



Practically Speaking

NUMBER 23, SUMMER 2007

Beyond Eureka!

Donaghue Annual Meeting and Conference Focuses on Turning What We Know into What We Do

On May 10, more than 200 people convened at the Hilton Hotel in Hartford for the Donaghue Foundation's Annual Meeting and Conference. Like last year's gathering, the 2007 conference — Beyond Eureka! — explored the challenges and opportunities in moving rigorous medical research into the realm of health care delivery and practice. The perspectives of keynote speakers and panelists represented the philanthropic, health systems and business sectors, as well as academia. "People of different perspectives engaged in seeking the same ultimate end of practical benefit to human life — some steadily following a long and winding road and some boldly darting across a shortcut — need to exchange views so they can better under-

stand one another, the complexity of the issues, and the importance of pushing steadily on all fronts," said Donaghue Foundation Trustee Ray Andrews in his introductory remarks. "The constructive collision of these various perspectives — and the lessons each can learn from the other and we can learn from them all — promise to be fascinating."

"Speeding Drug Discovery and Development: Breaking Down Barriers between the Ivory Tower and Corporate Boardroom" was the title of the presentation by the conference's first keynote speaker; **Scott Johnson**, founder and president of the California-based Myelin Repair Foundation (MRF),

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Made to Stick

With generous sponsorship from the Bank of America, the Donaghue Foundation and the Connecticut Council for Philanthropy are offering a presentation and workshop at the Hartford Club on Tuesday, November 13, 2007 featuring Chip Heath, co-author of *Made to Stick; Why Some Ideas Survive and Others Die...* Registration for the workshop is limited, so please register early! Visit our website at www.donaghue.org or www.ctphilanthropy.org for more information. ▢



FROM THE TRUSTEES

“Knowing is not enough; we must apply. Willing is not enough; we must do.”

This quotation from Goethe, which opens the Institute of Medicine’s 2001 report, *Crossing the Quality Chasm*, could easily serve as the Donaghue rallying cry. At the Foundation’s May 10th Beyond Eureka conference — highlighted in the feature article on page 1 — we continued our march to the drumbeat of Knowledge Uptake. We’ve been focusing our efforts for some time now on producing or prompting the assimilation of scientific advances that are “ready for prime time.” As we’ve done so, we’ve become increasingly frustrated by the slow and unsteady pace at which new knowledge finds its way — if at all — into use. Researchers as a rule are not equipped themselves to move their research results from publication to practice. Except for profitable development of new drugs or devices, there’s no industry sector dedicated to ending the disconnect between what we know and what we do. Adept as scientists are at mining nuggets of knowledge, they sometimes overlook what in Donaghue’s view is the ultimate purpose of their efforts: practical benefit to human life.

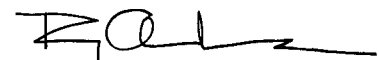
Albert Einstein once noted that “Perfection of means and confusion about ends is a hallmark of our age,” which calls to mind the fabled knights in shining armor of centuries ago, who polished their martial arts skills and then rode boldly abroad redressing human wrongs and chivalrously rescuing beautiful damsels threatened by fire-breathing dragons. It was never entirely clear which was the chicken and which was the egg for these intrepid fellows — was their first priority the rescue of damsels, or was it the rush obtained from slaying fierce dragons, with an occasional rescue being simply an incidental benefit of their sport?

And then, a bit closer in time, there is

the trenchant *New Yorker* cartoon a few years back that depicted two doctors immersed in conversation in a hospital hallway, with one saying, “The practice of medicine would be really great if it weren’t for the patients.” Confusion about ends.

Our May 10th conference speakers stressed the importance of speeding up the processes of both discovery and effective dissemination. The Donaghue staff is hard at work every day on these goals — and also on the discovery of ways to assist both clinicians and the public in actually using what they come to know. A recent Foundation success in this area was the accomplishment of a concrete “first” for both Donaghue and one of its funded research teams. As described more fully in the executive director’s report, the Connecticut Collaboration for Fall Prevention team, assisted by Foundation staff and a Foundation-funded consultant, has recently concluded an agreement with a health services vendor to embed in health plans the proven techniques of the Fall Prevention project.

