

PRACTICALLY *Speaking*

The Donaghue Foundation Newsletter: Focused on research and knowledge uptake initiatives.

Donaghue Grantee Gathering: Angels, Eagles and Vultures

Donaghue advisers and recent and current grantees met for an informal reception and presentation by Guy Fish, MD, MBA, Vice President of Fletcher Spaght Ventures. This first “Grantee Gathering,” held at the Hartford Marriott Farmington, provided an opportunity to reinforce Donaghue’s links with its grantees and to recognize the service provided by our science and policy advisers.

After a brief period for networking among the guests, Dr. Fish spoke to the attendees about the role of venture capital in moving medical research into application and addressed the question “Is Your Research Ready For Prime Time?”

He noted that the funding gap between university-based research and the markets that distribute health care innovations, where funding often dries up and is referred to as the “valley of death,” exists in all areas of discovery — drugs, IT, devices, and the kinds of behavior-based innovations that Donaghue funds. “When you’re in the valley of death and you hear wings flapping above you, you want to know if it’s an angel, a vulture, or an eagle.” Angel investors often provide smaller financial assistance to scientifically-based technologies with few or no strings attached. Venture capital firms are the “vultures” who provide larger financial assistance for products. Products are different from technologies in that they are specific applications of a technology to a particular problem, and to be successful they must also have a value proposition.



It was also inauguration day; a television was set up for people to watch the parade during the social hour.



Guy Fish discusses the funding gap between academic research and health care markets.

Venture capital firms assist in bringing the product to the market, but unlike angels seek a return on their investment. Corporate venture investors are referred to as the “eagles,” who can pick you up out of the valley, have some of the characteristics of the venture capital firms but focus more on providing financing to a company.

Dr. Fish also explained the basic economics of venture capital and the evaluation metrics used to determine the potential success of a technology or product. “What is the unmet need, how big is it, who is willing to pay for it, and why haven’t others been able to do it so far” are some of the issues that need to be assessed in the evaluation process.

Some universities provide centers for innovation to give feedback to investigators interested in taking an innovation to market. They can give guidance in developing a proof of concept, or they engage a panel of experts in financing, intellectual property and marketing to assess the strengths and weaknesses of an innovation.

In her introduction of Guy Fish, who has a MD and MBA from Yale University, Lynne Garner, Donaghue Trustee, acknowledged that some people were probably surprised that Donaghue is hosting a discussion by an officer in a venture capital firm but explained that “Donaghue is interested in knowing about all paths that get innovations to application.”

Letter from the Trustees

As in all organizations, transitions are an accepted and inevitable part of everyday business. Some transitions, however, are more significant than others. After 31 years in the banking industry and twelve years as the Bank of America representative to Donaghue, Sheilah Rostow is transitioning to a new chapter in her life — retirement. Sheilah has served as Fleet Bank's then Bank of America's representative to Donaghue since 1997.

Most of our readers haven't known a Donaghue without Sheilah. However, many of you also haven't known that Amy Lynch, who is a Bank of America Vice President, has been an active member of the Bank of America's resources to Donaghue for almost two years — participating in policy advisory meetings, strategic planning sessions, and grantee review deliberations. During the past year, Sheilah, Lynne and Amy have met together monthly to oversee the Foundation. Donaghue has already benefited from the unique perspective Amy brings based on her work at Bank of America with several other health-related philanthropies and her legal training. Thus, we are confident that this change will proceed smoothly and have no significant impact upon the overall work of the Foundation. In fact, the planned transition from Sheilah to Amy is one advantage in having a corporate trustee.

Yet, we wouldn't be honest if we didn't acknowledge that from a personal perspective this transition, though anticipated, brings some sadness. The Donaghue — Rostow pairing was a good fit. Donaghue benefited from Sheilah's deep knowledge of philanthropy, keen interest in health issues, and appreciation for the commonsense mission of practical benefit; her humor, intelligence and good nature made the "work" fun. And what senior vice president wouldn't love to have an assignment like Donaghue?

