

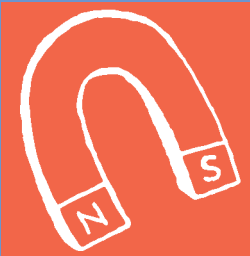


Making Research  
Relevant & Ready

# Practically Speaking

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

## INSIDE THIS ISSUE



PAGE 3  
**Save the Date**  
BeyondEureka!  
2013



PAGE 4  
**Philanthropic**  
Research  
Funders Work  
Together



PAGE 5  
**Institute for**  
Community  
Research

PAGE 5  
**Community Child Health Office**

PAGE 6  
**Ask the Trustees**

PAGE 7  
**Patient-Centered Workshop**

*Practically Speaking* is published three times a year by the Donaghue Foundation to communicate its grantmaking and knowledge uptake activities. Readers are welcome to contact the Foundation office for more information about the work of the Donaghue Foundation by calling 860.521.9011 or by sending an email.

President and Trustee: Lynne L. Garner, PhD  
garner@donaghue.org

Vice President: Nancy C. Yedlin, MPH  
yedlin@donaghue.org

Grants Administrator: Stacy Cloud  
cloud@donaghue.org

Administrative Assistant: Wendy Vachon  
wendy@donaghue.org



Mark Mercurio, MD from Yale-New Haven Hospital and Moreen Donahue, DNP, RN, from Danbury Hospital, joined Sue Sheridan (center) in a panel discussion to give their local, clinician-view of the importance of listening to the patient's voice.

## 5th Andrews Lecture – Sue Sheridan

Sue Sheridan, Deputy Director of Patient Engagement for PCORI (Patient Centered Outcomes Research Institute) was the speaker for the fifth and last Andrews Lecture on *The Voice of the Patient* October 9 at the Anlyan Center, Yale School of Medicine. In addition to Sheridan's discussion on the "Courage, Passion and Power of Partnerships," Mark Mercurio, MD and Moreen Donahue, DNP, RN participated in a panel discussion with Sheridan based on questions posed by the audience.

Sheridan's personal experience with the healthcare of her family motivated her to get involved in efforts to use the patient's perspective to improve healthcare safety. Her son, Cal, suffered kernicterus, a potentially fatal disease that results from untreated infant jaundice and causes brain damage. Several years later, her husband, Pat, died after his diagnosis of spinal cancer was not communicated and therefore not promptly treated.

Sheridan shared with the audience her experiences in forming a small group of mothers whose children also had kernicterus. The seven mothers started Parents of Infants and Children with Kernicterus and raised awareness of the risk of jaundice with JCAHO, *Morbidity & Mortality Weekly*, the National Quality Forum, and the CDC. In 2003, she was one of the

co-founders of Consumers Advocating Patient Safety. A year later, she was asked by the World Health Organization to lead their Parents for Patient Safety Initiative. Using a process that draws on the principles of participatory research, the group developed and tested in twelve countries a "Mother & Safer Baby Care" toolkit that informed mothers of the early signs of neonatal or maternal distress and when to request medical attention to treat these problems.

Sheridan then described her work at PCORI and the how the voice of the patient is being used to establish research priorities, review grant proposals, partner with researchers in designing and conducting research, and develop effective methods for communicating research results to healthcare providers and consumers. She described her role at PCORI as "building new partnerships to do research differently." As one concrete example of this goal, PCORI is requiring each submitted grant proposal to include a patient partner on the research team.

After Sheridan's remarks, Donahue described a Danbury Hospital project (originally funded by Donaghue) that promotes the voice of the patient by training para-professionals to use

— article continues on page 7





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

## Letter from the Trustees

This October Donaghue sponsored the last of our five Andrews Lectures on the Voice of the Patient. We were delighted to be able to bring the five lecturers to Connecticut to express their ideas about this important topic, and we were delighted to have this forum as way for the foundation to say “thank you” to Ray Andrews for his work as Donaghue’s first individual trustee.

During these years, our lecturers spoke from the view of a physician, family member, a collector of stories of patients with a life-changing conditions or diseases, and a patient advocating for greater reform in health care and research. We’ve had some memorable moments from each speaker across the series that gave us a new perspective on the voice of the patient. As we close our Andrews Lecture experience, we want to highlight one thought from each of these five speakers that meant a lot to us.