It is commonplace in our world to hear laments about new knowledge simply “gathering dust on bookshelves in academia.” We at Donaghue, and others similarly inclined (we hope their ranks will swell) — must move that knowledge off those shelves — and then make sure it doesn’t just gather dust on a clinician’s shelf or on the coffee table in someone’s living room. ▢



Raymond S. Andrews, Jr., Trustee



Sheilah B. Rostow
for Bank of America, Trustee

The Foundation’s Purpose, from Article Fourteenth of the Will of Ethel Donaghue:

The Foundation established hereunder is created and shall be operated solely for the purpose of providing financial assistance for research in the fields of cancer and heart disease and/or other medical research to promote medical knowledge which will be of practical benefit to the preservation, maintenance and improvement of human life.

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

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New Goals, Same Purpose

An important piece of business that was completed last year was reviewing and revising the Foundation's vision and mission and its goals and values (see box below). The vision and mission statement represent the Trustees' hopes for the larger impact that the Foundation might have based upon Ethel Donaghue's stated purpose. The goals serve as guideposts for the day-to-day work of the Foundation staff. Nancy Yedlin and I are fortu-

nate to have many opportunities to get involved in interesting projects, speak with people doing fascinating work, and attend horizon-broadening meetings and conferences. We use the Foundation's goals to keep these opportunities focused on those that serve to achieve the Trustees' mission.

Through a redesign of the Donaghue Investigator program, we are working on the *continued next page*

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Patrick and Catherine Weldon Donaghue Medical Research Foundation

Vision Statement: We envision constant improvement both in people's health and in the way research is converted into practical benefit.

Mission Statement: We will give the vision of Ethel Donaghue its best expression and thereby honor her and her family as an engaged, imaginative and collaborative participant in the process that begins with rigorous health research and ends in realized health benefits.

Goals:

- Promote knowledge uptake of health research into the realms of health care delivery, practice and policy.
- Strengthen and widen understanding of the Foundation's mission by other people and organizations who have the potential to improve health.
- Ensure that our grantmaking programs are structured to support rigorous research that more directly leads to a positive impact on health.
- Support promising researchers whose work specifically encompasses the principles of knowledge uptake.
- Create networks and collaborations to test innovative ideas related to health research and health outcomes.

Values:

- Steadfast in our commitment — The purpose entrusted to us by Miss Donaghue in her will is an immutable mandate for us, and we will be unwavering in our resolve to give her vision its proper meaning and best expression in a context of changing facts and conditions.
- Principled and practical — Guided by the balance between Miss Donaghue's lofty vision and her common sense practicality, we will ground our execution of her trust upon solid principles while applying them in ways that focus on the practical. While being ready to risk in our search for ways to make a difference in health, we will maintain the integrity and the prudence that mark the work of a fiduciary.
- Engaged to the point of effect — Our method of operation will be active engagement with those involved in seeking to benefit human health. As a complement to our research funding we will collaborate with others to promote uptake of health knowledge. Somebody should be seeing to it that scientific advances are actually taken up by users — and we are somebody.
- Respectful and reflective — We respect not only Miss Donaghue's intent but also, through an integration of ethics and science, the human subjects of research and those with whom we work for the betterment of human health. We will strive to balance: our pursuit of new knowledge with its translation into actual use; scientific exploration with thoughtful reflection upon the implications of discovery; and the gaining of knowledge with the pursuit of wisdom to temper its use for practical benefit to human life.

— Revised January 2007

Clinical and Community Health Issues Reminders

The next two application deadlines for the Clinical and Community Health Issues grant program are **noon on Friday, September 7, 2007 and Thursday, January 24, 2008**. In order to apply you must have been invited based upon a submitted letter of intent. Letters of intent are reviewed at intervals throughout the year. In 2007, dates remaining for submitting an LOI that would enable you to meet the January 2008 application deadline are August 31, and October 26. Letters of intent may be no more than two pages, on institution letterhead and signed by the Principal Investigator. **Procedures for submitting a letter of intent and all application materials are on the Foundation's website www.donaghue.org**. For further information, you may call Nancy Yedlin at the Foundation office at (860) 521-9011. ▀

