internal structures and added formal programs of giving in two additional areas: arts and humanities, and education. The foundation had a board of 15 to 18 members divided into several committees, including a group to oversee each of the three programmatic areas. The Medical Advisory Committee, which was responsible for the

medical research grants, would eventually prove to be the key body that would shape the bioethics programs.

It was the focus on geriatrics that brought the foundation into its first tentative encounters with bioethics. Care for the elderly, especially end-of-life decision making, presented numerous ethical challenges around issues such as the use of palliative measures, treatment decisions for people with reduced cognitive function, and efforts to keep people alive in spite of severe physical deterioration. In the mid-1980s, William Vaun, MD, the chair of the Medical Advisory Committee, and John Dugan, William Stubing's immediate predecessor as the foundation's president, began to explore whether the foundation should become more involved in ethical issues in end-of-life care. In 1987 the Foundation awarded just over \$200,000 to The Hastings Center, a bioethics think tank, to publish a report it had prepared on caring for dying patients and to publicize the recommendations made in the report. The lead investigator on the project was Susan Wolf, JD, an associate for law at the center. With Greenwall funding, Wolf traveled nationally and internationally to lecture about the center's *Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying*. The grant also led to publications in leading medical journals and appearances in popular media.

Bioethics at this time was a still-young field in a transitional phase. Although an older tradition of medical ethics could trace its historical roots back to the Hippocratic Oath, "bioethics," a term first used around 1970, signified a set of concerns that was broader and more diverse than those of earlier eras. The field emerged partly from a widespread sense among physicians, politicians, and members of the lay public that advances in biomedicine and the life sciences were racing far ahead of society's ability to contain them. The development of kidney dialysis in 1960 and the world's first heart transplant in 1967 were two of the most high-profile

developments. Medical progress was raising questions about how to allocate scarce living-saving resources, how to balance the risks and benefits of new procedures, and how to distinguish between "ordinary" and "extraordinary" means of prolonging life when previously cutting-edge technologies became routine.

Around the same time, revelations of the abuse of human subjects of scientific research raised disturbing questions about the integrity, even the humanity, of medical scientists.

Although American physicians and researchers might have distanced themselves from Nazi atrocities and the Nuremberg code in the years following World War II, the revelation in 1972 of the U.S. Public Health Service's Tuskegee syphilis experiment starkly revealed the potential dangers of unchecked inquiry in the name of science.

It was not only advances in science and medicine and the exposure of research abuses that influenced the development of bioethics; it was also a changing social environment.

Bioethics emerged in a moment of profound upheavals: the civil rights struggle and protests over American involvement in Vietnam, mass mobilization around poverty and social justice, and challenges to the power and status of institutions and authorities—not least to medicine and science. Hence the nascent profession's strong emphasis on respecting individual autonomy and protecting the rights of the vulnerable and marginalized against the abuses of the powerful.

In the 1970s and 1980s, the field of bioethics took shape with striking rapidity. It attracted a heterogeneous assortment of scholars, including theologians, philosophers, lawyers, and physicians; from its beginnings, it was a hybrid field characterized by a diversity of analytic styles and conceptual frameworks. Two centers devoted to the study of bioethical issues, The Hastings Center and the Kennedy Institute of Ethics at Georgetown University, were founded in 1969 and 1971, respectively; the *Hastings Center Report* became a forum for scholarly papers. In

the wake of the Tuskegee scandal, Congress established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, which in 1978 produced *The Belmont Report*, a landmark document that galvanized the creation of institutional review boards to oversee federally funded research. At the clinical level, hospital ethics committees proliferated, especially after the Karen Ann Quinlan court decision in 1976. Quinlan, a young woman in a persistent vegetative state, was at the center of a highly publicized legal fight pitting her parents, who sought to remove her life support, against hospital administrators. After Quinlan was taken off her respirator, she unexpectedly began breathing on her own and survived for another nine years in a permanent vegetative state before dying in 1985. Her case transfixed the public and brought attention to the painful decisions that medical progress was forcing people to confront.

It was thus in a highly unsettled environment that William Vaun, John Dugan, and other members of Greenwall's board began to explore the possibility of investing in bioethics. A diverse array of medical, scientific, legal, and philosophical issues demanded attention. Although bioethical principles were rapidly being codified in the form of laws, regulations, and institutional structures, bioethics remained an inchoate field of study with unclear status as a distinct scholarly entity. There was an urgent need for both theoretical work and empirical analyses to inform decision-making, and for an expanded pool of scholars with the capacity to develop guidance for research and clinical settings.

In 1988, Vaun and Dugan met with experts in this evolving field to engage them in candid discussions about the strengths and weaknesses of the field and seek advice on how to proceed. In March, they met with Samuel Thier, MD, the president of the Institute of Medicine, along with three of his senior staff members, to discuss the possibility of involving the institute

as a collaborating partner in a fellowship program. Vaun envisioned an interdisciplinary, university-based program that could provide academic and professional training in bioethics, with exposure to issues of both clinical practice and policy making. Six months later, Vaun and Dugan met with three representatives of Montefiore Medical Center in New York City, Alan Fleischman, MD, Nancy Dubler, LLB, and Ruth Macklin, PhD, all of whom were involved with the pioneering ethics consultation service Montefiore had established in the 1970s. Also at the meeting was Tracy Miller, JD, of the New York State Task Force on Life and the Law, which New York governor Mario Cuomo had created in 1985 to deal with public policy questions surrounding medicine and health care. The task force exemplified the kind of fledgling organization that was on the front lines of bioethics (and that might benefit from foundation support). Vaun and Dugan elicited the group's feedback on the most pressing issues and needs in the field.

The foundation's planning advanced in 1989, when the Greenwall board commissioned Susan Wolf of the Hastings Center to write a report on how the foundation might best contribute to the field of bioethics. In preparation for drafting her recommendations, Wolf interviewed 14 prominent scholars from a range of disciplines and professional settings, including medicine, law, and philosophy, who had taken leading roles in the field. Wolf's assessment of the field was blunt and highly critical. Bioethics, she argued, "does not command the attention of enough such sophisticated scholars." She reported that one of the respondents she interviewed had lamented "the generally low level of scholarship in biomedical ethics." Wolf's report noted that numerous small university-based centers devoted to the study of bioethics had sprung up over the prior decade, but that none was located at a top-tier university that had the necessary combination of

expertise spanning medicine, law, and philosophy. The lack of a preeminent center, she claimed, "has retarded the acceptance of this field."

Wolf's report stimulated considerable interest and discussion among members of the Greenwall board and the Medical Advisory Committee, but the question of how the foundation should proceed was by no means straightforward. Funding might take various forms, including operating support or endowment for a center, a fellowship program, and project grants. Nor was it even a foregone conclusion at that point that bioethics would evolve into a major or exclusive focus for Greenwall. Before 1988, about three-quarters of the foundation's budget was allocated to medical research. That year, with the addition of the programs in arts and humanities and education, that proportion was lowered to about half, with the balance divided equally between the other two focus areas.

• • • •

When John Dugan stepped down as Greenwall's president in 1989, the pool of potential candidates to replace him was small. The board wanted someone who had an interest in ethics as well as a track record of working effectively with physicians and medical researchers. William Stubing, the director of the New York Academy of Medicine, was an ideal choice. In addition to his seminary training, Stubing held a master's degree in higher education administration. He had many years of experience working with doctors, first at the headquarters of the American Medical Association in Chicago and then at the New York Academy of Medicine, where he had headed medical education before becoming the institution's director. That the academy had an endowment roughly the size of Greenwall's also made Stubing an attractive candidate. He assumed the presidency on January 1, 1990.

