

Practically Speaking

NUMBER 20, SUMMER 2005

To Confer and Conceal *Annual meeting focuses on health literacy issues*

The Donaghue Foundation annual meeting on May 13 featured a fascinating articulation of the importance of health literacy to health care providers and researchers. Rima Rudd, ScD, Senior Lecturer in Harvard University's Department of Society, Human Development and Health, urged those who do research, who write about their research, or who speak with patients to be aware of the importance of communicating in a way that will benefit the intended audience.

Taking a cue from the annual meeting location — Hartford's Mark Twain House and Museum — Dr. Rudd titled her talk "To Confer and Conceal Knowledge," borrowing from a quotation by Samuel Clemens: "All schools, all colleges, have two great functions: to confer, and to conceal, valuable knowledge." Dr. Rudd said at the outset of her remarks that a brief visit to one of the museum's galleries immediately before the meeting provided perhaps an even better quotation for the afternoon's focus. In the margin of one of the books from his personal library, Samuel Clemens had written "This beastly mess of incoherence is not English." Dr. Rudd suggested that many of us have felt the same sentiment in reading professional journals and books.

Research in the field of health literacy, which is growing rapidly, has shown that while the vast majority of Americans are literate — they read newspapers and novels, for instance — about one-half of the population has difficulty using printed material

to accomplish a health-related task, such as buying over-the-counter medications or using written post-operative instructions. Dr. Rudd used the example of the difficulty a person faces who has been advised to reduce salt in his diet and is trying to buy food that will help attain that goal. The nutrition labels refer to a food's sodium content, and "salt" is not listed. To use the nutrition label, one has to know that "salt" and "sodium" are the same things, and we shouldn't take for granted that everyone knows that. Immigration and the resulting challenge of adults not speaking English is another and a significant barrier to optimal use of health information.

The consequence of the gap between the level at which health information is written and the functional reading level of many people trying to read it is that many resources intended to help people with their health are missing the mark. In recognizing this problem, Health People 2010 has, for the first time, included a health literacy goal: to improve the health literacy of persons with inadequate or marginal literacy skills.

Dr. Rudd urged the health researchers in the audience to do "formative" research as a standard part of their process. Formative research is the part of the research process that evaluates the research tools, including the instructions to research subjects, to ensure that the communication process is not one that is riddled with unintended consequences.

continued on page 5



Dr. Rima Rudd

Executive Director's Report

This issue's Donaghue Dictionary focuses on *prudence* as a balance between caution and risk in selecting projects to fund. We also try to be prudent in the other phases of grant-making — in the more administrative aspects of philanthropy that are done after the decision has been made to invest in a project.

We use **funding agreements** to define the details of what is being funded and to describe many of the policies of the Foundation. With awards made in the Practical Benefit Initiative program, the agreements are specifically written for each project to define the essential elements that have been developed by the Foundation.

Principal Investigators are required to send us an annual **narrative progress report and a financial report** of the work done and expenses paid; with some larger grants we may have those reports sent to us twice a year, particularly during the start-up phase of the study. We *do* read the narrative reports, and in some cases we may refer them to our advisers for their review. We also review the amount spent in the grant as compared to the investigator's spending plan, and if a significant portion of the grant has not been spent we usually withhold the next installment of the grant until it is needed. We recently added a question to the narrative report that links the progress in

(continued next page)

FROM THE TRUSTEES

How Prudence Comes Into Play

This issue of *Practically Speaking* concludes a brief four-part trip through Donaghue's four stated values. In prior issues we highlighted Purpose, Principle and Practicality. The focus this time is on **Prudence**, one of the hallmarks of a responsible fiduciary. As pointed out in our Donaghue Dictionary entry, prudence doesn't exist as an isolated absolute; its meaning takes shape against a backdrop of uncertainty, ambiguity and risk. It is prudence that steers a fiduciary past the risky shoals that surround any worthwhile new undertaking. Committed as Donaghue is to accepting risks in our work, we view prudence not as the avoidance of risk but rather as the mastery of risks that are proportionate to potential benefits.

