

# Practically Speaking

NUMBER 19, SPRING 2005

## Taking the Initiative: A more proactive approach to grantmaking

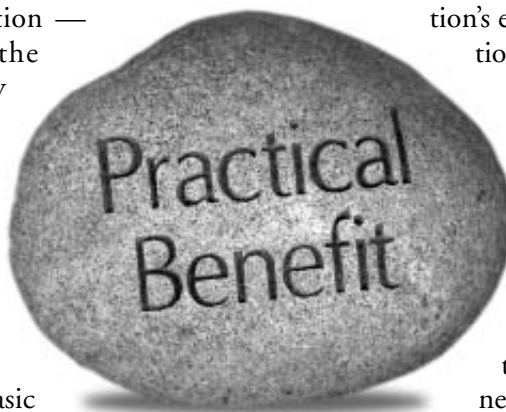
Long-time readers of *Practically Speaking* and the Foundation's annual reports have seen many references to the **Practical Benefit Initiative** program and the projects funded by it. Easy Breathing, Women's Health Research at Yale, Vital Signs, Fall Prevention — people who have heard of the Donaghue Foundation usually know at least one of these names. Still, from time to time enough people have asked us some fairly basic questions about our bedrock Practical Benefit Initiative program that we thought it would be a good idea to provide a "soup to nuts" description of it. What is the basic outline of the program? Why did it get started? And why does the Foundation spend so much of its grant funds — nearly half — on this one program?

### Background and Early Development of the Program

The Practical Benefit Initiative (PBI) program began in 1996 and arose from the Trustees' determination to apply creatively the testamentary guidance of Miss Donaghue to engage in unusual and non-standard activities in research funding, and to

promote practical benefit to human life — an objective the Trustees did not see widely embraced within traditional medical research circles, where serendipity was the order of the day. A study of medical research priorities during the Foundation's early years underscored the notion that research usually follows one of two paths — scientific opportunity or addressing a public need. With the unusual independence and flexibility afforded them by the Donaghue will, the Trustees determined they would lead the Foundation down the path that uses science to serve public need. The PBI program, then, was a major response to this course adjustment. Building upon the Foundation's traditional investigator-initiated grant programs, Practical Benefit Initiative research grants would be shaped more by the Trustees. The PBI program was a way to escape what the Foundation perceived as the inflexibility of traditional medical research funding, to encourage scientists to undertake studies not likely to be funded under conventional rules and practices, and to demonstrate the value of funder initiative in exploring new approaches to practical benefit.

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## Seeking a health return on investment

When the Foundation devoted an entire issue of *Practically Speaking* to our Clinical & Community Health Issues program a short time ago, the reader feedback was very gratifying. The CCHI coverage was both interesting and helpful to readers. Accordingly, we've focused this issue on one of the Foundation's biggest and most satisfying challenges: Practical Benefit Initiatives, which account for almost half of the Foundation's grant spending and which have produced some of our biggest successes.

PBI is not without its skeptics and critics, since it departs from the traditional pattern of health research grant-making and consumes resources presumably otherwise available for more conventional investigator-initiated research projects. So, one might ask, "Why has Donaghue gone down this unusual road in the first place?" The key to the answer lies in Miss Donaghue's will itself. The will is our road map, and it tells us quite clearly to pursue practical benefit to human life, being ready and willing to employ unusual and non-standard means. Edward DeBono, in his book *Lateral Thinking*, once observed that if the treasure isn't in the hole you're digging, then digging deeper won't locate it. We've learned that if practical benefit is not a feature of research that's being done, we have to make it happen by taking the initiative to promote different research.

Both our choice of PBI as a signature element of Donaghue and our methods of pursuing our initiatives reflect a stark fact: It is very hard to change any status quo. It has been hard for us to learn enough to initiate a course of research, and it has been hard for researchers to assemble teams, structure in-

terventions, and plod methodically through protracted studies involving scores of collaborators in the health care system (some of whom are among the skeptics). A great deal of coordination is involved, and controls are often precarious. But when a question of potential widespread public benefit can be answered through such a laborious process, it's the right thing for researchers to undertake and the right thing for Donaghue to promote and support.