Upon taking the job, the board gave Stubing the explicit charge to establish a program in bioethics. Stubing spent his first year on the job immersing himself in the world of bioethics and building upon the groundwork that had been laid over the prior three years by the consultations Vaun and Dugan had engaged in. He read voraciously, both scholarly and professional journals and articles in the popular media, such as the famous 1962 *Life* magazine article on the Seattle transplant center's "God committee" for allocating scarce slots for kidney dialysis to gravely ill patients. Stubing attended as many conferences and professional meetings as he could and followed up with people who had made especially interesting presentations. Attending conferences was a way to both gain substantive knowledge of issues in the field and to identify the most promising potential grantees—to see them in action and evaluate their work. He asked them not just about their own work, but about how they saw the priorities of the field.

In the summer of 1990, to explore the prospect of funding the establishment of a university-based center, Stubing interviewed faculty at three institutions where, over the prior decade, interest in bioethics had coalesced. At Harvard Medical School, a Division of Medical Ethics had been founded in September 1989. A few months later, a center for Biomedical Ethics had been created at Stanford University Medical School. At Yale University, a joint effort between the law school and the medical school had been undertaken; Yale had the longest-standing involvement with biomedical ethics, with faculty having done pioneering work since the 1950s, especially in the area of human subjects research. The presence of bioethics in academia was still relatively small but was rapidly expanding. Centers for the study of bioethics had been established at universities around the country; in addition to the programs at Harvard, Stanford, and Yale, there were prominent programs at the University of Washington, the

University of Chicago, Case Western Reserve University, and Baylor College of Medicine. Nine institutions offered graduate degrees in bioethics.

In marked contrast to the increasing presence of bioethics in the academy, Stubing found that the philanthropic world provided few sources of support for empirical or theoretical research in bioethics. In a report to the Greenwall board, he noted that although 51 foundations had given money to work in bioethics, no major foundation had a well-defined or financially significant program in the area. Over the previous five years, Stubing found 113 grants totaling about \$6 million had been made in the U.S. in bioethics, medical ethics, or the ethics of science and technology. The largest supporters of bioethics were the Pew Charitable Trusts in Pennsylvania, the Kaiser Family Foundation in California, and the Robert Wood Johnson Foundation in New Jersey. Most foundations that supported bioethics had given only one or two grants in the area, and most of the awards were for only small amounts (under \$20,000). The only other significant funder was the National Human Genome Research Institute's Ethical Legal, and Social Implications (ESLI) program, which in 1990 gave approximately \$1.3 million, or about 3% of the institute's budget.

In the spring of 1991, before the Greenwall board had approved a formal program in bioethics, the foundation gave \$450,000 over three years, its largest early grant in the field, to the Stanford University Center for Biomedical Ethics for operating support. Greenwall funding enabled what had previously been a shared interest among faculty in various parts of the university to come together in a formalized, multi-disciplinary program. The center was able to leverage Greenwall support to bring in other endowments, with the result that in the first year of funding, Greenwall support accounted for about half of the center's budget, while it represented

40% and 26% in the second and third years, respectively. In 1994, the foundation would follow up with a grant of \$200,000 over two years for additional operating support.

The funding given to Stanford in 1991 and 1994 would prove to be atypical; the foundation would later decide against providing grants for operating support. But what form its bioethics giving *would* take—whether it would emphasize project-specific grants, fellowships, or some other type of giving—remained unclear in the early 1990s. The consultations undertaken by the Foundation's directors and staff did not point unequivocally in any direction.

# II. The Interdisciplinary Program in Bioethics

Stubing's investigatory work over the course of his first 18 months as president culminated in late 1991, when the foundation formally created the Interdisciplinary Program in Bioethics. A five-year plan was devised. Grant-making was to begin immediately and continue provisionally through the end of 1995; awards would be accompanied by efforts to stimulate other funding and collaborate with other potential funders, possibly in the creation of interdisciplinary centers. A formal review and evaluation of the program was set for 1995.

The goals of the program were:

to stimulate applied research; to support development of education programs for health professionals as well as for lay people; to encourage collaboration—intra- and inter-institutional, regional, national, and international; to foster public discussion of issues and development of policy options to assure that information is used for the benefit of the individual and the benefit of society; and to assist in the development, evaluation, and utilization of standards of behavior and policy guidelines.

The wording of these goals indicated the extent to which the foundation saw bioethics as part of the public sphere—rigorous analysis conducted in a university could not be separated from its applications in policy and practice settings. The guidelines also made clear that the work of bioethics necessitated bridging the worlds of medicine, philosophy, theology, law, and the social sciences.

Responsibility for the success of the bioethics program would lie with the Medical Advisory Committee, the subset of the foundation's board that reviewed grant applications and made recommendations for funding. The number of members on the committee varied over time from six to nine, with the president serving ex officio. By the 1990s, the foundation was fortunate to have attracted an exceptionally accomplished and dedicated group to the committee. Members included Beatrix Hamburg, MD, a nationally known figure in child and adolescent psychiatry and the former president of the William T. Grant Foundation, and George F. Cahill, MD, a professor at Harvard Medical School, former president of the American Diabetes Association, and one of the country's foremost diabetes researchers. For all their medical and scientific expertise, however, the committee lacked the background to assess many of the philosophical questions at the heart of bioethics grant applications; moreover, some committee members in the early 1990s viewed the field of bioethics as "softer," somehow less rigorous, than the traditional biomedical research the foundation had funded. As a result, one of Stubing's projects over the years was to gently encourage the board to reorient its focus toward ethical issues and to recruit new members with interest and expertise in bioethics.

One of the people Stubing attracted to the foundation was Christine Cassel, MD. Stubing had met Cassel during his peripatetic first year of self-education in bioethics, when she was on sabbatical from her position as professor of medicine at the University of Chicago. Like many

medical professionals of her generation, she had been drawn to ethical issues in her work but had found a dearth of formal venues to receive training about them. She had pursued one of the few available opportunities, a fellowship with the Kaiser Family Foundation working with Albert Jonsen, a former Jesuit priest turned professor of bioethics and one of the leading national figures in the field. As a geriatrician, Cassel was especially drawn to end of life issues; she had published on research ethics and issues such as caring for patients with Alzheimer's disease. Stubing, recognizing the contributions Cassel could make to The Greenwall Foundation, interested her in the possibility of joining the board. She would go on to serve as the chair of the Medical Advisory Committee from 1993 to 1999, and would play a leading role in some of the most important decisions in the bioethics program.

Among the other experts who joined the Medical Advisory Committee during the 1990s were Harvey Goldschmid, JD, a professor at Columbia Law School with a broad background in corporate law, antitrust policy, and trade regulation; Joseph Perpich, JD, MD, trained in both law and psychiatry and the vice president of the Howard Hughes Medical Institute; James Tulsky, MD, an internist and professor at Duke University, who specialized in end-of-life issues and directed the Duke Center for Palliative Care; Troyen Brennan, JD, MD, MPH, professor of health policy at Harvard and expert in the U.S. health care system, public health law, and medical errors; and Richard Salzer, Jr., MD, an orthopedic surgeon and a grand-nephew of Frank Greenwall. In 2000, the chair of the committee was taken by Harvey Goldschmid. In 2006, when Goldschmid became chair of the full board, James Tulsky assumed leadership of the committee.

