

## 2008 highlights and progress

*FasterCures* / The Center for Accelerating Medical Solutions continues to work on clearing the path to faster progress, not just by analyzing barriers, but by overcoming these through action. In 2008, we implemented strategies that were identified in the *FasterCures* Blueprint for Change as key to finding new medical solutions.

We present highlights and progress made in the three areas of medical research we focus on:

- Research Leadership and Innovation
- The Medical Research Environment
- Research Tools and Resources

### RESEARCH LEADERSHIP AND INNOVATION

#### The Redstone Acceleration and Innovation Network (TRAIN) *Catalyzing innovation in disease research*

This year, *FasterCures* helped tell the story of venture philanthropy in medical research. TRAIN organizations' role in advancing biomedical research set the bar high for outcomes-driven innovative practices in the biopharmaceutical industry. Major scientific and investor meetings and conferences spotlighted TRAIN groups' best practices. 2008 TRAIN activities include:

- *FasterCures* facilitated an in-depth dialogue between representatives of 15 TRAIN organizations and Genentech's executive team at its San Francisco headquarters, **providing a glimpse into strategies to facilitate for-profit and nonprofit partnerships that further innovative research.** Art Levinson, Ph.D., Genentech's Chairman and Chief Executive Officer, along with the company's top executives and research scientists shared their insights with TRAIN groups.
- *FasterCures* convened a TRAIN meeting focused on the role that foundation funders of research can play in **shepherding promising research through the "valley of death"** that often exists between government-funded basic discovery and commercial development. The meeting featured Dr. Anna Barker, deputy director of the National Cancer Institute and director for Advanced Technologies and Strategic Partnerships, who spoke about the role NIH can and should play in setting the research agenda in a disease area, and the resources and capacity available at NIH to enable that, as well as demonstrations of tangible tools that facilitate research collaboration.
- *FasterCures* released the white paper "*Entrepreneurs for Cures*" that highlights how **nonprofit disease research organizations are finding and funding big ideas**, effectively paving the way for developing new business models to accelerate research. The paper articulates the impetus of the creation of many TRAIN groups – to cure disease and improve the lives of patients – and focuses on the need for and importance of more examples that will lead to medical breakthroughs.



- *FasterCures* organized opportunities to highlight the work of TRAIN organizations in settings that engaged biomedical research's renowned opinion and thought leaders. *FasterCures* brought the issue front and center by facilitating active dialogue about partnerships between nonprofit and for-profit disease research entities at the following meetings:
  - Biotechnology Industry Organization (BIO) Annual Convention
  - The Institute of Medicine (IOM) Workshop on Venture Philanthropy Strategies
  - BIO Mid-Atlantic Conference
  - BIO Investor Forum
  - IOM Forum on Strategies for Facilitating Sharing of Research Materials and Data

### ***FasterCures-Esquire Annual Leadership Forum***

#### ***Applying social entrepreneurship's lessons to the cure entrepreneurship movement***

More than 30 senior leaders from organizations that fund medical research and those from the social entrepreneurship discipline convened at what has become an annual leadership forum on medical research innovation brought together by *FasterCures* and *Esquire* magazine. The meeting explored lessons learned by social entrepreneurs that might be applied by those pursuing what *FasterCures* calls "cure entrepreneurship," or novel approaches to accelerating the process of treating and curing disease. The meeting reinforced the unique role that *FasterCures* can play in helping to build a "knowledge commons" to accelerate medical research – whether that is a collection of the best organizational practices of TRAIN groups, or continued work on the Philanthropy Advisory Service to make transparent information about the most effective medical research foundations, or perhaps an entirely new project to escrow vetted but unfunded proposals from funders.

### ***The FasterCures-InnoCentive Ideation Challenge***

#### ***Mining the wisdom of the crowd***

*FasterCures* and InnoCentive embarked on an experiment together by posting an ideation challenge on the InnoCentive site, one of the company's first "Public Policy and Citizens in Action" challenges seeking solutions to important issues facing society. *FasterCures* pursued this effort to benefit from the "wisdom of the crowd" by asking for novel approaches and/or incentives that might induce companies to invest more in biomarkers research and qualification.



