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and industry organizations that are trying to treat the disease.

Heywood's other brother, Stephen, who was diagnosed with Lou Gehrig's disease in 1999 and died in 2006, inspired the creation of PatientsLikeMe. In the family's quest to find answers, they began to ask "what would happen if you provided a platform for patients to collect, aggregate and share treatment and symptom information with other patients like themselves?" The answer was that patients could support and inform one another and help drive the research and development priorities in the pharma and medical arenas. The power of PatientsLikeMe hit home again for Heywood more recently, he said, when his young daughter was diagnosed with a small hole in her heart. "You start to ask 'what happens to patients like her?'"

Heywood ended his discussion by saying that "a lot of people talk about the importance of the patient in health care, but they (the patients) are never at that table." For good communication, listening well is as important as speaking well, and we all have to remember that informed patients can help transform the health care system.

After the presentations and a short break to get lunch, Jadad, Terry and Heywood sat down together for a panel discussion to respond to questions that had been gathered from the audience of approximately 250 people throughout



Sharon Terry discusses an online tool.

the morning talks. The discussion ranged from the viability of business models using new technologies, to how vulnerable populations are faring when it comes to their access to all the patient information and advocacy tools on the web. At the end of the hour long discussion, all three panelists indicated that while they had not met before coming together at the Donaghue conference, they intended to look for opportunities to collaborate in the future. Terry summed it up well in her remarks at the close of the panel by stating "my reaction to the presentations of my colleagues here (Jadad and Heywood) is that I'm glad to meet my brothers and...I think that there may be more brothers and sisters in the audience" who will want to work, using all the tools now available, to bring about accelerated improvement in health.

THE DONAGHUE FOUNDATION



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# PRACTICALLY *Speaking*

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

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## Donaghue Foundation 2009 Beyond Eureka! Conference Examines healthcare on the brink of technology-enabled transformation

Donaghue's 2009 conference was held on April 29 at the Hartford Marriott Farmington. The fourth in its *Beyond Eureka!* series, Donaghue's topic this year was ***Innovation in the quest for better health: Patient-driven transformation in research, technology and treatments.*** The conference probed the realities of a healthcare system in flux, as consumers and healthcare providers embrace new technologies that enhance connectivity, research, innovation and collaboration. Lynne Garner, Trustee and President of the Donaghue Foundation, noted in her opening remarks that one of the exciting aspects of this year's conference was how the three keynote speakers challenged the Foundation to more fully embrace these new technologies. As a result, Donaghue launched its first blog in connection with the conference and the speakers' presentations are posted on the internet through Vimeo.

The first speaker **Dr. Alejandro (Alex) Jadad**, Chief Innovator and Founder of the Centre for Global eHealth Innovation based in Toronto, set the stage by showing how immediate access to information and the ability to communicate across the world through the web is changing relationships among generations. In his talk entitled "*Will we be able to innovate in time? Meeting*



Alex Jadad spoke about innovative ways to use ordinary communication technology to improve health care.

*the health care expectations of the Obama generation*" Jadad noted that unlike earlier times when parents were more informed than their children, parents and children now have the same access to information. In that sense, we are all of the "Obama generation." However, as younger people are more comfortable with the new information and social technologies, Jadad reminded the audience that adults are the bottlenecks to innovation and therefore need to work in partnership with young people to improve health. If we don't, Jadad warned, we will continue to see a rise in chronic disease and health care costs.

Speaking from the perspective of an "outsider" (Jadad is a Canadian citizen, born in Columbia) Jadad gave an overview of the current health care challenges and urged the US to partner with healthcare innovators in other countries. Jadad gave several examples from across the globe of new business models and innovations in healthcare that are using technology to improve patient outcomes and health systems. Citing his own reluctance to embrace new ways of communicating with patients and how he has been pushed by his own children, Jadad also talked about the fears physicians have in using new technology to communicate with their patients. Dr Jadad talked about his own practice in palliative care being a mixture of both high tech and high touch to meet his patients' needs.

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Seated with Alex Jadad and Sharon Terry, Ben Heywood responds to a question during the panel discussion.

## Letter from the Trustees

A short while ago, Geoffrey Canada, President and CEO of the Harlem Children's Zone, the award-winning comprehensive program of health, parenting and educational services, was on NPR's Talk of the Nation, and he said something that caught our ears. In describing the impetus for Harlem Children's Zone, Mr. Canada explained that before its founding he had been working in programs that served 100 or 200 children at a time. It was good and important work but didn't come close to meeting the needs of the thousands of children that could benefit from those services. He said "dealing with scale is one of the issues we need to tackle in this nation." A short while later, in discussing the inspiration for the Harlem Children's Zone, he said it was "not some kind of a brilliant Eureka" but rather putting into place what is already known to be effective in a way that works.

