



Practically Speaking

NUMBER 22, FALL 2006

From Discovery to Action

Annual Meeting and Conference Focuses on Putting Knowledge Into Practice

More than 150 people gathered in the impressive halls of the Connecticut Convention Center on May 10 for the Donaghue Foundation's annual meeting. In combining the usual business of its annual progress report and recognition of grant recipients with a full-day conference program focused on bridging the gap between science and public health, Donaghue enjoyed a "Eureka!" moment in its 14-year mission to promote practical benefit to human life. As Lynne Garner, PhD, Executive Director, said, "Knowledge At Work" has been an important idea of the trustees for several years. As part of our recent five-year plan, they recognized the Foundation needs to learn how to do more in this area. This conference is one response to that mission."

Bringing together dynamic panelists with diverse specialties in research activism, social marketing and journalism, the program urged participants to connect the dots between scientific research, the communication of new discoveries that result, and "health knowledge uptake" by clinicians, institutions and individuals whose practices and behavior choices ultimately influence public health.

As Donaghue Foundation Trustee Ray Andrews said in his opening remarks, "It's fascinating to discover something new, to be the first person on the


planet to grasp a new fact. That tantalizing allure, I suspect, is what drives the scientific community to work to uncover more and more secrets. But what becomes of the accumulation of the discoveries?

"What needs discovery is better ways of putting new knowledge to useful work. I am haunted by the vision of countless glittering nuggets of new discovery piled up in the mine from which they have been extracted at great cost, with nobody getting about the business of carting the nuggets to town where their value can be realized. At Donaghue, we keep

looking for ways to get these precious nuggets down from Mount Discovery, down from Eureka Mine, to the Town of Practical Benefit."

Before the panelists began their presentation, Ms. Garner introduced the 2005 grant recipients, "the ones who are currently very hard at work in the mines," to

borrow Andrews' metaphor. The class of honorees — many of whom were present to be recognized — included nine recipients of new grants under the Clinical and Community Health Issues program, as well as two recipients of research grants under the Practical Benefit Initiatives program. (For a complete list of grant recipients, see the 2005 annual report, available on the website or by calling the Donaghue office.)



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— Ray Andrews, Trustee

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Clinical and Community Health Issues Letters of Intent

There is one more opportunity this year for letters of intent for the Clinical and Community Health Issues program to be reviewed, the first step in submitting an application to the program. Letters of intent must be received by the Foundation office by December 16 in order to be eligible for the January 25, 2007 submission deadline for grant applications. Procedures for submitting a letter of intent are on the Foundation's website (Donaghue.org), and for further information you may call the Foundation office at (860) 521-9011.

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

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

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

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

From reception to conference: the evolution of the Donaghue annual meeting

From the opening remarks of Trustee Ray Andrews

The Donaghue Foundation began with a conventional acceptance of the primacy of serendipity in scientific endeavor, with a focus on basic research. Careful study of the language of Miss Donaghue's will — and in particular, the choice of the expression "practical benefit to the preservation, maintenance and improvement of human life" — made it clear that we should aim at real solutions that would show benefit to people. As a lawyer, Miss Donaghue knew how to choose, and use, words. And we took her words very seriously. We spent years fine-tuning our own understanding of what practical benefit is, or can be.

Miss Donaghue urged the Trustees to pursue practical benefit in bold and imaginative ways, and this we've been hard at work doing for 14 years now, concentrating on the use of initiative to found or support health studies that *but for our interest* might not be done because of the priorities of other funders. The Donaghue Foundation has now invested over \$64 million in research, almost all of it in Connecticut. That's \$11 million more than Ethel Donaghue started us out with.

We realized early on that basic science alone wasn't going to satisfy Miss Donaghue's purpose. New knowledge in the laboratory, or in the pages of a scientific journal, weren't the answer to practical benefit. So we focused on programs in applied research, addressing actual clinical or public health issues. And we focused on knowledge in useful forms in the hands of users.

