About the Health Research Alliance

The Health Research Alliance’s (HRA’s) roots can be traced to 1998, when a group of private funders convened at a meeting jointly organized by the American Cancer Society (ACS), the Burroughs Wellcome Fund (BWF), the Howard Hughes Medical Institute (HHMI), and the Pew Charitable Trusts. The meeting, “Strengthening Health Research in America: Philanthropy’s Role,” considered the future of biomedical research in light of major changes in funding streams for research within academic health centers. The group met again in 2000 and 2002 to consider the role of private funders in training the next generation of biomedical scientists and to share best practices with respect to basic operational processes, such as electronic grantmaking.

A subset of this initial group, consisting of a mix of private foundations and voluntary health agencies, began to meet periodically, informally calling itself the Clinical Research Alliance. Over the years, the Clinical Research Alliance contributed to several developments in health research, including:

- Collecting data demonstrating a doubling of the private, nonprofit sector’s combined contribution to the career development of clinical investigators during the period 1997-2001. The effort revealed a need for a new health research awards database.

- Piloting award programs for clinical investigators that included repayment of educational loans and encouraging other funders to do likewise.

- Cosponsoring a 2004 national meeting, “Partnering to Advance Health Research: Philanthropy’s Role,” which focused on building partnerships among like-minded nongovernmental funders as well as governmental funders and for-profit entities. Another national conference was held in 2006, “Building Strategic Partnerships to Advance Health Research.”

Positive response to these activities underscored the need for nongovernmental funders of health research to forge collaborations around common interests and to share best practices. The Clinical Research Alliance was incorporated as HRA in 2005, reflecting the group’s concern for research that leads to better health. With infrastructure support and leadership provided by BWF, representatives from HRAs 35 member organizations lead its working groups, which
are focused on building a database of member organizations’ grants, program evaluation, grants administration, and developing new funding models for drug development. In 2006, the national conference, “Building Strategic Partnerships to Advance Health Research,” was held in Washington, D.C.

Through its convening efforts and working groups, HRA fosters collaboration among not-for-profit, nongovernmental funders to support the continuum of health research and training from biomedical science to applications that advance health by improving communication and collaboration:

- **Internally**, among member organizations, to share data and best practices, informed by current information on the landscape of the health research enterprise; and

- **Externally**, by encouraging communication and collaboration among grantmakers and the broader health research and policymaking communities.

### About This Conference

According to the Foundation Center, the private philanthropic sector in the United States is growing at a steady pace, with private foundations now numbering nearly 71,000, with an asset base of roughly $550 billion. Despite the dramatic increase in the amount of foundation giving since 1995, the contribution of foundations to biomedical research and training is still dwarfed by the contribution of the public and industry sectors. However, recent trends have served to highlight the critical catalytic role that private funders play. The flat National Institutes of Health (NIH) budget and fluctuations in the national economy compel nonprofit funders to carefully consider how to target their investments for greatest impact and strategically leverage their resources.

To discuss strategies and opportunities for strategic philanthropy in this changing environment, HRA convened its 2008 National Conference, “Accelerating Medical Discovery Through Strategic Philanthropy,” in Washington, D.C., March 4-6, 2008. The conference drew participants and speakers from 64 not-for-profit, nongovernmental funders of health research, as well as from industry, research institutes, academic health centers, and government agencies. Topics discussed included new opportunities in science, strategic planning in philanthropy, methods of strategic giving, training the translational researchers of tomorrow, issues in grantmaking, and managing change.
To open the conference, HRA Board Chair and BWF Senior Program Officer Nancy Sung provided background on HRA in the context of philanthropic support for health research.

There has been steep growth in U.S. philanthropic giving over the past 40 years, with a doubling occurring between 1996 and 2006, Sung said. Overall foundation giving tripled between 1996 and 2006, with more than 71,000 foundations paying out $40.7 billion of their $550 billion combined assets.

Funding for the biomedical research enterprise exceeded $120 billion in 2006, with private, nonprofit funders holding steady in their proportion of funding, relative to the public and industry sectors (see Figure 1). These groups fund research across the entire health research continuum, from the most basic laboratory studies to health services research (see Figure 2). They are free to test new strategies, create innovative structures, and provide risk capital for underfunded and neglected areas.

Sung said that in interviews with HRA organizations about the future of the health research enterprise, six major challenges were identified. The first is responding to insufficient funding by the federal government. As the number of grant applications to NIH continues to rise, the percentage of proposals funded continues to drop. This trend is especially hard on early career scientists, who are likely to be a critical source of innovation.

A second critical challenge is navigating the complex regulatory and technology transfer environments, where ethics reviews of proposals...
are taking longer, informed consent practices are becoming more onerous, regulatory approval can take years, and the science needed to support regulatory and safety requirements lags behind needs. In addition, vast resources are being spent negotiating intellectual property agreements that often result in unwieldy restrictions on progress.

HRA members also expressed frustration with the misaligned priorities and culture of many academic health centers. The incentives currently in place work against translational studies, creating competitive environments that foster unnecessary duplication of effort and result in “breakthroughs that fill journals rather than medicine chests.”

Figure 2. Funding the Health Research Continuum

A fourth challenge is to create incentives to draw investigators into clinical and translational science. Sung cited studies showing that physicians are less likely than Ph.D. scientists to reapply for funding once denied and often do not reapply even when funded in the first round. A survey by the Association of American Medical Colleges (AAMC) found that more than one in four positions for assistant professors conducting patient-oriented research go unfilled.

Despite the growth of private foundations, HRA members said they were concerned that health research might not always be a high priority for donors looking for short-term progress. Investing in research is long-term and risky, often with no immediate payoff.

Finally, members expressed concern that the United States is lagging internationally in the conduct of clinical research. Clinical trials are often outsourced to other countries where they can be conducted more efficiently, more expeditiously, and less expensively.

Sung concluded by urging private funders to address these challenges through a variety of mechanisms, emphasizing that philanthropic efforts should not attempt to supplant or duplicate federal funding. Rather, they should identify important problems that might be fixed with creative and sometimes collaborative application of limited resources.

**New Science for Discovery and Translation**

Meeting participants had the opportunity to hear from three prominent scientists/entrepreneurs about exciting developments concerning the role of genomics in discovery and translation, the trajectory and prospects for personalized medicine, and the role of complexity and systems biology in discovery and translation. Speakers identified opportunities open to funders to advance science, develop new funding models, and benefit from expanding philanthropic resources in the decade to come.

**Moving Genomics into Clinical Application**

It took 50 years from the discovery of the double helix of DNA in 1953 to completely sequence the human genome through the Human Genome Project, said Francis Collins, Director, National Human Genome Research Institute. Since 2003, the genomes of other organisms also have been sequenced, for example, the mouse, the chimpanzee, the dog, the honeybee, the sea urchin, and the macaque. Comparative genomics—in which genomes from diverse species are compared for similarities and differences—is providing a wealth of information about the human genome, helping us understand commonalities and differences along species.

In addition, since the Human Genome Project first began, the process of DNA sequencing has undergone revolutionary technical advances, reducing both the costs of sequencing and the amount of time it takes. These advances have facilitated several ambitious projects to exploit the technology to better understand health. For example, the “1000 Genomes Project”— an international consortium of U.S., U.K., and Chinese scientists—will sequence 1,000 genomes from 11 different populations over two years using new technology and with immediate public release of data. The goal is to identify nearly all variants with a frequency of 1 percent or greater in order to better understand the significance of specific variants to disease and health. The Cancer Genome Atlas is a comprehensive and coordinated effort to accelerate understanding of the molecular basis of cancer through the application of genome analysis technologies, including large-scale genome sequencing. Collins said that the project offers many opportunities for collaboration between public and private funders.