These two issues — implementing what we already know to be effective to make health improvements and doing so on a scale to benefit *many* people — are two of the biggest challenges to creating practical benefit through research. We've spent quite some time in considering these challenges, and it's clear that there are at least three conditions that underlie them.

- **There's lot of money for research but precious little to implement research findings.** Miss Donaghue was ahead of her time when she stated that research conducted with her money should be done with practical benefit as its goal. With the purpose that she gave us, we need to give serious thought to what is our obligation to assist in the implementation of research findings that result from our grantmaking.
- **It's nobody's job.** Wouldn't it be great if every organization had a Chief Implementer of Empirically-Based Improvements with a sizable staff and budget? At least one organization is working on this; the Canadian Health Services Research Foundation is a leader in promoting the use of knowledge brokers, and they are currently developing a knowledge brokering demonstration site competition.
- **Research creates knowledge, but knowledge in and of itself doesn't create benefit.** Although researchers are certainly motivated by the hope that their work will lead to making change, the majority of research is conducted in academic settings. And frequently, the funding and career realities of academia don't allow research on the model under consideration to go far enough to tackle the difficulties of its effective deployment over the long term. Knowledge in and of itself doesn't solve problems; effectively implemented and managed solutions solve problems.

### 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](http://www.donaghue.org) and signing up. Look for the link at the bottom of our home page.



Lynne Garner, PhD, Trustee and President  
and Amy R. Lynch, JD, Bank of America, Trustee

These conditions are far larger than Donaghue can change on its own. That's why we are excited to be working with other funders on these issues (*please read about our Funders Forum on page 7*). We hope our combined efforts can be of the scale to undertake changes in funding structure and processes that will allow research to make a larger impact. Perhaps these combined efforts will yield a new structure that includes jobs intended to link research to decision makers.

Although we aren't spending a lot of dollars on new grants now, we are working to shape our grant making programs to be more focused on using research to solve health problems. Maybe this involves starting with those who have the health care problems and then look for research-based solutions. Maybe the research team should be a partnership with those who are ultimately the end users. Or maybe, like Geoffrey Canada and the Harlem Children's Zone, funders like Donaghue need to be willing to stick with one issue for several years in order to make real change.

We're interested to know what you think about these issues. Please email us at [trustees@donaghue.org](mailto:trustees@donaghue.org) to let us know your thoughts on the challenge of creating practical benefit from research.

Amy R. Lynch, JD  
Bank of America, Trustee

Lynne Garner, PhD  
Trustee and President

## Ask the Trustees



**Q:** I really enjoyed the Donaghue Beyond Eureka! conference this year, but how does doing this conference relate to your mission of funding research?

**A:** First, we're glad to hear you enjoyed the conference. We had an overwhelmingly positive response to our speakers and their presentations. This is gratifying, because it takes a significant amount of our resources, both in dollars as well as staff time and effort, to organize an event of this size and complexity.

And we assume this is at the heart of your question. Why spend all those resources? There are three basic reasons why we believe the Donaghue annual conference is an important component of our activities.

First, the conference serves as an open, transparent window into what Donaghue is doing and where we are headed. While our annual report also serves this purpose, it puts more emphasis on past activities, grantees and expenditures during the past calendar year. The conference is more forward-looking and highlights ideas that we view as important to our future work. The conference also complements the written annual report by facilitating conversations; most of our grantees from the previous year attend and welcome questions from individuals about their work during the times set aside for networking. Donaghue trustees, staff and many policy advisers are also there and enjoy conversations with Foundation friends and meeting new people.

As a second reason, we seek to engage the Donaghue community in a discussion that will gently challenge all of us into thinking anew about what can be accomplished through medical research and its application for practical benefit. Review of the post conference evaluations confirms that

many of our attendees feel our speakers do this and value the Donaghue conference for providing them an opportunity to reflect on new ideas and approaches.

Finally, the conference directly relates to two of the five goals that support our mission. These are:

- Strengthen and widen understanding of the Foundation's mission by other people and organizations who have the potential to improve health, and
- Create networks and collaborations to test innovative ideas related to health research and health outcomes.