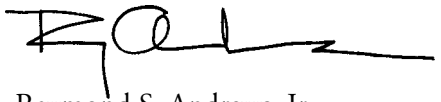
Though each of our values warrants attention on its own, they all actually function in unison, in a careful equilibrium, as we carry out the Foundation's work and its planning for the future. Often we find ourselves discussing how adherence to principle must be in a context of practicality or how being practical can't involve abandoning principle. Often we've debated how our sense of purpose, involving the boldness and imagination Miss Donaghue would herself have shown, must be tempered by the prudence that characterizes fiduciary work. (And, of course, how we must not let an excess of prudence for our own peace of mind hinder our aggressive pursuit of practical benefit to human life).

Donaghue's pursuit of practical benefit was graphically illustrated by the keynote speaker at our recent annual meeting, which

is described in the feature article in this issue. Rima Rudd, ScD, an expert on communication, pointed out how people can miss out on health benefits simply because they "don't speak the language" that is so familiar to practitioners and scientists. Or perhaps more to the point, the experts don't translate their knowledge into terms the public can understand and apply. We at Donaghue have committed ourselves to overcoming obstacles to health benefit so that the scientific discoveries produced by our funded research find their way into beneficial practice. The philosopher Pogo Possum once observed regarding

We view prudence not as the avoidance of risk but rather as the mastery of risks that are proportionate to potential benefits.

the human condition that "we are surrounded by insurmountable opportunities." Donaghue has an opportunity to help make a difference in people's lives by bridging the communication gap separating science and the street, whether that gap be in the language used to give patient instructions or in the time it takes to convert new knowledge into changed behavior. It is prudence that will tell us which opportunities are truly insurmountable obstacles for a little foundation. The rest we will work to overcome. ▣



Raymond S. Andrews, Jr.
Trustee



Sheilah B. Rostow
for Bank of America, Trustee

The Donaghue Medical Research Foundation

Office: 18 North Main Street
West Hartford, CT
06107-1919

Executive Director:
Lynne L. Garner, PhD
Email: garner@donaghue.org

Tel: 860-521-9011
Fax: 860-521-9018
Web: www.donaghue.org

**Director of Program
Communications and Management:**
Nancy C. Yedlin, MPH
Email: yedlin@donaghue.org

Practically Speaking is published quarterly by the Donaghue Medical Research Foundation, 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 Fleet National Bank and Raymond S. Andrews, Jr., 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.

Awash in Data but Starved for Knowledge

Meeting explores use of integrated databases in strategic decision-making

This summer the Donaghue Foundation teamed with the Connecticut Council for Philanthropy to sponsor a half-day meeting on “Using Data to Support Strategic Decision-Making.” Dennis Culhane, PhD, Associate Professor of Social Welfare Policy at the University of Pennsylvania, was the keynote speaker.

The purpose of the meeting was to examine the development and use of integrated databases in Connecticut and to facilitate a discussion among Connecticut foundations on the value of integrated public databases to their missions, the experiences of other states and regions in constructing and using integrated databases, and data resources currently available in Connecticut. Approximately 35 people representing 12 Connecticut foundations attended the meeting, which was held at the Lyceum in Hartford.

In addition to Dr. Culhane, other presenters at the meeting were Michael P. Meotti, President of the United Way of Connecticut, and Jim Farnam, of Holt, Wexler & Farnam, LLP. Howard Bailit, DMD, PhD, Professor Emeritus at the Connecticut University Health Center and long-time Donaghue Foundation adviser, was the moderator for the meeting.

Dr. Bailit set the theme of the meeting by referring to futurist John Naisbitt’s observation that we are awash in data but starved for knowledge. Large amounts of information are stored in city and state databases, but these are currently unavailable to the public. Foundations and non-profit community organizations could make their work more productive by using these resources to target their efforts on the challenging issues of improving health, education, and the quality of life in our cities; they could also be used to track a foundation’s progress towards these goals.

A number of data projects in Connecticut which are currently available to foundations and the public were discussed at the meeting. These resources include DataHaven (<http://research.yale.edu/datainitiative>) and Hartford Info (<http://www.hartfordinfo.org>), two sources which serve as gateways to infor-

mation about the regions, as well as other resources that are focused on health care.