Stubing and the Medical Advisory Committee established a process for reviewing grants that was unusually painstaking and thorough. Potential applicants were encouraged to contact the foundation and have an informal conversation with Stubing about their interests, their proposed

research, and their long-term plans, and to determine how all these fit with the foundation's goals. Stubing would take the time to learn more about the investigator's qualifications if it was someone whose work he did not know; he would inquire with members of the Medical Advisory Committee, who were well-connected in their fields, or he might contact the applicant's colleagues or faculty at the same institution. To give investigators a sense of whether their planned work fit with the foundation's focus, Stubing maintained a list of the projects in bioethics the organization had funded; he also made clear what the foundation did not fund (sabbaticals, books, or operating support). Stubing did not critique the plans that prospective grantees described to him, nor did he provide comments on drafts of proposals; he knew from his days as a grant-seeker at the New York Academy of Medicine that investigators sometimes tried to shoehorn a proposal to fit a funder rather than staying true to the work they wanted to do.

After Stubing conducted his initial screening, he then sent proposals—from 10 to 20 semi-annually, on average—to a member of the Medical Advisory Committee who served as a second reviewer. The position of second reviewer would rotate among the committee members with a background in bioethics. (Occasionally a proposal would be sent to an outside reviewer if the topic area was highly specialized or beyond the expertise of committee members.) After the second review, Stubing and the reviewer would meet face-to-face and winnow the proposals to fewer than 10 that would be brought before the Medical Advisory Committee for consideration. At its semi-annual meetings, the committee would then thoroughly discuss the merits and potential problems of each proposal. Because of Stubing's and the reviewers' careful prescreening, the large majority of proposals brought before the Medical Advisory Committee were approved and sent to the full board with a recommendation for funding. This vetting process was

unusual in the world of philanthropy because most foundations were too large and received too many proposals, but it proved critical to the success of Greenwall's grant-making.

In the early days of the bioethics grant-making, the pool of applicants was relatively small. In the summer of 1991, only 11 of the 60 proposals reviewed by the Medical Advisory Committee were for bioethics work; the foundation's better-established programs in geriatrics and diabetes continued to attract the majority of applications. As the Interdisciplinary Program in Bioethics became more widely known, it began to receive more requests each year during the 1990s. The foundation deliberately refrained from identifying specific topic areas within bioethics that it wanted to fund; rather, the direction of giving was driven by the interests of investigators. The proposals that were received generally reflected the issues that were most prominent in the field, although projects often took these issues in novel or innovative directions.

The following sections provide illustrations (a highly and necessarily selective sample) of some of the projects funded through the Interdisciplinary Program in Bioethics. Headings are provided to illustrate the broad topic areas investigators addressed, but it should be noted that many projects the foundation funded over the years spanned multiple domains or defied easy categorization.

End-of-Life Care. If there was a single issue that dominated the field of bioethics in its formative decades, it was care at the end of life. As early as the 1950s, new technologies for keeping alive patients who in prior eras might have died presented a thicket of difficult ethical questions: how to define precisely the point at which life ended; whether there was a morally significant difference between withholding and withdrawing care; whether to honor requests from patients or their families to terminate life support; how to assess quality of life and balance it against the duration of life. All these issues remained urgent throughout the 1990s.

Two of the earliest grants funded under the Interdisciplinary Program in Bioethics, in 1991, went to the New York State Task Force on Life and the Law to study and provide public education about the state's recently passed health care proxy law, which allowed residents to designate someone to make decisions on their behalf should they become incapacitated and require medical care.

In 1994, the foundation gave a \$350,000 grant to the organization Choice in Dying, which advocated for the rights of terminally ill patients and their families in the area of medical and psychosocial needs. The award funded a five-year project to develop a curriculum on care for dying patients and integrate it into existing medical school education and training. A dozen leading medical schools around the country signed on to offer the curriculum and to participate in an evaluation of it; all medical students who participated were to be surveyed before and after to gauge changes in their knowledge and attitudes.

In 1996, the Foundation awarded \$61,700 to the Oregon Health and Science University to support its work on end-of-life care. The grant supported the university's Task Force to Improve Care of the Terminally III, which developed and publicized educational materials, including a directory of resources and contacts, *The Final Months of Life: A Guide to Oregon Resources*, and statewide training programs for primary care physicians in pain and symptom management. In October of 1997, in the midst of the task force's work, the state legislature passed the Oregon Death with Dignity Act, which allowed terminally ill state residents to end their lives with medications prescribed by a physician. With Greenwall support, the task force was able to publish a 15-chapter book, *The Oregon Death With Dignity Act: A Guidebook for Health Care Providers*, before any state resident had ended his or her life as allowed under the new law.

One of the most important outcomes of Greenwall's grant to the Oregon task force was that it allowed the group to widely disseminate its "physician orders for life-sustaining treatment," or POLST, forms, which the group had begun developing and piloting several years earlier. The POLST was a simple one-page form and wallet card on which people who were gravely ill or near the end of life could record what kind of emergency life-support measures they wanted to receive. Even more significant than distribution within Oregon was the rapid adoption of the forms outside the state: within a decade, more than half the states had either created or begun developing their own POLST program. Susan Tolle, MD, Director of Oregon Health Sciences University's Center for Ethics in Health Care, later described this "ripple effect" as one of the grant's most important outcomes.

Organ Donation. An issue closely bound up with end-of-life decision making was procurement of organs for transplant. In the 1960s, advances in transplantation capabilities gave new urgency to precisely defining when life ended so that surgeons could remove organs for transplant. After the development of the category of "brain death" by a Harvard committee in 1968, cessation of brain function rather than the stopping of the heart had become the most commonly used criterion for defining death. But with the number of people needing transplants far exceeding the number of available donors, some surgeons sought to use the organs from donors whose heart had stopped beating.

One of the earliest, smallest, and ultimately most high-impact grants the foundation was to make in its bioethics program was awarded in 1992 to the University of Pittsburgh School of Medicine to address the sensitive issue of how organs for transplantation should be taken from a donor whose heart had stopped. These organs were often suboptimal because they began to deteriorate as soon as heart function ceased, but methods for preserving the organs, including

post-mortem perfusion, raised extremely challenging ethical issues around familial consent and respect for the wishes of the dying. Although the desperate need to increase the supply of organs for donation was widely acknowledged, there was no professional consensus on the matter. The Pittsburgh investigators brought together experts from around the country for a workshop to address these questions and develop guidelines.

By the scale of most medical grant-making, the amount Greenwall gave to the Pittsburgh investigators was minimal—only \$4,600. But the workshop it funded on the topic resulted in a raft of high-impact publications in top-tier medical journals such as the *Journal of the American* Medical Association, Transplantation, and the Kennedy Institute of Ethics Journal, as well as two books. The conference also brought the issue to attention in the popular media through articles in the Wall Street Journal and the Washington Post and a segment on the television news magazine 60 Minutes. Within several years, most local procurement agencies in the country that had policies on non-heart-beating organ donations were following the policy guidelines set forth in the Pittsburgh project. And in 1997, the Institute of Medicine released a report, Non-Heart-Beating Organ Transplantation: Medical and Ethical Issues in Procurement, that drew heavily on the work the Pittsburgh investigators had pioneered. The principal investigator of the grant, Robert Arnold, MD, became a nationally known expert in the field of transplantation, and began an ongoing collaboration with Stuart Youngner, MD, who went on to direct the Center for Bioethics at Case Western Reserve University. That such a small amount could have resulted in such far-reaching impacts led Stubing many years later to call it "the single most effective grant" the foundation had ever made.