We understand that we cannot reach our mission alone and that we must collaborate with others to achieve it. Through our annual conference, we are able to inform more people about the work of the Donaghue Foundation and connect with other people and their respective organizations. We have found that these collaborative efforts contribute in a broad sense to the Foundation's knowledge uptake and often lead to fruitful associations, including our association with our thought provoking speakers.

As you might expect, Donaghue staff members are already hard at work securing speakers for the 2010 Donaghue conference. Watch for information about who they will be and the date of the next conference in early 2010. We hope to see you there!

## Donaghue Dictionary: Discovery

**T**he dictionary definition of "discovery" is simple: the act of finding knowledge for the first time. That's what scientists funded by Donaghue do, and for many years Donaghue has applied the term to refer to the activities of those scientists. But as we doggedly pursue ways to get new knowledge into beneficial practice, we find ourselves embarking on our own fascinating voyages of discovery, searching creatively in new ways and in more and more new places for the keys to Knowledge Uptake. We're scanning the horizon to discover the missing link between knowledge and its effective use.



## Ethel Donaghue Memorial in Elizabeth Park

In addition to the medical research foundation created by Miss Donaghue as a memorial to her parents, her Will established a much smaller trust for improvements in Elizabeth Park. The park is located in Hartford and West Hartford and is just a few steps from Ethel Donaghue's residence on Prospect Avenue. Lynne Garner and the Bank of America, represented by Amy Lynch, are also Trustees for the park trust.

Over the past seventeen years the Ethel Donaghue Trust for Elizabeth Park has quietly spent hundreds of thousands of dollars in Park improvements, including a major tree pruning, the building of the Sunrise Overlook on the east side of the park, improvements to the Pond House, restoration of the two greenhouses and the historic orchid greenhouse, and most recently the granite curbings and

crosswalks in the expanded parking area near the Asylum Avenue entrance.

In recognition of Miss Donaghue's beneficence to both medical research and Elizabeth Park, Ray Andrews, who was trustee at the time, and Sheilah Rostow, who represented the Bank of America, initiated three projects in Elizabeth Park that fulfill Miss Donaghue's wish to improve it, while also recognizing her life and philanthropic achievements: a new gateway for the Prospect Avenue entrance, a vegetated swale to reduce the soil erosion from rain and melting snow, and a small, quiet sitting area at the junction of existing paths near the Park's pond.

The projects were designed by Anne Penniman Associates and constructed by Mountain View Landscapes and Lawncare.



### Materials used in the Elizabeth Park projects

- 22 trees
- 99 shrubs
- 2,866 herbaceous plants
- 1,720 ferns
- 700 spring bulbs
- 250 pounds of grass seed
- 1,800 linear feet of granite paving, new and recycled
- 415 linear feet of curbing, new and recycled
- 56 square feet of monolithic granite benches
- 1,600 square feet of concrete sidewalk
- 228 tons of gravel
- 15 tons of granite for the arbor piers
- 1,525 feet of rebar in granite piers
- 7 bollard lights



## 2nd Annual Andrews Lecture

We hope you have Wednesday, September 16 circled on your calendar to attend Donaghue's 2nd Annual Andrews Lecture at 4:00 PM in the Anlyan Center at Yale School of Medicine. This year's lecture speaker will be Karen Barrow, producer of the *New York Times* on the web multi-media feature *Patient Voices*. Ms. Barrow's topic, "More than an Anecdote: The New York Times Patient Voices Series," will focus on her experience in bringing the photographs and commentaries of people living with a significant disease or illness to the Web at The Times' WellBlog. She is the creator and producer of this series, which currently has more than 12 installments. Barrow obtained a master's degree in biomedical journalism from New York University and a bachelor's degree in biology from Cornell University.



Karen Barrow

The lecture will be open to the public, and additional information about the lecture is available on the Foundation's

website. A reception will be held following the lecture in the Atrium of the Anlyan Center.

David Smith, PhD, Director of the Yale's Interdisciplinary Center for Bioethics, will introduce Barrow. "Having read many of the Patient Voices installments, I'm eager to hear from Karen Barrow about how these stories are created and how over the series her experiences with patient voices have influenced her work."

The Andrews Lecture was established to honor Ray Andrews' stewardship of the Donaghue Foundation over his 14 years as Trustee. The annual lecture series focuses on the voice of the patient and gives expres-

sion 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.