The meeting included ample opportunity for general discussion among the speakers and those in attendance. It was pointed out that successful initiatives by other cities and states to integrate data have been grounded in a particular action for civic improvement being undertaken by a city agency. Prof. Culhane gave the example of a database being used in Baltimore, Maryland, begun with the desire to reduce the number of abandoned houses in the city. Speakers also underscored that an important element in creating a sustainable data integration project is that sponsors must be cognizant of the impact these resources have on the culture of public agencies and how they do their work.

Another issue related to the sustainability of a public data project is the need to help community organizations understand the value of integrated data and how to use them for their everyday work. Mr. Meotti said that “The country is littered with failed data initiatives because many lack the ability to engage and instruct people about issues related to information.” Giving people the skills to use the database is perhaps as important as having the data available. To that point, Prof. Culhane described the training offered by his project on Philadelphia’s “Neighborhoodbase” — the interactive, web-based tool which is publicly available to analyze neighborhood conditions. He said that at the beginning of the project they planned to do about two training sessions a year; the class is now offered twice a week because it is always filled up. He said, “One time the class was filled with fire chiefs; another time we had an entire seventh grade class,” and trainers never know who will sign up to learn how to use the database.

The examples provided by Prof. Culhane were about data efforts based on city-owned databases, but most of the participants spoke about the possibility of developing Connecticut-wide databases. Although Connecticut is small and may be conducive to a state-wide effort, Prof. Culhane said that starting with

continued on page 5

Executive Director (cont’d)

completing the aims of the research with the amount of money spent.

Each year the Foundation conducts a **financial audit** of a sample of its grants through an external auditor. With the number of grants that the Foundation has open and with grants running for two or three years, any grant has about a 10% chance of being audited. Our choice of grants to audit is somewhat random, but each year we try to include a diversity of Foundation programs and grantee institutions. Sometimes there is an unusual feature in a funding agreement that causes us to be curious about how the tracking of funds and expenses is done. We usually audit grants that are currently underway, rather than completed, on the assumption that any issues that need to be addressed are better resolved while the grant is still in progress. Our basic reason for doing audits is not that we expect to find wrongdoing. Rather, we learn from these audits and can improve our own processes and sometimes head off a problem. Of course, it doesn’t hurt for people to know that we do, from time to time, check the numbers.

On a few occasions the Foundation has conducted an **interim assessment**. As with the main purpose for doing audits, these reviews are a way for us to reflect on an issue that may be of particular interest to the Foundation. And as was discussed in our last issue of *Practically Speaking*,

(continued next page)


Patient Safety Research Initiative Update

At its annual meeting in May, the Foundation provided more details on its \$1 million patient safety research initiative announced a year ago. Since that time, the Foundation has continued to move forward on the initiative by developing an advisory committee (see sidebar) which will assist the Foundation in determining the specific details of the request for proposals and selection criteria, in reviewing proposals, and in monitoring the selected grants during the course of their award. Working with this committee, Elizabeth Bradley, PhD, Associate Professor at Yale School of Epidemiology and Public Health, is serving as a consultant to the Foundation in this initiative.

The Foundation is also pleased that it will be collaborating with The Commonwealth Fund on our patient safety initiative. The mission of The Commonwealth Fund is to promote a high performing health care system. Based in New York City, it makes grants throughout the U.S. for research and projects to improve health care practice and policy. The Commonwealth Fund will be assisting the Foundation on the content of its initiative and in considering productive ways to disseminate information that results from the research. It will also be looking for opportunities to co-fund with Donaghue.

The overall goal of the initiative is to fund three or four projects, lasting no longer than three years, that conduct research focused on the role of organizational leadership in improving patient safety. Leadership can be defined as the CEO, chief medical officer, the board of directors, or any of these in combination. Actual measures of changes in safety are not required, but the outcomes measures must be factors known to have an impact on safety. Research designs may include qualitative methods.

Acute care hospitals within the six New England states may submit a letter of intent with an academic researcher as a collaborator.

The Foundation expects to have full details of the RFP process distributed in the fall. Anyone interested in receiving a copy can email us at office@donaghue.org. Information about the RFP will also be listed on the Foundation's website. 