So, we are all wishing Sheilah well and we'll be watching with interest to see to where she devotes her time and her many talents in this next phase of her life.

Donaghue is also involved with another transition — and unlike the one posed by Sheilah's retirement, this transition was not expected, is more prolonged, and its end is uncertain. This transition, of course, is the change that is occurring in endowment and donor-based philanthropies due to the current recession. As one television pundit said a short while ago, "this is more than a recession; it is also a restructuring." His comment was focused on the



Sheilah Rostow, Bank of America, Trustee and
Lynne Garner, PhD, Trustee and President

macroeconomic issues. However, the same restructuring can be said to be occurring within the non-profit sector in general and Donaghue more specifically. It is uncertain what the nonprofit world will look like in three or four years as a result of this recession; some analysts believe that it will be more consolidated with fewer organizations doing the same breadth of work that is done now. This is because a major source of their revenue, the philanthropic sector, has fewer resources to give them. Donaghue has fewer resources right now, too. One consequence of this is described in this issue — collaborating with another funder. This is an example of our commitment to find innovative ways to leverage the grant dollars that we do have to further the Donaghue mission.

To quote another observer of our current situation, "never let a good crisis go to waste."

Donaghue is working to restructure our efforts to creatively respond to this opportunity and continue in the best ways to achieve our mission. Stay tuned.

Sheilah Rostow
Bank of America, Trustee

Lynne Garner, PhD
Trustee and President

Sign up for Emailed Donaghue News

Don't miss out on emailed news from the Donaghue Foundation. You can now sign up to receive electronic updates, including video highlights of Donaghue events, by visiting www.donaghue.org and signing up. Look for the link at the bottom of our home page.

Ask the Trustees



Q: I thought that foundations were required to give away a certain amount of their assets each year or they would lose their non-profit status. If Donaghue is giving only one grant this year, won't that be a liability to your tax status?

A: It's true that although Donaghue will be making only one new grant in 2009, it will still be providing more than \$3 million in 2009 for research grants. The majority of our grant spending in 2009 will be for continuation grants that were started in previous years. Donaghue usually gives two-, three-, or four-year grants; in some cases the grants are for longer than that. So even though we are limiting the number of new grants this year, we are still providing a significant amount of funding for research due to the continuing grant commitments that we have to various institutions.

Having said this, even if Donaghue did not have the obligation of its continuation grants, one or two years of lowered spending would not result in a penalty with the IRS. Private

foundations with a non-profit tax status are required to distribute a minimum of 5% of their assets each year, and this amount may include both grant distributions as well as administrative expenses that are necessary to run the organization. However the calculation to determine the minimum distribution is based on a five year average of the foundation's previous assets and spending. Donaghue's generous spending over the past several years have exceeded the minimum payout requirement for the foundation which has resulted in what is called "excess distribution" in IRS-speak. What that means is that Donaghue has distributed amounts in excess of its 5% of assets, and this provides a cushion to help satisfy current year payout requirements.

Interview with Nancy Yedlin

In the Winter 2006 issue of *Practically Speaking*, readers were introduced to Nancy Yedlin, who had recently joined the Foundation. At that point, her position was half-time grant management and half-time developing strategies to improve the dissemination of promising research results. Since then, Nancy has turned her attention 100% to the knowledge uptake part of her job, which was made possible by Stacy Cloud joining Donaghue in 2008 as its Grants Administrator. We thought this would be a good time to have a conversation with Nancy to learn more about her role with Donaghue:



Nancy Yedlin

The research needs to be relevant to the people who work in the health care system or to patients and be done in such a way that makes it feasible to adopt research findings.

2. Why is this interplay between grants and adoption so important to a medical research foundation?

This work isn't important to all medical research foundations — many have significantly different missions than Donaghue, such as educating scientists or supporting basic research. But it is critical to our mandate. Unless the research is adopted into use, there really isn't any practical benefit.

