

PRACTICALLY Speaking

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

Hearing the Patient's Voice by Writing It

The third annual Andrews Lecture was held on October 7 at the Anlyan Center at Yale School of Medicine. Perri Klass, MD, was the 2010 Andrews Lecturer, and more than 130 attended to hear her speak about "Patients and Providers: Stories and Secrets." Linda Pellico, PhD, APRN, Assistant Professor of Nursing at Yale University, introduced Klass.

Klass is Professor of Journalism and Pediatrics at New York University. A much admired author of both fiction and non-fiction, Klass writes extensively about medicine, children, literacy, and knitting. Her short stories have won five O. Henry Awards and she is a frequent contributor to *Health Affairs* and *The New York Times*.

In her presentation, Klass spoke about the role of writing in assisting clinicians to gain perspective on their work and to "see" their patients in a more empathetic light. She also spoke of how she uses writing to dissipate the concerns that come at 1:00 AM when worrying "if I did the right thing." She told the audience that keeping a journal is important because it helps you remember how you felt the first time you encountered something new.

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Perri Klass describes how writing helps her to hear her patients' stories.

Many Thanks to Three Policy Advisers



Trustee Lynne Garner, Judge Alvin Thomson, George Hastings, Trustee Amy Lynch, and Katherine III.

Donaghue said "thank you" to three of its Policy Advisory Committee members who retired from the committee this fall. Alvin Thomson, George Hastings, and Katherine III each served 15 years on Donaghue's PAC. In addition to their long term of service to Donaghue, Katherine III was the PAC's first chairperson, and she was then succeeded in the position by Alvin Thomson.

The PAC was created in 1995 when then-Trustee Ray Andrews recognized the need to complement science advisers with a group of trusted individuals who would provide "a measure of ongoing, informed, thoughtful and diverse perspective and insight" into the policy and program issues that the Trustees need to consider as they carry out their duty. Unlike many philanthropic organizations, Donaghue does not have a board of directors but rather has two Trustees who make all the decisions for the Foundation. Although the PAC never votes on any position, the PAC serves as a useful

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Letter from the Trustees

One of the most gratifying aspects of being Trustees is the relationships we build with so many people. We are fortunate to have ongoing connections with some of our former grantees; with individuals engaged in other philanthropies, non-profit organizations and businesses; with scientists; health care providers; university administrators; and, of course, our advisers. We continue to learn a tremendous amount from these individuals and are grateful for their contribution to Donaghue. Even in this era of FaceTime, Skype and webinars, the ability to meet with people in-person remains important.

The article about our three Policy Advisory Committee members who retired this past fall highlights the importance of relationships. Alvin Thompson, George Hastings and Katherine Ill worked with Ray Andrews, Donaghue's former Trustee, in his role as attorney and partner at Robinson & Cole. Beyond his years at that firm, Ray continued his friendship with each of them. When he decided to establish a group of policy advisers, he first turned to these three individuals who he respected and trusted.

Donaghue will continue to evolve over the years, as in our sharper focus on knowledge uptake, and we may seek grantees and advisers from beyond Connecticut. There were many reasons that went into the previous Trustees' decision to shape Donaghue as a Connecticut-focused funder. Certainly one reward of that decision has been the strong ties to many people in close proximity. It will be part of our challenge to find ways to keep these linkages strong, even though face-to-face meetings may be more difficult, because of the benefit these relationships bring to Donaghue.



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

A handwritten signature in blue ink that reads "Amy R. Lynch".

Amy R. Lynch, JD
Bank of America, Trustee

A handwritten signature in blue ink that reads "Lynne Garner".

Lynne Garner, PhD
Trustee and President

BEYONDEUREKA!

The Trustees of the Patrick and Catherine Weldon Donaghue Medical Research Foundation invite you to our 2011 Conference.

Friday, May 6, 2011
7:30am - 12:30pm
Hartford Marriott Farmington
15 Farm Springs Road
Farmington, Connecticut

Register Now @ www.donaghue.org

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Co-Founder
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designing for health:
better information, experience & outcomes

Sign up for emailed Donaghue news. Don't miss out on emailed news from the Donaghue Foundation. You can now 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.