Organ transplantation issues of a different sort arose in 1993, when the foundation awarded \$130,000 over 14 months to the Institute of Medicine to study xenografting—the

process of transplanting cells, tissues, or organs from one species to another. These procedures had captured media attention the previous year when doctors transplanted the liver of a baboon into a 35-year-old woman; a few months later, a woman with liver failure had received a replacement organ from a pig. Faced with acute shortages of suitable human organs for transplantation, surgeons and medical institutions around the country were pressing ahead to investigate the use of xenografts, in spite of the serious scientific, ethical, and policy issues the procedures raised, including the high levels of mortality, poor quality of life following the transplantation, and the costs of the procedures to families, recipients, and society.

The Institute of Medicine wanted to convene a workshop to study the issues, and though the Greenwall grant covered about half the cost, the institute had difficulty raising money to cover the rest. In 1995, doctors in San Francisco transplanted bone marrow from a baboon into a man critically ill with AIDS, once again catapulting the issue into public prominence. Because of this renewed attention—and because Greenwall had already committed half the funding—other funders came forward to support the workshop.

Genetics. The effort to identify the approximately 23,000 human genes was one of the most important and closely watched scientific endeavors of the century. Equally scrutinized were the numerous ethical and legal issues that arose from expanding genetic knowledge. In 1993, the foundation awarded \$17,000 to Dartmouth Medical School to support production of a video documentary, *The Burden of Knowledge*, that would help patients and clinicians grapple with issues surrounding prenatal genetic testing, such as the right to refuse testing, perceptions of disability, and the choice to pursue selective abortion in the case of some positive tests. In a similar vein, the Massachusetts Corporation for Educational Telecommunications received \$25,000 in 1997 to produce educational materials for medical practitioners about the ethical

implications of genetic tests for conditions such as diabetes, Alzheimer's Disease, and depression. Another 1997 grant of \$48,000 enabled researchers at the University of Michigan School of Public Health to study popular attitudes toward such issues as genetic screening, privacy and confidentiality of genetic information, and the need for government laws and regulations in this area.

*Professional Behavior.* The scope of doctors' and researchers' professional duties—to their patients and subjects, to each other, and to society at large—was a time-honored focus of medical ethics, one that grew more complicated in the late twentieth century. Major research universities and medical institutions were weaving closer collaborations with for-profit entities such as pharmaceutical companies and medical device manufacturers. Would such partnerships undermine the integrity of clinical practices? Would the profit motive taint research findings? A major obstacle to addressing questions such as these was lack of basic knowledge about the extent of academic-industry partnerships. In 1993, investigators at Tufts University received a grant to study "Academic-Industry Linkages: An Assessment of Scope, Potential Conflicts of Interests, and Journal Disclosure Policies." The grant funded the creation of a database of scientists who were affiliated with both academia and industry so that analyses could be done of the nature and extent of these relationships. The authors were able to determine that of approximately 800 scholarly articles published in 1992, about one-third of the lead authors had a financial stake in the subject matter of the research—and almost none had disclosed these potential conflicts of interest. The project was an example of the way that careful empirical study was a necessary precondition to establishing ethical guidelines and practices.

• • • •

In the summer of 1996, as planned, the Greenwall board commissioned a review of the first five years of the Interdisciplinary Program in Bioethics, focusing on the accomplishments of the funded projects, the grant-making process, and possible future directions for the program. To write the report, the Medical Advisory Committee turned to three nationally known scholars in the field: Ronald Green, PhD, a professor in Dartmouth University's Department of Religion; Patricia King, JD, a professor of law, medicine, ethics, and human rights at the Georgetown University School of Law; and Bernard Lo, MD, a professor of medicine at the University of California, San Francisco. The three reviewers commended the foundation's "highly effective use of limited resources"—grants such as the one for the Pittsburgh transplant conference that produced large impacts proportional to the amount of money given. In a relatively short period, the foundation "has become a leader in funding innovative and important projects in bioethics," they noted.

In making suggestions for how the program might be made even more successful, the three reviewers urged that applicants "be asked explicitly to address how their projects would affect either public policy or clinical practice." They also noted that on the few occasions when a grant had proved to be unsuccessful, one reason was that the investigator had not convincingly shown that he or she was prepared through prior work to carry out the project.

One of the questions raised in the report was whether the foundation should adopt targeted, issue-specific funding designed to increase work in a defined topic area of bioethics, such as end-of-life care, or whether it was preferable to maintain a more open-ended approach that allowed individual investigators to direct the work of the field. When Bernard Lo presented the review at the meeting of the Medical Advisory Committee in the fall of 1996, the merits of each approach were discussed. Although at the time the committee declined to take a strong

stance one way or the other, preferring to strike a balance, the foundation would move increasingly in subsequent years toward an investigator-driven approach. "It was good to let people come up with their own ideas," Lo later recalled. The most talented and innovative people, the Medical Advisory Committee increasingly saw, could produce through their varied efforts a more vibrant field than foundation-directed giving in defined areas.

The involvement of Bernard Lo as one of the three reviewers for the five-year evaluation was auspicious. In the next decade, Lo would go on to play a central role in creating and developing one of the foundation's flagship bioethics initiatives, the Faculty Scholars Program.

• • • •

The project grants grew steadily in volume over the 1990s. In 1991, the foundation awarded five grants in bioethics totaling about \$500,000; in 1998, it awarded 25 grants totaling some \$3.4 million. About a third of the grants awarded during the 1990s were multi-year grants. As the project grants continued through the end of the decade and into the 2000s, the foundation funded work in established areas of bioethics, as well as venturing into new realms.

Research Ethics. As noted earlier, the protection of research subjects and the promotion of autonomy, justice, and beneficence in the conduct of human subjects research was a prominent focus of bioethics. The 1990s saw a series of high profile episodes that signaled renewed attention to these issues. In 1994 and 1995, a federal commission conducted a formal inquiry into experiments the U.S. government had carried out for three decades after the end of World War II on the effects of ionizing radiation on humans, including many subjects who did not give informed consent. In 1997, President Bill Clinton issued an apology in a White House ceremony to the eight surviving subjects of the Tuskegee experiment. The radiation inquiry and the Tuskegee apology were sobering reminders of the ways that human subjects research could

present grave risks and that the dignity and consent of subjects could be violated in the name of science.

In 1999, the foundation awarded \$300,000 to the Institute of Medicine for a study, "Protection for Human Subjects of Research." The institute prepared a report that reviewed whether existing guidelines for the protection of human subjects were adequate and recommended changes both in the ways that institutional review boards were run and in the procedures followed by individual investigators. As was generally the case with the institute's reports, the audiences for the recommendations were diverse: the academic research community, officials at federal agencies, congressional staff members, and policy makers.