The true payoff from genome research, however, will be in eventual clinical applications. Collins said that experimental approaches to determining genome function are moving forward rapidly. For example, the HapMap project and the first phase of the Encyclopedia of DNA Elements (ENCODE) are critical tools that will allow scientists to apply biological data to important medical issues. These projects also deepen understanding of the architecture and function of the genome. As a result the genetic factors in many common diseases are being rapidly revealed.

Perhaps the most spectacular advances in genomic medicine come from the intense focus on genome-wide association studies. These studies search the genomes of large numbers of individuals in an unbiased way for statistical associations between the most common form of genetic variation—called single nucleotide polymorphisms, or SNPs—and the occurrence of disease. Such studies have been made possible because of HapMap data and the ability to genotype individuals rapidly,
Francis Collins sees dramatic opportunities for government partnerships with philanthropic organizations in the development of novel therapeutics for rare and neglected diseases.

accurately, and inexpensively, looking at hundreds of thousands of SNPs on miniaturized gene chips. Collins said that in 2007, genome-wide association studies provided exciting information about genetic markers for common chronic disorders such as diabetes, heart disease, Crohn's disease, and several common cancers. These data offer new targets for drug development, as well as the development of enhanced tests for screening, diagnosis, and prognosis of common chronic disease. Collins said the challenge now is to go beyond the prediction of disease toward prevention.

Collins also noted that although genome-wide association studies are attractive to pharmaceutical companies because of their ability to provide information about common (large-market) diseases, we need to ensure that rare and neglected diseases are not ignored or lost in the shuffle. NIH Roadmap's Small Molecule Initiative is an effort to test the potential usefulness of more than 300,000 small molecules in treating rare disease or diseases of the developing world, such as schistosomiasis. Collins sees dramatic opportunities for partnerships with philanthropic organizations in the development of novel therapeutics for such diseases.

Collins concluded by urging private funders to consider supporting educational and informational activities to help usher in genomic medicine in the most productive and beneficial way. As of this meeting, Congress had yet to pass legislation outlawing genetic discrimination. Healthcare providers remain woefully underprepared to translate complex genetic information in the course of primary care. And several companies are engaging in direct-to-consumer marketing of genetic tests. He encouraged participants to consider supporting the development of educational materials for high schools, both to prepare the American public to be better consumers and to recruit young scientists as researchers in genomics.

The Challenge of Complexity: A Systems Approach to Better Healthcare

Systems biology is the cornerstone of future research, said Leroy Hood, President, Institute for Systems Biology, with the promise of revolutionizing the understanding of cell function and disease. “A systems approach to biology and medicine is the solution to dealing with healthcare complexity,” said Hood. Traditional biology has operated by taking things apart, much as one would disassemble a radio to see how it works. The Human Genome Project has done that, giving us the parts. Now we need to understand how biological information is arranged in
networks, said Hood. If we can understand how these networks are perturbed, we can understand how disease occurs and progresses, that is, a systems view of disease.

Hood added that computational science has allowed us to think about biology in a systems manner, as an informational science. The convergence of genetics and genomics, systems biology, modern computing, and nanotechnology is leading us toward “P4 medicine”—Predictive, Personalized, Preventive, and Participatory.

Hood explained that there are two types of biological information—the digital information of the genome (i.e., base pairs of As, Cs, Ts, andGs) and the environmental information that encroaches on and modifies that digital information. Biological information is handled by biological networks that capture, transmit, integrate, and disperse biological information to molecular machines that then execute biological functions.

Because biological information is hierarchical, a systems approach to healthcare requires the integration of many different levels of biological information along the spectrum from DNA and mRNA all the way to populations and ecologies. At the Institute for Systems Biology, Hood and his colleagues are using a systems approach to understanding immune function, cancer, neurological disease, and model organisms, with the goal of applying it to P4 medicine. The institute employs a rigorous crossdisciplinary approach relying on biology, computation, and technology to process biological information.

Hood’s work has looked at the effects of prion-induced perturbation on cell death in mice. From this, his laboratory is learning how biomarkers of dynamic changes might be used to predict future disease. Finding diagnostic markers is a bit like the needle in the haystack problem. Hundreds of thousands of proteins are present in cells, tissue, and serum, but which ones are indicators for a specific disease? Hood said that despite NIH’s $1 billion investment, strategies for ascertaining biomarkers have not been effective.

Hood believes that organ-specific blood proteins will make the blood a window into health and disease. The premise is that as many as 50 major organs or cell types are secreting unique blood protein molecular fingerprints, which can be used to assess the status of that organ and thus distinguish health from disease. In theory, organ-specific biomarkers in blood could be used for disease diagnostics, pharmacoproteomics (e.g., determining drug dosages, responses, toxicities), drug target discovery, and the identification of disease-perturbed networks. They also hold the potential to be used in wellness assessment, where longitudinal phenotypic information is collected and the patient becomes his or her own control.

Key technologies currently available will assist in transforming systems biology into P4 medicine:

- High-throughput DNA sequencing and individual human sequencing.
- Nanotechnology and organ-specific molecular fingerprints in blood.
- Single-cell analyses—deciphering the interplay of the digital genome and the environment.
- In vivo and in vitro molecular imaging technologies—following disease phenotypes dynamically.
- Computational and mathematical tools to deal with billions of data points on individual patients.

Next-generation DNA sequencing brings the promise of in vitro blood protein diagnostics. In this scenario, a drop of blood gathered through a handheld device could be rapidly analyzed to provide a profile of the health status of individual organs, ultimately leading to the selection of appropriate therapies or combination therapies.

Hood is confident that driven by systems approaches to disease, new measurement (nanotechnology) and visualization technologies, and powerful new computational tools, P4 medicine will emerge over the next 10 to 20 years. The predictive part will be solved through science,
and the personalized aspects will be achieved through the ability to make sense of billions of data points on an individual. Prevention will focus on design of therapeutic and preventive drugs through systems approaches, an emphasis on wellness, and the development of targeted vaccines, especially for infectious diseases. Perhaps one of the more challenging Ps will be “Participatory,” as patients and physicians struggle to understand and participate in medical choices (see Box).

Finally, the digitalization of biology and medicine will transform medicine by facilitating the analysis of single molecules, single cells, and single individuals. Ultimately, this will lead to dramatically lower healthcare costs, as prevention and early detection increasingly become routine for many diseases. In addition, therapies will be more precise and more effective. Organ-specific fingerprints will allow us to access the effectiveness of drug treatment, identify adverse drug reactions early, get drug doses right, and assess drug toxicities. The technologies are becoming cheaper with each new generation. Moreover, the increased use of information technology will accelerate and organize large amounts of clinical information that can be employed in research and patient care. However, significant challenges remain.

Hood said that to reap the benefits of a systems approach to healthcare, we need to transform our educational strategy, focusing more on conceptual principles and less on irrelevant details. And, fundamentally new ideas need new organizational structures. “You solve hard problems through strategic partnerships,” said Hood, urging private funders to help establish or support partnerships that use systems approaches and that are based on cross disciplinary fundamentals.

### New Models for Drug Development: The Role of Philanthropy

William Haseltine, President, Haseltine Foundation for Medical Sciences and the Arts, asserted that new approaches are needed to accelerate the translation of knowledge into clinical practice. Renowned for his

### Major Technical Challenges for P4 Medicine

- Developing methods for individualized genomics.
- Validating the blood protein molecular fingerprint for each organ.
- Correlating organ-specific fingerprints with health and disease states.
- Identifying organ-specific disease-perturbed networks from blood protein measurements.
- Developing more sensitive and specific, and less expensive, blood protein measurement technologies.
- Using organ-specific fingerprints for assessing drug toxicity and drug dosage, and determining response to therapy.
- Learning to employ drug perturbations to prevent normal networks from becoming disease-perturbed.
- Using in vivo molecular imaging to follow disease, drug response, drug effectiveness, and drug dosage determinations.
- Developing new mathematical and computational methods for extracting maximum information from blood fingerprints, genomes, and molecular images.
- Appropriately handling enormous personalized datasets.
- Educating patients, payers, regulators, and physicians about P4 medicine.
scientific research in cancer and AIDS, Haseltine is also known for his business acumen, having founded nine biotechnology companies including Human Genome Sciences, Inc. Citing the dismal rate of new drug discoveries and approvals in recent years, Haseltine said that industry is trapped in a “systematic distortion” where marketing drives R&D and companies have grown too large. “If marketing and sales are $50 billion annually,” he said, “you cannot invest in a drug that doesn’t have a huge market and bottom line.” Even good ideas that come out of the biotechnology sector are often killed once licensed to big pharmaceutical firms. Increasingly, companies are cutting costs by outsourcing their research. Haseltine said that countries like China are building a huge infrastructure to conduct pharmacotoxicology studies, high-throughput screening, and clinical trials.