See page 5 for more information on our upcoming conference.

Ask the Trustees

Q: The stock market was certainly healthier in 2010 than 2009 — does that mean that Donaghue will soon be extending its grant programs?

A: Since the economic crisis that began in October 2008, Donaghue has focused its grant making on commitments made prior to that time and has made three new awards — one in 2009, one in 2010 that was awarded in partnership with the Mayday Fund, and one that began early this year. Although each grant is quite sizable (\$880,000 over four years), the proportion of spending for new grants has been significantly lower than previous years.

It's true that with the overall economic climate slowly improving, Donaghue's portfolio is improving as well. However, organizations that rely upon an endowment to fund their grants face the reality that portfolio growth is dampened by the continual payout of those funds for grants. Thus, Donaghue's portfolio has yet to reach the level it was at before October 2008. Temporarily reducing our commitments to future grant spending and constraining administrative expenses are two ways that Donaghue is working to get its portfolio to grow to the level that can support more grant spending. When will this happen? At this point it is too soon to make a prediction.

Donaghue is not alone in this challenge. In a survey of its members conducted in the first part of 2010, the Health Research Alliance (an organization of non-profit, non-governmental medical research funders) found that three-fourths

of its members have reduced their expenses by changing the payouts of grants and reducing administrative expenses, including the expense of peer review. To reduce grant expenses, organizations have decreased the number of new awards, decreased the size of awards, and paid the total award out over a longer number of years. In addition, foundations reported that they have curtailed the use of face-to-face meetings to reduce the expenses associated with peer review and have expanded the use of videoconferencing or conducting peer review by email or online.

Guidestar, an online database of philanthropic organizations, recently reported that contributions received by public charities were higher in 2010 than 2009. Therefore, research funders who rely upon an ongoing donor base, such as the American Cancer Society and the American Heart Association, can be cautiously optimistic that an economic recovery may be underway for their part of the philanthropic sector.

Donaghue Dictionary: Adviser

The dictionary definition of "adviser" is straightforward: a person who offers advice, particularly in an official or professional capacity. Although this is certainly true of Donaghue's many and varied advisers, this standard definition doesn't adequately convey the informed, thoughtful, and generous contribution that our advisers have made over the years and continue to make to Donaghue's work. And in sharing their guidance, our advisers have always taken Ethel Donaghue's mandate very seriously, bringing their professional and personal experiences into our ongoing discussion of the best way to put action to that purpose.



Donaghue Starts Group on Translating Research

Donaghue has initiated a working group of the Health Research Alliance that focuses on getting research results put into use. HRA has other working groups that work to more quickly advance the benefit of research into application, but these are focused on pharmaceutical solutions to diseases. The new group, called TRIPP — Translating Research into Practice and Policy — will focus on evidence-based interventions that prevent disease or improve the health status of those with a chronic disease, including studies about organizational and individual behavior change, health services and effectiveness research, and bioethics. By starting this group, Donaghue hopes that it will join with the growing community of researchers, health systems, quality improvement organizations, and funders who are focusing on the challenges of scaling-up and adopting these health improvements.

Kate Ahlport, HRA Executive Director, says that much of the work of HRA is accomplished through its working groups. “The working groups are flexible and change over time to accommodate the needs of the membership,” Ahlport noted.

“We were pleased that Donaghue initiated this group, and were impressed by the number of organizations that indicated an interest in having a staff member serve on this group.” The groups meet in person as part of Members’ Meetings and also convene by conference calls and webinars throughout the year.

HRA, an organization of not-for-profit, non-governmental funders that support health research and training, has 50 member organizations. Although each has a different mission, all are focused on using research to improve health. The purpose of the Alliance is to improve communication and collaboration among these funders as well as between non-governmental, not-for-profit funders and the other sectors of the health research enterprise. HRA working groups also include the Grants Administration Working Group, Early Career Scientists Working Group, the Working Group for Funders Focused on Drug and Other Therapy Development, Discovery Science Working Group, and the HRA Program Committee, which plans HRA’s membership meetings.