## **THE MEDICAL RESEARCH ENVIRONMENT**

### **Philanthropy Advisory Service (PAS)**

#### ***Helping philanthropists make informed investment decisions***

In 2008, *FasterCures* Philanthropy Advisory Service focused on building its online platform and developing a business and marketing infrastructure that will **meet the needs of the philanthropy marketplace** as well as encourage utilization of PAS among key audience segments.

PAS was developed to fill the funding gap related to high-impact biomedical research by providing philanthropists and those that advise them with better resources and more transparent information. PAS is set to offer **qualitative information on effectiveness, not just efficiencies** of organizations, and its metrics have been developed to set the standard for ensuring transparency in biomedical research efforts.

In anticipation of a spring 2009 launch of the PAS beta version, *FasterCures* has convened scientific advisory and organizational review boards to guide the research, development, and assessment processes that need to be in place to develop a scientifically accurate, credible, and viable resource.

The PAS program is supported by the Bill & Melinda Gates Foundation and the Pioneer Portfolio of the Robert Wood Johnson Foundation.

Fifteen Years.



That's how long it takes to develop new medical treatments.

But the thousands of people diagnosed with a deadly disease today cannot wait 15 years. That's why FasterCures is working to create a medical research system for the 21st Century that saves lives by saving time.

**FasterCures**  
A Patient and Family Center  
www.fastercures.org

Michael M. Fagan, M.D., Director, Center for Human Genome Research, National Institutes of Health  
David Baltimore, Nobel Laureate, Director, National Institute of Health  
Gregory D. Siskind, M.D., Director, National Institute of Health  
Nancy Lurie King, M.D., Director, National Institute of Health  
Michael R. Taylor, M.D., Director, National Institute of Health  
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**FasterCures Intramural Research Program Task Force Calling for New Mission and Focus for NIH IRP**  
FasterCures convened a task force headed by Nobel Laureate, and FasterCures Board Member, Dr. David Baltimore to recommend to the incoming Administration a framework within which to refresh the National Institutes of Health (NIH) Intramural Research Program (IRP), giving it a distinct mission and identity in the service of improving public health. The IRP consumes nearly ten percent of the budget of the NIH and has a highly regarded history of discovery but today lacks a clearly defined mission within the overall NIH effort.

The IRP mission, as defined by the Task Force, is three-fold:

- **to focus on translational research**, especially work that utilizes the unique capabilities of the NIH Clinical Center;
- **to be prepared to respond expeditiously to new scientific opportunities and challenges**; and
- **to focus on high-risk, long-term basic research goals that would be difficult to pursue in the extramural research environment.**

### Biomedical Research Policy Efforts

#### *Creating a more effective medical research environment*

This year, our nation's policy makers and influencers turned to *FasterCures* in efforts to address some of the most pressing concerns plaguing the biomedical research system. *FasterCures* addressed the following audiences:

- The **U.S. Senate Health, Education, Labor and Pensions Committee** at a hearing on cancer challenges and opportunities in the 21st Century. Arguing that the nation can no longer afford the human and financial toll from cancer, *FasterCures* president Greg Simon in his testimony to the HELP Committee said that "we cannot fight this war on cancer with the strategy we've got. We've got to fight it with the strategy we need." He told the Committee that the systemic barriers to finding effective cancer treatments are the same barriers that hold back progress in all disease research areas.
- The **American Health Information Community** on the importance of incorporating medical research into the Nationwide Health Information Network. Greg joined a panel of research leaders that called on AHIC to expand its scope and mesh data standards for medical research with its work on standards for e-health records.
- *FasterCures* sponsored The **National Academies of Sciences Committee on Management of University Intellectual Property** meeting where Greg provided testimony on the value of considering human capital when discussing university technology transfer policies.
- The **U.S. Department of Health and Human Services' National Summit on Personalized Healthcare: Innovation in Healthcare Delivery** where Greg moderated a panel on patient involvement in personalized healthcare. Participants developed a shared vision about personalized healthcare, identified major barriers, and identified strategies and action plans for making personalized healthcare a reality.