Public Health Ethics. Public health ethics emerged in the 1990s as a distinct subfield within bioethics. Whereas bioethics typically focused on individual patients in the context of clinical care or research participation, an increasing number of scholars were drawn to issues involving the protection of entire populations through measures such as quarantine, mass vaccination, or reporting of disease statistics. Public health ethicists argued that such community-level interventions might require a different set of considerations and principled judgments than were used in bioethics. Respect for individual autonomy, for example, might not be the most important consideration when dealing with contagious threats; justice and equity might assume more salience.

One of the foundation's earliest grants in bioethics had supported a public health project. In the midst of an outbreak of drug-resistant tuberculosis in New York City, pitched battles were waged over potentially coercive measures to control the spread of the disease, with civil libertarians arguing that the human rights of infectious patients were being violated in the name of safeguarding the public's health. In 1992 a grant of approximately \$12,000 had enabled the

United Hospital Fund to convene an expert panel and issue a report with guidelines and recommendations.

Over the next decade, public health ethics continued to grow in salience, especially in the context of re-emerging infections and bioterrorism. In the early 2000s, the foundation added public health ethics as a new focus area. Two grants in 2006 illustrated this focus. The foundation awarded \$53,000 to the University of North Carolina Chapel Hill School of Public Health to study "Ethics in Public Health Emergencies." North Carolina was at the vanguard of emergency preparedness because of its vulnerability to hurricanes; investigators there sought to build on this experience to prepare for an outbreak of pandemic flu. The same year, a grant of \$50,000 was given to the University of Michigan School of Public Health for a pilot study "Public Health Issues in Practice." The study consisted of approximately 40 face-to-face interviews with employees of local health departments in Michigan about the types of ethical dilemmas they confronted in their work and the approaches they used to resolve the issues.

Embryonic Stem Cells. The issue of embryonic stem cells burst onto the scene in 1998 when a biologist at the University of Wisconsin developed the first line of the cells, which have the potential to generate any type of cell in the body and held out the promise of therapy for conditions such as Alzheimer's Disease and cancer. Because creating new cell lines entailed the destruction of fertilized embryos, the process became enmeshed with the issue of abortion and debates over whether life began at conception. In 2001, the Berman Bioethics Institute at Johns Hopkins University received an award of \$300,000 for "Ethics and Stem Cell Engineering: The Next Generation," to study these emerging issues "before they became political footballs," in the words of investigator Ruth Faden, PhD. It was already becoming clear that the issue was politically charged. In August of 2001, President Bush issued an order prohibiting federal funds

from being used for research on any stem cell lines other than those in existence. Within a few years, Korean researchers announced important advances in stem cell research; their work fueled criticism that the Bush administration's policy was causing the U.S. to fall behind in this critically important area of scientific inquiry. Meanwhile, California and New Jersey took steps to provide funding that would fill the void left by the Bush administration's ban.

The Hopkins project involved three phases. In the first phase, a working group considered criteria for selecting the embryos from which stem cell lines were to be drawn. The group also examined issues relating to the potential creation of inter-species "chimeras" via stem cells. In the second phase, investigation of chimeras continued, with the focus on ethical issues arising from the grafting of human neural stem cells into non-human primates in order to enhance their cognition. The third phase of the project, funded in 2004, turned attention to the first human trials of treating neurological conditions with stem cells and questions related to informed consent, subject selection, and risks and safety of the trials. The three phases of the project resulted in a series of articles in leading journals of ethics, medicine, and health policy.

In 2004, the foundation gave a one-year grant of \$50,000 to the Institute of Medicine to support the project "Guidelines for Embryonic Stem Cell Research." The institute used the grant to review existing guidelines and develop recommendations both for technical aspects of the conduct of stem cell research, such as sources of cells, and the ethical issues, including the consent of potential stem cell donors.

<u>Neuroethics</u>. The field of neuroethics emerged in 2002 and quickly attracted enormous interest. This field was broadly concerned with ethical issues related to the study of the brain. As science revealed more about the neurological basis for personality traits and behaviors, how did concepts such as responsibility, altruism, and wrong-doing change? How should scientists

evaluate the safety and morality of cutting-edge procedures such as brain scans to detect falsehoods? Greenwall gave grants to the University of Pennsylvania Center for Bioethics and Stanford University to study the ethics of neuroimaging, and in May of 2002 a conference attended by some 150 ethicists, neuroscientists, psychiatrists, psychologists, and legal scholars drew wide attention to the subject.

Kornfeld Program in Bioethics and Patient Care. A partnership between The Greenwall Foundation and another grantor led to a special sub-category of project grant, for work focused on clinical ethics. In 2004, Stubing began conversations with the executive director of the Emily Davie and Joseph S. Kornfeld Foundation, a small New York-based philanthropy that concentrated much of its giving in palliative care initiatives and research into amyotrophic lateral sclerosis (Lou Gehrig's Disease), with occasional support for bioethics. Discussions about a potential partnership progressed over the next two years, and in 2008, the Kornfeld Foundation committed \$1 million to a grant program that would be administered by Greenwall and would focus on patient care.

In the first round of the Kornfeld grants, researchers at Columbia University received funding to study the ethics of pre-implantation genetic diagnosis, the process of determining whether embryos developed outside the womb for implantation had genetic abnormalities that might lead to serious illness. Embryos could also be selected for implantation because they contained traits desired by the parents. Some ethicists believed that screening out "undesirable" traits or attempting to select "desirable" ones carried overtones of eugenics; some European countries had banned the procedure. The Columbia investigators conducted interviews with physicians and patients to better understand ethical judgments in this area and to develop guidelines and policies for the use of pre-implantation genetic screening. The same year,

researchers at St. Jude Children's Research Hospital were funded to develop a decision-making tool for children and adolescents near the end of life to help them express preferences about options such as palliative care or entering a clinical trial.

# III. Fellows and Faculty Scholars

Creating a post-doctoral fellowship program in bioethics had been one of the earliest possibilities discussed when Medical Advisory Committee chair William Vaun and President John Dugan had begun exploring how the foundation might invest in bioethics in the 1980s. Almost immediately after the creation of the Interdisciplinary Program in Bioethics in 1991, the foundation began receiving requests for fellowship support. Several members of the Medical Advisory Committee, mindful of their own early career experiences, were acutely aware of how valuable formal post-doctoral training could be, and how difficult it could be to obtain in the area of bioethics. The committee initially deferred these requests, however, because they believed several fundamental questions had to be resolved first. Most basically, was funding a fellowship program more important than other kinds of support the foundation could provide? If a fellowship program were put in place, should it be be limited to one or two institutions or should it be awarded to individuals around the country? By what criteria should fellows be selected? How long should support be available?

Stubing began exploring the idea in informal conversations with colleagues outside the foundation. He spoke with Renee Fox, PhD, the sociologist whose seminal book *The Courage to Fail* had examined bioethical issues in early kidney dialysis and transplantation, and Ronald Green, the Dartmouth professor of religious ethics who would later go on to conduct (with Patricia King and Bernard Lo) the evaluation of the first five years of Greenwall bioethics

giving. Both strongly endorsed the idea of a fellowship. At its meeting in October 1993, the Medical Advisory Committee resolved to move forward with creating a fellowship program. It seemed a propitious moment financially. The foundation's endowment was steadily increasing with the strong stock market, and the board had chosen to eliminate the diabetes research program in order to be able to devote greater resources to bioethics. Building on Stubing's conversations with Fox and Green, the Medical Advisory Committee consulted with a broad range of experts representing private and public bioethics organizations around the country to plan how the program could best be structured. The committee considered the examples of two small university-based fellowship programs. The MacLean Center for Medical Ethics at the University of Chicago had a one-year fellowship program for primary care physicians in fields such as general medicine, family medicine, pediatrics, or geriatrics, who wanted to pursue an academic career that included clinical ethics. A training program in the Division of Medical Ethics at the Harvard Medical School had a program, also one year long, in which fellows who had external funding pursued an independent research project. Another potential model the group considered was the Robert Wood Johnson Foundation's clinical scholars program.