1. How is your work related to the research grant function of the Foundation?

My work is related to the grants we give in a number of ways. For some of the grants, I have gotten involved in a range of activities to help sustain the work after the research has been completed. For example, connecting grantees with resources that can help with business and strategic planning or directly helping to find new sources of (non-research) funding support. One of the other roles I play is to take what I'm learning about how non-research organizations adopt "evidence-based" interventions and approaches so we can incorporate this understanding into the design and evaluation of our grant programs. The decision to structure our Research Leadership Program to include a transdisciplinary team that may include investigators from outside of academia was based on what we've learned.

3. One of your major responsibilities is to develop the Foundation's annual conference. How does the conference relate to the Foundation's overall mission?

We see each year's conference as having a few interrelated goals. It's the Foundation's opportunity to bring together folks from sectors across the health care spectrum and provide a forum to hear from leading thinkers and to discuss some of the innovations, big questions and emerging trends that both present challenges and offer great potential for improving health. The Beyond Eureka! theme positions the conference to focus on what Donaghue is all about in a BIG PICTURE way — once we have a discovery, or a new idea, then what happens? How can we take what we learn and improve health?

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Beyond Eureka! Conference April 29, 2009

The Foundation's 2009 conference will be held on Wednesday, April 29 at the Hartford Marriott Farmington between 8:00 am and 2:00 pm. Donaghue will be expanding on its previous three Beyond Eureka! Conferences with this year's program titled *Beyond Eureka! Innovation in the quest for better health: Patient-driven transformations in research, technologies and treatments.*

Three speakers will focus on the way the web and other communication technologies are putting new tools in the hands of patients and driving change in health care and medical research. Each of these speakers have themselves been innovators in this area of technology-driven innovations that change the relationship between patient and provider or researcher.



Alejandro (Alex) Jadad, MD, DPhil, FRCPC, FCAHS is Chief Innovator and Founder of the Centre for Global eHealth Innovation based in Toronto. The Centre seeks to help improve health and wellness through information and communication technologies that will enable the public to shape the health system and society. Dr Jadad and his colleagues

build tools to support encounters between the public and the health system and to promote knowledge translation and mentorship of health professionals. The Centre provides online resources to support social networks, to respond to major public health threats, and to support international collaboration to improve health. His topic *"Will we be able to innovate in time? Meeting the health care expectations of the Obama generation"* underscores Dr. Jadad's interest in matching the reality of how younger people communicate and get information with the practices of our health care system.



Sharon Terry, MA, is President and CEO of The Genetic Alliance, which is at the forefront of consumer participation in genetics research, services and policy. Ms. Terry is also a member of several governmental advisory committees on medical research. Her talk at the Conference, *"Participants*

at the center: Accelerating the pathway from research to health" is based on her leadership at the Genetic Alliance that brings together diverse stakeholders to create novel partnerships in advocacy and to ensure that individual, family, and community perspectives are at the center of efforts to improve health systems and use of genetic information. Ms. Terry also oversees the Genetic Alliance biobank which serves as a catalyst for translational genomic research on rare genetic diseases.



Ben Heywood is Co-Founder and President of PatientsLikeMe, the leading online community for people with life-changing conditions. Through his discussion, *"The power of sharing with patients like you: Transforming research, treatments, and care,"* Mr. Heywood will describe how PatientsLikeMe has created a platform for collecting and

sharing outcome-based patient data and real life experiences amongst patients. The site has brought about data-sharing partnerships with doctors, pharmaceutical and medical device companies, research organizations, and non-profits for a growing number of diseases and health conditions. PatientsLikeMe is leading the way in offering better, more effective ways to capture valuable results and share them with patients, healthcare professionals, and industry organizations that are trying to treat the disease.

The three speakers will also participate in a panel discussion based on questions from the audience. The Conference and its lunch are free, although registration is required.

More information, including links to the websites of the speakers' organizations, their blogs, and videos, and a link to the registration page, are available on the Foundation's website at donaghue.org.

