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 Aetna 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
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 lectures 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 the 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?
“Treat the patient or heal the human? You have to think about the difference between treating and healing. I want to talk about the difference between treating and 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.”

“Patients and providers: Stories and secrets”

“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.”

Perr Klass, MD on Patients and providers: Stories and secrets
“I’d like for people to think about how you interact 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 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: How 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 K. Lynch, JD
U.S. Trust, Bank of America, Trustee

Lynne Garner, PhD
President and Trustee
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 investment, providing comprehensive data on funding for research by these charities, and increasing the capacity in regulatory science without burdening the FDA 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 resource 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 in grants is funded by the federal government on research — the National Institutes of Health, the National Science Foundation, the U.S. Department of Defense being the largest funders. Pub Med Central provides access to the public around the world to these publications.

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 their articles written with funding from the HRA members. Donaghue has decided to take advantage of this capability, and going forward Donaghue will require its grantees 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 seamless for the one they use now for their federally funded research.

In another initiative, HRA has developed a database to analyze trends in the 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 and fund $1.5 billion for medical and health-related research over to 5,500 researchers annually. This database will expand the understanding of the contributions to biomedical and health-related research supported by philanthropies, and it is hoped that this database may be able to cooperate with NIH’s funding database. A recent article in Academic Medicine summarizes the funding trends from 2006-2008 (vol. 87, no 1, pp 157-185, November 2013). The database, called gRHa署s (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 in regulatory science, and to foster interactions between FDA and the health care 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 2011, several lectures will be combined in a full-day workshop on the strategic regulatory science priority area of emerging technologies in 2013. More information on the Health Research Alliance’s strategic plan on “Advancing Regulatory Science at FDA,” is available at http://www.fda.gov/ Health-Professionals/Training/SpecialTopics/RegulatoryScience/UCM162525.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 and improve health outcomes in diverse communities around the world. The Institute’s community-based approach is devised to explore and understand existing and potential ways to conduct critical research in community contexts. In the interest of bringing the benefits of research directly to communities, ICR’s programs have been involved in 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 these are studies of substance use and prevention 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 1998 that has sought to reduce the spread of HIV/AIDS and other sexually transmitted and infectious diseases that have disproportionate urban impact. Another important area of work is the development of culturally appropriate health information on ICR’s conducted community action research. Translation studies designed to improve influenza vaccination acceptance and oral health self-man- agement among diverse populations.

ICR’s funding database includes the technical infrastructure needed to accelerate the use of large simple trials in settings that are more integrated and combines large simple trials with patient registries and therefore requires very little or no data collection. They also are being conducted in settings that are more integrated and combines large simple trials with patient registries

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

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

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

The Connecticut Children’s Medical Center of Hartford has launched a new endeavor designed to synergize, support, and sustain the local and national community-oriented programs targeted at promoting children’s optimal health development.

The new Office for Community Child Health (OCC) was founded by Dr. Paul H. Dworkin, a nationally recognized pioneer in pediatric health care. The overall 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 eventually to create an innovation incubator for new programs addressing critical child health issues,” says Dworkin. The Child Health and Developmental Disabilities Program of the OCC is a partner in the OCC, sharing some staff and resources to test new models for organizing and delivering child health services.

Dworkin and the OCC 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 measures, 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 OCC 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 fall under the OCC umbrella. One example is a program that was piloted in Hartford in 1997 and has been replicated in 15 states; Easy Breathing, which was launched in Hartford with support from the American Heart Association.：“We recognize the Office for Community Child Health as a pioneering, signature part of that effort.”

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CCMC Launches Office of Child Community Health

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“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 contraception, the use of community health workers, and the focus of the study are using injectable contraception. 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-Encarnal, 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; 2001:004).

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 developing 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 scale-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, 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, not all reviewers seemed quite interested in their perspective, as well. We will continue to use this method for incorporating other stakeholders for 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

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 16-18, 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’s leadership on key issues 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 particularly interested in 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.”

5th Andrews Lecture – Sue Sheridan

School of Medicine; Linda Pellico, Associate Professor, Yale School of Nursing; Shelleah 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 strong 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.
continued from page 7 —

Before the workshop, each participant was asked to complete an online 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.