Then we came to realize how hard it is to transfer knowledge, both to the user, and to a form understandable by the user. We concluded that, even with knowledge in hand, users (meaning both practitioners and the public) are

obstructed by formidable barriers — of inertia, of habit, of human nature — from adopting practices and making changes that will produce practical benefit. It shouldn't take an average of 17 years, for instance, for proven therapies to become common practice; we shouldn't see that patients in "the best health care system in the world" receive recommended therapies only 55% of the time.

So we've been focusing lately on two things: 1) the necessary link between knowledge and behavior; and 2) the need for the Foundation to take direct responsibility for moving knowledge not only from the journals to the street, but also over that behavior barrier

that separates us from the benefits that can be realized from the effective use of scientific knowledge. We've made a commitment to "health knowledge uptake," and to mastering ways to produce effective uptake that will advance our bedrock target of practical benefit to human life.

Fourteen years ago, our annual meeting started as a reception to honor grant recipients. We later added poster sessions and presentations about research, telegraphing our intentions through our annual report and trustee remarks. Now we've progressed to the point where the conference — a gathering of experts engaged in a dialogue about moving from discovery to action — is the focal point of our gathering, with a few bits of annual meeting business interspersed throughout. It's about progression, and connections, and our target of practical benefit. It's about getting the results of research out of the labs and journals and into the practices and behaviors of the practitioners and the public. ▣

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What I Did Last Summer

We don't take a summer vacation at the Foundation office, but the phone seems to ring less frequently, so there is an illusion that it is a different time of year. But the Donaghue Foundation's summer was truly notable this year due to some fascinating visits we had with representatives of two other medical research foundations.

In June we had a meeting with Rusty Bromley, COO of the Myelin Repair Foundation (MRF), and in July we met with Kathy Giusti, CEO and founder of the Multiple Myeloma Research Foundation (MMRF). Both of these meetings were open to our science and policy advisers and invited guests. In August we also met with Scott Johnson, the founder of MRF. These two foundations are different from Donaghue in that they fund research for a specific disease, but we were interested in learning about their new models for funding research and in considering what aspects of these models Donaghue could adopt.

The founders of these organizations don't come from science or academia — they're from the business world. They use the tools and experiences of business to frame their approach, and they have no reverence for the NIH model of research used in academic medicine. These foundations hand pick the best scientists in their field and with them develop a research agenda based on specific goals and timelines — for example, develop a target for myelin repair in five years. With this plan in hand, they “hire” scientists to conduct the studies in a highly collaborative network. Collaboration to these folks means monthly phone conferences with their funded researchers and science advisers to check progress against goals, agreements

among researchers to share data immediately — even before publication — and contracts and intellectual property agreements among university researchers and pharmaceutical companies. Whatever problem threatens success, these foundations step in to resolve. When the lack of tissue samples impeded progress, for instance, MMRF created the Multiple Myeloma Research Consortium, which currently has 11 member institutions that bank and share tissue. MMRF and MRF partner with their funded scientists and actively push a research agenda. They do not, as Scott Johnson says, “fund and forget.”

This new model of funding research is getting a lot of attention outside Donaghue, too. Publications that have featured these organizations include *The Economist*, the *New York Times*, and the *Wall Street Journal*, among others. The Harvard Business School is developing a case study on MRF, and recently MMRF was profiled on NBC Nightly News.

What have been their results so far? Before MRF was created, myelin experts believed it would be 20 years before a target for treatment was developed. After three years into their research plan, MRF has identified nine new myelin repair drugs and ten new research tools. For a person with multiple sclerosis, that difference holds real promise. And when Kathy Giusti was diagnosed with myeloma in 1997, she was offered the same treatment that had been used for her grandfather; today MMRF has contributed to three new compounds now in the market and has several others in the pipeline.