Executive Director's Report (continued)

Foundation's goal of ensuring that its grant making programs are structured to support rigorous research that more directly leads to a positive impact on health. This fall will be the last year for the selection of grantees from the Donaghue

Investigator program, which started in 1997 and was designed to be a ten-year program. Of course, we will continue to support the

program's grantees in their continuation years through 2012. By that time, the Foundation will have invested close to \$18 million in this program by awarding grants to approximately 30 of Connecticut's most promising medical researchers. Over the years, feedback from a

number of sources has indicated this is an important part of the Foundation's spending. Therefore, the Trustees would like to establish another award program that, like Donaghue Investigator, is focused on a researcher's career rather than on one specific research study. We expect that this new program will more explicitly leverage the ongoing research findings to improve health and therefore to move the Foundation closer toward achieving its mission.

To do this redesign we are beginning to discuss different program characteristics and attributes for what we are referring to the "Donaghue Investigator replacement program." By first of October we expect to have one or two program models for the Trustees to consider, and an announcement of the new program will be possible in early winter.

The Trustees would like to establish another award program that, like Donaghue Investigator, is focused on a researcher's career rather than on one specific research study.

Considering another Donaghue goal — promoting the knowledge uptake of health research into the realms of health care delivery, practice and policy — we are excited to report on recent developments with the Connecticut Collaboration for Fall Prevention (CCFP), a seven-year, \$3M signature grant by the Foundation to Yale researchers on preventing falls among the elderly. Their findings have prompted international interest in the provider arena and they have been

called on as experts to help lawmakers craft legislation in Connecticut that will embed research-based fall prevention screening and training programs into services for the elderly.

The Foundation has been active in assisting the Yale group to secure revenue that will sus-

tain their ability to do their outreach and education work after the research funding ends. By authorizing the Yale project to use some of its grant funds to work with a business consultant, we provided support that enabled the CCFP to successfully execute a three-year non-exclusive agreement with LifeCare, Inc a work-life company that serves over 4.5 million lives through 1,500 client companies. LifeCare, Inc helps workers achieve a productive work-life balance by providing a host of services including assistance with caring for aging parents.

We welcome hearing from Donaghue grantees about their efforts, including successes, failures and "lessons learned," in moving their research findings into the realms of clinical practice, health systems or policy. ▀

Clinical and Community Health 2007 Spring Awards

Principal Investigator	Project Title	Institution	Award Amount
Vinod Srihari, MD	Specialized Treatment Early in Psychosis (STEP)	Yale School of Medicine	\$239,502
Thomas Gill, MD	Enhancing Independent Bathing in Community Living Elders	Yale School of Medicine	\$239,999
Nina Kadan-Lottick, MD, MSPH	Survivors of Cancer in Adolescent and Young Adults	Yale School of Medicine	\$240,000

Beyond Eureka! (continued from page 1)

a nonprofit research organization created in 2002 for the sole purpose of accelerating the rate of discovery and translation of myelin repair drug targets leading to treatments for multiple sclerosis (www.myelinrepair.org). “If you told me five years ago that I would be working on medical research with a nonprofit, I would have thought you had lost your mind,” said Johnson, a highly successful businessman who was diagnosed with MS 30 years ago.

So why change careers after heading up three startup companies in the Silicon Valley? “In 2001, I was reading *Business Week* and I saw a news brief on myelin repair and MS,” recalled Johnson. “I had never seen the words ‘repair’ and ‘MS’ in the same paragraph before, so I contacted a researcher at Yale and found out two things: that myelin repair is possible in the central nervous system and that the medical research process is incredibly inefficient.”

Johnson’s discoveries led to the 2004 founding of MRF and the development of a unique, outcome-driven research model — known as Accelerated Research Collaboration (ARC)TM — to discover and develop myelin repair treatments. While the ARC approach is not groundbreaking in the business world, it turns scientific research on its head by “replacing traditional investigator-driven research with a model that coordinates the efforts of multiple investigators into a highly collaborative, outcome-focused effort. As noted in a September 2004 *Wall Street Journal* article on MRF: “To make progress against this disease, you have to do things differently.”