By early 1994, the Medical Advisory Committee had reached consensus about several key characteristics of the fellowship and felt ready to move forward. Funding should build upon the strength of existing academic programs rather than try to establish something where nothing existed. Fellowships should be based at either one or two institutions with depth of expertise not just in medicine and ethics but in the social sciences. The emphasis on interdisciplinary work reflected the influence of Oscar Ruebhausen, LLB, the former chair of the Greenwall board (he had led the search process that resulted in the hiring of William Stubing). Ruebhausen had retired in 1991 and assumed the title of chair emeritus, but he remained a prominent voice within the

foundation. A lawyer, Ruebhausen had been a close adviser to New York Governor Nelson Rockefeller and served as president of the bar association of New York City. Ruebhausen strongly supported the idea of ensuring that social sciences, philosophy, and law, not just clinical disciplines, were brought into medical decision-making.

In addition to being interdisciplinary, the program was to be solidly grounded in the real world of policy and practice. It could not deal in "idle theory," as Cassel later recalled—it would have to result in changes to how things were done, whether in clinical encounters or in legislative debates. The need to have a strong focus on policy was driven home during the debates in 1993 and 1994 over the ill-fated Clinton administration plan for universal heath care. Numerous aspects of the plan had important implications for equity, justice, and rationing, yet few policy makers grasped these ethical dimensions, and few bioethicists spoke the language of policy well enough to participate in the political debates over the plan. Indeed, in 1993 the Medical Advisory Committee minutes had noted that "policy more than the bedside now presents the real cutting edge in bioethics."

The foundation received a dozen letters of intent for the fellowship program. Stubing and Cassel did an initial screening and requested full proposals from two applicants: Yale University and a collaboration between Johns Hopkins and Georgetown University. At the October 1994 meeting of the Medical Advisory Committee, representatives of the two applicants gave presentations on their proposals. Both programs offered many strengths, but the Hopkins-Georgetown program had what were seen as critical advantages: proximity to Washington, D.C., allowing for exposure to the policy-making process, and a long history of close collaboration among the institutional entities involved. The committee recommended an award of \$1.25

million over five years, with Greenwall support covering both faculty salaries and stipends for the fellows.

From its inception, the program was a collaboration of Johns Hopkins and Georgetown Universities. The lead entities within these universities were the Johns Hopkins Berman Institute of Bioethics (which was founded about the time the program began), the Georgetown University Law Center, and the Kennedy Institute of Ethics at Georgetown. The philosophy departments of both universities were also actively involved, as were faculty from the Johns Hopkins Bloomberg School of Public Health. The principal investigator was Ruth Faden, one of the most respected bioethicists in the country. Trained in social psychology, she had written (with Tom Beauchamp, PhD) a seminal book, *A History and Theory of Informed Consent*. She also had had extensive involvement with public policy; for example, she had chaired the committee that investigated the U.S. government's radiation experiments, and had served as the principal investigator on the series of Greenwall grants on the ethical and policy implications of embryonic stem cells.

Faden had a long-standing interest in how bioethics scholars and professionals should best be educated and mentored. She was sure, for example, that she did not want the program to be structured like a traditional post-doctoral program in the hard sciences where the fellow worked in a lab on someone else's project—she believed it was important for each fellow to have an independent project of his or her own. The program would provide a range of mentoring opportunities, including a seminar and colloquium series in which fellows did in-depth reading on ethical and policy issues and then engaged in discussions with leading policy makers, legislators, and scholars who were active in those areas. Faden and her colleagues saw their mission as comprising two types of mentoring. "Professional mentoring" aimed to help them develop as thinkers and scholars—to increase fellows' mastery of substantive intellectual issues

in their discipline and in ethics, health policy, and public health. In contrast, what Faden termed "careerist mentoring" sought to help them advance and succeed in the field of bioethics: to navigate the often byzantine procedures for academic promotion and tenure, negotiate sensitive issues of salary, to develop original publications and win grant support.

The training included service in a government agency. Sites for service included the Agency for Health Care Research and Policy, the Office of the Assistant Secretary for Planning and Evaluation in the Department of Health and Human Services, the National Bioethics Advisory Committee, the HIV/AIDS Bureau of the Health Resources and Services Administration, and the offices of senators such as Edward Kennedy and James Jeffords who were active in health policy issues.

In selecting fellows, Faden recalled, the program looked for scholars with "complementary but not overlapping" backgrounds, skills, and interests. A demonstrated capacity for excellence in another field was an essential component of the people chosen for the fellowship. All the fellows would have been, in Faden's words, good "something else's"—good physicians, lawyers, philosophers, social scientists—if they had not received additional training in bioethics and health policy. Personality was also important; the program placed a great emphasis on establishing a mutually supportive cohort who would learn from each other.

Because of the relatively short lead time for recruitment to the new program, there was only one fellow in the first year, David McCarthy, who held a PhD in philosophy. The following year four fellows joined him, and this second-year cohort exemplified the interdisciplinarity the program strove for: Ellen Agard, RN, who held a public health master's degree and was completing a doctorate in religious studies with a focus on feminist ethics; Lauren Randel, an MD with a background in paralegal work and human services administration; Andrew Siegel, a

JD who was completing a PhD in philosophy, whose interests included the relationship between law and psychiatry; and Leslie Wolf, a JD with a master's in public health. Each year thereafter, three or four fellows were admitted to the program.

The Hopkins-Georgetown Fellowship program was initially funded for three years. Since 1998, its funding has been renewed three times.

• • • •

The post-doctoral fellowship program fulfilled a critical need in the field of bioethics. But Stubing and the Medical Advisory Committee also realized that there was another gap in support: a funding mechanism that would take people through the next stage of their careers as junior faculty members, an often difficult period when young scholars are expected to be at their most productive, publishing original papers, securing grants to develop an independent portfolio of funded research, and navigating the process of promotion and tenure. The NIH supported the career development of young scholars through its "K" Awards, but these were almost exclusively for biomedical researchers. Such support was especially needed in bioethics because scholars so often worked (or wanted to work) across disciplinary boundaries or to carve out expertise in innovative areas where there might be little funding or mentoring available. Work that was not easily pigeonholed could be a hard sell in the world of academia and government funding, which was often rigidly segmented along lines of discipline and profession. Moreover, active engagement with audiences outside of the academy, such as policy makers or the general public, generally carried no weight in decisions around tenure and promotion, so there was little incentive for junior scholars to make efforts in these areas. Stubing envisioned a program whose goal would be, in the words of the proposal he submitted to the Medical Advisory Committee, "to strengthen the scholars' effectiveness as academic leaders, role models, and mentors for

future generations—to create a group of mutually supportive men and women prepared for leadership roles at their institutions and nationally."