When Miss Donaghue authorized her Trustees to spend trust principal, that imposed on us a duty to actively use that power to further her purpose. We've done it in two ways: structuring our investments for total return because we can spend other than the income they produce, and making sizable multi-year grants that promise a health return to the public. In similar fashion, when Miss Donaghue expressly anticipated the need for us to engage in unusual activities to serve her ends, she imparted to us a responsibility to seriously consider less-traveled roads. ■



Raymond S. Andrews, Jr.  
Trustee



Sheilah B. Rostow  
for Bank of America, Trustee

“...We’ve focused this issue on one of the Foundation’s biggest and most satisfying challenges: Practical Benefit Initiatives, which account for almost half of the Foundation’s grant spending and which have produced some of our biggest successes.”

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*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.

## EXECUTIVE DIRECTOR'S REPORT

During the past few months the Foundation has conducted its annual site reviews. Each year we select approximately three grants and establish visits for Foundation Trustees, staff and Policy Advisory Committee members to attend. The process for selecting the visits is fairly random — we like to include each of the Foundation's programs, go to projects at different institutions, and learn about research that is conducted up and down the translational path.

The process is one of several that the Foundation uses to monitor and evaluate its grant making — a subject that the next *Practically Speaking* will discuss in greater depth. It is also a way of developing and maintaining connections with Connecticut researchers. One advantage, after all, of being Connecticut-focused is our ability to meet our investigators and learn more about their work. Site visits are also, as Trustee Ray Andrews likes to say, a way of visiting our money.

This year we visited Donaghue Investigator **Barbara Kazmierczak, MD, PhD** at Yale School of Medicine, who is researching the role of epithelial cells in fighting opportunistic infections; **Richard Fortinsky, PhD**, University of Connecticut School of Medicine, who is studying how ethnic-minority family members of dementia patients can reduce the stress of their caregiving burden;

and **Samuel Varghese, PhD**, St. Francis Hospital and Medical Center, who is working to understand the intersection of gastric diseases and osteoporosis. Drs. Fortinsky and Varghese are Clinical and Community Health Issues grant recipients.

We come away from these visits mightily impressed with the work being done and the energy and enthusiasm of our principal investigators and their research staff. Even with their busy schedules, they seem to genuinely enjoy taking the time to explain their work to people who — let's face it — might not really understand all the details of what they are saying. Yet we learn a tremendous amount about the research topic and the organization of the work. I'm certain the Policy Advisory Committee members who attend site visits get a better understanding of what the Foundation funds, and these visits serve as an important backdrop to their discussions of the Foundation's work.

We have recently begun inviting people who have ongoing business connections with the Foundation to attend site visits, having realized that these people know of some of the specific grants we make but only from a peripheral perspective. It is another small way that the Foundation can connect medical research to the larger public and share the enthusiasm and respect we have for this important work. ▀

— Lynne L. Garner, PhD



Lynne L. Garner, PhD  
Executive Director

## 2004 Annual Meeting and Reception to be held Wednesday, May 11, 2005 at the Mark Twain House & Museum in Hartford

Preceding the Donaghue Foundation Annual Meeting, selected Donaghue grant recipients will make a public report to the Trustees and their advisers on their research. There will be four short presentations, two during each session. You are cordially invited to attend and bring colleagues or friends who might be interested in the topics.

### Session I / 1:30-2:00 PM

- **The Donaghue Initiative in Biomedical and Behavioral Research Ethics** — Members of the Initiative will describe their research regarding human subject protection.
- **The Role of Epithelial Cells in Host Defense Against Pathogens** — Barbara Kazmierczak, PhD, Assistant Professor of Internal Medicine, Yale School of Medicine will present her recent findings.