Eric Cassell, MD on *Treating the patient or healing the person: What should be the goal of medicine?*  
*“What I’m talking about is changing the direction of medical care to having well-being as a primary goal, not a secondary goal. The difference between treating and healing is that you treat a disease but you heal a person.”*

Karen Barrow on *More than an anecdote: The New York Times Patient Voices Series*  
*“Everybody is going to be a patient at sometime, and one of the themes of the (New York Times) patient voices series is about choice. Every time you are confronted with a diagnosis, you’re also confronted with choices – whether it’s to take what the doctors says at face value or get a second opinion; use a standard treatment or try something new; be an advocate for your disease or not. It’s really in your hands, what you do with the situation that has been given to you.”*

Perri Klass, MD on *Patients and providers: Stories and secrets*  
*“I’d like for people to think about how you intersect with other people’s lives and, especially for those in healthcare, that when you walk into a room and introduce yourself and start asking questions you’re not starting a story there. You’re walking into a story that has already been started. You have some choice as a professional about what role you’re going to play, but the story has been going on and will continue to go on after you leave the room. And how you understand the shape of that larger story is very powerful.”*

Lee Woodruff on *A Caregiver’s Journey*  
*“It’s important for the nurses and doctors to remember to focus on the caregiver and to focus on hope. Of course the patient is the primary focus, but the circle needs to be widened to include those family members and those caring for that person.”*

Sue Sheridan on *Voice of the patient: Now making a difference in treatment, research, and patient safety*  
*“The voice of the patient is the most underused resource in healthcare today.”*

We have learned a great deal from these five lectures, and we’ve made some wonderful connections with our lecturers and with those who attended these lectures. We hope that these five lectures have been informative and inspiring to researchers, health care professionals and students, and to patients so that the voice of the patient might sound a little stronger and be listened to a little more closely in health care because of this series.

Amy R. Lynch, JD  
 U.S. Trust, Bank of America, Trustee

Lynne Garner, PhD  
 President and Trustee

## Save the Date! BEYONDEUREKA!

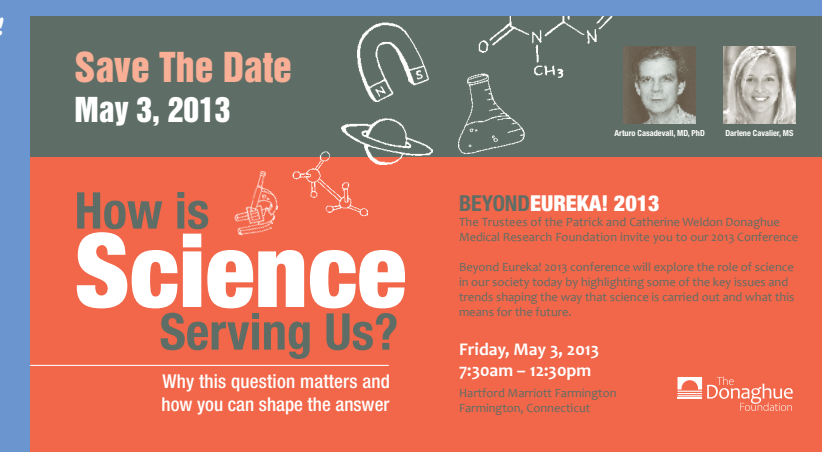
How is Science Serving Us? Why the question is important and how you can shape the answer.

Donaghue’s *BeyondEureka!* conference will be on Friday, May 3, 2013 from 7:30AM to 12:30PM at the Hartford Marriott Farmington in Farmington. The two keynote speakers will be Arturo Casadevall, MD, PhD, Professor of Microbiology & Immunology at the Albert Einstein College of Medicine and Darlene Cavalier, MS, founder of SciStarter.com

Casadevall will offer a historical perspective on modern science, including the achievements science has made to human health and prosperity as well as the how public views of science and scientists today have evolved over time. He will speak about current external threats to science, such as a low level of science literacy, and internal threats brought about by how scientific research is conducted, rewarded, and funded. Casadevall will offer ways that science can be restructured to better serve society.

Cavalier will focus on topics related to citizen involvement in the conduct of science including promoting science literacy and engagement through initiatives such as SciStarter and Science Cheerleaders. She will also discuss her work in creating the political will necessary to furnish to our elected officials and the public authoritative and objective analyses of the complex scientific and technical issues that affect our world today.