Hearing the Patient’s Voice —continued from page 1

Klass teaches writing to both journalism and medical students, and she sees differences in what each group of students brings to their writing. In general, she feels that the journalism students have better writing skills, but they aren’t as strong in developing the plot of their stories. In contrast, the medical students “have plot coming out of their ears” due to their medical school experiences.

The role of privacy in writing about one’s experiences, which often includes other people’s experiences, was also discussed by Klass. When writing for *Health Affairs*, Klass says she certainly changes the name and will often change the age, sex, even the medical condition of the person she is writing about. What she doesn’t change is her subjective connection to that experience. Newspapers have different standards, however. *The New York Times*, she adds, is uncomfortable with even using initials rather than a full name. She also said that she has written about a patient, carefully changing the name and circumstance to keep their privacy, only to find the patients were disappointed because they welcomed people knowing about their role in the stories.

After the lecture and a reception, which was held in the atrium of the Anlyan Center, Klass conducted a writing workshop for approximately 20 nursing and medical students. As a part of the workshop, Klass asked each student to start writing a story; in one version the students used the first person subject and in a second version they used the third



Ray and Barbara Andrews speak with Katherine Ill and Amy Lynch before the lecture begins.

person subject. They were then asked to consider which one was easier to write; how comfortable were they writing each one, and how each viewpoint affected what they chose to write about.

Although Klass finds the time to be a prolific writer, one student asked if she writes every day. “No,” she answered, “but I will when I grow up. And eat more vegetables, too.”

The choice of Klass to be this year’s Andrews Lecturer came from a group

convened by Donaghue to make speaker recommendations for the series. The group was chaired by Judy Kunisch, Lecturer at Yale School of Nursing, and included Ray Andrews; Nancy Angoff, Associate Dean, Yale School of Medicine; David Smith, Director of the Yale Interdisciplinary Center for Bioethics; and Sheilah Rostow, former Bank of America Trustee for Donaghue.

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.

Look for an interview with Klass about the patient voice, writing and knitting at www.donaghue.org.

Beyond Eureka! Conference May 6

The Foundation's 2011 conference will be held on Friday, May 6 at the Hartford Marriott Farmington between 7:30 AM and 12:30 PM. The theme for this year's event will be **Design thinking — designing for health: better information, experience & outcomes**. Three speakers will describe how design thinking — as opposed to analytic thinking — can be used to foster innovation in health care.



Jeneanne Rae, Co-founder of Peer Insight. Rae is an expert in design strategy and innovation. She has worked with dozens of large corporations, including Procter & Gamble, Hewlett Packard, Standard & Poor's, IBM, Masco Corporation, and Pepsi-Cola and recently joined the Expert Panel for the AHRQ Innovations Exchange.



Camille Kubie, Manager, Global Brand and Design, GE Corporate. Kubie leads GE's corporate brand strategy, including 360-degree advertising programs to support GE's Ecomagination and Healthymagination initiatives. She has pioneered the use of data visualization as

new way to tell GE's story, simplify complexity, and advance the conversation around health and energy.



Ben Fry, Co-founder, Fathom. Fry's information graphics have illustrated articles for *Nature*, *New York Magazine*, and *The New York Times* and his work has been featured at Whitney and Cooper-Hewitt design exhibits. Ben is author of *Visualizing Data*. He has created many of the data visualizations for GE's Healthymagination.



C. Todd Staub, MD, FACP, a Connecticut internist and board chairman of ProHealth Physicians, will moderate a panel discussion with conference speakers and attendees following the presentations.

Although registration for the conference is required, the conference is free, and anyone interested in learning about innovative approaches being used to improve personal and community health and wellbeing are welcome to attend. More information, including links to the speakers' websites and a link to the registration page, are available on the Foundation's website donaghue.org.

Three Policy Advisers —continued from page 1

sounding board for the Trustees by providing a range of perspectives and expertise in the ongoing discussion of major Foundation initiatives.