### Session II / 2:15-2:45 PM

- **Sister Talk Hartford: The Hospitals & Churches Partnership to Improve Health** — Judith Fifield, PhD, Professor of University of Connecticut Health Center, will discuss the Sister Talk project.
- **National Patient Safety Foundation: Patient Safety** — Diana C. Pinakiewicz, Executive Director, will describe the NPSF research program and its collaboration with the Donaghue Foundation.

### 3:00-4:30 PM

- **Rima Rudd, ScD**, Senior Lecturer on Society and Human Development, Harvard School of Public Health is our keynote speaker. She will be discussing the issue of health literacy. Her topic is titled "To Confer, and to Conceal, Valuable Knowledge."

A reception will immediately follow the Annual Meeting. Tours of the Mark Twain House will be available for Donaghue guests during the reception. We hope you will attend. Please contact the Foundation to RSVP at [Office@donaghue.org](mailto:Office@donaghue.org) or (860) 521-9011.




“...Unsolicited grants are used in many charitable organizations. It may not be a large part of science funding, but it certainly fits a more mission-oriented foundation.”

### Donaghue Investigator Program

The Donaghue Investigator Program is a five-year, \$100,000-per-year award to investigators who have demonstrated an exceptional potential for an outstanding career in health research. Senior investigators may apply if they propose a substantial change in research direction.

As with last year's program, this year the Trustees will accept applications only in the fields of pain management, patient safety, injury prevention, the organization of health delivery services, complementary or alternative medicine, ethics of health care or research, or programs that are testing interventions to relieve suffering or prevent disease.

The application date for this program is noon on Thursday, April 28, 2005. Please contact Jacqueline Daniel, Program Administrator at [jacque@donaghue.org](mailto:jacque@donaghue.org). 

### The PBI Program (continued from page 1)

In its first years, the PBI program had two components: “Targets of Research Opportunity” (the heart of the program, then and now), aimed at individual projects, and “Focused Centers of Research,” aimed at the development of sustainable research programs at Connecticut institutions. Over the course of time the program has incorporated two additional components, separately identified because of their specific purposes within the overall framework. These are the “Knowledge at Work” program, aimed at dissemination of knowledge gained through research so as to promote actual use for practical benefit, and the “Trustee Initiatives” program, established as a method of occasionally spending small amounts on purpose-related endeavors that do not warrant independent merit review. The Trustee Initiative expenditures are quite small in relation to other Foundation grants and usually support collaborative projects of area foundations that generally advance philanthropic causes that complement Donaghue's purpose.

#### Basic Elements

The PBI program encourages interested scientists to invest in the development of complex collaborations by assuring them that the Foundation will work with them to develop a fundable project and they will be funded if the initiative passes scientific review. This approach is different from the usual practice of simply approving or disapproving an application proposed by an investigator. We feel that working with an applicant to attempt to accomplish research rooted in some of the more intractable health problems of the public is key to the success of the program. In reality, few investigators can afford to build innovative research projects tackling difficult public health subjects; it is too risky to invest the considerable amount of time and effort to build the science and community collaboration without a reasonable hope of that work coming to fruition. Without advance assurance, what is typically proposed is what *can* get done rather than what *needs* to be done.

Developing a Practical Benefit Initiative research grant involves three key elements. The first element, and perhaps the most

striking to researchers, is that applications are invited on specific topics identified by the Trustees, with invitations going to specific researchers who are known for their meritorious work in the area. (Of course, in order to be invited, the specific subject must warrant the Foundation's support and the invited proponent must be suitable for it.) This feature, combined with the Trustees' policy of funding Connecticut investigators, often means that the more usual process of soliciting and receiving many proposals has little value in the context of the PBI program, although there is nothing which rules out that process in an appropriate case.