Haseltine challenged private funders to fund innovative scientists who want to take their ideas all the way to drug development, essentially bypassing the pharmaceutical industry. He urged them not to shy away from the development aspect of R&D, saying that there are many emerging models for drug development internationally that are avoiding the enormous failure rate of the current pharmaceutical enterprise.

Haseltine recalled his own experiences as a physician scientist, observing that a successful approach to translational research is to start at the bedside, because that reveals what problems need to be addressed. The disease can then be stratified according to phenotype, which leads to the identification of drugs that can address the problem. He argued that such an approach would avoid the need to consistently enroll thousands of patients in clinical trials, which is costly, time-consuming, and not always scientifically justified.

Haseltine lamented the “culture and bureaucracy of skepticism” that has impeded innovation in science. Although NIH leadership is innovative, good ideas get bogged down and lost in the peer review system. Private funders can circumvent this problem by being more responsive to ideas with greater promise to affect health. Like Hood, Haseltine thinks that a new training paradigm is needed, not just for scientists, but for physicians as well. He advocated a new approach to medical training, in which health professionals are trained as an integrated staff, and are responsible for delivering treatment and generating evidence.
Transforming the Biomedical Research Enterprise for Scientific Risk-Taking and Innovation

Speakers addressed the need to think differently about how we train investigators for the future world of science and medicine and how to more strategically spend public dollars.

Breaking the Training Mold to Favor Translational and Clinical Research

Critical to reaching the potential described by speakers Collins, Hood, and Haseltine is ensuring that a sufficient number of new investigators are trained in translational research—the wide and somewhat ambiguous area of research on the spectrum between basic and clinical science. Nancy Andrews, Dean, Duke University School of Medicine, warned that although scientific advances have put us in an unprecedented position to understand and alleviate disease, limited human resources prevent us from taking full advantage of this position.

New scientific advances are shaping medicine of the future, for example, describing physiology through large datasets, imaging across many orders of magnitude, and developing targeted therapies and designer drugs. P4 medicine will yield new, more precise definitions of health and disease, patient-centered rather than disease- or organ-centered care, and gray-scale rather than black-and-white predictions. Said Andrews, “All or none concepts like ‘diagnosis’ and ‘disease’ may become anachronisms.”

Physician scientists will be needed to develop the science and application of gene-environment interactions, focusing on interventions at the beginning of life, predictive medicine, and the development of measures to minimize deleterious consequences of genetic endowment and environmental effects. However, there are numerous challenges to building the requisite physician-scientist workforce, said Andrews.

Physician scientists represent a small fraction of medical school graduates. The current cadre of physician scientists is aging and is not being replaced fast enough. Andrew Schafer, representing the Association of Professors of Medicine, noted that the physician-scientist workforce is diminishing, with an ever-smaller percentage of medical students entering and remaining in this career path. The success rate of getting funding from NIH has also declined for these researchers, and the
percentage of individuals successfully competing for grants has dropped. Although proportions of women and members of underrepresented minority groups are increasing in medical schools, they are underrepresented among physician scientists. Institutions should proactively (aggressively) promote the advancement and minimize the attrition of women in physician-scientist careers. However, there is little flexibility in traditional physician-scientist training pathways, which makes it a less attractive career choice for many.

Nancy J. Brown, Associate Dean for Clinical and Translational Scientist Development at Vanderbilt University, reviewed the AAMC Task Force II on Clinical Research recommendations related to training clinical and translational investigators and presented an accelerated model that will be piloted at several academic health centers beginning in 2009. The Independence Before 35 (IB-35) Project recommends that every future physician receive a thorough education in the basic principles of translational and clinical research starting in medical school and continuing through residency training, and that the time to independence should be shortened. The recommended model would include an extra year in medical school and integration of research training through residency and fellowship.

Andrews said that, ideally, there should be multiple career entry points beside the traditional M.D.-Ph.D. programs, such as research residency pathways; formal clinical research training; tailored (nondegree) medical education for Ph.D. students, postdoctoral fellows, and faculty; and opportunities for late entry, re-entry, or second careers for nontraditional candidates.

According to Schafer, a survey by the Association of Professors of Medicine found that current trainees are experiencing more unpredictability in funding and more debt. Funds are needed to invest in those most likely to succeed, providing debt relief, stabilizing salaries, protecting time for research, and providing support to allow the best candidates to develop without fluctuations and uncertainty of grant cycles.

Influences that keep investigators on the physician-scientist track include intangibles, such as interest and enjoyment, innate curiosity, and good role models. Schafer emphasized the importance of mentoring, which led to a discussion of whether innovative contributions by foundations are needed to compensate mentors. Mentoring takes time and is not something that scientists do for the monetary rewards. Unfortunately, changes in academic health center financing, and the resulting need for investigators to fund their salaries through clinical time or percent effort on research grants, have left little time for mentoring. The disincentives have made it more challenging, if not impossible, for good mentors to spend adequate time helping trainees gain the full range of skills they need to launch their careers.

Andrews said that academic health centers are the natural home for translational research because of their access to patients and laboratories, with a wide range of trained health professionals. But, clinical and translational researchers continue to face multiple challenges, such as an ambiguous training path, regulatory burdens, difficulties in data collection, the recruitment of patients into studies, and lack of support for core facilities, such as biostatistics, computing, and tissue banks. Moreover, the individualistic academic reward system is not calibrated for translational and clinical research, which usually requires a team effort.

Andrews provided a list of several options for funders to consider to enhance and accelerate translational and clinical research:

- Pilots for new training models in social sciences, medical informatics, and clinical investigation.
- Grants to redesign, rationalize, and re-legislate regulatory requirements, to decrease burdens for translational and clinical investigators, and to standardize patient data collection.
• Funding mechanisms to improve training opportunities and career development for top foreign medical graduates.

• Grants to support methods design for clinical investigators and statisticians.

• Support for Institutional Review Boards (IRBs), biobanks, biostatistics, information technology, and other core functions (multi-institutional).

• Exploration of the advantages, risks, and ethics of moving clinical studies overseas.

• Development of standardized methods for recording, storing, protecting, accessing, and analyzing patient data.

• Seed funding to enhance collaborations and mentorship.

• Innovation grants for people (rather than projects).

• Funding for educating the public about how biomedical investigation has changed/is changing their lives.

There also was discussion about how clinical research has been turned into a “soft money” enterprise. One of the major reasons for the reliance on soft money is that until the last few decades, clinical departments in medical schools could make a sizeable profit on their clinical practices (“hard money”), and this revenue was used to subsidize research education. That margin is now gone. The question was asked, “what do we need to stabilize the physician-scientist workforce?” In response, it was noted that it is important to make a strong business case to medical schools and academic medical centers that more commitment is needed to solidify the physician-scientist pipeline and that this would generate a large return on investment.

Finally, investigators and institutions are squeezed from many directions. Sources of revenue are limited and do not go as far as they used to. Most funders do not pay the full cost of doing business, let alone leave a margin for facilities upkeep, enhanced infrastructure, and innovation. Private funders could play a critical role in sustaining and maintaining the infrastructure so that when the right ideas come along, progress will not be delayed.