2nd Annual Andrews Lecture on the Patient's Voice

The second Annual Andrews Lecture on the Voice of the Patient will be held Wednesday, September 16 at 4:00 pm at the Anlyan Center on the medical school campus of Yale University. The speaker will be Karen Barrow. Ms. Barrow is a web producer for the health section of The New York Times and produces the Times' multimedia series "Patient Voices." She obtained a master's degree in biomedical journalism from New York University and a bachelor's degree in biology from Cornell University. A reception will be held in the courtyard of the Anlyan Center following the lecture.

Ms. Barrow's lecture, "More than an Anecdote: The New York Times' Patient Voices Series," will focus on her work with Patient Voices and the impact that it has had. By combining audio interviews, photography and print media, Ms. Barrow strives to create a patient-voiced column. In each installment of "Patient Voices," six to ten individuals living with a particular ailment share their experiences. Some of the illnesses featured in the series are pancreatic cancer, psoriasis, bipolar disorder, ADHD, AIDS and HIV, stroke, and multiple sclerosis. All speak to the highs and lows that every person



Karen Barrow

experiences following a serious diagnosis.

Ms. Barrow previously worked as a writer for Healthology.com, producing educational health articles about a range of topics that were accessible to the general public. For her article, "Forecasting Heart Disease in Women: Will White Blood Cells Count?" Ms. Barrow was awarded The Excellence in Women's Health Research Journalism Award, presented by the Society for Women's Health Research.

The Andrews Lecture was established to honor Ray Andrews' stewardship of the Foundation from 1993-2007. The annual lecture series focuses on the voice of the patient and gives expression to the patient's experience from a variety of perspectives,

such as an individual's perception of illness, a person's view of him or herself as a "patient," or the patient's interaction with family and health care practitioners, the health care system and broader society. Last year's lecture was presented by Eric Cassell, MD.

The lecture will be open to the public, and additional information about the lecture will be available later this summer on the Foundation's website.

Nancy Yedlin — continued from page 3

4. "Practical benefit" has always been a part of the Foundation's mission. What is different about its current "knowledge uptake" orientation?

I think that the way Donaghue views practical benefit or knowledge uptake is largely a natural evolution in the history of the Foundation's 16 years. If you look back at our annual reports over this time span, you can see there was always an interest in and attention to the practical benefit of the projects funded by Donaghue even when much of what was funded in the early days was more basic science. Over time, Donaghue shifted more of its resources to support applied clinical and public health research, with the view that these areas are closer to being applied to the health problems that we have now that need be solved. What has also changed over time at Donaghue — and we are not alone in this — is the recognition that traditional research channels for vetting and dissemination like publishing in academic journals and presenting findings at conferences are very limited in their ability to drive the "uptake" of evidence so that it is used in the health care world. We have learned this in part by following with great interest, and trying to support where we can, the efforts of Donaghue grantees over time to get their work adopted after their research has been completed. Just putting your work out there, doesn't mean someone is there to "catch it" and use it.



With Lynne Garner and Sheilah Rostow, Nancy listens to former Trustee Ray Andrews. "Do you think he's serious about this?"

5. Can you envision how Donaghue might be different in two or three years because of these efforts?

Donaghue will continue to evolve. Some of the changes will be a result of work we are engaged in now. For example — we have been spending time with other foundations and organizations that also have a great interest in the challenges

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Donaghue Partners with Mayday in Program for Research Leadership

This year, Donaghue is pleased to be partnering with The Mayday Fund to award the 2009 Program for Research Leadership, a grant program that supports transdisciplinary teams to conduct research on an important health issue while exploring the best ways to move knowledge into practice. The winning team will be led by a senior investigator from a Connecticut research institution, and team members may be from academic or non-academic institutions in or outside of Connecticut. The goal of this year's program is to fund rigorous health research in the area of human physical pain while creating opportunities for the team members to learn and demonstrate new approaches to translating knowledge from research into practice.

The Mayday Fund is dedicated to alleviating the incidence, degree and consequence of human physical pain. Like Donaghue, Mayday understands that sometimes existing knowledge is not effectively used and concentrating on closing the gap between knowledge and its application is important to improving health.