Donaghue is impressed with the practicality of their approach, and we look forward to continuing to learn more from them. *Practically Speaking* readers can also learn more about these organizations through their websites — themmrc.org, themmrf.org and myelinrepair.org. ■

Annual Meeting '07

Plans are already underway for the Donaghue Foundation's next conference and annual meeting in May of 2007. We're building on the great interest shown by our 2006 conference attendees and their interest in our continuing to examine how to bridge the gap between research and its use in improving the public's health. Our program will showcase innovators from the philanthropic, business and health sectors, all of whom are working successfully to make sure that medical and health-related research makes an impact on health. Confirmed speakers include **Scott Johnson**, CEO of the Myelin Repair Foundation (see Executive Director's report at left); **Dale Whitney**, President of the *Bridges to Excellence* program (a broad-based coalition dedicated to using provider and patient incentives and rewards to cross the quality chasm) and Vice Chair of the *Leapfrog Group*; and **Michael Mustille, MD**, of the Permanente Federation and the Council of Accountable Physician Practices. Presentations by our innovators will be followed by a distinguished reactor panel featuring **Robert J. Alpern, MD**, Dean of Yale School of Medicine and **Peter J. Deckers, MD**, Dean of the University of Connecticut School of Medicine. Drs. Decker and Alpern will discuss the challenges and opportunities these innovations present to academic medical centers as they educate future generations of clinicians, researchers, policymakers and administrators.

A “*save the date*” postcard will be coming soon.

Welcome to New Foundation Employee

Callers to the Foundation office have been hearing a new voice answering the phone these days. Diana Martens joined the staff of Donaghue as Administrative Assistant earlier this year. Diana works for the Foundation 20 hours a week, and is in the office in the morning. In addition to her work there, Diana is also employed by the Antiquarian and Landmarks Society as the Site Administrator of the Butler-McCook House, and in her spare time she is an artist and a member of Another Octave choral group. We know you will enjoy getting to know Diana, and we appreciate her contribution to the Foundation. ■



Donaghue Announces Patient Safety Research Initiative

The Donaghue Foundation has committed \$1 million to a program of patient safety research that focuses on the impact made by hospital leaders in promoting patient safety. The Foundation expects to award three or four research grants in this program. An applicant must be a nonprofit, acute care hospital from within the six New England states, and its proposed research project must include collaboration with an academic researcher. The process to apply for one of these grants has three steps: 1) a letter of intent, 2) an invited application, and 3) a presentation by finalists on the proposed research made to the Trustees and a panel of reviewers.

A Request for Proposals is available on the Foundation's website (Donaghue.org) that describes the goals of this research funding program, eligibility requirements, applications requirements and process, and standards for selection. The RFP also contained a summary of the important dates in this process. Letters of intent, which have a maximum size of 500 words, are due on November 30, 2006. Invited applications are due on May 1, 2007. ■

From Discovery to Action (continued from page 1)

The first presenter was **Diane Meier, MD**, Professor of Geriatrics and Internal Medicine for the Dept. of Medicine at the Mount Sinai School of Medicine, and Director of the Center to Advance Palliative Care and the Hertzberg Palliative Care Institute in New York City. Dr. Meier described herself as “a product of standard academic medicine” — like so many in the field, she pursued NIH funding and publication in the top-tier journals, which were considered the “brass ring.” Over time, however, this approach seemed almost irrelevant to the needs of her patients, she said, and she became very frustrated with the quality of care in the hospital setting and “the things we were doing in the name of helping people.” As she considered leaving the practice of medicine, a number of nonprofit and philanthropic organizations were beginning to speak out about our health care system, and about palliative care in particular. Instead of a career change, she decided to lead the charge and take advantage of the rapid growth in resources in the field.

“Palliative care medicine is where it is today,” she said, “solely as a consequence of private sector philanthropy — not policy at the federal level, not the NIH, certainly not the hospitals or medical schools themselves.”

Dr. Meier gave a fascinating, detailed talk about how end-of-life care has evolved in this country over the past several decades. Unprecedented gains in life expectancy have led to a shift in cause of death from tuberculosis, influenza and pneumonia to chronic illness, such as heart disease, cancer and degenerative diseases of the brain. With the exponential growth in the number of frail elderly, and the rising cost of medicine, health care professionals were inadequately prepared and trained to care for the elderly and the dying, and people started to suffer in large numbers in hospitals and other settings. A private study in the late 1980s, for instance, revealed alarming statistics about the experiences of patients in their final weeks and

days of life, including unconscionable levels of pain, sometimes even created by doctor-initiated procedures of little value to the patient's care. Later studies showed that family members were extremely dissatisfied with hospitals as the last place of care for their loved ones, because the culture was focused almost exclusively on curing illness and prolonging life.