** NIH’s Look Forward **

Raynard Kington, Deputy Director, NIH, said that the agency is constantly looking forward, which can be a challenge given the agency’s complex structure, congressional mandates, and the constant pressure from many constituencies to change in many different directions. However, 21st-century medicine will be more preventive with the growing ability to understand preclinical molecular events and intervene before symptoms appear. NIH sees this future and has as its mission complementing the investment of the for-profit private sector in forward-looking health research. Private sector spending on research is more than double that of NIH.

Kington described new activities that reflect NIH’s evolving thinking about its mission and its effort to push more toward transformative research and greater clinical applications.

• The NIH Office of Portfolio Analysis and Strategic Initiatives (OPASI) resulted from a functional reorganization aimed at better understanding the total NIH portfolio for strategic purposes and

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**The individualistic academic reward system is not calibrated for translational and clinical research, which usually requires a team effort.**
making better investment decisions. One of OPASI’s projects is the Research, Condition, and Disease Categorization System, which semi-automates NIH reporting processes, making it easier for NIH and outside groups to account for spending across all NIH institutes and centers.

- The NIH Reform Act of 1994 authorized processes to facilitate trans-NIH research, although the amount available for such efforts is only 7 percent.

- The Roadmap for Medical Research (1.7 percent of the total budget) was developed to increase synergy across NIH and to incubate new ideas. One Roadmap initiative is the Clinical and Translational Science Awards, aimed at transforming and integrating the research infrastructure within academic health centers.

- The NIH Director’s Pioneer Awards encourage bold thinking by individuals who have untested, potentially groundbreaking ideas.

- The Director’s New Innovator Award supports new investigators who have not yet obtained a traditional R01 grant, but who have proposed high-risk, high-return research.

- NIH is reviewing and revising its policies on peer review, public access to research results, facilitating public-private partnerships, and forming closer relations with the Foundation for the NIH, a 501(c)(3) organization established by Congress in 1990 and incorporated in 1996.

- NIH is building shared resources, such as genome-wide association studies.

### Strategic Philanthropy

*This portion of the conference addressed issues of strategy in philanthropy broadly, and also zeroed in on the relative merits of funding open-ended discovery research as opposed to milestone-driven, project-based research. Finally, four foundation CEOs shared their thoughts on current strategic questions facing their organizations.*

**Mark Kramer, Managing Director of FSG Social Impact Advisors,** said that strategy, innovation, and evaluation are the central features of strategic philanthropy. Highly effective donors typically make the transition from “how do I give away money?” to “how do I solve a specific problem?” Philanthropists should not pick the biggest problem, but rather choose one where the biggest difference can be made, said Kramer. This requires an assessment of internal resources—such as
values, culture, finances, and constraints—as well as a review of the external environment, for example, what are other groups doing? Where are there opportunities for impact? Which partners might we engage? This “positioning” by foundations is critical to understanding and managing overlap, assessing potential impacts on systems, and leveraging expertise.

In health-related giving, individual donors’ personal experience or sense of urgency often triggers the decision to donate funds or create a legacy in the form of a foundation. Funding strategies should focus on ways to be innovative—perhaps to challenge orthodoxy in peer review—or to leverage public funds. Kramer said that there is plenty of room for innovation in philanthropy, particularly with regard to financing models and new types of investment. Financing vehicles such as advanced purchase agreements, drug development partnerships, leveraging private sector investment, and financing at the margin can provide donors the opportunity to tackle big problems with limited resources.

With regard to evaluation, Kramer noted that “it used to be about accountability.” That is, is this project worth this investment? He advocated for an approach that is more forward thinking—one that asks “what do we need to know to make a better decision tomorrow?” Once you’ve picked a problem and taken responsibility for solving it, it becomes easier to measure progress, said Kramer.

Kramer challenged HRA members to think about whether their mission is health or research. The answer will help determine how much risk is acceptable. Investing in research is always risky, so funders should be trying to minimize the risk by asking “what is the probability of success weighted against the goal?” Donors need to understand up front that some research investments do not pay off and that failure is part of success. “It is important, however, to be focused about the risks one is taking and to recognize that not all risks are equal,” said Kramer.

**Developing Grants Portfolios and Funding Strategies: Broad Versus Focused?**

Foundations, especially newer ones, face the question of how to situate and set their portfolios. Should their programs be unfettered (i.e., funding the most promising science and allowing investigators to explore tangents) or directed (i.e., with a specific goal, such as the development of a new therapeutic)? Which approach is more likely to
advance progress in disease-related research? Which funding strategy most closely matches the foundation goals?

Susan Fitzpatrick, Vice President, The James S. McDonnell Foundation, said that answering these questions requires “a willingness to take a hard look at some myths and assumptions about disease research.” Arguments and assumptions made in favor of the unfettered (traditional) approach are that the serendipitous nature of scientific discovery yields the greatest benefits, that understanding causative disease mechanisms is necessary to developing effective therapies, and that basic science knowledge ultimately yields applications.

In contrast, said Fitzpatrick, arguments favoring a more directed approach are concerns that a particular disease is insufficiently researched or that the pace of the existing research efforts is incommensurate with the urgency of a particular disease. That is, positive results in the laboratory do not always translate into effective therapies. Funders in this group often take a venture philanthropy approach, which is more goal-directed, with more hands-on management by the funder.

Fitzpatrick added that “questioning these myths and challenging these assumptions could reveal that a better strategy might require multifaceted programs and investments.” Furthermore, the tensions between what researchers are drawn to and what funders care about affects how research progresses and why it may fail to map to treatments. Fitzpatrick said, “It is time to think of the different funding mechanisms that disease organizations are using as neither right or wrong, nor better or worse, but rather as natural philanthropic experiments from which we can learn.”

Funding agencies might ask themselves whether they have explicitly articulated philosophical beliefs about how scientific knowledge advances and whether doing so would alter the selection of funding strategies. Part of that self-assessment should be determining the opportunity costs of committing to one funding strategy in place of another and developing metrics for evaluating whether a particular strategy is appropriate to the knowledge needs.

William Thies, Vice President of Medical and Scientific Relations, Alzheimer’s Association, said that his organization has pursued a mixed approach to portfolio development. He cited the assumption mentioned by Fitzpatrick that unfettered research is often serendipitous and unpredictable. And, even though the return on investment in such research might be great, it might be 30 to 40 years away. More directed research, for example, at the development stage also provides easier metrics in terms of scheduling and milestones and return on investment in a time period acceptable to a business environment and appealing to donors. Thus, the key is to match assumptions with investments.

Thies said that applying resources to any stage of the development can accelerate that stage. However, regardless of stage, all resources must be focused on achieving the best outcome. Where an organization chooses to invest depends on a range of factors, such as the following:

- How mature is the organization’s field of interest?
- Who else operates in this space (public and private)?
- Who else is investing in the area, what are they investing in, and how much are they investing?
What is the likelihood of attracting new investment (what is the organization’s donor base)?

What is the state of the science?

Allan Tobin, Senior Scientific Advisor to the CHDI Foundation, said that it is often possible to define milestones, which justifies a more focused approach. If a funder believes that impact can be maximized through directed therapeutic development or can identify bottlenecks in the process or that a problem is “ripe” for funding, then focused funding is in order. Tobin said such investments might be useful for developing disease models, therapeutic targets (e.g., using assays or genomics), assessment tools (e.g., imaging, biomarkers), or pharmacological tools.

This approach requires a sophisticated and highly trained scientific staff, said Tobin, because the organization must have the requisite inhouse skills and expertise to assess the state of the science. Other ways to obtain good ideas for potential support include convening free-association workshops or supporting exploratory research.

Focused research investments can be measured according to timelines and deliverables embedded in the business model, said Tobin. Development should include assessment tools that emphasize short- and long-term goals broken down into achievable milestones. He advocated for nonprofit funders to become better acquainted with industry because companies are likely to be sitting on large, untapped knowledge bases and libraries of compounds. Although industry might not see the benefit of developing certain aspects of that knowledge, disease-focused funders might envision a potential project that meets their mission and matches their resources.