Each award will be \$200,000 a year plus a 10% indirect cost rate for four years. The Program for Research Leadership requires three components in each proposal – research, knowledge uptake, and team-building. While it is expected that the majority of project budgets will be for research, the application procedures require a plan for knowledge uptake and for team building activities.

"We're very pleased to be working with The Mayday Fund through this program," said Lynne Garner, Donaghue Trustee and President. "Donaghue has done some collaborative funding in the past, but not to this extent. We know we will learn a great deal through this new partnership."

"We share the excitement," said Christina Spellman, Mayday Fund Executive Director. "For Mayday, this partnership will enable both foundations to bring resources to develop a Connecticut-led model to inform better practice



for the care of pain that will be broadly disseminated."

The Program for Research Leadership has a three-step application process. The first step is a letter of intent, which is expected to assist prospective applicants to know if their ideas are "on target" without investing a significant amount of time in a lengthy application process. The second step is an invited application. Applications will be reviewed by a specially selected committee that is comprised of scientists with specific knowledge in the topics and research being proposed and with expertise in knowledge uptake. The third step is an interview of finalists by advisers and the Trustees and staff from both Mayday and Donaghue.

Letters of intent are due to the Foundation by Monday, April 13, 2009 and applications are due on Friday, July 17. Finalists will be interviewed in November, and the grant term will begin January 1, 2010.

A full program description and application materials are available on Donaghue's website. Questions about the program can be emailed to Leadership@donaghue.org. More information about The Mayday Fund and its programs can be found at maydayfund.org.

Yale School of Management Healthcare Conference

Again this year, Donaghue will be a sponsor of the Yale School of Management's annual health care conference being held at the Omni Hotel in New Haven on Friday, April 3. This year's program "*Where is the Value: Managing Cost and Quality in a Healthcare System Facing Reform*" will bring together industry professionals, public and non-profit leaders, as well as students, faculty and alumni from all areas at Yale University. The conference will explore the idea of the patient as the central stakeholder in healthcare and will frame a variety of issues around how the healthcare industry identifies and meets the needs of consumers-patients. Keynote speakers include Samuel Nussenbaum, MD, Chief

Medical Officer of Wellpoint and Helen Darling, President, National Business Group on Health. There are also two breakout sessions on various topics and an executive panel discussion moderated by Robert Galvin, Director of Global Healthcare at General Electric.

Nancy Yedlin, Donaghue's Vice President, serves as a member of the conference advisory board.

To learn more about the conference and to register go to www.yalehealthcare.com.

Donaghue Participates in Database

Donaghue, as a member of the Health Research Alliance, an organization of not-for-profit, non-governmental funders that support health research and training, has begun to upload information about its grant awards to the HRA database. An initial key project of the Health Research Alliance, gHRAsp or “Grants in the Health Research Alliance Shared Portfolio” is a new database currently receiving data submissions from member organizations. It is the first comprehensive repository of health research awards made by non-governmental, not-for-profit grantmakers.

The need for the database was recognized in the late 1990’s when the predecessor of the Health Research Alliance, the Clinical Research Alliance, attempted to quantify the investment of the private, not-for-profit sector in the career development of clinical investigators. Obtaining such information currently requires an extensive search of myriad websites. The new database will pull this information together in one location.

gHRAsp will be searchable using standard search tools, and organizations participating in the database are required to update their information annually. The new database should be of interest to policymakers (e.g., to examine the scope of the financial commitment by non-governmental not-for-profit grantmakers in the area of clinical cancer research in a given year), applicants and awardees (to view examples of clinical research awards made by different

grantmakers), and grantmaking organizations themselves (e.g., to examine how many privately-funded grantees are conducting research in cancer genomics). After all members have completed their first round of data submission, HRA will be conducting tests to determine the validity of data and standard reports. Member organizations will be able to request both ad-hoc and standard reports.