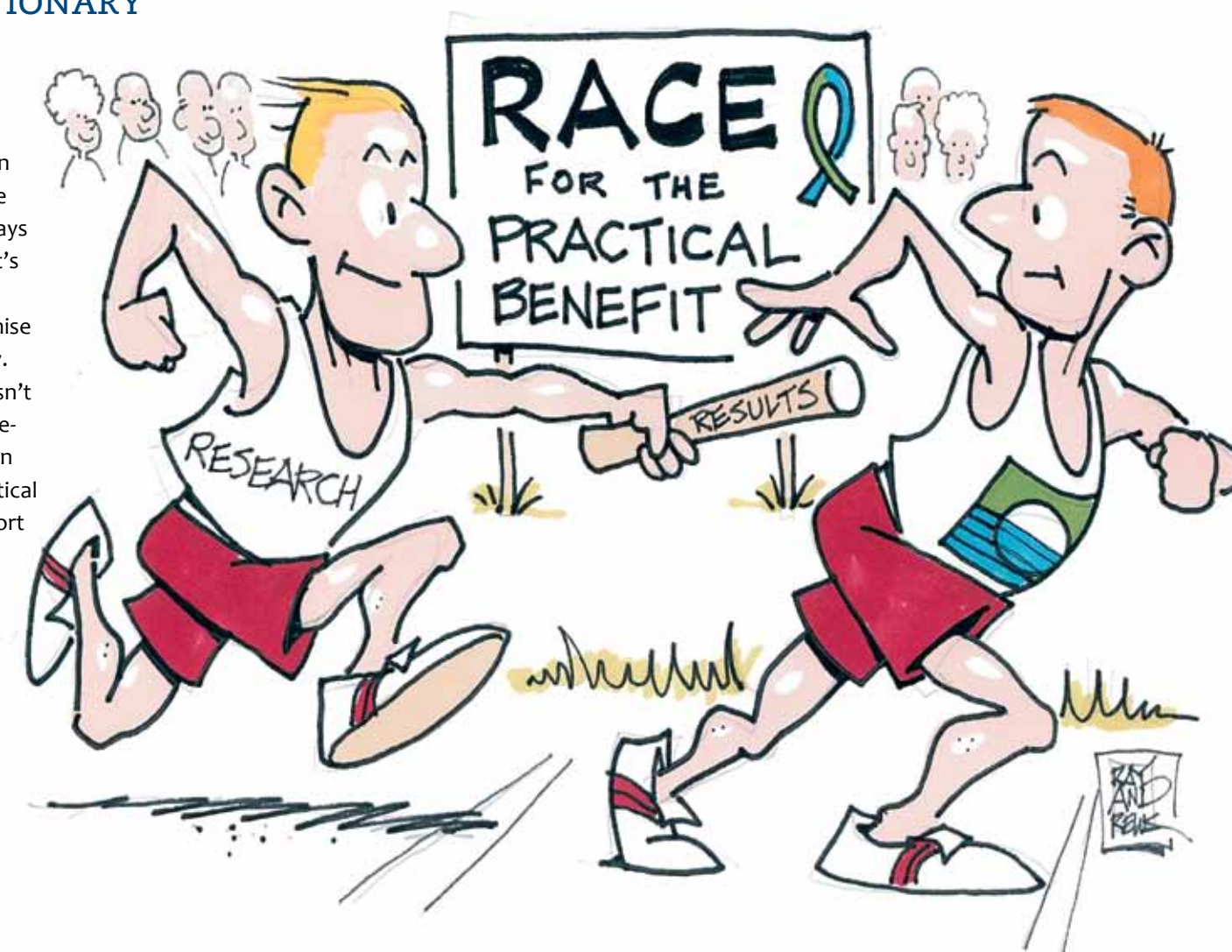
Registration for the conference will be open in early January.



## DONAGHUE DICTIONARY

### “Ready”

A standard dictionary definition of “ready” is “prepared for use or action.” When Donaghue says we fund relevant research that’s ready, we’re emphasizing that the work we support has promise for being acted upon promptly. The use or action we foresee isn’t further studies but rather implementation of research results in practice so as to produce practical benefit within a reasonably short time.