Charting a Course for Private Funders in a Changing Environment

Four foundation chief executive officers of nongovernmental not-for-profit funders of health research and training discussed their experiences in leading their agencies in an ever-changing scientific and funding landscape. Four very different approaches were presented.

The March of Dimes (MOD) Foundation, established in 1938, has continuously evolved from its initial mission to stamp out polio, said President Jennifer Howse. “We’ve moved from tin cups collecting dimes to raising $250 million a year as an operating foundation,” she said. “But even so, we periodically have to go back and communicate our major mission—our fixed points—to our partners and donors: 1) bringing science into service for people; 2) gathering the power of volunteers; and 3) converting public trust into public good.”

Howse said that MOD also works hard to exploit the public’s willingness and optimism to tackle big problems affecting children’s health through its operating programs, advocacy, and grantmaking. Its grants program aims to be focused, sustainable, and diversified, with an emphasis on quality and results. Over the past 70 years, the portfolio has expanded from basic research to community health services and global programs.

Howse described MOD’s Prematurity Research Initiative, which has funded 34 grants for a total of $11 million. The preterm birth rate has been rising in recent years, underscoring the urgent need for a sustained, comprehensive plan to address this growing crisis. To help set priorities for research funding, MOD convened a scientific symposium of scientists from multiple disciplines to brainstorm on the scientific and clinical causes and implications of preterm birth. The ideas emerging from that symposium provided the basis for the current program.
Howse said that in her role, she is always trying to find ways of dealing with “environmental challenges” such as a poor economy, declining federal investment in research, trends in “mega philanthropy” and “donor-directed” giving, and the politicization of science. The key is partnering. “Partnership is critical to solving major league problems,” said Howse. She urged foundations to consider reinvention regularly and added that change in leadership is good and healthy. She said that it might be hard to change your business model when you are doing well, but that it is important to be looking to the future constantly.

Partnering also is a cornerstone of the Foundation for the NIH (FNIH), said Amy McGuire Porter, FNIH’s Executive Director. McGuire Porter said that FNIH came into existence in 1996 with little guidance on how to operate other than to use NIH priorities as its points of reference. As such, it is still feeling its way, but has found that partnering with the NIH institutes and private funders has allowed it to underwrite biomedical initiatives that might not be attractive for private funding alone or that may not be appropriate for wholly public funding. FNIH has established strong scientific, managerial, administrative, and logistic capabilities and aims to provide a neutral forum and be a preferred partner for federal and private sector collaborations to

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**The Foundation for the NIH**

FNIH is the sole entity authorized by Congress to raise private funds in support of NIH’s mission. It is an independent nonprofit 501(c)(3) public charity created and incorporated in 1996. FNIH:

- Creates innovative public-private biomedical partnerships that complement NIH priorities and enhance NIH activities.
- Involves NIH and other federal partners, industry, academia, and the philanthropic community.
- Provides a neutral forum able to engage all partners to work together with an equal ability to contribute.

It is currently supporting more than 50 projects and has raised more than $410 million since 1996. In some cases, it is developing public-private partnerships that build on existing NIH programs, for example, the Genetic Association Information Network, the Alzheimer’s Disease Neuroimaging Initiative, and the Schizophrenia Metabolic Initiative. In other cases, its support enables private partners to help offset the gap in funding and work with NIH to expand the number of funded grants.

FNIH also:

- Organizes or funds training programs and career development activities for young scientists that build on opportunities within NIH research programs.
- Facilitates the participation of NIH intramural laboratories in collaborative research networks with external partners.
- Develops partnerships for “on the ground” clinical and public health studies to collect data that will directly contribute to improved prevention of and early intervention to treat childhood diseases.
- Establishes comprehensive research programs, including the means for the solicitation, review, award, and administrative and scientific oversight of research grants to academic, for-profit, or governmental organizations.
- Organizes and manages multipartner consortia, bringing together organizations such as governmental agencies, the pharmaceutical industry, voluntary health organizations, and professional societies with a common purpose to accelerate scientific discovery.
achieve shared goals. Porter said that FNIH provides an extremely flexible infrastructure to deliver solutions needed by partners and donors.

Hala Moddelmog, President and CEO, Susan G. Komen for the Cure, said her foundation’s strategy has focused on community outreach, research, and public policy. Over the past 25 years the agency has spent $1 billion on research and wants to spend another $2 billion over the next 10 years. To achieve its goals of outreach and research, Komen ensures that 75 percent of funds raised stay in the community, while the rest goes to research. The group’s research strategy includes:

- Promise Grants, where investigators from basic and clinical backgrounds must team to conduct interdisciplinary research ($7.5 million over five years).
- Investigator-Initiated Research Grants ($600,000 over three years).
- Career Catalyst Research Grants ($450,000 over three years).
- Postdoctoral Fellowships.
- Disparities Research.

Other activities include holding conferences on health disparities, conducting global outreach, and developing training modules. Moddelmog said that several themes have emerged in her short tenure at the foundation. The first is the need to “take a breather every once in a while, to stand back and realign priorities.” Another is the need to look at different ways of funding research that considers the roles of industry and communities. A third theme is focusing on how to catalyze activity that is responsive and nimble. Moddelmog said that foundations should not under-estimate their convening power, that is, their ability to bring diverse parties to the table to figure out what must be done. Finally, she added that for many diseases, especially chronic diseases, foundations should be thinking globally, because this can reap advantages for both research and cures.

The growth and expansion of the philanthropic community in health is providing a diverse and innovative array of strategies for setting priorities, creating programs, reviewing applications, and disbursing funds.

The Flinn Foundation offers yet another model for an innovative private foundation. The foundation has a current endowment of $215 million, overseen by a nine-member board. It distributes $10 million annually in Arizona. John W. Murphy, President and CEO, said that its success is based on the premise that “health-care is being recast as an economic priority, not just a service.” Its philosophy is based on the assumption that it is still possible to leapfrog ahead on biomedical progress with targeted investments. Flinn’s “business” is helping to grow Arizona’s bioscience sector, not make grants to support biomedical research. The foundation’s funding is based on a few large projects with future economic potential where there is capacity to pool institutional resources. Murphy’s mode of operation is to “be engaged, not just write checks” and to signal to other funders the value of the projects chosen. His agency aims to be a “bioscience champion” by convening, connecting, catalyzing, and serving as a source of intellectual capital. The group does not attempt to control the agenda or manage, implement, or market projects. Leveraging is the central focus of Flinn’s strategy.
Operational Issues in Grantmaking

The growth and expansion of the philanthropic community in health is providing a diverse and innovative array of strategies for setting priorities, creating programs, reviewing applications, and disbursing funds. Over the two-day meeting, participants attended several sessions in which foundation executives discussed their experiences in grantmaking, including best practices in peer review and postaward monitoring, grantmaking in international health, and using funds for capacity building.

Peer Review and Postaward Monitoring: Strategies for Success

Peer review has been the mainstay for allocating biomedical research funds in both the public and private sector. During a session on the topic, Sally McNagny, Vice President, The Medical Foundation, and Marc Hurlbert, Scientific Director, Avon Foundation, discussed best practices for managing scientific peer review and monitoring progress once an award has been made.

McNagny said that The Medical Foundation does not have inhouse medical expertise or employees to staff scientific review committees, but rather creates and oversees 11 Scientific Review Committees for its clients’ grants programs. Some of the best practices the organization has found useful for selecting committee members include, after first selecting a chair, getting recommendations from leaders in the field and cross-checking with peers; using the NIH CRISP database and other resources such as PubMed (to see who has published in top journals); and using the eTBLAST search engine. In selecting reviewers, it is important to consider personality, geographic distribution, differing viewpoints, and seniority. She also noted that a chair must have good people skills to manage personalities and keep balance on the panel, discussed ways of handling conflict of interest, and stressed the importance of having a signed conflict-of-interest statement and making conflict-of-interest policy transparent.