These conditions created what Dr. Meier called the “burning platform,” or the imperative for change. “Enormous amounts of



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— Diane Meier, MD

money were being pumped into the system, and yet consumers were completely unhappy with the product,” she said. “We had lots of research demonstrating a quality problem, but there was a huge chasm between acknowledging the problem and actually doing something about it.”

Rather than pursuing more research or journal articles about the problem, Dr. Meier's response has been to apply social change theory to health care systems to make the Center to Advance Palliative Care an agent for meaningful change in care for the elderly and dying. The Center, with support from Robert Wood Johnson Foundation and other funders, has brought about significant increases in the number of palliative care programs across the U.S. since its inception in 1999.

The Center has focused its efforts principally on hospitals, Meier says, because there is enormous motivation to make change in the hospital environment, where the sick and the dying are “breaking the bank.” Ninety-eight percent of Medicare decedents spend at least *some time* in a hospital in the year before death; a full three-quarters of the Medicare

budget (\$198 billion) is spent on hospital care. “You cannot get off the planet, in the U.S. in particular, without serious time in a hospital and — if you’re really ‘lucky’ — serious time in the ICU. *That’s* the ritual of death in this country.”

Financial results from the Center’s work across the country show that palliative care reduces direct patient costs prior to death and shortens the typical length of stay; from the patient/family perspective, the quality of caregiving is up. As a *Wall Street Journal* headline in 1994 noted, “Unlikely Way to Cut Hospital Costs: Comfort the Dying.”

The Center’s success, says Dr. Meier, is attributable in part to social marketing strategies used to tailor messages to target audiences, mimicking the tools used by Madison Avenue to sell products and services. “Change in behavior and culture occurs both through the heart and the head — data alone are insufficient motivators.”

With the help of surveys and other research, palliative care advocates have been able to focus on what makes clinicians, hospital administrators, referral sources and families each passionate about better managing end-of-life care (it’s not necessarily the same thing). A key finding, for instance, was the revelation that “death” and “dying” are anathema to patients and families who want improvement in quality of life, relief of suffering and compassionate support. “As long as we’re marketing a ‘good death,’ no one is buying,” says Dr. Meier.

The next speaker would echo this theme of aligning the message to the audience as an important catalyst to the uptake of information that ultimately influences behavior. In a presentation called “Creating A Market for Healthy Behaviors,” **Alan R. Andreasen, PhD**, Professor of Marketing at the McDonough

School of Business at Georgetown University, defined marketing as “the development of programs designed to influence the voluntary behavior of target audiences.” In the private sector, he said — where many companies are *very good* at it — the goal is generally to increase the profit for shareholders.

In the nonprofit sector, however, it’s called “social marketing” and the goals are different. “Generally you’re interested in improving the lives of target audiences, or the society or world in which they live,” says Dr. Andreasen, whose Social Marketing Institute has helped an impressive number of nonprofit organizations market their message, including the World Bank, Boys and Girls Clubs of America, AARP, and American Cancer Society, among others.

The first 25 years of social marketing, according to Dr. Andreasen, were focused on people with problem behaviors (such as smoking, spousal abuse or littering). More recently, social marketing has also been used to influence legislators, media, funders and other sectors that shape our society, and is no longer a “secret science” but is widely practiced, accepted and even institutionalized. The Centers for Disease Control, for instance, now has a Center for Health Marketing.

The first step with social marketing is to identify the behaviors you are trying to influence. “What do you want people to *do*?” asks Dr. Andreasen. “Problem behaviors suggest many possible responses: you may want to get people to stop...or avoid...or switch to something else...or not start something to begin with.”