The American Cancer Society, a founding HRA member organization, provided leadership and infrastructure support for the early development of gHRAsp. In 2008, the HRA Board of Directors selected Innolyst to implement and provide additional enhancements to the database. Innolyst is the developer of the Research Crossroads database of public health research awards (www.researchcrossroads.com). The selection of Innolyst will allow HRA eventually to release non-restricted data fields in gHRAsp to the public Research Crossroads site, placing private awards data in the context of public awards. This will essentially provide the Donaghue Foundation with an additional venue to publish its research awards. The further development of gHRAsp, including policy related to data use, is overseen by the gHRAsp Oversight Committee, composed of representatives of member organizations.

Questions about the gHRAsp data base or the information that is being submitted to it can be answered by contacting the Donaghue office.

It’s a Family Affair... to Prevent Diabetes

The first *Donaghue Program for Research Leadership* grant has been awarded to the Yale Center for Clinical Investigation, in partnership with the Fair Haven Community Health Center.

The grant funded a four-year clinical outcome trial to demonstrate that interventions targeting obesity can improve health outcomes for inner-city women at risk for Type 2 diabetes. William V. Tamborlane, MD, Professor and Chief Pediatric Endocrinologist at the Yale School of Medicine, will lead the project along with a team of practitioners based at Fair Haven Community Health Center headed by Anne Camp, MD, Diabetes Program Director.

The team will be examining whether the risk of diabetes can be markedly reduced by an intensive healthy lifestyle program that can then be replicated in clinics across the country. The study will offer nutrition education, behavior modification instruction, and a structured exercise program. Participants will attend sessions three to four times per week, conducted both in



Donaghue Program for Research Leadership recipients from the Yale Center for Clinical Investigation and Fair Haven Community Health Center

Spanish and English, and behavior modifications will focus on the entire family in an effort to ensure lasting change. Participants will be encouraged to bring their children to each session to take part in fitness games and activities.

The *Program for Research Leadership* is a Connecticut-focused grant program that supports transdisciplinary teams of health researchers led by a senior investigator who has demonstrated leadership in innovative and useful health research and in transferring knowledge gained from research into clinical and/or public health practice. The overall goal of the program is to fund rigorous health research while creating opportunities for team members to learn or demonstrate new approaches to translating knowledge

from research. Therefore, the grant project must contain three components: research, knowledge uptake, and team building. This is a four year award granting approximately \$200,000 per year. (see *description of the 2009 award and its changes on page 6*)

Nancy Yedlin — continued from page 5

of moving health research into use. I think you will see us undertake initiatives and do more collaborative grant funding with like-minded organizations. While historically we have funded work being conducted at academic medical centers in Connecticut, our mandate for supporting research is quite broad. Given what we are learning now about the lack of mechanisms and structures that exist for moving university-based research out of academia into the broader world, I can see us engaged in activities that might build such structures and perhaps look to other kinds of research organizations to fund. I can see a different funding portfolio emerging (after the economic situation improves and we are able to provide more funding) that could include monies in the area of implementation science or make funds available to help researchers study the process of “uptake” and sustainability of their own work. Donaghue is fortunate to have not only an exciting mission but also a breath of possibilities to achieve it.

Important Dates

Program for Research Leadership letter of intent deadline – Monday, April 13 at Noon

Beyond Eureka! 2009 Conference – Wednesday, April 29 from 8:00 AM – 2:00 PM

Program for Research Leadership application deadline – Friday, July 17 at Noon

2nd Annual Andrews Lecture – Wednesday, September 16 at 4:00 PM

THE DONAGHUE FOUNDATION



The Patrick and Catherine Weldon Donaghue Medical Research Foundation is a charitable trust created pursuant to the will of Ethel F. Donaghue, late of West Hartford, Connecticut. The Foundation, which began operations in 1991, is governed by Bank of America and Lynne Garner, Trustees. The Foundation is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code of 1986, is a private foundation within the meaning of Code Section 509(a), and is subject to the jurisdiction of the Probate Court for the District of West Hartford.



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