McNagny emphasized the need to be thorough in committee selection and to respect the committee’s funding recommendations; require confidentiality about conflict-of-interest and nondisclosure policies; focus on transparency by posting committee rosters and funding success rates; require at least two reviewers per application; and have a system in place for managing discordant scores.
Marc Hurlbert described how the Avon Foundation uses progress reporting and postaward monitoring to facilitate Avon’s communication to the public about its programs and also to help grantees understand and evaluate their programs and to aid in their growth and development. A quarterly progress report is required for patient services programs that provide access to treatment (frequently involving community outreach), for example, monitoring the number of women educated at public health fairs, the number of women navigated into breast health care, and the daily functions of patient navigators.

Hurlbert said that reporting is more complicated on the research side. For individual research grant awards, quantitative goals and a timeline are agreed on at the outset; however, there is flexibility to shift the direction of the research. In addition, traditional tracking measures are used, such as monitoring presentations, publications, and new intellectual property claims. Projects typically are funded for two years in specific mission-oriented areas. Researchers are expected to report back to Avon at 6 months, 12 months, and 24 months, although Avon often interacts with investigators during the intervening periods. In addition, Avon brings 12 to 25 researchers working on a similar topic together for meeting at the start of their research projects and after years one and two. Avon has found this to be highly useful to maximize the impact of awards, as beginning researchers may strengthen their studies or find a collaborator. The purpose of these activities is not to police the investigators, but rather to serve as an active partner.

Other issues to consider are fiscal audits and the importance of reporting results back more effectively to the public. The public needs a clearer understanding of what constitutes research and why a given funder is supporting certain projects.

Using Funds to Build Capacity in the Health Research Enterprise

Some foundations are using their resources not to fund projects, training, or career development, but rather to develop infrastructure and capacity. The goal of these efforts is to build momentum that can be sustained in the interest of health.

For example, the Avon Breast Cancer Crusade of the Avon Foundation provides support for named centers of excellence to conduct research and support care in their neighborhood. Awardees received $10 million for breast cancer research with only one condition—the grantee must
Grantee institutions, proud of the Avon award, work hard to sustain the effort and have benefitted by attracting new funds from other sources.

establish clinical and/or education programs in breast cancer for underserved members of its community. Hurlbert said that $120 million has been awarded to 10 Avon Centers of Excellence since 2000. A sample program is Emory University and its partnership with Grady Memorial Hospital. Together, the institutions launched “The Ladies in Pink,” a 200-member group of community health advocates who serve as navigators for women seeking breast cancer prevention, early detection, and treatment services. Grantees typically use the funds for defined research projects, such as understanding the causes of breast cancer, developing new treatments, pilot research, recruiting new investigators, clinical trials efforts, and core facilities. Hurlbert said that the high-risk approach pays off. Grantee institutions, proud of the award, work hard to sustain the effort and have benefitted by attracting new funds from other sources. Grantees must report to Avon on their progress, and if expectations are not met, a program can be discontinued.

The Flinn Foundation takes a different approach to capacity building, with its focus on supporting Arizona’s bioscience economy. Matthew Nelson, Assistant Vice President for Research and Technology, said that the foundation works with partners to make strategic investments in research infrastructure and commercialization, recruit intellectual capital, and provide guidance, support, and information on the biosciences. The foundation awards grants to nonprofit organizations in Arizona, primarily to improve the competitiveness of the state’s biomedical research enterprise. It also supports the Flinn Scholars Program, which offers top Arizona high school graduates full-ride financial benefits to attend one of the state’s public universities.

Flinn’s Capacity-Building Grants have gone to such groups as the Translational Genomics Research Institute (TGen), a nonprofit organization focused on developing tools for earlier diagnoses as well as smarter treatments for diseases such as melanoma and Alzheimer’s. Another recipient is C-Path, the Critical Path Institute, which creates innovative collaborations in research and education that enable the safe acceleration of the process for developing new medical products. Read said that Flinn’s small staff of eight full-time professionals focuses its efforts on leveraging collaborations and investments to build research capacity.

Patricia Pedersen, Associate Vice President for Development, Yale University, spoke from the perspective of an organization receiving the largesse of capacity-building funds. She said that capacity building is “the process by which universities enhance effectiveness, through increased speed of innovation, and increased flexibility, responsiveness, and productivity.” She noted that this is an interesting time because although giving is up, so are the pressures to provide results. In addition, more often than not, funds are restricted, which may stifle innovation.

What has been sorely lacking, said Pedersen, are metrics for measuring outcomes from investments in capacity building for core facilities, broad programs, and education. She suggested these metrics should include broad-based descriptors of the benefits of capacity building rather than only quantitative measures that focus on project-specific results. These might include benchmarks to track progress by setting guidelines and timelines, and short-term measures such as publications and citations that can be used in a system of continuous feedback.

Participants agreed that developing the criteria for the review and funding of capacity-building grants is more challenging in the international arena. Regardless of the
location of the grantee institution, certain key questions should be asked:

- Does the institution or organization have a proven track record or acknowledged strengths in key areas?
- Does the institution or organization have the capacity to receive and effectively utilize the funds?
- Can the institution or organization achieve the goals?
- Does the institution or organization have the capacity to deliver clinical care as well as conduct research?

**International Health Research Grantmaking**

Several issues arise in international health grantmaking that make it all the more complex and challenging, including managing from afar, dealing with currency fluctuations, research agreements arising from differing legal codes, and labor and intellectual property law. In addition, different cultures have dissimilar views of what constitutes conflicts of interest, oversight, and accountability, which can make it challenging to determine which standards should prevail. Presentations were made by representatives from four foundations investing heavily in international health—Foundation Leducq, the Doris Duke Charitable Foundation (DDCF), the Carter Center, and the Juvenile Diabetes Research Foundation International (JDRF).

**Elaine K. Gallin, Program Director for Medical Research, DDCF** said that the strategy for the foundation’s AIDS program in Sub-Saharan Africa is to support research and related capacity building to determine how best to care for and treat HIV/AIDS patients. She emphasized that in designing programs, “context is critical but hard to understand from afar, and even when it is understood, situations can change quickly.” Since 2000, DDCF has spent $17.7 million on AIDS research. The major focus has been on slowing the spread of the pandemic in low-resource areas. DDCF has teamed with the Aaron Diamond Foundation on projects related to HIV/TB comorbidity.

In international grantmaking, context is critical but hard to understand from afar, and even when it is understood, situations can change quickly.

DDCF criteria for making awards include alignment with foundation objectives, the ability to fill a critical need, building on ongoing projects or established teams that can provide ongoing oversight and sustainability, and leveraging funds when possible. In trying to distribute funds in the international setting, Gallin said “be prepared for delays.” Delays can come from protracted Institutional Review Board (IRB) approvals, inadequate staffing, policy changes that affect patient accrual, and failure of the drug pipelines. She said that currency fluctuations can make multiyear projects difficult to manage, but that despite these challenges “responding quickly and being willing to take a risk can be more important than the size of the grant.”

Moreover, although investing in infrastructure can be risky, it can be critically important to achieving goals. For example, a 2001 DDCF grant of $1.5 million provided 46 percent of the costs of building the first phase of the Doris Duke Medical Research Institute at the Nelson Mandela Medical School. The second phase was completed in a year with support from new research grants and other sources.