Without focusing on steps that actually influence behaviors, a social marketing campaign may end up merely educating the target population or changing attitudes — but not produce the desired results. Early campaigns

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2006 Donoghue Investigators Named

Becca Levy, PhD, Associate Professor in the School of Epidemiology and Public Health, **Hal Blumenfeld, MD**, Associate Professor in the Department of Neurology, both of Yale School of Medicine, and **Quing Zhu, PhD**, Associate Professor in the Bioengineering Program, University of Connecticut at Storrs, are the 2006 recipients of the Donoghue Investigator award. This award provides \$500,000 over five years for their research programs. The three awards reflect divergent research topics. Dr. Levy’s research explores different interventions to promote improved health in older individuals through positive age beliefs, Dr. Zhu’s award will allow her to continue her work on novel imaging devices for the diagnosis and treatment of breast cancers, and Dr. Blumenfeld’s work on the mechanisms and consequences of impaired consciousness in epilepsy has potential applications for a number of different conditions. The winners were selected from an impressive group of applicants. ▢

Clinical and Community Health Spring Awards

Principal Investigator	Project Title	Institution	Award Amount
Chirag R. Parikh, MD, PhD	Novel biomarkers to detect delayed graft function	Yale School of Medicine	\$197,144
Kalpana Gupta, MD MPH	Cranberry for urinary tract infection prevention in nursing homes	Yale School of Medicine	\$238,710
Meredith Stowe, PhD & Carrie Redlich, MD	Reducing isocyanate exposure in the Connecticut auto body industry	Yale School of Medicine	\$239,888

From Discovery to Action (continued from page 5)

to get people to stop smoking, for instance, focused on educating people about the health risks of smoking — which they were successful at doing — but the vast majority who tried to quit *failed*. “It was

presumed by some at the time that if people are still doing self-destructive behaviors after they *know* something is bad for them, they must simply have a character defect,” says Dr. Andreasen.

Subsequent research, however, showed that smokers didn’t know *how* to quit — the social marketing

campaign hadn’t given them the tools and tips to do so — or were afraid of the public failure associated with trying to quit and being unable to do so, so they didn’t *try*.

“The answer lies inside the heads of the target audience,” emphasized Dr. Andreasen. “Rather than thinking of the target audience as your enemy, you have to recognize that they are the ones who control your success.” Rigorous listening, pre-testing and re-testing is necessary for a successful social marketing campaign, he said — just as it is in the private sector, where millions and millions of dollars are spent doing market research before a product rollout.

These principles were used to great effect in a recent campaign that significantly reduced smoking by public middle and high school students in Florida. When they talked to student smokers, Dr. Andreasen said, they learned that what kids really want is *rebellion*. So in a brilliant stroke — which demonstrates how the target audience holds the answers — the campaign was framed to incite rebellion toward the tobacco industry. “By getting inside the heads of kids and focusing on the benefits that kids care about, social marketing was able to make a big difference.”

Paul Raeburn next came to the podium, begging the question, “Why don’t journalists tell the truth?” which, he admitted, was a bit of a bait-and-switch since re-

porters, of course, do not *purposefully* submit untruths to their publishers.

Because of the subjective nature of a shared conversation, however, or a misunderstanding about a complex fact, or a simple matter of emphasis, scientific reporting is an imperfect art form — but it plays a very important role.

“Scientific research is hard — it sometimes takes years to answer what seems like a simple question,” said Mr. Raeburn, who has been a science writer and editor for *Business Week* and the Associated Press, and is the author of the memoir, *Acquainted With The Night: A Parent’s Quest to Understand Depression and Bipolar Disorder in His Children*.

“After an investigator finally publishes that journal article, corks the champagne, and celebrates his new discovery, he may tell a reporter in all the excitement, ‘This is the most significant finding since I’ve been in business.’ The next morning’s paper might carry that exact quote, which probably overstates the value of the research — newspapers are often publishing such proclamations — but it demonstrates the challenges that journalists face in reporting health research stories fairly and accurately.”