As had been the case with the creation of the fellows program, the process leading to the faculty scholars was thorough and painstaking, involving almost two years of discussions and consultations among Medical Advisory Committee members and leading scholars in the field. The committee once again looked to other programs as potential models, including the Kaiser Family Foundation's faculty awards in general internal medicine and the MacArthur Foundation's "genius" awards, in which the use of the funding was left entirely to the grantee. An especially promising model was the Open Society Institute's Project on Death in America. Inaugurated in 1994, the project was a multifaceted effort to enhance understanding among professional audiences and the lay public of the complex issues surrounding the end of life. Among other components, the project included a fellowship program that offered three years of support to young scholars, with the goal of creating a cadre of leaders in the area of end-of-life and palliative care. In addition to training in substantive intellectual areas, the fellows received skills building in areas such as leadership and media relations.

In March of 2001, Stubing and three members of the Medical Advisory Committee, Christine Cassel, James Tulsky, and Harvey Goldschmid, met for a consultation with five nationally known leaders in the field: Robert Arnold, the Pittsburgh researcher who had led the project on non-heart-beating organ donation; Bernard Lo, who had been one of the three reviewers of the Interdisciplinary Program in Bioethics at its five-year mark; John Arras, PhD, a professor of philosophy at the University of Virginia; Baruch Brody, PhD, professor of biomedical ethics at Baylor College of Medicine; and Barbara Koenig, PhD, an anthropologist

and the executive director of the Stanford University Center for Biomedical Ethics (and an early grantee of the foundation). Together the group drew up the broad outlines of the program.

Each year, three scholars would be given two-year awards and would be required to devote 60% of their time to the grant. The scholar would carry out a specific, defined research project; in addition, he or she would create an individual professional development plan to identify mentorship and other activities to build the skills needed to be a leader in the field. The program would also include a professional development component, through which all the scholars would come together for annual meetings. A few changes were later made to the specifics of the program—awards would be over three years instead of two, and a commitment of 50% time would be required instead of 60%—but the basic elements remained. The program would be funded at \$2.5 million for its first three years. The board agreed that the ongoing need for the program would be assessed at the end of the initial funding period.

Key to the faculty development program was the creation of an advisory board, made up of five senior scholars in the field. (Stubing would also serve *ex officio* on the advisory board.) In addition to carrying out the traditional functions of advisory board members, including reviewing applications, selecting grantees, and giving input on program guidelines, the board members took far more active roles than was typical of such bodies. They were to serve as mentors and role models for scholars, giving advice on setting career paths, for example, and critiquing articles and grant proposals in draft form.

Especially critical to the conception of the program was the role that the director of the program would play. The director had to be someone with experience running a professional development program and sufficient seniority to negotiate with deans and department chairs on potentially sensitive issues such as gaining release time for a faculty scholar to work on bioethics

issues. Stubing and Cassel approached Bernard Lo, who had been part of the group that had helped to create the program. Like Christine Cassel, Lo had cut his professional teeth in bioethics at time when there were few formal opportunities for career development in the field (he had also studied under Albert Jonsen after completing his residency) and was devoted to creating mentoring opportunities. He was a clear fit in other ways: a member of the Institute of Medicine, he was a widely known scholar in the field and had held numerous high-profile policy positions, including the chair of the working group that developed regulations for stem cell research funded by the state of California. Lo agreed to become the program director.

The first three scholars, chosen in 2002, set the tone for subsequent cohorts in terms of their interdisciplinarity, their productivity, and the topicality of the work they undertook. Jason Karlawish, MD, a geriatrician at the University of Pennsylvania, developed a research agenda focusing on people with cognitive impairments such as Alzheimer's Disease and dementia. He conducted important empirical work on cognitively impaired persons who were unable to give informed consent, and examined whether federal regulations designed to protect such subjects might impede needed research on dementia and critical care medicine. He continued exploring elements of this topic with an analysis of the ethical, legal, and social issues raised by people with dementia voting in elections. Jonathan Oberlander, PhD, a political scientist in the Department of Social Medicine at the University of North Carolina School of Medicine, studied health care politics and policy. During his time as a faculty scholar, he studied the Oregon Health Plan, the innovative and controversial system that the state's voters had enacted in 1994 for prioritizing and rationing health care services. As health care reform has continued to be the focus of political battles, Oberlander's work on the determinants of success and failure in reform efforts have informed debate and figured prominently in both scholarly journals and the popular

press. Anna Mastroianni, JD, MPH, a law professor at the University of Washington, studied ethics and policy in the genomic era, with a focus on the numerous complex issues surrounding the use of embryonic stem cells. In addition to writing several publications on the topic for scholarly journals, Mastroianni played a prominent role in policy discussions around the issue, including memberships on National Institutes of Health advisory committees on genetics and recombinant DNA.

Subsequent cohorts of Faculty Scholars continued to reflect disciplinary diversity and eclectic interests. Thomas Gallagher, MD, of the University of Washington, carved out expertise in the field of medical errors. His research determined that patients and physicians differed in how they wanted medical errors to be disclosed: patients preferred disclosure of—and an apology for—all errors, whereas physicians believed that only errors that caused harm should be disclosed. Michelle Mello, JD, PhD, of Harvard University, studied the ethical obligations of pharmaceutical companies. Amy McGuire, JD, PhD, of Baylor University, examined issues surrounding privacy and consent in the collection and analysis of human genomic data.

The disciplinary mix of scholars has varied over the years, with MDs representing the greatest number of scholars. (One topic of discussion in planning the program was the difference in the stipends paid to MDs, JDs, and PhDs because of the wide disparities in the salaries across the fields. Although PhDs could be funded far more cheaply than either JDs or MDs, the foundation determined that applicants' degrees would not influence their selection and remained open to choosing three of a single discipline in any one class of scholars.)

Within four years of the program's inception, the three scholars who went forward for tenure all received it, an especially impressive achievement since they were being reviewed by committees at their institutions that had minimal familiarity with bioethics. Many scholars have built on their Greenwall-funded work to receive highly competitive R01 and "K" awards from the National Institutes of Health. Four people who had been fellows in the Hopkins-Georgetown program later went on to be funded as faculty scholars: Leslie Wolf, JD, MPH, who was part of the first full cohort of fellows in year two; Anne Lyerly, MD, who studied women's health and reproductive medicine; Debra Matthews, PhD, MA, who studied genetics and stem cells; and Jon Tilburt, MD, whose research focused on cross-cultural factors in doctor-patient communication.

In addition to pursuing individual research agendas, several scholars undertook collaborative projects with their peers. Thomas Gallagher and Michelle Mello successfully applied for funding from the Robert Wood Johnson Foundation to study the ways physicians reported on medical errors. They published four papers together on medical errors and malpractice reform, including one paper with Anna Mastroianni. Amy McGuire collaborated with Scott Halpern, MD, PhD, on a series of papers on patient decision making and consent. The collaborations reflected what Bernard Lo later referred to as the "multiplier effect": Greenwall-supported researchers coming together to carry out projects and address topics they would not have done, or have been able to do, by themselves. Although members of the Faculty Scholars advisory board had expected some collaboration, the extent of it came as a pleasant surprise. "We were all a little skeptical," Stubing recalled. "We hoped it would happen, but we weren't sure that it would."

Key to the program's success has been the semi-annual two- to three-day meetings, which feature workshops on special topics, such as communicating effectively to reporters and other members of the media. Equally important was the environment of mutual support the meetings fostered—a sense that the scholars were part of a community. As Bernard Lo noted, one of the goals of the program was to give fellows and scholars "collaborators, critics, second

pairs of eyes" to review and comment on their work. The results of their work—publications in the highest-impact journals, receipt of competitive federal grants, promotion and tenure at top-ranked universities—suggested that the effort was a success.