## Conference —continued from page 1

Next, **Sharon Terry**, President and CEO of Genetic Alliance, picked up on many of the themes presented by Jadad in her talk on consumer participation in genetics research, services and policy. In her talk at the conference, "*Participants at the center: Accelerating the pathway from research to health*," Terry discussed how Genetic Alliance evolved from its traditional roots as a membership organization representing patients and families affected by rare genetic conditions. Today the organization acts as a conduit as it convenes diverse stakeholders to create networks and novel partnerships in advocacy and thereby ensures that individual, family, and community perspectives are at the center of efforts to improve the use of genetic information.

Terry described her journey into advocacy, which started with her children being diagnosed in 1994 with PXE, pseudoxanthoma elasticum, a rare condition which usually results in blindness and shortened life expectancy. Terry recounted the difficulties she and her husband experienced in learning about the PXE and its treatments. She underscored what technology has made possible. For example, Genetic Alliance, along with several partners, has created two wikis – WikiAdvocacy, which provides information, advice and resources to help individuals and groups build their capacity for advocacy, and WikiGenetics, an open source site that provides credible and up-to-date information on human genetics to the public. Terry also talked about other resources that she and others have created to expand access to information on genetics and enable improved translation of research into services and individual decision-making. An online tool called "Trust it or Trash It" enables families and

health professionals to rate the quality of currently available genetic education material; Private Access, another online tool, enables physicians to offer and patients to volunteer for clinical trials.

Terry began and ended her talk by focusing in on the principles of openness and transparency adopted by Genetic Alliance that have allowed it to dissolve boundaries between organizations and create more effective partnerships. She noted that this approach has helped accelerate the path from research to health but could also be effective when applied to other areas of advocacy.

The final speaker before the meeting broke for lunch was **Ben Heywood**, who described PatientsLikeMe, of which he is Co-founder along with his brother, Jamie Heywood, and Jeff Cole. He began by noting PatientsLikeMe is 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*," Heywood described how PatientsLikeMe has created a platform for collecting and sharing outcome-based patient data and real life experiences among 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 and communicate the real-life experiences of patients, including symptoms, the progression of disease, and treatment outcomes, and then share them with others patients, healthcare professionals,

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## Interview with Stacy Cloud

*Stacy Cloud joined the Donaghue Foundation staff in January 2008 in a newly created position of Grants Administrator. In this issue, we're checking in with her to better understand her role at Donaghue.*

**In general, what are the responsibilities of the Grants Administrator at the Foundation office? What do you actually do?**

My job as the grants administrator is to manage all aspects of the Foundation's grant programs — from the soliciting letters of intent to the final grant report once the research project is completed. What I strive to do is to work with applicants and grantees, as well as with the other Donaghue staff, trustees, and scientific reviewers, in a way that ensures quality in all aspects of the grant "lifecycle." My job is based in process and procedure, but I like to think of my role as a grants administrator that also understands and believes in the mission of the Foundation. I also realize that to be effective I must be amenable and responsive to the realities of the researchers we fund.

To say the least, my first year and a half at the Donaghue Foundation has been a great experience working with the applicants, grantees, and scientific reviewers. I will even venture to say the challenging (and sometimes arduous) task of finding the perfect ad hoc reviewer for an application has given me moments of feeling that I've achieved a personal success. And of course, developing the management and review framework for the Donaghue Program for Research Leadership has been a great opportunity.

**How has the fact that Donaghue is only making one new grant this year changed your job?**

It has been a year of housecleaning! This year has allowed the "Donaghue Dream Team" (what I call the team of Wendy Vachon, administrative assistant extraordinaire, and me) to not only review our existing grants under a closer lens but also to be proactive in streamlining the process for the reporting of grant progress and financial reports. [Editor's note: you'll meet the second half of the "Donaghue Dream Team" in the next issue of *Practically Speaking*.]

As the grants administrator, it is such a gift to be able to have the time to address each of the Foundation's investments and manage the progress of the grant both for content and fiduciary oversight, which in turn has given us valuable insight as we think about best practices. It will be helpful to have this experience already completed as we look to the future and the renewal of our grant programs.

Secondly, it has given us the opportunity to do more reflection and evaluation of our grant programs. I will be completing an evaluation of our Clinical & Community Health



Issues grant program, which is on hiatus. This evaluation will be used, in part, to measure the impact of the Foundation's investment, as well as a tool for using lessons learned as we move forward.

Lastly, although we are not awarding grants from our Clinical & Community Health Issues program or Practical Benefit Initiatives program, we are still making some grants. The decision to partner with the Mayday Fund to award one grant for the Program for Research Leadership has been a great experience and allowed the Foundation to continue its newest grant program.