Gallin described a “new and catalytic” effort, the African Health Initiative, which responds to the crisis of diminishing life expectancies in seven African countries. Population Health Implementation and Training (PHIT) partnerships—five to seven grants ranging from $8 million to $20 million—will be focused on delivering integrated primary healthcare to populations in Africa, strengthening regional health systems and the local workforce. Gallin said that letters of interest have been received from 137 teams in 9 countries. Critical challenges include “getting the staffing and management
right,” ensuring an “African voice,” and achieving local buy-in. One of the main goals of the African Health Initiative is to improve health systems planning by providing strong evidence to the global health community on what works and what doesn’t in implementing large-scale, integrated primary healthcare. For this reason, DDCF asked the Institute of Health Metrics and Evaluation (IHME) to prospectively develop an Implementation Research Framework for the PHIT Partnerships. The framework will be adapted to suit the context and specific activities of each PHIT Partnership.

Gallin said that DDCF expects that it will be a helpful guide for applicants as they develop rigorous implementation research plans to document outcomes and impact and foster innovation and continuous process improvements.

Other presenters emphasized the importance of collaboration and finding diverse partners to both cofund and support a particular mission. Foundation Leducq’s mission is to improve human health through international efforts to combat cardiovascular disease. To conduct its work, David Tancredi, Scientific Director, said it relies on a combined European/North American Scientific Advisory Committee, international, multilingual staff, and international diversification in investment and grant programs.

The field of juvenile diabetes provides another model for giving and participation in the international arena. JDRF provided $122 million in 2006 to support more than 500 investigators in 20 countries. JDRF chapters and international affiliates raise money for research, provide support for patients, serve as advocates for research, and participate in JDRF activities.

Concepcion Nierras, Director of Research, Partnerships and Consortia, JDRF, emphasized the benefits of partnering in research programs, beginning with the belief that the best science is not limited by geography. Partnering leverages funds, facilitates knowledge exchange, and can streamline rather than replicate efforts, particularly in sharing infrastructure and biological samples. The agency has benefitted from special congressional funding—$1.4 billion over 10 years—that supports tools for discovery, the collection and storage of patient samples and data, clinical resources, and clinical trial infrastructure. JDRF is one of many partners in this effort, others being several NIH institutes, the Centers for Disease Control and Prevention, the Department of Defense, and NASA. JDRF’s role is to hold scientific meetings abroad where it can promote pooling of resources, samples, and data by the international community.

JDRF also supports the European Consortium for Human Islet Transplantation and stem cell research in the United Kingdom and administers the Islet Transplantation Program in Australia on behalf of the Australian government.

The Carter Center has focused on health education and low-technology solutions to eradicating Guinea worm disease (dracunculiasis). An international coalition led by the Carter Center is now close to achieving this goal, said Nicole Kruse, Chief Development Officer, Health Programs. With its unique access to world leaders, the center has been able to mobilize government officials for its eradication effort, while simultaneously working at the village level to empower and educate communities to take simple measures to prevent the disease from recurring. Kruse said that when the Carter Center began its eradication campaign in 1986, there were 3.5 million cases of the disease in 20 countries in Africa and Asia. Today, there are fewer than 10,000 cases in 5 African countries and 6 Latin American countries.

The center supports health education and low-technology measures to promote behavioral change. Guinea worm disease is contracted when a person drinks stagnant water that is contaminated with microscopic water fleas carrying infective larvae. Simple but revolutionary devices provided by the Center enable people to drink water safely no matter where they are. The center’s goal is to eventually turn its work over to the World
The report of this conference, now sixth in a series of similar meetings since 1998, captures the benefits of learning together about emerging issues. Those leading and staffing these private philanthropic efforts find value in convening in a neutral venue where we can think collaboratively about the research enterprise and where it is headed.

Health Organization (WHO) for a sustained eradication program. The center relies on multiple partners in its global health programs, including the Centers for Disease Control and Prevention, WHO, UNICEF, the United Nations, and ministries of health in countries of operation.

Participants in this session agreed that partnering and conducting international health research provides some unique challenges. Cultural sensitivity is essential, and for cultural and historic reasons, some organizations are not as comfortable with partnering as others. Conflicts can arise over what constitutes ethical research, with different countries allowing practices that would be prohibited elsewhere. Gallin encouraged funders to rely on government agency partners in the country where the research is being funded to help enforce compliance with local regulations and ethical standards. With regard to management and oversight, reporting standards and expectations might differ, with some partners resisting such measures. Exchange rate issues can challenge even the best accountants. And, said Gallin, sometimes it is better to directly purchase equipment and supplies than provide cash, as cash has “a way of disappearing the closer it gets to your target.”

Closing Statement

Queta Bond, President of the Burroughs Wellcome Fund, was instrumental in HRA’s origins by providing intellectual capital, a collaborative spirit, and the support of BWF to the nascent organization. On the occasion of her retirement, she was asked to write a closing statement to the 2008 conference proceedings.

“Early in my tenure at BWF, I searched for but could not find a forum where private nonprofit funders of medical research, made up of voluntary agencies such as ACS, private philanthropies such as the Doris Duke Charitable Foundation or medical institutes such as HHMI, could meet to discuss gaps and opportunities in health research. Now, 14 years later, on the eve of my retirement from BWF, I attended the 2008 HRA meeting and am delighted in how well this still young organization is filling that void and how bright its future is to mobilize resources and advocate for the health research enterprise.
Kathleen McCarthy, director of the Center on Philanthropy and Civil society at the City University of New York, has noted that ‘foundations have always made their impact doing four things…, building institutions, forging partnerships to leverage their grants, training new managerial elites in new fields, and investing in new ideas.’

HRA is an example of a new institution that can provide just these opportunities and learning space for private funders of health research.

Early conferences were planned by a loose confederation of interested organizations such as The Pew Charitable Trusts, ACS, HHMI, and BWF, but changes in staff of the various organizations quickly made it apparent that a new organization was needed for long-term sustainability of a forum. Here we could learn best practices from each other, assess the role of private philanthropy in the light of the much larger federal and industry dollars that flow to medical research, and provide an opportunity to network and find partners for our work.

The report of this conference, now sixth in a series of similar meetings, captures the benefits of learning together since 1998 emerging issues. Those leading and staffing these private philanthropic efforts find value in convening in a neutral venue where we can think collaboratively about the research enterprise and where it is headed. Similarly, the CEOs on the panel I moderated pointed out the importance of our individual organizations pausing occasionally to reposition and refocus missions given the rapidly changing environment for science and medicine, as well as for the funding of research by private philanthropy, by the government, and by industry.

The HRA leadership has been deeply involved in crafting a strategic plan to guide future evolution of the organization. Among its plans is the development of a database of private sector grants that can be used to document the substantial and important investment made by private philanthropy. This information can legitimize advocacy efforts, help guide strategic investments by individual grant makers, and help forge new partnerships. Not only will such a database help identify who is being funded and how much our community spends on health research but it should also be helpful in identifying some of the new and innovative approaches that private philanthropy is inventing and implementing to find new treatments for patients. The biannual national conferences and regular members-only meetings are valuable ongoing activities to promote communication and networking. The events foster ongoing efforts to evaluate our work and to learn the gaps and opportunities that exist for catalytic investments in health research.

HRA has more than fulfilled my early vision for a meeting place. HRA would not be where it is today without its founding leaders and board of directors, who have worked so hard to bring this organization into being. My thanks and congratulations to all on a job well done and my best wishes for the continued successful evolution of this very important organization.”

*Carnegie Reporter, Spring 2007.*
Tuesday, March 4
4:00-9:00 pm  Registration
7:00-9:00 pm  Welcome Reception for HRA Member Organizations

Wednesday, March 5
7:30 am  Registration opens
8:30 am  Opening and Welcome
   Nancy Sung, Ph.D., HRA Chair and Senior Program Officer, Burroughs Wellcome Fund
   HRA overview of private funding trends for health research, stressing new models and methods being explored by private funders to accelerate translation.