## Donaghue Grant News

Donaghue’s R3 program is underway. We’re expecting to receive nine applications by December 7; they will be reviewed by the R3 advisory committee in mid-January, with awards to begin February 1. R3 (*Making Research Relevant & Ready*) was open to current and former Donaghue grantees. The funds will be used to access experts in areas relevant to implementing health innovations that were demonstrated to be effective with Donaghue research grants.

A second new grant program for investigator-initiated research is being developed by the foundation. Although the program is still being defined, awards are expected to be \$100,000 for two years of research. The research projects funded under this program will use datasets that already exist and therefore the collection of new data will not be covered with this award. We also expect that the program will require researchers to work with an individual who represents the intended user of the research findings to provide input on the research questions and/or the way the research product is communicated. A full description of the program will be available in January 2013.



## “Large Simple Trials” workshop at the Institute of Medicine

Donaghue recently attended an Institute of Medicine meeting held on November 26 and 27 in Washington D.C. that explored accelerating the use of large simple trials (LSTs) to increase the speed and reduce the cost of research to improve health care. This meeting was part of IOM’s Roundtable on Value & Science-Driven Health Care.

LSTs use data in electronic health records or patient registries and therefore require very little or no data collection. They also are designed to use fewer endpoints to address the research question being asked, and the endpoints are designed to answer specific questions focused on health care practice. LST costs are significantly smaller — often on the order of a five-fold reduction — than traditional clinical trials, and they are usually conducted in settings that are more integrated into patient-care. Michael Lauer, MD, who directs the Division of Cardiovascular Sciences at the National Heart, Lung, and Blood Institute (NHLBI), part of the National Institutes of Health (NIH) and is a member of the workshop planning committee, said that LSTs are a disruptive technology in the current research world.

The workshop presented several examples of LSTs conducted in different settings: a population-based trial of vitamin D and omega 3 fatty acids using a mail-based plus an in-clinic component; a collaboration with a health insurer to assess the impact of waiving co-payments on drug adherence and health outcomes; the HOPE (Heart Outcomes Prevention Evaluation) study that was conducted in 19 counties; and a system to evaluate general practice treatment choices developed in the UK.

Challenges to increasing the use of LSTs include the technical infrastructure needed to access and use good quality clinical and administrative data that reside in electronic health records and registries, developing research protocols that minimize the impact on patient care, and improved methods to increase the acceptance of participating in clinical studies by both patients and providers. Some workshop speakers also discussed the implications for privacy and informed consent by patients.

More information about the workshop, including a detailed agenda, and information about the Roundtable on Value & Science-Driven Health Care is available from the IOM website.

## Philanthropic research funders working together: public access, analyzing funding data, supporting FDA

The Health Research Alliance, a membership organization of over fifty public and private charities that fund medical research, is working on three initiatives to optimize its members’ investment in health research. These initiatives include offering the infrastructure to require public access of scholarly articles written from their support, providing comprehensive data on funding for research by these charities, and increasing the capacity in regulatory science within the U.S. Food and Drug Administration.

Pub Med Central, the public access archive for biomedical and life sciences journal literature operated by the National Library of Medicine, has been an indispensable resources for researchers and others in the health services world. Pub Med Central provides free access to all scholarly articles that are written about research that was funded by the federal government. Each year nearly \$40 billion is spent by the federal government on research — the National Institutes of Health, the National Science Foundation, and the Department of Defense being the largest funders — and Pub Med Central provides access by the public around the world to these resources.

Now, the Health Research Alliance has contracted with the National Library of Medicine to allow its members to use the Pub Med Central portal to allow public access to the articles written with funding from the HRA members. Donaghue has decided to take advantage of this capability, and going forward Donaghue will require its grantee to make publishers aware of the public access condition that is associated with their funding. Donaghue will provide its grantees with the details on how to do this, but because of the arrangement that HRA has developed with the National Library of Medicine, the process will be similar to the one they use now for their federally funded research.