- The **Milken Institute Global Conference** where *FasterCures'* Greg Simon moderated panels on 21st Century health, global health in an interconnected world, and the rate of return on your philanthropy. The global conference also featured *FasterCures'* COO Margaret Anderson who moderated panels on the role of genomics in your life and the future of healthcare reform.
- The **World Stem Cell Summit** panel on state and federal initiatives where Greg provided comments on how industry, state, academic and federal efforts can effectively interface to develop stem cell business and therapy.
- The **Organization for Economic Cooperation and Development's** expert workshop on knowledge markets in the life sciences where Greg presented strategies for breaking barriers and accelerating innovation as part of the session on intellectual assets in health: current inefficiencies and future trends.
- The **Index Ventures Conference** in Taormina, Sicily, Italy, where Greg participated in the roundtable discussion "Alternative Business and Financing Models in Drug Discovery and Development.

*Nature Medicine* named **Greg Simon one of the ten most influential people to watch** in biomedical policy. The article presented "a handful of influential people who quietly help keep the wheels of biomedical science turning." According to the article --

*"...influence can take many forms. When it comes to biomedical science policy in the US, the names of some people with clout are obvious. But beyond the Nobel laureates and university presidents there is another set of people who wield power. Some of these influential players, such as patient advocates or experts who churn out reports for think tanks, are well known within their own communities. Others, such as Senate staffers or policy makers at the US National Institutes of Health (NIH), operate under the radar."*

### ***Accelerating the Pace of Discovery and Translation in Melanoma through The Melanoma Research Alliance***

*FasterCures* helped incubate and establish The Melanoma Research Alliance, a new public charity founded with a defined purpose: to change the rate of scientific discovery, development of needed treatments and the outcomes of patients with melanoma. In 2008, the MRA made significant strides under the leadership of its president and CEO Alison Martin, MD, its scientific advisory board, and its board of directors:

- awarded eight million dollars in grants to fund 17 innovative, high-impact research worldwide and solicited additional requested for proposals with emphasis on translational science;
- helped facilitate a collaborative process and early sharing of data; and
- began exploring synergistic multisector partnerships that would lead to better prevention, diagnosis, treatment and an elimination of death due to melanoma.

*FasterCures* chairman Mike Milken and president Greg Simon are members of the MRA Board. COO Margaret Anderson is Secretary to the MRA Board.

Also this year, *FasterCures* played an active role in the following coalitions:

- **Coalition for a Stronger FDA** – *FasterCures'* COO Margaret Anderson is on the board of this coalition that calls for renewed public commitment to and increased support for the Food and Drug Administration and its unique role in protecting American consumers and patients.
- **Health IT Now** – broad-based effort to promote the rapid deployment of health information technology.
- **Research!America's Your Candidates Your Health Program** – *FasterCures* is one of the organizational sponsors of this voter education initiative focused exclusively on health and research issues.
- **Coalition for the Advancement of Medical Research** – advocacy and education effort that focuses on stem cell research, somatic cell nuclear transfer, and related research fields with a mission to develop treatments and cures for individuals with life-threatening illnesses and disorders.
- **Partnership to Fight Chronic Disease** – member of this partnership that is committed to raising awareness of the number one cause of death, disability, and rising healthcare costs in the U.S.- rising

rates of preventable and treatable chronic diseases.

- **Partnership to Improve Patient Care** –part of this newly-created effort to promote comparative effectiveness research that protects patient access to optimal care, preserves patient-physician decision-making and supports continued medical innovation as a solution to healthcare challenges.
- **Alzheimer's Study Group** –provided strategic counsel and key insight to this taskforce of national leaders charged with creating an Alzheimer's National Strategic Plan to overcome the mounting Alzheimer's crisis.
- **HHS' Electronic Health Records Clinical Research Working Group** – member of this working group convened to provide a roadmap towards a process of integrating the environment that provides both patient care and data for clinical research.

## RESEARCH TOOLS AND RESOURCES

*FasterCures* believes that more patient-driven resources must be readily available to the research community in order to drive and support medical research that can work faster and more efficiently. This year, we made progress in moving forward efforts to empower patients to contribute to medical research, including:

### BioBank Central

*Providing the biobanking community with a networking and communications platform*

We continue to address the information needs of the biobanking community by ensuring current and accurate content on BioBankCentral.org. This year, we added a new element, Spotlight on Innovation, which highlights exemplary practices in biobanking.