Pointing to a story from the previous day’s *New York Times* about promising cancer research involving mice subjects, Mr. Raeburn asked, “What is the truth?” In the example cited, the truth could be that the researchers have found mice that don’t get cancer; or it could be that in a few years, we could all get an injection of the same substance and *we* won’t get cancer. Or the truth could be that there was a serious error in the experiment and the injection does not in-

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— Alan R. Andreasen, PhD

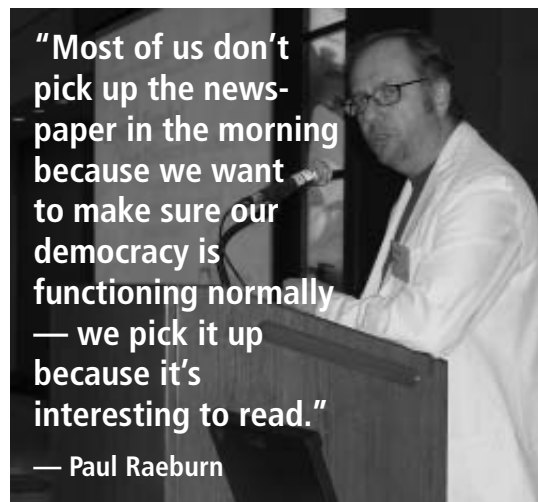


Annual Report

Copies of the Donaghue Foundation’s 2005 Annual Report, “Progression,” are available from our office (see contact info on page 2) or may be downloaded from our website in Acrobat (pdf) format.

“Most of us don’t pick up the newspaper in the morning because we want to make sure our democracy is functioning normally — we pick it up because it’s interesting to read.”

— Paul Raeburn



hibit cancer — in which case the truth is: nothing happened at all.

“Figuring out what is accurate is not always easy to do, even in the best of circumstances,” said Mr. Raeburn.

Another limitation on reporting is the deadline-driven structure of news production. When stories come in, journalists are obligated to get them on the air or on the wire as soon as possible, because news providers are competing to be first with important information. “When you get off the phone, the clock is running. With those incredible time pressures, occasional mistakes are inevitable.”

How do newspapers decide what to cover? Why do topics that might seem very important to researchers sometimes seem less important to the media? Between the emails he receives, a daily stack of mail several inches tall, and a steady stream of phone calls, Mr. Raeburn said he typically has several dozen possible stories vying for his attention during any publication cycle — but only room typically for *one* article. “There’s a lot of discretion — we do the best we can with the vast amount of information that comes in.”

Social marketers hoping to use the media as a tool face great competition for their message. In prioritizing what stories he will focus on for his next deadline, Mr. Raeburn reflects: “I first ask: is a story interesting? If it’s interesting to *me*, then it’s probably interesting to a majority of our readers. Then I

ask: is it important? Sometimes a story is interesting but *not* important, and that’s okay — if it’s interesting, that’s often enough. Sometimes, though, a story is important but *not* interesting, and you have to go ahead and put it out there because it’s important. There’s another one: is it entertaining, does it capture your attention because it’s fun or unusual? Most of us don’t pick up the newspaper in the morning because we want to make sure our democracy is functioning normally — we pick it up because it’s interesting to read. Newspapers need to be interesting and timely and entertaining — *all* those things — if they’re going to have readers.”

Mr. Raeburn said that it’s important for social marketers to remember that journalists are not “social partners.” “They do not have an agenda to advance health — they care about reporting information accurately.”

After a box lunch break, **Sheilah Rostow**, Senior Vice President of Bank of America, Trustee, introduced **Michael Rion, PhD**, Principal of Resources for Ethics and Management, who moderated the afternoon panel discussion, an engaging exchange between the speakers themselves and audience participants who posed questions from the floor.