In another initiative, HRA has developed the only database to analyze the size and scope of philanthropic research in biomedical and health-related fields. Each year, details of grant awards made by the HRA membership

are collected and classified as to the type of research that is done with its funding, the awardee’s name and institution, the amount of the award and other relevant information. HRA has over fifty members that fund \$1.5 billion for medical and health-related research to over 5,500 researchers annually. This database will expand the understanding of the contribution to biomedical and health-related research supported by philanthropies, and it is hoped that one day it may be able to coordinate with NIH’s funding database. A recent article in *Academic Medicine* summarizes the funding trends from 2006-2008 (vol. 87, no. 11, pages 1574-1581, November 2012). The database, called gHRAsp (grants

in the Health Research Alliance shared portfolio) is in its third version.

Finally, HRA has worked with the U.S. Food and Drug Administration to support a lecture series intended to strengthen scientific expertise at the FDA and to foster interactions between FDA and the scientific community. Outstanding scientific leaders will go to the FDA to serve as Distinguished Lecturers and participate in workshops with FDA staff. Speakers for the lecture series include experts in molecular

imaging, systems biology, and other areas relevant to regulatory science.

A lead gift from the Burroughs Wellcome Fund and additional funding from the Juvenile Diabetes Research Foundation International and the Doris Duke Charitable Foundation enabled HRA to work with FDA to plan the program. After launching the program with a single inaugural lecture in 2012, several lectures will be combined in a full-day workshop on the strategic regulatory science priority area of emerging technologies in 2013.

More information about the FDA’s strategic plan on “Advancing Regulatory Science at FDA,” is available at <http://www.fda.gov/downloads/ScienceResearch/SpecialTopics/RegulatoryScience/UCM268225.pdf>.



## “Health Research Alliance is working on three initiatives to optimize its members’ investment in health research.”

## The Institute for Community Research Celebrates 25 Years of Research for Community Benefit

In October, the Institute for Community Research (ICR) celebrated its 25th anniversary. ICR’s mission is to conduct research in collaboration with community partners to promote justice and equity in a diverse, multiethnic, multicultural world. The Institute’s community-based approach is devised to explore and expand understanding of what it means to conduct ethical research in community contexts. In the interest of bringing the benefits of research directly to communities, ICR programs have explored the creative intersection of science, art, ethics, and social action to achieve new understanding and innovative responses to long standing health problems.

ICR has worked consistently in several areas of research and public programming that have direct benefit for diverse communities. Among them are studies of substance use and preventive interventions to reduce the impact of drug use on communities and their members, from the young to the very old, such as ICR’s continuous program of research since 1989 that has sought to reduce the spread of HIV/AIDS and other sexually transmitted and infectious diseases that have hit impoverished urban communities hard. Another important area of work is the development of culturally appropriate health information on Alzheimer’s for Latino families and intervention studies designed to improve influenza vaccination acceptance and oral health self-management. The Donaghue Foundation supported ICR to conduct a three-year study to explore depression and anxiety and identify challenges in



ICR’s 25th anniversary open house included visual displays of their work over the year and opportunities to engage in similar activities.

accessing mental health services among seniors living in low-income housing projects in Hartford. The study also identified ways to address these issues by including the use of arts-based intervention approaches to reduce the social isolation that leads to symptoms of depression.

With its history of partnerships with community residents, ICR has provided assistance to residents to conduct participatory action research (PAR), and with these skills to discover within their neighborhoods both the assets and the larger forces that undermine them. ICR staff has conducted ongoing programs to train youth and young adults in PAR methods. ICR’s arts development and cultural conservation programs have identified traditional artists and bearers of cultural knowledge, supported their work, brought awareness of their cultural history, artistic representation, and diverse aesthetic

## Two Hartford organizations work to increase community health benefit from local models

The Institute for Community Research, celebrating its 25th anniversary, and CCMC’s Office for Community Child Health, which began this past summer, both work to improve the health of those who live in the greater Hartford community by scaling successful models of community-based health improvement programs. Each organization was invited to provide an overview of its work for *Practically Speaking* readers.

forms to broad public audiences, and thereby helped to build healthier communities.

In conducting this research and public programming, ICR uses collaborative models working with community organizations, public and private housing management and other service providers, hospitals, the University of Connecticut Health Center and other regional universities, and affected members of the community to address a range of health and mental health issues that seniors face.

Exhibits illustrating the history of ICR programming and creative efforts to use the results of research for direct community benefit are open for viewing from 9:30-4:30, Monday-Friday until December 15th at ICR offices located at 146 Wyllys Street in Hartford.