In his remarks, Johnson cited several examples of why “scientific research does not equal drug discovery,” including the lack of coordination between scientific disciplines, the isolation of basic science from patient needs, and the lack of disease-based research roadmaps, a factor that was a revelation to Johnson. “I assumed somebody out there had a plan to tackle MS,” he said.

Essentially, the ARC model channels the talents of some of the world’s leading neuroscientists who approach the study of myelin from five different perspectives — immunology, genetics, developmental biology, molecular biology and proteomics.



“Half the money we have raised to date comes from folks with no connection to MS. They are betting our model will work for them.”

— Scott Johnson, Founder and CEO, Myelin Repair Foundation

“We sought out the best scientists in their respective fields and asked if they would be willing to work as a team on a coordinated research plan,” said Johnson, who recently was named one of *Scientific American’s* “Top 50” worldwide for business, science and policy leadership. “After they all agreed that everything of significance was to be shared, a business plan was developed.”

According to Johnson, as a result of that business plan and ARC model, MRF is on a path to license its first drug target in 2008 — a dozen years faster than the traditional investigator-driven approach. “In just two-and-a-half years, we have filed eight new patents, identified a dozen new targets (two of which are ready for validation) and raised \$16.5 million. Collaboration is ongoing and constant, and principal investigators are publishing at even a more rapid rate...As a nonprofit we don’t care who gets there first. We just want to get there as quickly as possible. You can’t let life take you where it wants to go.”

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Donaghue Adviser Joins Global Filariasis Eradication Effort

Donaghue Policy Adviser and Donaghue Investigator review committee chairperson **TV Rajan, MD, PhD**, Professor of Pathology at the University of Connecticut Health Center, has recently joined the World Health Organization’s Global Filariasis Eradication Program as an expert panel member. Lymphatic filariasis is a parasitic disease that is a leading cause of disability in many lower income countries and therefore has a significant negative impact on public health and economic growth. WHO’s eradication plan for lymphatic filariasis combines both treatments to block the human-to-human transmission of the disease and strategies to prevent the occurrence of the disease. Dr. Rajan’s laboratory has laid the foundation for the possibility of identifying very young children who are susceptible to the disease and then treating them prophylactically. Dr. Rajan is hopeful that with these efforts “we can eliminate this disease from the face of the earth.” ▣

Patient Safety Research Program

Applications were received this May for Donaghue's patient safety research program. After reviewing 39 letters of intent, the Foundation received 17 applications from acute care hospitals in five New England states. As required by the program, all of the research topics focused on the role in leadership in improving patient safety. Eight hospitals have been named as finalists, and in September each will provide to Foundation Trustees, staff and advisers a presentation on their research proposal. Final decisions on award winners will be made in October, and the research projects will start in January 2008. A listing of the finalists will soon be on the Foundation's website. ▀

Beyond Eureka! (continued)

Next to speak was **Michael Mustille, MD**, associate director for external relations with the Permanente Federation in Oakland, California and a senior advisor to the Council of Accountable Physician Practices (CAPP), whose presentation entitled, "Linking Integrated Delivery Systems for Rapid Learning: Putting Evidence into Practice" focused on models for accelerating the use of research into a different realm of health care — physician group practices.

Speaking primarily with his CAPP (www.amga.org/CAPP) hat on, Mustille focused on the ability of the accountable physician group model to aid in the transformation of the American health care system. "I hope to make two points today," said Mustille. "One is that we won't be successful in translating research into practical use until we make the health care delivery system more effective, efficient and accountable. Point number two is that organized delivery systems — like the multi-specialty group practices (MSGP) represented by many CAPP member organizations — offer a very good opportunity to serve as a test-bed to determine effective delivery systems."

Mustille emphasized that MSGPs focus on an evidence-based approach to care, enhance the effectiveness of clinical trials, readily share knowledge and equipment among physicians, tend to have better clinical information systems through the advanced use of health information technology (HIT), and are more transparent in their performance and practice. "Organized multi-specialty practice groups are much more likely to use shared decision-making," he said. "There is no place to hide when you are practicing shoulder-to-shoulder with colleagues."