At their final PAC meeting, Thompson, Ill and Hastings each spoke about their time on the PAC and what has made it an important component of Donaghue. In their remarks, they identified the real role of the PAC as “keeping the Trustees true to Ethel Donaghue’s mission.” They also reminded other PAC members that the Foundation was created by “a very unusual trust document by a very unusual person” and that the overall intent of the will is more important than any specific word in it.

The Policy Advisory Committee meets as a group two or three times a year, and from time to time the Trustees call upon advisers individually to discuss issues that are under consideration. Three new PAC members, whose terms began in October of this year, joined the September meeting to hear the retiring members’ observations of Donaghue (more on the new PAC members in an upcoming Practically Speaking).

Existing PAC members include:

Nancy Angoff, MD New Haven Associate Dean, Yale School of Medicine	T.V. Rajan, MD, PhD Farmington Professor, University of Connecticut School of Medicine
Cheryl Beck, DNSc Tolland Professor, University of Connecticut	Michael Rion, PhD West Hartford Principal, Resources for Ethics and Management
John Charde, MD Salisbury Health care consultant	<i>New PAC members who began their term in October 2010 are:</i>
Bruce Gould, MD West Simsbury Associate Dean, University of Connecticut School of Medicine	Carrie Brady, JD Wilton Health care consultant
David Knecht, PhD Storrs Professor, University of Connecticut	Lisa Davis, BSN, MBA Glastonbury Branch Chief, Connecticut Dept of Public Health
Dennis May Guilford CEO, Connecticut Hospital Association (Retired)	Marie Massaro Wethersfield Philanthropy and community affairs consultant

Donaghue Mayday Grant leveraged into second major study

Last year Donaghue and The Mayday Fund partnered to award a \$880,000 grant to Yale and the West Haven VA Medical Center to study improving pain treatment among the VA's patients. From that initial investment, The Mayday Fund has committed another \$453,000 to extend that research for two years into the Community Health Centers, Inc. in Connecticut. In working together on these two grants, researchers and clinicians from the West Haven VA and the 12 sites of the Community Health Centers, Inc. have created a rare collaboration among federally qualified health centers and the VA Health System.

Similar to the VA study, the first phase of the CHC study will focus on implementing pain management within primary care. CHC will begin by examining the prevalence and severity of pain among CHC's medical and behavioral health patients, as well as surveying every CHC provider to better understand their knowledge about pain management and current practices. Using its findings, CHC will then develop protocols and procedures for pain medication therapy, form a peer support group for consultation on challenging cases,

and provide pain management education to all CHC providers that include use of medication and behavioral strategies and patient-doctor communication.

The second and third steps of the model will be implemented during the study's second phase. CHC's integrated behavioral health and medical teams will work together to develop co-managed treatment, and CHC will build links with community resources that offer complementary and alternative therapies.

In the final phase of the study, CHC will evaluate the adapted model and its success, as well as develop a plan for sustainability across its 12 sites. The model and findings will also be shared with community health centers across America.

In reflecting on this new grant, Christina Spellman, Mayday Executive Director, says that "The Mayday Fund Trustees are excited by the promise of these grants, as they bring the better care of pain squarely into focus in the world of primary care. The leadership at Donaghue has introduced Mayday to the resourcefulness of medical and health professionals in Connecticut, and our partnership has enabled the Fund to achieve a much greater impact than we ever imagined."

Volunteer Day

In August, the Friends of Elizabeth Park sponsored one of their Volunteer Days, and on this particular day the volunteers were employees of Northeast Utilities. These generous individuals worked on maintaining the recently installed improvements in Elizabeth Park created by the Ethel F. Donaghue Trust for Elizabeth Park. They weeded, raked, trimmed, and hauled away debris, and as a result the plantings of rhododendron, epimedium, and ferns are greatly improved.