## CCMC Launches Office of Community Child Health

The Connecticut Children’s Medical Center of Hartford has launched a new endeavor designed to synergize, support, and incubate a broad array of community-oriented programs targeted at promoting children’s optimal healthy development. The new Office for Community Child Health (OCCH) was founded by Dr. Paul H. Dworkin, a nationally recognized pioneer in pediatric health care.



Paul H. Dworkin, MD

“The goal of the office is to promote the effectiveness of the wide range of community-oriented programs currently supported by the Medical Center, promote synergies across such programs, and serve as an innovation incubator for new programs addressing critical child health issues,” says Dworkin. The Child Health and Development of Connecticut is a partner in the OCCH, sharing some staff and resources to test new models for organizing and delivering child health services.

Dworkin and the OCCH staff will function in what he calls “a discreet leadership role to enable programs to be more effective.” Support services offered to programs include assistance with budgeting, defining performance metrics, setting goals, fund-raising, communications, and policy advocacy. Synergy will be encouraged to avoid duplication of services and maximize available resources. As an innovation

incubator, the OCCH will develop and test health service delivery models that address community, state and health system needs. New programs will be piloted in Hartford with the eventual goal of seeing them replicated on state and national levels.

Eleven Connecticut Children’s programs now under the OCCH umbrella are Help Me Grow, a program that was piloted in Hartford in 1997 and has been replicated in 15 states; Easy Breathing, which was launched in Hartford with

Donaghue funding and is now a nationally recognized asthma treatment and training program; Special Kids Support Center; Growing Up Healthy/Hartford Childhood Wellness Alliance; Co-Management between primary care and subspecialty physicians; Practice Quality Improvement related to the Child Health and Development Institute’s EPIC (Educating Practices in the Communities) program; REACH (Resident Education in Advocacy and Community Health); LAMPP (Lead Action for Medicaid Primary Prevention); Injury Prevention; Charter Oak at Connecticut Children’s and HIV prevention.

The OCCH has earned the early support of the Connecticut Children’s leadership, its board of directors, and the Connecticut Children’s Foundation. “In our new strategic plan, we have set the ambitious goal of making Connecticut’s children the healthiest in the country,” says Connecticut Children’s CEO Marty Gavin. “We recognize the Office for Community Child Health as a pioneering, signature part of that effort.”



## “AIDED” to Improve Health

Several Yale-based researchers have developed a model for scaling-up family health interventions that have been found effective in low and middle-income settings. Using key informant interviews and a systematic review of relevant peer-reviewed literature and papers published by government or non-profit agencies (“gray literature”), the authors developed a model that describes successful strategies for providing greater impact.

The three health “innovations” that were the focus of the study are using injectable birth control, exclusive use of breast feeding, and the use of community health workers. These interventions were considered innovations because they hadn’t been previously used in the setting they were being applied to. The study was funded by the Bill and Melinda Gates Foundation, which has been a significant funder of international programs to improve family health. The BMGF was motivated to fund this study to learn how to get a broader impact from their programs.

The authors, led by Elizabeth Bradley, PhD, included Leslie Curry, PhD, Rafael Perez-Escamilla, PhD — all of whom have been Donaghue grantees — David Berg, PhD, who is currently working on one of Donaghue’s Program for Research Leadership, as well as seven others. The paper is published in *BMJ Open* (2012; 2e000987).

The results of the study showed that key factors in successful scale-up include assessing the landscape to understand the receptivity of users groups and the environmental context; innovating the design or package of the intervention to make it reflect local preferences; developing support from groups who may provide resistance; engaging with user groups throughout the entire process; and devolving the efforts to spread the innovation to local user groups and their peer networks. These actions (Access, Innovate, Develop, Engage and Devolve) were found to be used in different ways with various pathways among the components.

The AIDED model underscores the challenges in scaling an initial investment by a government or non-profit organization. One of the study’s key informants noted that often the original funder of a health innovation does not appreciate the complexity required to scaling-up the project to get wider impact. “There’s a lot of magical thinking about what this ‘pilot project’ or ‘proof of concept’ will do because it’s not very real in terms of the stakes necessary to actually sustain it for impact and scale.”

The group is working on a number of different projects to refine and test the AIDED model.