To demonstrate how organized delivery systems can speed up the application of research, Mustille shared the experience of Group Health Cooperative, which was able to rapidly translate the benefits of a groundbreaking heart study into improved medical treatment for its patients. "Just 15 months after the publication of the Heart Protection Study in the *Lancet*, Group Health...had placed new clinical practice recommendations into their clinical information system, developed educational materials for their



"We won't be successful in translating research into practical use until we make the health care delivery system more effective, efficient and accountable."

— Michael Mustille, MD,
senior advisor to the Council of
Accountable Physician Practices

physicians and patients, and redesigned important roles and tasks in their care teams. By comparison, some estimate that it takes an average of 17 years for innovations in medical care to disseminate."

A recent Rand Corporation study indicated that even when providers know what they are supposed to do to treat a particular condition, only 50 percent of physicians follow those guidelines. Mustille strongly believes that organized health care delivery systems — like the multi-specialty practice groups affiliated with CAPP — will play a critical role in increasing that 50 percent and, most importantly, improving patient outcomes by ensuring that research-based evidence is put into practice. "We see a real convergence of missions between CAPP organizations and the Donaghue Foundation," Mustille concluded.

Getting health care providers to be more effective, efficient and accountable is also a goal shared by the conference's last keynote speaker, **Dale Whitney**, vice chair

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Scenes from the day...



A box lunch was served between the morning and afternoon sessions.

Above left:
Conferees catch up
during a break.



Right: Trustees
Ray Andrews and
Sheilah Rostow
confer while Robert
Alpern checks his
notes.




Viewing the timeline...



Above and left:
Panelists fielded several
questions from the floor,
broadening the dialogue.

Welcome to New Foundation Employee

Anyone who calls the Donaghue Foundation has been hearing a new voice answering the phone. Wendy Vachon joined our staff in March 2007 as Administrative Assistant. She works 20 hours a week, and is in the office in the morning. When Wendy is not working in the Foundation office, she divides her time between both of her children who play a variety of sports year round. Wendy lives with her husband along with her son and daughter in East Hartford, CT. 



Beyond Eureka! (continued)

of the Leapfrog Group and past president of Bridges to Excellence (BTE) — organizations that partner with large employers in order to use their collective purchasing power and business acumen to drive the use of evidence-based medicine to improve in the delivery of health care services and their outcomes.

A veteran of more than 30 years with UPS, including 15 in the company's health and welfare function, Whitney opened his

remarks, which were entitled, "Purchaser-driven Best Practice: Our Role in Improving Patient Care," by emphasizing that purchasers have to be part of the solution to America's costly and inefficient health care system. "We are stuck in a 20th century health supply chain," he said. "Large purchasers believe three things: that the effectiveness and efficiency of the current system can and must improve dramatically; that the health supply chain must be transformed into a consumer-driven market; and that information technology and continuous process improvement are key agents for change — just like they are in business."

Whitney noted that more than 200 companies working with Leapfrog and BTE are using incentive and reward programs to improve health care systems. "Bridges has brought about a change in how medicine is practiced through the use of financial (and non-financial) incentives and an insistence that information be extremely visible. Patients see transparency as an indication that someone is a high-quality provider."

Whitney went on to emphasize that consumer-driven health care can bridge the gap

between research and practice by accelerating the uptake of clinical guidelines, aligning incentives to promote health behavior change, and by ensuring that consumers and purchasers value clinicians who use clinical practice guidelines and deliver evidence-based care. "Without incentives to examine and change the way medicine is practiced, little progress will be made."

Looking to the future, Whitney sees the convergence of HIT, the medical home model, genomics and personalized medicine as an

emerging opportunity to dramatically impact the effectiveness and efficiency of the health care delivery system. "We are going to discover cures that are simply too expensive for our current health care system," he said. "We must have the vision and system to look at health care on the basis of long-term value, not short-term cost. Large purchasers can — and should — play an important role in seeing that we get there."