Foundation-initiated grant projects are sometimes met with a questioning eye by scientists, but Sheilah Rostow, Senior Vice-President of Bank of America, one of the Foundation's two co-Trustees, notes that “unsolicited grants are used in many charitable organizations. It may not be a large part of science funding, but it certainly fits a more mission-oriented foundation. As a Trustee, I'm very comfortable with our mix of investigator-initiated and Foundation-initiated grants.”

“I know that some people are troubled by the Foundation actually seeking out investigators to develop projects, rather than the investigator seeking out the funding source and competing for the grants dollars,” says co-Trustee Ray Andrews. “While some believe the traditional model of peers selecting the investigators yields the best science, we are interested in yielding the *best benefit of research* by doing research.”

Once a research topic and team are developed, the second element in the program is the use of peer reviews for scientific merit. Although peer reviews are standard practice in research funding, some aspects of the PBI review process differ from those used in Donaghue's other programs. Because of the wide range of topics covered in the program, the Foundation relies on ad hoc panels selected for each specific initiative, including reviewers from the Foundation's two standing review committee when the subject matches the scientist's expertise. The reviewer's job is not to rate the application against competing proposals, but rather to focus on the one application under consideration.

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## Putting the Elements Together: The PBI Program in Action

*A quick glance at three PBI grants will help illustrate the processes used to create research projects which address a public need.*

### **Public-Private Alliance for Prevention.**

As its first foray into initiating research projects, the Foundation Trustees contacted Howard Bailit, DMD, PhD, of the University of Connecticut Health Center. Dr. Bailit was one of the science advisers with whom Trustee Ray Andrews discussed his ideas for the Foundation to fund more results-oriented research, and someone who understood that Donaghue's mission was broader than simply funding research. The first of the Public-Private Alliance for Prevention projects, Easy Breathing, used the expertise of Michelle Cloutier, MD, to develop a study to test the effectiveness of a more standard approach to diagnosing and treating childhood asthma in clinical settings in Hartford. National experts reviewed the proposal and, when the project was funded, served on a steering panel that reviewed the study's progress and its initial results. The Donaghue-funded study has ended, but use of the guidelines developed through the project has been expanded from Hartford to several cities in Connecticut, and \$10 million of additional research on asthma treatment has been obtained from state and federal sources as a result.

**The Connecticut Collaborative for Fall Prevention.** Aware of the serious consequences of falls among the elderly, Ray Andrews and Sheila Rostow became interested in research by Mary Tinetti, MD, Yale School of Medicine, which demonstrated that falls could be prevented in a tightly controlled clinical setting. But most falls happen outside that environment; could this research be replicated in the community? A collaborative committee of the Connecticut Hospital Association and the Connecticut Association for Home Care worked with Dr. Tinetti to develop a project to answer this question. The Connecticut Collaborative for Fall Prevention, started in 2000, is the result. Dr. Tinetti and Dorothy Baker, PhD, Yale School of Public Health, designed a quasi-experimental study to compare

rates of falls in two regions of the state, one getting the fall prevention intervention focused on providers and elderly patients. Tinetti and Baker worked for a year to develop the proposal for science review and to establish the collaborative — which initially included a dozen or so providers but has grown to more than a hundred. Now in its fifth year, the study has begun exploring the role that organizations play in embedding and reinforcing fall prevention practices.

**Donaghue Initiative for Biomedical and Behavioral Research Ethics.** The challenge to increase knowledge about protecting human research subjects is a good match for Donaghue's interest in the ethics of health care and research. Discussions with members of the Yale Bioethics Project to develop an initiative in this area took place over the course of more than a year during 2000-2001. Donaghue and the project leaders shared a strong interest in linking academic work to the state's Institutional Review Boards, which have the job of protecting research subjects. The funding agreement was written to ensure certain activities are completed, but with enough flexibility to allow unanticipated and productive avenues of inquiry. The Initiative is in its second year and has conducted several seminars and conferences open to the public on various topics related to research ethics.