## Ask The Trustees

**Question:** *PCORI uses patients and stakeholders in the grant review process in addition to peer clinical researchers. Does Donaghue do this?*



**Answer:** Indeed — we heard from Sue Sheridan at the Andrews Lecture that the Patient-Centered Outcomes Research Institute (PCORI) will be including patients and other stakeholders on each of its grant review panels. Donaghue is aware of other medical research funders that use individuals who are not scientists but are trained by the funder organization in reviewing grant applications; these include The Juvenile Diabetes Foundation, Komen for the Cure, The Food Allergy & Anaphylaxis Network, and the American Cancer Society.

In 2008, Donaghue began using “knowledge uptake” experts in its grant review process with its Program for Research Leadership. These individuals are highly knowledgeable about using evidence in organizations to change practice or behavior, but they aren’t researchers. Each application had a “knowledge uptake” expert assigned as a reviewer along with two clinical researchers. These individuals add the important perspective of how viable the proposed clinical innovation will be in its intended environment.

We have been impressed with how well this systems works. The “knowledge uptake” experts add a dimension to the discussion that as funders we find critically important. Also, our clinical reviewers seemed quite interested in their perspective, as well. We will continue to use this method or incorporate other stakeholders in the review process for all of our research grant programs.

In our R3 program, we are using a group of individuals who have extensive experience in bringing ideas into scalable businesses. And because the aim of the R3 program is to promote the knowledge created from previously funded, and previously reviewed, Donaghue grants, this review process focuses on the future use of the intervention.

### What is PCORI?

The Patient-Centered Outcomes Research Institute (PCORI) is authorized by Congress to conduct research to provide information about the best available evidence to help patients and their health care providers make more informed decisions. PCORI’s research is intended to give patients a better understanding of the prevention, treatment and care options available, and the science that supports those options. To get involved with PCORI, visit [www.pcori.org/getinvolved](http://www.pcori.org/getinvolved)

Different from the question of using stakeholders in the review process, but related to the issue of seeking ways to improve how grants are reviewed, we’ve recently learned that the National Science Foundation is experimenting with using a blinded review process (*Science*, vol. 336, pages 969-970; May 25, 2012). One group of reviewers received only the applicant’s research idea and did not know who the applicant was, their co-authors on published papers, or their institution; a second group of reviewers had that identifying information along with the research idea. The two groups of reviewers recommended nearly completely different applicants to receive grants.

Can knowing who the applicant is prevent the best ideas from being funded? NSF would be the first to say that they don’t know this is happening, but NSF is continuing to analyze the feasibility and impact of blinded reviews.

Should Donaghue try this method? Should we use other kinds of stakeholder reviewers? Write to the trustees at [garner@donaghue.org](mailto:garner@donaghue.org) to let us know what you think about these issues.

## Donaghue Attends Patient-Centered Research Workshop

Some 150 patients, researchers and other members of the healthcare community, including Nancy Yedlin, Donaghue’s Vice President, gathered in Washington, DC, October 26-28, right before Hurricane Sandy swept in on the East Coast, to participate in PCORI’s first patient engagement workshop on “*Transforming Patient-Centered Research: Building Partnerships and Promising Models*.” Participants first learned about innovative patient-researcher partnerships and then spent the remainder of the workshop providing input to PCORI leadership on key questions facing the organization on how to “re-imagine” patient-centered research. Participants rotated through lively and meaningful sessions on issues such as how PCORI should identify and select research questions, review research proposals for funding, match patients and stakeholders with researchers, disseminate research to the community, and evaluate PCORI’s Patient and Stakeholder Engagement Programs.

Donaghue has been following PCORI’s progress with interest since it was established with the passage of the Affordable Care Act in 2010. The PCORI mandate to fund comparative effectiveness research that matters to patients and that will help patients and families make choices about medical treatments aligns well with Donaghue’s mission that health research should promote practical benefit.

“I wanted to attend for both professional and personal reasons and was excited to apply for a spot and then get selected” explained Yedlin. “I hoped that I would learn some tools and techniques from the PCORI workshop that Donaghue can incorporate into the way we

decide on research topics and priorities. On a personal level, I wanted to contribute the insights I’ve gained from being the primary care giver for family members with serious and life threatening illnesses.”

— article continues on page 8



Martin Hatlie, CEO of Project Patient Care and one of the workshop facilitators, chats with a participant after a brainstorming session.