### ThinkResearch/Electronic Health Records

*Ensuring a health information system that can improve patient care and enable medical research*

Besides addressing the American Health Information Community, *FasterCures* remained active in other efforts to help ensure research is included in the health information technology discussion. *FasterCures*, along with over 175 industry and nonprofit groups, pushed Congress to act on widespread adoption of health IT. As part of its effort to urge institutions to "think research" as they struggle with the adoption and implementation of EHR systems, *FasterCures* actively participates in the Health IT Now coalition and the HHS' Electronic Health Records Clinical Research Working Group.

### Personalized Healthcare

*Putting patients at the center of healthcare*

Embedded within each patient is the information – medical records, biological material such as tissue, blood, and DNA, and our biology as observed in clinical trials – that is crucial to understanding and managing disease. But too often that information remains isolated – unknown and unavailable to researchers.

*FasterCures* released "*Patients' and Consumers' Interests and Perspectives in Personalized Healthcare*," a white paper on the cutting-edge possibilities of personalized healthcare and the need for patient involvement. The paper looks into how "personal" personalized healthcare is and what consumers think about the advent of this era. This paper was commissioned by the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services, as part of Secretary Michael O. Leavitt's Initiative on Personalized Health Care.



### **FasterCures Partners with the Milken Institute in Facilitating Global Conference Health Sessions**

*FasterCures* worked with the Milken Institute in organizing global conference sessions in the “*Fast Track to Faster Cures*,” portfolio, featuring 11 expert panels covering a broad spectrum of health-related issues. We published special editions of the *FasterCures* SmartBrief which featured daily highlights, session summaries, and blogs from the global conference.

### **FasterCures Expands its Reach, Delivers Key Messages**

This year marked a milestone in *FasterCures*’ media coverage portfolio having been quoted in top-tier outlets including *Newsweek*, *Wall Street Journal*, *U.S. News & World Report*, key trade publications like *Science*, *Nature*, *BioWorld*, and *the Pink Sheet*, and featured in the 75<sup>th</sup> anniversary issue of *Esquire* magazine. Media articles covered *FasterCures*’ key messages on the need for improving the medical research infrastructure, addressing the “valley of death” funding gap, and a call for more innovative approaches to biomedical research.

*FasterCures* expanded its social network by engaging a captive audience through its blog, launching a Facebook page, establishing a presence in SecondLife (a virtual reality interface that features dedicated segments for the nonprofit community), and adding multimedia components to its Web site. *FasterCures* communications vehicles continue to gain traction. Among this year’s highlights:

- SmartBrief, the *FasterCures* bi-weekly newsletter now goes to more than 6,000 opt-in subscribers.
- Our newly-redesigned Web site was perused by an average of 9,000 unique visitors each month.
- The *FasterCures* blog now features a growing list of active subscribers, is widely picked up by major online feeds, and is circulated among key listservs.

### **Office Move**

*FasterCures* moved to its new home at 1101 New York Avenue, NW, one of two "green" buildings in Washington. The state-of-the-art suite and office space for Knowledge Learning Corporation, Melanoma Research Alliance, Prostate Cancer Foundation, Milken Institute, and the National Institute for Excellence in Teaching.

### **Staff Updates**

- **Cecilia Arradaza** joined us in April as communications director. Cecilia was most recently at Chandler Chicco Agency, a health PR firm working on public affairs and foundation communications programs.
- **Loren Becker** joined us in October as global health program analyst for the Philanthropy Advisory Service. Loren comes to us from the Results for Development Institute, where she was a program officer in charge of developing and implementing health financing projects at the global and country level.
- **Patricia Wolf** joined *FasterCures* as the executive and meetings administrator. She comes to us with over 22 years of professional office experience in the entertainment, legal, and marketing industries.

### **Intern Program**

- **Erin Knievel** joined as *FasterCures*’ fall/winter intern after completing her degree in Chemistry from the University of Florida.
- **Shannon Bush** joined as a summer intern shortly after returning from a semester abroad in Copenhagen, Denmark where she studied Politics of the European Union and Biomedical Ethics.
- **Katie Reiser** joined as a summer intern while pursuing bachelor’s degrees in biology and in philosophy at Tufts University.
- **Laura Johnson** joined as a spring intern while finishing her MBA program at Georgetown University.