While PBI projects generally take many months of planning and coalition-building before they come to fruition, the Trustees believe the payback in practical benefit is well worth the effort. PBI grant monies not only help improve clinical practices surrounding important public health issues — i.e., impact people's lives *today* — but also seed the development of long-term programs and future research support from other funders. The PBI program creates projects which are results-oriented and transportable — and *that* bodes well for practical benefit. ▀

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### The PBI Program (continued from page 4)

Reflecting the activist nature of the PBI funding program, this review process is designed to fix research design flaws by giving the applicant a chance to respond to the critique and suggest adaptations to problems noted by the reviewers.

A final, and very important, element of the program is the use of detailed funding agreements written specifically for each initiative. These agreements, negotiated with the invited proponent, contain specific requirements expressing the key elements of the Foundation's goals with respect to the study, such as collaboration, sustainability or dissemination beyond academic writing. Most of the larger projects have an ongoing relationship with the Foundation through the use of a steering committee, advisory committee or similar mechanism, and these are also specified in the funding agreement.

### The Future of PBIs

The development of new PBI projects was suspended during 2003 and 2004, based on the Trustees' decision to slow spending temporarily to regain principal strength, but new applications are now in development.

The program is now in its ninth year, and it seems well suited to some of the difficult issues that clinical researchers are grappling with today. Demonstrating an effective clinical or public health intervention is one thing, but embedding that change within the organization of health delivery services is another. This is in large measure the issue of *behavior* that the Foundation announced two years ago as a funding priority. The PBI program is well suited to address how successful interventions can be adapted to achieve benefit in the face of the complexities of community life and health care organizations, and be successfully diffused and sustained within the larger organizational structure.

In 2002, when the Trustees met with policy advisers to ask for their thoughts on how the Foundation should spend its temporarily reduced funding budget, one adviser answered by posing his own question back to the Trustees: “What program has produced the most practical benefit?” Based on the developing knowledge about health and health care, the incidental health benefits achieved through the research program, and useful knowledge acquired about funding research, the answer was the Practical Benefit Initiative program. ▀

## Donaghue Welcomes Two New Members to its Clinical & Community Health Issues Program Committee

**Dr. Adam Borgida** is a full-time Attending Perinatologist at Hartford Hospital, where he is Director of Maternal Fetal Health. He has been on the University of Connecticut School of Medicine faculty for the past 10 years and holds the rank of Associate Professor of Clinical Obstetrics and Gynecology. During that time he has been recognized twice with the CREOG National Faculty Award for excellence in resident education. He has also been recognized three times with the APGO Excellence in Teaching Award for undergraduate medical education. Dr. Borgida has authored and co-authored numerous papers and chapters and has presented his research at many national meetings. His current interests include fetal echocardiography, first and second trimester prenatal diagnosis, and ultrasonography.



**Dr. Mark Metersky** is Associate Professor in the Department of Medicine, Division of Pulmonary Medicine and Critical Care Medicine at the University of Connecticut School of Medicine. Since 1994 Dr. Metersky has been the Director of the Pulmonary/Critical Care Fellowship Program at the Medical School.



From 2001-2004 he was named one of America's Top Doctors (Castle Connolly) and in 2002 won the Alfred Soffer Research Award for best clinical research presentation at the American College of Chest Physicians Annual National Meeting. Dr. Metersky has authored and co-authored research papers, reviews, editorials and chapters in several journals. Since 1995, he has received numerous invitations to national and international meetings to present his research.

## Policy Advisory Committee Member Publishes *The Expert Guide to Beating Heart Disease*

We are pleased to announce that Donaghue Foundation Policy Advisory Committee member **Harlan M. Krumholz, M.D.** has just published *The Expert Guide to Beating Heart Disease — What You Absolutely Must Know*, released by Harper Collins.