After a box lunch and some catching up among those in attendance, the meeting reconvened to address a few business matters

and to listen to reactions to the morning's keynote speakers from two distinguished representatives of the academic world: **Robert J. Alpern, MD**, dean of the Yale School of Medicine, and **Peter J. Deckers, MD**, dean of the University of Connecticut School of Medicine and executive vice president for health affairs at the UConn Health Center with **Elizabeth Bradley, PhD**, professor of public health and director of the Health Management Program in the Division of Health Policy and Administration at the Yale



"Information technology and continuous process improvement are key agents for change — just like they are in business."

— Dale Whitney, Vice Chair,
The Leapfrog Group and Past
President, Bridges to Excellence



After lunch, Elizabeth Bradley, PhD (left), professor of public health and director of the Health Management Program in the Division of Health Policy and Administration at the Yale School of Medicine, introduced deans Alpern and Deckers, who reacted to the issues raised in the morning session from their vantage point in the academic world. Ms. Bradley then moderated a panel discussion and fielded questions from the audience.



“In academia... how do you balance being goal-oriented with allowing for creativity.”

— Robert J. Alpern, MD, dean of the Yale School of Medicine



“Why are we all here today if we are doing so well? Because we aren’t doing so well when it comes to prevention.”

— Peter J. Deckers, MD, dean of the University of Connecticut School of Medicine and executive vice president for health affairs at the UConn Health Center

School of Medicine, moderating the discussion and audience’s questions.

In his remarks, Alpern, a board certified nephrologist who has conducted groundbreaking research on the regulation of kidney transport proteins, reviewed how Yale Medical School currently undertakes research to improve patient care using the traditional Basic – Translational – Clinical Research Cycle. He added, however, that in October the School of Medicine had been given a \$57.3 million Clinical and Translation Science Award by the NIH, part of a nationwide initiative to transform how researchers move laboratory discoveries into human studies. “We are excited about the grant’s potential to enhance continuity between basic research and clinical research,” said Alpern. Alpern went on to say that in the academic world the focus has not been particularly goal oriented. “I was struck by Scott Johnson’s comment that in business you need a plan. In

academia, we thrive on academic freedom, so the question is, how do you balance being goal-oriented with allowing for creativity and free expression... Those are the challenges those of us in academia face in trying to make all of this happen... I will be watching with interest to see how the MRF model works.”

Peter Deckers began by raising the following: “There has been a staggering revolution in health care research and delivery in my 40 years in medicine... We treat disease and we do it very well. We teach all of this to our medical students and we do it very well. So why are we all here today if we are doing so well? Because we aren’t doing so well when it comes to prevention. The question is: How and when will we more effectively and efficiently apply what we learn and know?”

To drive home his point, Deckers, who remains active as a general surgeon, cited

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Credit Where Credit Is Due

At the Foundation's annual meeting, special recognition was given to the following advisers celebrating milestone anniversaries with the Donaghue Foundation:

Katherine C. III, MD (10 years); **George C. Hastings, Esq.** (10 years); **The Hon. Alvin W. Thompson** (10 years); and **Harlan Krumholz, MD** (5 years).

"We thank them and all the members of our advisory committees for their unselfish and timeless dedication to the Foundation," said Sheilah Rostow, Senior Vice-President of Bank of America, Foundation Trustee.

Beyond Eureka! (continued)

"mind-boggling" problems that appear in hospital settings, including MRSA staph infections, which kill thousands of patients every year. "We know that hand hygiene and environmental cleanliness prevent these infections," he said, "but having that knowledge doesn't change behaviors. Physicians practice proper hand hygiene only 30 percent of the time and nurses only 60 percent of the time. Their excuses are too numerous to count. Why is change so difficult even when

we know it works?" Deckers emphasized that changing behaviors must require the engagement of "a whole lot of people," including patients and their families.

In concluding, Deckers noted that most academics lack the business sense of people like Scott Johnson. "Business sense is what is going to be needed in academic medicine if we are to bridge the gap (between research and practical use). Most of us have never had that type of training."

Will feedback on this year's conference lead to Beyond Eureka, Part III? Stay tuned. ▮



Donaghue Foundation staff and trustees (front row) pose with speaker-presenters. From left to right: Nancy Yedlin, Peter Deckers, Sheilah Rostow, Robert Alpern, Ray Andrews, Michael Mustille, Lynne Garner, Scott Johnson, Wendy Vachon, Dale Whitney.