Reflecting on Mr. Raeburn’s comments about the competition for news stories, Dr. Meier said that media training — learning how

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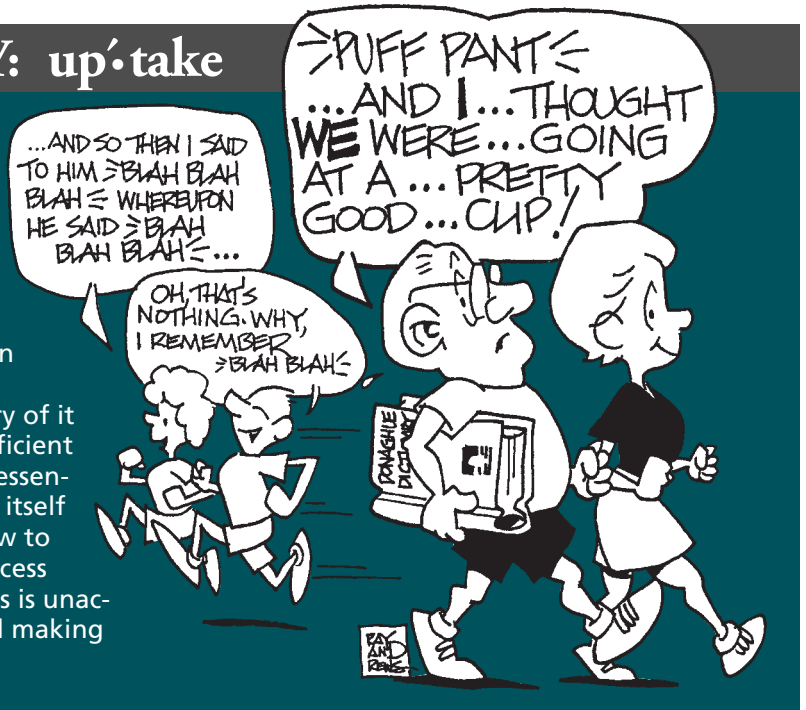


Donaghue Foundation adviser Michael Rion, PhD, moderated the panel discussion.

DONAGHUE DICTIONARY: up·take

Serious runners are certainly familiar with the concept of oxygen uptake as a factor in endurance. Not only is the oxygen breathed in by the trained runner in the same intensity as other folks breathe it, but it is efficiently absorbed and utilized by the body. Just as a moist sponge absorbs water faster than a dry one, a conditioned body does a much better job at oxygen uptake than an untrained one.

So is it also with health knowledge. The delivery of it to the potential user is necessary but not alone sufficient to produce a health benefit. Uptake by the user is essential, and the Donaghue Foundation has committed itself to working on improving knowledge uptake — how to do it and then how to get it done. Because the process of converting new discoveries into healthy practices is unacceptably long, the Donaghue trustees have in mind making all of us “quick on the uptake.” ▀



From Discovery to Action (continued from page 7)

to *submit* interesting, timely and important news — is crucial for anyone who wants to promulgate behavior change methods. As in all other adult activities, she said, relationship building is a key to success. Dr. Andreasen concurred: “Instead of thinking about how your story will benefit your organization if only it were to be published, think instead about how your story would benefit the *publication* and why *they* might find covering your story valuable. Again, know thine audience.”

A discussion about trust between journalists and social marketers seeking coverage ensued. “It’s the journalist’s job to take my words and put them out there,” said Dr. Meier, “So I’d better choose my words really carefully.” Mr. Raeburn advised newsmakers to always tell the truth, *all* the truth, from the beginning. “As a reporter, the more I can sense you’re deceptive or hiding something, it will triple my doubts,” he said.

Barriers to effective knowledge uptake were discussed. Many people, for instance, do not *like* to be marketed to — they mute commercials, discard junk mail unopened,



use spam filters on email — and a lot of messages just don’t get through. “It’s almost as if the nuggets tumble down from the mountain, but the residents of Practical Benefit swiftly put them in the weekly trash,” one audience member suggested.

In response, Dr. Andreasen said that social organizations, like their peers in the private sector, are learning to use the Internet and other new technologies to talk to people with very targeted messages. “Such tools as blogs, e-newsletters and search engines strike me as very useful vehicles for social marketing around health issues,” he said. “Certainly one of the things we have to get better at is using the new electronic media.”

“And repetition is key in any social marketing campaign,” said Dr. Meier. You have to give your message a chance to reach its audience.”

Speaking of repetition, next year’s Donaghue Foundation annual meeting and conference program (see page 3) promises to be another invigorating exchange of ideas about best practices for getting “beyond eureka.” Watch this space, and the Donaghue website, for more information about the date and location. ■



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