9:00 am  Plenary: New Science for Discovery and Translation: Philanthropy’s Opportunity to Encourage Scientific Risk-Taking
   Leroy Hood, Ph.D., Co-Founder and President, Institute for Systems Biology (ISB)
   William A. Haseltine, Ph.D., President, Haseltine Foundation for Medical Sciences and the Arts
   Raynard S. Kington, M.D., Ph.D., Deputy Director, National Institutes of Health

11:15 am  Breakout Sessions
   A. International Health Research Grantmaking
      David Tancredi, M.D., Ph.D., Scientific Director, Fondation Leducq, Moderator
      Concepcion Nierras, Ph.D., Director of Research, Partnerships and Consortia, Juvenile Diabetes Research Foundation International
      Elaine Gallin, Ph.D., Program Director for Medical Research, Doris Duke Charitable Foundation
      Nicole Kruse, Chief Development Officer, Health Programs, The Carter Center
   B. Basics of Grantmaking—Best Practices in Peer Review and Post-Award Monitoring: Strategies for Success
      Sally McNagny, M.D., M.P.H., Vice President, The Medical Foundation
      Marc Hurlbert, Ph.D., Scientific Director, Avon Foundation

12:30 pm  Networking Lunch

1:30 pm  Plenary: Charting a Course for Private Funders in a Changing Environment
   Queta Bond, Ph.D., President, The Burroughs Wellcome Fund, Moderator
   Jennifer Howse, Ph.D., President, March of Dimes Foundation
   Amy McGuire-Porter, Executive Director, Foundation for the NIH
   John W. Murphy, President & CEO, The Flinn Foundation
   Hala Moddelmog, President & CEO, Susan G. Komen for the Cure

3:30 pm  Break

4:00 pm  Plenary: Focused Venture vs. Broad Portfolio: Opportunities and Risks
   Susan Fitzpatrick, Ph.D., Vice President, The James S. McDonnell Foundation, Moderator
   William Thies, Ph.D., Vice President of Medical and Scientific Relations, Alzheimer’s Association
   Allan Tobin, Ph.D., Senior Scientific Advisor to the CHDI Foundation

6:00-7:30 pm  Networking Reception
Thursday, March 6

8:30 am  Plenary: More New Science for Discovery and Translation: The Role of Genomics  
Francis S. Collins, M.D., Ph.D., Director, National Human Genome Research Institute

9:30 am  Break

9:45 am  Plenary: Training the Translational Researchers of Tomorrow: The Role of Academic Health Centers  
Nancy Andrews, M.D., Ph.D., Dean, Duke University School of Medicine

10:30 am  Break

11:00 am  Breakout Sessions

C. Careers & Training: Strategic Directions in Careers & Training: Shortening Time to Independence  
Nancy J. Brown, M.D., Associate Dean for Clinical and Translational Scientist Development, Vanderbilt University, and Member, IB 35 Working Group, Association for American Medical Colleges  
Andrew Schafer, M.D., Chair, Department of Medicine, Weill Cornell Medical College, and Association of Professors of Medicine

D. Issues for Grantmakers: The Case for Using Funds to Build Capacity in the Health Research Enterprise  
Lynne Garner, Ph.D., Trustee & Executive Director, The Donaghue Foundation, Moderator  
Mathew Nelson, Assistant Vice President, Research and Technology Programs, The Flinn Foundation  
Marc Hurlbert, Ph.D., Scientific Director, Avon Foundation  
Patty Pedersen, Ph.D., Associate Vice President, University Director of Corporate & Foundation Relations, Yale University

12:15 pm  Lunch/Closing Plenary: Managing Change: Moving Toward Strategic Philanthropy  
Mark Kramer, Managing Director, FSG Social Impact Advisors

1:30 pm  Adjourn
Conference Attendees

Jessica Abeita
Assistant Director, Research Administration
Prevent Cancer Foundation

Kathryn Ahlport
Executive Director
Health Research Alliance

Marla C. Amann
President & CEO
Innovative Meeting Resources, Inc.

Margaret Anderson
Chief Operating Officer
FasterCures

Nancy Andrews
Dean
Duke University School of Medicine

Carolyn Asbury
Senior Consultant
Dana Foundation

Ann Ashby
Deputy Executive Director
Foundation for the NIH

Mitchell Balk
President
Mt. Sinai Health Care Foundation

Deborah Banker
VP Research Communications
Leukemia & Lymphoma Society

Leny Bautista
Program Assistant
Howard Hughes Medical Institute

Rita Berkson
Executive Director
Goldhirsh Foundation

Suzanne Bliss
President
Lymphoma Research Foundation

Virginia Boldt
Director Strategic Planning & Development
Alliance for Cancer Gene Therapy

Queta Bond
President
Burroughs Wellcome Fund

Chris Boshoff
Project Manager
Foundation for the NIH

Ann Brazeau
Associate Director
MPD Foundation

Brian Brewer
Director of Communications
Cancer Research Institute
One Exchange Plaza

Rusty Bromley
Chief Operating Officer
Myelin Repair Foundation

Donald Brown
President
Life Sciences Research Foundation

Jeanne Brown
Program Officer
The Medical Foundation

Kyle Brown
CEO
Innolyst/Research Crossroads

Nancy S. Brown
Robert H. Williams Professor of Medicine
Vanderbilt University School of Medicine

Lindsey Caldwell
Research Assistant
Foundation for the NIH

Russ Campbell
Communications Officer
Burroughs Wellcome Fund

Scott Campbell
VP Research Programs
American Diabetes Association

Maria Carrillo
Director, Medical & Scientific Relations
Alzheimer’s Association

Gerard Carrino
Chief of Staff and Vice President
March of Dimes Foundation

Daniel Carucci
Director of Science
Foundation for the NIH

Margaret Cianci
Executive Director
Alliance for Cancer Gene Therapy

Stacy Cloud
Grants Administrator
The Donaghue Foundation

Timothy Coetzee
Executive Director
Fast Forward, LLC

Sophia Colamarino
Vice President Research
Autism Speaks

Francis Collins
Director
National Human Genome Research Institute

Nancy Daly
Director of Grants
ASCO Foundation

Felicia DeRosa
Executive Assistant/ Program Manager
Friedreich’s Ataxia Research Alliance

Lorraine Egan
Executive Director
Friedreich’s Ataxia Research Foundation

Robin Elliott
Executive Director
Parkinson’s Disease Foundation

Jennifer Farmer
Executive Director
Children’s Brain Tumor Foundation

Susan Fitzpatrick
Vice President
The J. S. McDonnell Foundation

Roxanne Ford
Program Director
American Heart Association

Maryrose Franko
Senior Program Officer Grants and Special Programs
Howard Hughes Medical Institute

William Galey
Director, Graduate and Medical Education Programs
Howard Hughes Medical Institute

Elaine Gallin
Program Director for Medical Research
Doris Duke Charitable Foundation

Lyndie Garner
Trustee and Executive Director
The Donaghue Foundation

Cindy Geoghegan
Exec. Advisor, Scientific Community Relations
Susan G. Komen for the Cure

Beth Goldsmith
Executive Director
The Craig H. Neilsen Foundation

David Goodman
Director, Corporate & Foundation Relations
AACR Foundation

Shirley Hamilton
Assistant Director of Programs
EyeSight Foundation of America

Kathy Hammitt
Director of Research
Sjogren’s Syndrome Foundation

Kathi Hanna
Freelance Writer

Leslie Hanrahan
Vice President, Education and Research
The Lupus Foundation of America

John Hardin
Chief Scientific Officer
Arthritis Foundation

Lynne Harmer
Director of Grants Administration
Cancer Research Institute

William Haseltine
President
William A. Haseltine Foundation for Medical Sciences and the Arts

Sharon Hesterlee
VP Translational Research
Muscular Dystrophy Association

Patricia Hinton
Director, Research Administration & Info Svcs
American Heart Association

Leroy Hood
President
Institute for Systems Biology

Jennifer Howse
President
March of Dimes Foundation

Marc Hubbert
Scientific Director
Avon Foundation
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<td>Melissa Jenkins</td>
<td>Program Assistant, Howard Hughes Medical Institute</td>
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<tr>
<td>Michael Katz</td>
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