Donaghue Nutrition Research Grants

Each year the Donaghue Nutrition Research Initiative at the University of Connecticut Health Center provides \$100,000 in grants for new and meritorious clinical research on the impact of nutrition to prevent or reduce disease and to achieve and maintain optimal health.

Recipients of the 2007 awards are Richard Bruno, PhD, Department of Nutritional Sciences, University of Connecticut for "Metabolism and Bioavailability of Dietary Soy Isoflavones in Postmenopausal Women" and Jeff Volek, PhD, RD, Department of Kinesiology, University of Connecticut for "Effect of Varying the Fat Composition of a Carbohydrate Restricted Diet."

An RFA will be available this fall for the 2008 awards. For further information on the program, contact Anne Kenny, MD (kenny@uchc.edu) or the GCRC at the University of Connecticut Health Center. ▮

Donaghue Investigator Leads Development of the Crohns & Colitis Foundation's (CCFA) National Pediatric Education and Research Agenda

Francisco Sylvester, MD, a 2003 recipient of the Donaghue Investigator award, which provides nearly \$600,000 over a five-year period to support the research program of promising Connecticut-based researchers, is a member of the National Board of Directors of the Crohns and Colitis Foundation and is chair of their section on pediatrics. This committee is involved in all of the CCFA pediatric education programs and is currently in the process of developing a pediatric research network, which will enable multiple collaborative centers to study important research questions specific to pediatric IBD.

The CCFA currently invests approximately \$14 million in research programs. Dr. Sylvester held a CCFA Senior Research Award in 1998-2000 for his work on the "Pathophysiology of Bone Loss in IL-10 Knockout Mice with Colitis." With Donaghue funding he studies calcium uptake and bone loss in children.

Dr. Sylvester also serves as the academic director of the Kids' Center for Bone Health and a pediatric gastroenterologist with Connecticut Children's Medical Center, Digestive Diseases & Nutrition Division. **D**

DONAGHUE DICTIONARY: risk

The dictionary defines "risk" as simply the possibility of loss or injury — exposure to a hazard or danger. The word "risk" is used all too cavalierly, sometimes becoming a scare factor instead of a guide to prudence.

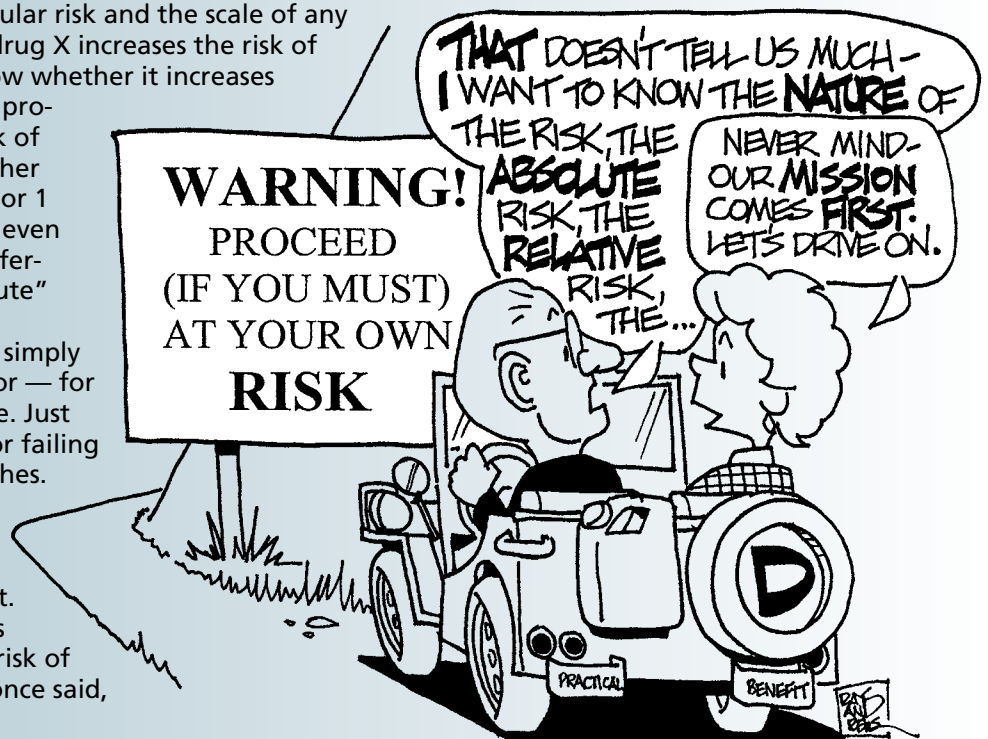
When one is described as being "at risk," does it mean minimally, marginally, overwhelmingly...? That makes a lot of difference in a world that's by nature not risk-free.