At the time Ethel Donaghue created the medical research foundation named for her parents, she also created a trust for improvements in Elizabeth Park, located in Hartford and West Hartford and just a few steps from Ethel Donaghue's residence on Prospect Avenue. Over the past 20 years, the Ethel Donaghue Trust for Elizabeth Park has quietly spent \$1.5 million in 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, the granite curbs and crosswalks in the expanded parking area near the Asylum Avenue entrance, and most recently the improved entrance from Prospect Avenue and a seating area near the pond.

But even with Miss Donaghue's Trust and the contributions of many people who also love our urban parks, volunteers are needed to keep the park lovely and well-used. And for those who assist in this way, we say "thank you!"



Volunteers from Northeast Utilities work with the Friends of Elizabeth Park to help maintain the park grounds.

Connecticut Health Funders Jointly Fund Planning Grant

Three Connecticut-based health funders — Donaghue, the Connecticut Health Foundation, and the Universal Health Care Foundation of Connecticut — have teamed up to award \$35,000 for the Community Health Center Association of Connecticut to develop an application to the Agency for Healthcare Research and Quality. This application is in response to AHRQ’s request for demonstration projects to study new methods for improving the quality, safety, effectiveness and efficiency of health care in ambulatory settings and in the transitions between care settings while reducing costs. The work of the planning grant is being led by Jennifer Granger, CHCACT’s chief operating officer, and Mark Borton of Equity Health Partners, LLC.

Since August, representatives of 12 federally qualified health care centers who serve 227,000 patients each year and the managed care organizations who have contracts with the Connecticut Department of Social Services to manage Connecticut’s Medicaid services have been meeting to design a “First Contact for Care” strategy that improves the efficiency of primary care practices in responding to urgent care requests and therefore reduces avoidable emergency department visits and inpatient stays. The goal of the project is to share the cost savings from the reduced utilization of higher-cost services among the managed care organizations, health centers, and their providers. If funded by AHRQ, the project developed by CHCACT will demonstrate the impact of payment reform among Connecticut’s federally qualified health care centers and Medicaid payers.



Mark Borton works with members of the planning group to develop outcome measures for the AHRQ grant.

As in many funding partnerships, each funder had a different interest in choosing to support the effort to successfully apply for the AHRQ grant. Funding the planning process allowed Donaghue to observe an underused method developing a research project — one that is driven by the research “conditions” themselves. For Frances Padilla, Vice President of the Universal Health Care Foundation, “the AHRQ grant is a way of testing some of the principles of Sustinet while providing improved health services to many individuals.” And Pat Baker, Connecticut Health Foundation President noted that “this project will be an important demonstration of how primary care can reduce racial health disparities in Connecticut and nationwide.”

Feedback from Grantees

In the fall of 2010, Donaghue surveyed former and current Donaghue Investigator grantees to have them anonymously offer their insights on program characteristics and the administration of the Donaghue Investigator program. Knowing their perspective will be important to Donaghue as we think about future grant programs.

For ten years, the Donaghue Investigator program supported particularly promising medical researchers holding faculty appointments at Connecticut institutions; the program emphasis was on the researcher and his or her overall program of research rather than upon a specific research project. Awards were \$100,000 per year for five years plus indirect costs and yearly cost of living increases.

Donaghue received feedback from more than 50% of the grantees. All respondents felt that the longer time frame of five years and the flexible nature of the program were very important to their success. Most felt the amount of the grant

was appropriate to their program goals, although a few said that it wasn’t enough for what they were pursuing.

The majority of respondents said they stay in touch with Donaghue through the annual report (88%) and newsletter (65%), and nearly half attend its conference or other events. More than 80% suggested that Donaghue continue the practice, as was done with this program, of hosting an annual gathering of grantees.

In the upcoming months, Donaghue will survey Clinical & Community Health Issues awardees to request their opinions as well. In the meantime, if you have any comments about Donaghue’s grant programs, please send them to Stacy Cloud, Donaghue’s Grants Manager at cloud@donaghue.org.



The 2010 Andrews Lecture gave people an opportunity to hear Perri Klass, MD speak on listening to and writing about the patient's voice, get an autographed book, and meet with colleagues at the reception.

THE DONAGHUE FOUNDATION



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