2004 Annual Report Available



Copies of the Donaghue Foundation's 2004 Annual Report, "Attitudes," are available from our office (see contact information on p. 2) or may be downloaded from our website in Acrobat format.

Executive Director (cont'd)

we also conduct **site visits** to funded projects, usually three each year.

We also take a look at our own activities from time to time. This year the Foundation engaged Wellspring Consulting, a management consulting firm for non-profit organizations, to do an assessment that would help us find ways to improve our own practices. We asked the consultants to focus on the way the Foundation's Policy Advisory Committee is structured and used, how best to approach evaluating the Foundation's grant making — always a challenge when research is the purpose of the grant — and to provide some insight on how others perceive the Foundation and the job we are doing. To do this, Wellspring interviewed about 30 people, including Trustees and staff, science and policy advisers, grant recipients, applicants who did not receive an award, leaders of other Connecticut foundations, and administrators in the institutions that receive the Foundation's grants. The perspectives provided by these people, combined with the consultants' expertise, have given us a number of ways to continue shaping the day-to-day work of the Foundation so that we can more effectively put prudence into our practice. 

Patient Safety Initiative Advisory Committee

The following individuals have agreed to serve on Donaghue's Patient Safety Initiative Advisory Committee. More names will be added in the coming weeks.

- **James Bagian, MD** had a career at NASA, including over 300 hours of space flight, before being named the first director of the Veteran Administration's National Center for Patient Safety.
- **William A. Gillespie, MD** is Senior Vice President at United Health Group.
- **James Conway**, former CEO at Dana-Farber Cancer Institute, is now a consultant to Dana-Farber and to the Institute for HealthCare Improvement.
- **Elizabeth Bradley, PhD**, a 2002 Donaghue Investigator, is Associate Professor of Public Health at Yale University.
- **Mary Jo Koran, MD** is a senior project officer with The Commonwealth Fund.
- **Robert Galvin, MD** is the Director of Global Health at General Electric.
- **Jeff Cooper, PhD**, winner of the 2003 John M. Eisenberg Award for Patient Safety, is Chair of the National Patient Safety Foundation Research Committee.
- **Suzanne Graham, PhD, RN** is the Patient Safety Leader for the California Regions at Kaiser-Permanente.

Confer and Conceal (continued from page 1)

As a final message to her audience, Dr. Rudd encouraged listeners to support adult education and adult literacy programs in our communities. These are programs, often short on funding, which provide resources for people trying to improve their literacy skills.

The Health Literacy website at Harvard University (www.hsph.harvard.edu/health-literacy) has several resources for those seeking additional information on the topic.

Before the business portion of the meeting, the Foundation hosted four presentations by selected grant recipients. The purpose of these presentations is to help the public to understand more about the Foundation's grant making and the work of its grant recipients. Diane Pinakiewicz, Executive Director of the National Patient Safety Foundation, presented a description of NPSF's work, including the research projects to which the Donaghue Foundation made grants in 2002 and 2003. Members of the Donaghue Initiative for Biomedical and Behavioral Research Ethics presented an overview of the project, summarizing some of the small grants that are provided within that project for ethical analyses of medical research issues. Barbara Kazmierczak, MD, PhD described her

Donaghue Investigator research focused on epithelial cells and opportunistic infections.

In a fascinating first for the Foundation, Judith Fifield, PhD, included some of the participants in her SisterTalk Hartford intervention study as she and several team members outlined the project and discussed the roles of the various partners in it.

A reception followed the meeting, and Foundation guests were afforded the opportunity to tour the Mark Twain House. ▢

Awash in Data (continued from page 3)

city information has several advantages. "There are a lot of records that the city has that the state doesn't have, and many of those are directly related to quality of life issues." Examples are real estate purchases, tax records, education records, city public health and police records. Many of these data sources have significance for understanding health issues.

Several of the meeting participants expressed the desire to continue the discussion of the benefits to foundations and philanthropy's role in developing this resource for Connecticut.

Donaghue Grants Announced

This March the Clinical & Community Health Issues Committee convened to review the Spring 2005 applications. We are pleased to announce the following grant awards:

Michal Assaf, MD, Senior Research Scientist, Olin Neuropsychiatry Research Center, Institute of Living, will apply an optimal diagnostic criterion to patients experiencing a first psychotic episode to establish its reliability in differentiating between patients who have bipolar disorder or schizophrenia.