## 5th Andrews Lecture – Sue Sheridan

continued from page 1 —

SBAR (situation, background, assessment, recommendation) technique to carry patients concerns to a credentialed member of the clinical staff. Para-professions spend more time with patients in acute care settings than other staff members, and they therefore more frequently hear the questions, concerns and issues that patients may have.

The second panel member, Mark Mercurio, MD, a neonatologist, discussed the challenges of listening to the voice of the patient when the patient is only a few days old and the challenge of weighing what that voice may be saying, what the family is saying, and what clinical practice can accomplish.

Sheridan was introduced by Judith Kunisch, RN. Kunisch is a Lecturer in the Yale School of Nursing and has more than 20 years experience as a senior nurse executive. She is also a member of the Expert Panel for AHRQ’s Innovation Exchange and was a member of Donaghue’s first Policy Advisory Committee. In her introduction, Kunisch reminded the audience that everyone either has been or will be a patient and therefore “this is about us.”

The choice for this year’s speaker came from a group convened by Donaghue to make speaker recommendations for the series. The group was chaired by Kunisch, and included Ray Andrews; Nancy Angoff, Associate Dean, Yale



The reception before the lecture gave people a chance to network and meet Sue Sheridan.

School of Medicine; Linda Pellico, Associate Professor, Yale School of Nursing; Sheilah Rostow, former Bank of America Trustee for Donaghue; and David Smith, Senior Scholar, Yale Interdisciplinary Center for Bioethics.

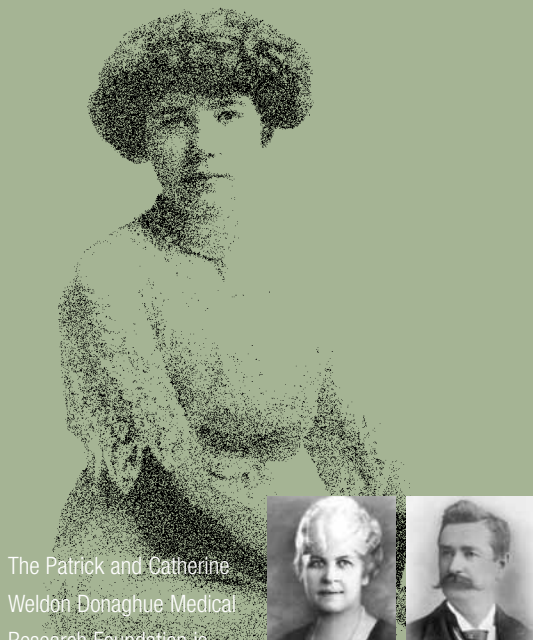
The Andrews lecture series was inaugurated in 2008 to honor Ray Andrews’ stewardship of the Donaghue Foundation as its individual trustee from 1993 through 2007. Because of Ray’s abiding interest in making sure that the voice of the patient is heard by those in clinical research and practice and by health systems leaders, the lecture series has sought to inform and educate a medical audience by addressing the patient’s experience from a variety of perspectives. (Please see the Letter from the Trustees on page 2 for a brief overview of the series.)

A video of a short interview with Sue Sheridan is at [www.donaghue.org](http://www.donaghue.org).



Andrews Lecturer Sue Sheridan describes her work with the World Health Organization.





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.



Fall 2012 *Practically Speaking* The Patrick and Catherine Weldon Donaghue Medical Research Foundation

## Donaghue Attends Patient-Centered Research Workshop

*continued from page 7 —*

Before the workshop, each participant was asked to complete an on-line questionnaire about what they hoped to gain and contribute by attending. Each attendee was paired with another participant and expected to have a phone conversation to share their answers before arriving in DC. “Making a connection with my workshop partner over the phone and then meeting her at the workshop was very meaningful,” said Yedlin. “I was also impressed with all the people I met who had significant personal or family medical challenges and who wanted to use their experiences to improve the research enterprise to better address patient and family needs.”

Summing up her experience, Yedlin observed that “what was most impressive to me was that the PCORI senior leadership spent the two days listening, not talking, and really taking in all the input they were getting from participants.”

To learn more about or get involved with PCORI, go to [www.pcori.org](http://www.pcori.org).



Linda Kenney, founder of MITSS (Medically Induced Trauma Support Services) and a workshop participant offers input to the PCORI Board on the effects that medical trauma has on patients and family members.