Based on widely held expert opinion and national guidelines, this book explains:

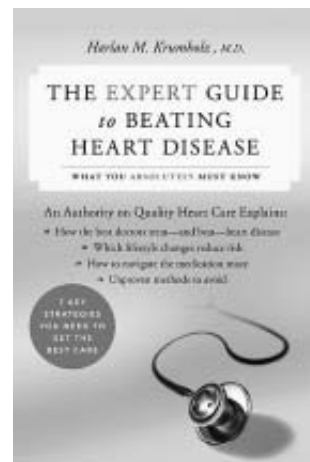
- How the best doctors treat — and beat — heart disease

- Which lifestyle changes reduce risk
- How to navigate the medication maze
- Unproven methods to avoid

In an interview with WebMD.com, Dr. Krumholz says, “One of the great problems we have in medicine today is in spite of our great gains in knowledge, [that] knowledge is not always made available to all the people who could benefit from it. I wrote this book to put the critical, most essential infor-

mation in people’s hands and to make that information easily understandable so that they can use it to get the very best care and give themselves the best chance of beating heart disease.” (To read the entire interview, see [http://my.webmd.com/content/chat\\_transcripts/1/106037.htm](http://my.webmd.com/content/chat_transcripts/1/106037.htm).)

Dr. Krumholz is a Professor of Medicine and Epidemiology and Public Health at Yale University School of Medicine. *The Expert Guide to Beating Heart Disease* may be



purchased at Amazon.com, Barnes & Noble and other prominent booksellers. ]

## DONAGHUE DICTIONARY

### prac'ti.cal'ity

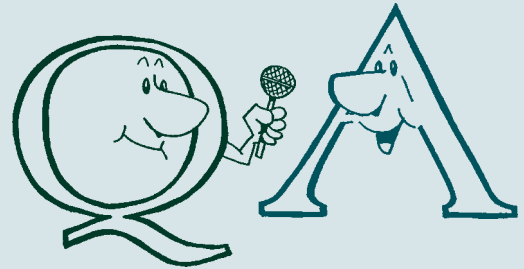
**P**racticality is the third of four stated Donaghue Foundation values, selected because of the emphasis placed upon it in Miss Donaghue’s will — and in her life. “Practical,” in common usage, means useful, as opposed to any number of other adjectives someone other than Miss Donaghue might have attached to the “benefit” she charged her Trustees with pursuing through the Foundation.

Serendipity, whereby there may be gained an incidental, accidental benefit in the course of the pursuit of pure knowledge, seems to be a primary value of basic science, which certainly is a noble pursuit and merits substantial funding support. It’s not quite the same for Donaghue, however, with our benefactor’s preference for practicality. The search for a direct route to beneficial results from research is at times a harder course for a funder, but it’s the right thing for Donaghue to do. ]



## ASK THE TRUSTEES

**QUESTION: Is Donaghue concerned that awarding huge grants without a competitive review can be interpreted as giving favored people an unfair advantage over others equally or better capable of completing a project?**



In a word, yes. We recognize that outsiders may misinterpret our processes as denying some interested researchers an opportunity to compete for grant money. We understand that persons lacking full information on any particular project and its development might be suspicious about the basis for “favor.” But we’re convinced that the overall benefits of a program structured like our PBI program outweigh that public relations disadvantage. Where we can realize the benefits through a competitive approach we will do so, but our determination to prompt research into important areas not being addressed is paramount, and in the PBI projects we’ve funded in the past it was not feasible to invite all comers. We had specific purpose-driven goals requiring a substantial commitment by a proponent just to pass a science review (e.g., assembling a large team of collabo-

rators to prove capacity for doing the work). We had many challenging performance requirements imposed after months of negotiation. We didn’t need a comparison of several applicants — in some cases there weren’t any realistic alternatives — in order to be satisfied that the project would be conducted in a high quality manner. And we haven’t wanted simply to foster a “follow the money” mindset among researchers; we’ve sought out scientists with a clearly demonstrated capability and motivation for pursuing a subject.

Donaghue doesn’t set about fostering misconceptions, but when they are a side effect of our pursuing an important goal, we don’t shy away from the pursuit simply to avoid the side effect. “Be with caution bold” means balancing caution and boldness. ■



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