Jeffrey Kluger, MD, Director, Heart Rhythm Service, Hartford Hospital, will study oral magnesium lactate's effect on the number of heart rhythm disturbances and shocks a patient receives and will determine if this therapy can improve a patient's quality of life.

Rajesh Lalla, PhD, Assistant Professor, Oral Diagnosis, University of Connecticut Health Center, will study the use of multivitamins for patients with Recurrent Aphthous Stomatitis (RAS), also known as canker sores. RAS is the most common soft tissue disease of the mouth.

Julie Ann Sosa, MD, Assistant Professor, Department of Surgery, Yale School of Medicine, will determine whether surgery improves common memory, concentration, and depression problems at the time of diagnosis of primary hyperparathyroidism. ▢

DONAGHUE DICTIONARY: pru·dence

Prudence is the fourth and last of Donaghue's stated values. It's a common requirement among those who hold resources to be used for the benefit of others. A person known for prudence is one exhibiting shrewdness in the management of his or her affairs, one who exercises skill and good judgment in the handling of resources. Donaghue is a bit different from most organizations entrusted with resources; while caution in all things may be a watchword for traditional foundations, we are expected by our purpose to welcome risk in our grant-making, for without risk there is less chance of discovery. Accordingly, we don't liken prudence to risk averseness; we talk of taking risks prudently. Sound contradictory — like rushing slowly? Or hurtling deliberately? We think not, and we carefully look before we willingly leap into innovative research initiatives. ▢



ASK THE TRUSTEES

QUESTION: Why does Donaghue change its grant programs and policies so often? It's hard to keep up with who's eligible for grants or figure out what the Foundation stands for.

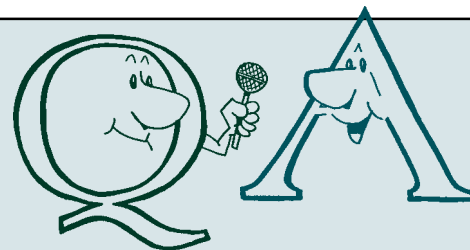
ANSWER: There are at least two parts to a proper answer to this question. First, in actuality we don't change much or very frequently. "Often" is in the eye of the beholder and depends on one's frame of reference. Second, we change promptly when we see either a need to correct a problem that emerges in grant administration or an opportunity to make our programs more helpful to researchers we hope to encourage. We actively look for ways to improve our programs and our overall contribution to human health. That requires a willingness to change.

Time horizons in research and grant-making are quite long compared to the time frames of operating a foundation, and the Donaghue philosophy is to drive our own destiny rather than track behind the practices of others. The cycles of grant-making may make it appear to scientists that we change often; we have, for example, made adjustments in our Clinical & Community Health program almost every cycle, but they are largely administrative improvements endorsed — or even pro-

posed — by our scientific advisers, in the interests of being more responsive to researchers' needs (e.g., increasing funding amounts or reducing time delays). From our inside perspective, failing to make the changes we've made would mean being sluggish, and "Because we've always done it that way" is not a good answer for doing something we know can be improved.

In our Donaghue Investigator program, begun eight years ago to help develop leadership in Connecticut across a wide band of research fields, we've made a few major changes, driven by stock market reverses (fewer awards) or a concentration of grants in a narrow band of disciplines (focus on different fields of study). This, we believe, was nothing more than sensible midcourse corrections in the face of changed facts.

As to what Donaghue stands for, it's pretty clear and straightforward: practical benefit to human life through health research and its translation into practice. All of our changes are in pursuit of that end. ■



18 North Main Street
West Hartford, CT 06107-1919

ADDRESS SERVICE REQUESTED

Clinical and Community Health Issues Program

The Foundation will be accepting Letters of Intent for the Clinical & Community Health Issues program on September 30, October 30, and November 30 for the January 26, 2006 deadline.

Applications will be available by October 1, 2005. Please call the Donaghue office or visit our website for more details.

NONPROFIT ORG.
U.S. POSTAGE
PAID
HARTFORD, CT
PERMIT NO. 2648