Though perhaps risk is usually thought of in a negative sense — "risky behavior," "risky investments," and "proceed at your own risk" come quickly to mind — life wouldn't be very interesting, or foundation work very challenging, in the absence of it.

In the world of medical research, the term "risk factor" — something that creates, suggests, or perhaps increases a hazard — is ubiquitous (maybe we'll do that word in the next newsletter). With so much made of risk factors, it would be helpful if the public understood the scale of magnitude of any particular risk and the scale of any increase in risk. For example: If drug X increases the risk of a heart attack, shouldn't we know whether it increases it .001% or 100%? If behavior Y produces a 100% increase in the risk of cancer, shouldn't we know whether the risk being increased is 1 in 2 or 1 in 1,000,000? How many people even know the meaning of, or the difference between, the terms "absolute" and "relative" risk?

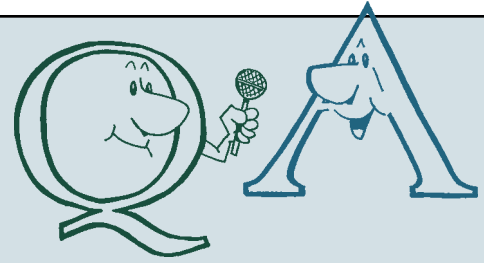
In Donaghue's world of risk, simply being a foundation is a risk factor — for less than exemplary performance. Just being a trust is a risk factor — for failing to carry out the benefactor's wishes. We at Donaghue welcome these risks. We believe in appropriately risky behavior. We're comfortable outside the zone of comfort.

In a world where discovery is what it's all about, the greatest risk of all, as songwriter Harry Chapin once said, is being afraid to take a risk. **D**



ASK THE TRUSTEES

QUESTION: The Foundation seems very focused on issues of knowledge uptake these days. Won't this involve a substantial commitment of Donaghue money and, if so, are there problems with a research foundation spending its money on things other than research?



ANSWER: A very timely question, given the direction the Donaghue Foundation is headed. The Foundation certainly is focused on knowledge uptake and recognizes all too well what a seeming departure it is from a traditional view of research and research funding. What's important to bear in mind is the Trustees' bedrock targeting of practical benefit — and the fact that research alone doesn't come close to producing it. Donaghue is all about promoting benefit, not simply research, and it's clear that somebody needs to be doing something about the huge gap between discovery and benefit. Uptake is what it's all about. So, to answer the question...

First, the dollar investment we plan to make over the next few years to investigate and advance knowledge uptake is not substantial, certainly not in comparison to either our research funding (about 1.5% of it) or the benefit we hope to produce, either directly, by leveraging

and collaborating, or — believe it or not — by motivating others to follow our lead.

Secondly, as to whether it's in our power to divert money from straightforward funding of scientific studies, it's critical to note the latitude — and therefore responsibility — Miss Donaghue gave her trustees to figure out how best to perform a public function with her money. She didn't say "Make research grants only." She gave us discretion, and we'd be remiss in our duties if we simply took a narrow, "safe" approach to spending and thereby abetted the mere accumulation of knowledge, without a thought — and a serious effort — about translating it into results beneficial to people. We can and we should and therefore we will invest in learning about and accomplishing the absorption and utilization of the knowledge about health that already exists or that our funded researchers produce. ▣



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