# IV. Retrospect and Prospect

In September 2011, two decades after he had spoken to senior staff members at the New York Academy of Medicine about the Greenwall Foundation's exploration of potential grantmaking in bioethics, William Stubing addressed a joint meeting in Baltimore of current and former Faculty Scholars and the Hopkins-Georgetown Fellows, and took stock of what they had achieved. By the fall of 2011, Stubing noted, 52 fellows were working at 34 institutions in 18 states and the United Kingdom. From the Faculty Scholars program, 30 scholars were on faculty at 20 institutions in 14 states. To convey the critical importance of the work the fellows and scholars were doing, Stubing turned to the fable of the sorcerer's apprentice. He likened modern biomedical science to the apprentice who heedlessly created a mad army of assistant brooms that flooded the sorcerer's castle with water. In their rush to create innovation, Stubing said, some scientists and researchers were unleashing advances without having considered the profound issues of right and wrong they raised. "And that, of course, is where all of you come in," Stubing told his audience. The fellows and faculty scholars provided critically important analysis, reflection, and response to advances in medicine and the life sciences that raised challenging ethical questions.

The 20 years of the Interdisciplinary Program in Bioethics coincided with a period in which medical science captured unprecedented attention in the media, policy and legislative debates, and the popular imagination. Controversial topics such as embryonic stem cells and end-

of-life decision making raised fundamental questions about how a diverse and pluralistic society should make value-laden decisions about science. At the turn of the new century, these questions were often, and increasingly, cast in the terms of a strident and polarized political discourse. The case of Terri Schiavo, the Florida woman in a persistent vegetative state whose husband sought to remove her feeding tube against her parents' wishes, exemplified how a personal tragedy could become a proxy in partisan battles between left and right. In the context of highly charged debates such as these, the careful, rigorous analysis that the Greenwall Foundation has funded has been all the more critical, providing guidance on virtually every significant bioethical question of the day.

Four themes that have characterized Greenwall's bioethics grant-making are worth highlighting in this conclusion. First has been the foundation's willingness to fund risk-taking. The foundation has repeatedly taken on issues that might be politically controversial, such as non-heart-beating organ donors, xenotransplantation, chimeras in stem cell research, euthanasia, and assisted suicide. These projects would have been unlikely to have been funded without Greenwall because, as Ruth Faden recalled, "no other agency would touch them." It also funded intellectually risky work, such as empirical studies that attempted to measure concepts such as empathy and voluntariness.

Second is the foundation's ability to yield large results with small grants. Almost half the grants awarded in bioethics were under \$50,000, and many led to far-reaching changes in policy and practice. Of special note in this respect is the long relationship between the foundation and the Institute of Medicine. Beginning in the mid-1990s, the foundation provided support for the institute's work on ethical issues. The amount of support has been modest but the outcomes have been impressive—a steady stream of critically important reports that have guided and informed

policy and practice: Health Outcomes for Older People (1996), Approaching Death: Improving

Care at the End of Life (1997), Organ Procurement and Transplantation (1999), Responsible

Research: A Systems Approach to Protecting Research Subjects (2002), and When Children Die:

Improving Palliative and End-of-Life Care for Children and their Families (2003).

Third is a commitment to ongoing evaluation of its own work and that of its grantees. The foundation's emphasis on concrete, measurable impacts on policy and practice has been paramount in the Medical Advisory Committee's discussion of proposals. This focus has been backed up with periodic reviews the foundation commissioned: the 1996 evaluation of the first five years of project grants; evaluations of the Greenwall-Hopkins fellowship program conducted in 1998 and 2005 and of the faculty scholars program; and surveys in 2000 and 2004 of former grantees to gauge their assessment of the impact of Greenwall funding on their work. Evaluation has also taken the form of site visits to grantees to see first-hand the effects of their work. In the 21 years he served as the foundation's president, Stubing by his own reckoning earned 50,000 frequent flier miles per year on site visits through which he could see how the foundation's money was being used. These trips also enabled him to keep his finger on the intellectual pulse of the field.

Finally, the foundation has been notable for its emphasis on mentoring and cultivating mutual support as a way to foster innovation and achievement. Through their commitment not just to excellence but to comity and collaboration, the leaders of the Greenwall Foundation's bioethics program—William Stubing, the members of the Medical Advisory Committee, Ruth Faden and her team at Hopkins-Georgetown, Bernard Lo and the members of the Faculty Scholars advisory board, and many others—did more than enhance the rigor and expand the

knowledge base of bioethics. They fostered an ethos of mutual respect, even—especially—in debates over highly charged questions of ethics, policy, and law.

• • • •

The culmination of Greenwall's philosophy of investing in people was the decision to concentrate the foundation's giving into the next iteration of the Faculty Scholars Program.

The foundation's endowment took a hit in the 2008 world financial crisis. Taking a hard look at the foundation's assets, the board determined that it could not sustain an arts program and a bioethics program with three elements (project grants, fellows, and faculty scholars). In the years since the Hopkins-Georgetown fellowship had been created, other fellowship programs in bioethics had proliferated around the country, and there were other opportunities for post-doctoral training for scholars in the field. But there was nothing else in bioethics that was comparable to the Faculty Scholars Program. The board determined that if the foundation were to concentrate its resources in one program, the Faculty Scholars Program was the logical choice.

Stubing, in collaboration with three long-time members of the Medical Advisory

Committee, Christine Cassel, James Tulsky, and Joseph Perpich, conceptualized the next generation of the Faculty Scholars Program, which would henceforth be the foundation's sole focus. The mission of "FSP II" was broad and ambitious: "to reinvigorate the role that the creative intellectual plays in a democratic society." The four put forth their proposal in an "entrepreneurial spirit," they wrote, with full recognition of the risks that such an approach might entail. "Investing in individuals is unpredictable, but it is in the uniqueness of individual personal and scholarly paths that innovation can often be found." The plan reflected an optimistic, even idealistic, vision of grant-making and a commitment to fostering open and productive discussion around highly charged topics.

The reformulation of the bioethics program coincided with a change in leadership at The Greenwall Foundation. After 21 years of service, William Stubing stepped down as the foundation's president in 2011. The foundation's board conducted a wide-ranging search for his successor and found an ideal candidate who they knew well. Bernard Lo, who had served as the program director for the Faculty Scholars in Bioethics Program since its inception in 2001, was named the sixth president of The Greenwall Foundation.

As biomedical science and the ethical issues it raises become exponentially more complex, the cadre of leaders produced through Greenwall's Faculty Scholars Program will be critical. "Bioethics has often been very reactive," was the assessment of Joseph Perpich, "focusing on what demands immediate attention." Scholars are therefore needed who are forward-thinking, nimble, and broadly equipped—both intellectually and professionally—to anticipate and grapple with new challenges, to range across topics and disciplines, and to serve as effective researchers and advocates in a dynamic and unpredictable field. Bernard Lo reflected that a central challenge in the future, as more scholars are funded and graduate from the program, will be to keep past and current cohorts connected to each other so that the synergistic effects of their work can continue. Investing in people with a shared sense of purpose and a commitment to excellence has been the Greenwall Foundation's greatest legacy. Continuing that mission will be its challenge in the years to come.