**Before coming to Donaghue you were Director of Member Services at the Connecticut Council for Philanthropy. What were the key components of that position and how has it influenced your work at Donaghue?**

In my former role as Director of Member Services, I managed the program implementation, member services and membership development for the Council, which is a regional association for foundations in Connecticut. My experience from the work at the Council has influenced my work here at Donaghue because I was able to take one of the key components of the Council — providing educational opportunities and best practices for philanthropic grant making — and put them to use here at Donaghue.

**You've been with Donaghue for more than a year now — what has surprised you the most?**

When I was at the Council, I was impressed with the amount that Donaghue funded each year and the large size of each award. Of course, there are other funders who fund larger amounts, but among the members of the Council, Donaghue is a very substantial funder. Within my first year that changed as Donaghue adapted to the decline in the financial markets. What really surprised me was the number of activities that we began working on that kept us moving towards the mission but were different than funding large grants for research projects. Everyone at the Donaghue office has been working more on the "practical benefit" part of the mission in ways that were unexpected to me.

# Donaghue and Robert Wood Johnson INQRI Sponsor Forum

**D**onaghue teamed up with the Robert Wood Johnson Foundation's INQRI (Interdisciplinary Nursing Quality Research Initiatives) program to sponsor a forum that brought together health funders to discuss "Creating Opportunities and Breaking Down Barriers to Adoption" on July 8 and 9. The agenda was developed by Donaghue's Lynne Garner and Nancy Yedlin, with Mary Naylor, the University of Pennsylvania Marion S. Ware Professor in Gerontology (INQRI Director), and Lori Melichar, senior program officer at the Robert Wood Johnson Foundation. The purpose of the forum was to begin a conversation among health funders to determine more effective ways to ensure their philanthropic investments are successfully implemented to improve health and health care.

The forum began with dinner and a presentation by Elizabeth Bradley, PhD, about "Diffusion of New Ideas: What Works." Bradley's determinants of diffusion (features of the innovation, alignment of the external environment, features of the adopting organization, and dissemination strategy) was used by forum participants during the following day's discussion.

The next day, Lucas Held, Director of Communications for the Wallace Foundation, spoke about the challenge of dissemination in the education arena. Before you can implement a change, he noted, people have to recognize there is a problem. In addition, the change has to be perceived as creating a relative advantage to the adopter. Held also spoke to the challenge of collaboration. "In the battle of strategy and culture, culture wins every time" so it's important for the collaborating organizations to have a good fit. Comparing logic models is an effective way to determine fit; "you have to yoke your agenda onto the other's."

Charles Cutler, MD, gave the third presentation ("Research, Innovation and Practical Solutions") and spoke to the forum participants from the perspective of an organization that actively seeks out new health care strategies. Because "organizations want solutions, not innovations," he spoke to the importance of starting projects intended to create change with the end in mind.

The last presentation was a panel of three Robert Wood Johnson INQRI researchers, whose projects share the goal of testing hospital-based interventions aimed at improving care. With promising results at the research phase and working with hospital stakeholders, the panelists discussed the challenges of bringing these interventions to scale and identified ways that funders might help with diffusion.

In addition to Donaghue, the Robert Wood Johnson Foundation and the INQRI program, participants in the forum represented the John A. Hartford Foundation, the Commonwealth Fund, The Californian HealthCare Foundation, the Gordon and Betty Moore Foundation, the Fannie E. Rippel Foundation, the W. K. Kellogg Foundation, Grantmakers in Health, the Universal Health Care Foundation



The two-day forum was held at the Robert Wood Johnson Foundation office in Princeton NJ.



Forum planners Lori Melichar and Mary Naylor share a laugh during one of the discussions.



Chris Langston (John A. Hartford Foundation) listens to keynote speaker Chuck Cutler with Lucas Held (keynote speaker from Wallace Foundation), Mark Pauley (INQRI program) and Wynne Norton (University of Connecticut).

of Connecticut, Agency for Healthcare Quality and Research, and the V.A. Center for Implementation Practice and Research Support.

A blog ([bendingthecurve.blogspot.com](http://bendingthecurve.blogspot.com)) was created by the forum planners to engender enthusiasm and to connect participants following it.

The planning group (RWJ, INQRI, and Donaghue) is now reviewing input from the forum participants to formulate possible next steps. As Lori Melichar indicated in her opening remarks, "creating powerful partnerships...can dramatically affect the care America receives." Donaghue looks forward to being one of these partners.