

Making Research Relevant & Ready



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

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Practically Speaking is published three times a year by the Donaghue Foundation to communicate its grantmaking and knowledge uptake activities. Readers are welcome to contact the Foundation office for more information about the work of the Donaghue Foundation by calling 860.521.9011 or by sending an email.

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Darlene Cavalier spoke about the role of citizens in science.

# Science Under the Microscope

Donaghue's seventh Beyond Eureka conference focused on the question "How is Science Serving us? Why this question matters and how you can shape the answer."

The first keynote speaker, Arturo Casadevall, MD, PhD, spoke on the topic of "Science at a Crossroads: Time for Reform?" and expressed the view that although science holds the keys to solving our greatest problems — epidemics, hunger, climate change, genocide — reforms are needed to improve science's productivity and to keep it healthy. Some of these reforms are external to the enterprise — such as workforce imbalance, an anti-intellectual bias in society, and inadequate funding. Casadevall, however, focused on needed reforms that are internal to science: a winner-take all system of rewards, the economics systems for funding science, overspecialization, and poor communication with the public. He believes that the increase in the rate of retractions from scientific journals — and the higher than expect rate of fraud — is not only damaging to science but a symptom of the current dysfunction in the enterprise.

One antidote, according to Casadevall, is to put the "Ph (philosophy) back in the 'PhD.'" Casadevall notes that when the discipline of natural philosophy, the precursor of today's science, was separated from philosophy in the seventeenth century, it became divorced from the fields of epistemology, logic, ethics and metaphysics. These fields are essential, Casadevall argues, for a broader and therefore more successful type of scientific pursuit.

The second speaker, Darlene Cavalier, MLA, focused her remarks on the role of citizens in the scientific enterprise and described two major initiatives that she has started to foster greater involvement of the public in science. SciStarter. com is an online citizen science community that is a one-stop-shop for potential citizen scientists and a space for researchers to describe their research and to recruit participants. SciStarter currently has over 600 scientific projects that are available for participation by children or adults. Go to SciStarter.com to see the projects listed, and maybe sign up for one yourself!

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

"We're intrigued with the possibility that has recently emerged of significantly greater efficiency in clinical trials by using electronic records that are already collecting data for clinical and administrative purposes."

# Letter from the Trustees

Dear Friends,

e're pleased that Donaghue will be opening new grant programs in 2014. After several years of lean funding levels, we're happy that our financial situation will enable us to do more robust grant spending. At this point, we're planning on committing approximately \$2 million yearly to fund new grant programs. However, it is a challenge for us is to decide what those grant programs will be.

Miss Donaghue gave us the purpose of funding medical research in the fields of cancer, heart disease, and/or other medical research that would promote knowledge of practical benefit to improve health. This statement of purpose provides for expansive possibilities, yet our resources are quite limited. There are so many directions in which we could go — the possibilities are dizzying.

Beginning earlier this year, we've been having conversations about this challenge with several individuals and organizations that represent some of the ultimate users of medical research — those who use new knowledge created through research in the pursuit of better health for others. We're asking them about the kinds of evidence they use when adopting new treatments or practices, what kinds of organizational barriers or business concerns they face when incorporating new evidence into practice, and what health problems they feel are in need of more research.

We're still in the process of consolidating the results of these conversations and understanding the major themes, but so far we can say that we've heard two major themes. Many people spoke about the health delivery system itself as needing to be the focus of new knowledge. In addition, many expressed that consumer and patient engagement in health care is important but that it's unclear how best to make that goal a reality. We were somewhat surprised by the how many fewer comments we received about specific diseases or health concerns as needing to be the focus of research.

In addition to deciding what might be the best topics for Donaghue to put forward in new grant programs, we will also need to answer the question of how best to organize the way we fund. For this, we're intrigued with the possibility that has recently emerged of significantly greater efficiency in clinical trials by using electronic records that are already collecting data for clinical and administrative purposes. Often referred to as large simple trials or low-cost randomized controlled trials, these methods of research can significantly reduce the cost from traditional research designs. Using large data sets also has the advantage of producing results more representative of the population in general versus those obtained with more standard approaches of recruiting individuals to participate in studies.

We're fortunate to have many advisers and friends who are willing to spend time on these issues with us. So far, we've discussed the topics of new grant programs with over fifty individuals. These have been wonderful opportunities for us to hear from a wide range of people about concerns that touch Donaghue's purpose — we've learned a tremendous amount! Still, we have a bit more work cut out for us before we are able to announce in early 2014 our new grant programs.

Until then, if you have thoughts about this subject, please feel free to contact the Donaghue office to discuss this with any of the Foundation staff members or with Lynne. As always, we look forward to hearing your comments.

Amy R. Lynch, JD

U.S. Trust, Bank of America, Trustee

Lynne Garner, PhD
President and Trustee

Lyune Garner

### Ask the Trustees

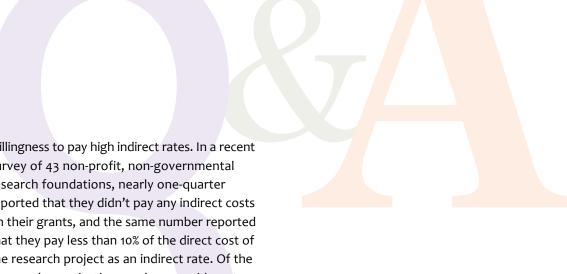
How does Donaghue set its indirect rate

Direct costs are expenses for activities, personnel, equipment or supplies that are necessary for a specific project; indirect costs are the expenses for the institution that sponsors the funded program. Indirect costs, or F&A (Facilities and Administrative costs) as they are called by research institutions, are usually calculated as a percent of the project's direct costs.

Although at one time Donaghue had an allowable indirect rate of 20%, the Foundation currently has an indirect rate of 10% for all its grants. (We say "allowable" because institutions could take a lower percentage if they choose to do this — that would be okay with us!)

Private and public foundations are notably different from the federal government in their willingness to pay high indirect rates. In a recent survey of 43 non-profit, non-governmental research foundations, nearly one-quarter reported that they didn't pay any indirect costs on their grants, and the same number reported that they pay less than 10% of the direct cost of the research project as an indirect rate. Of the surveyed organizations, only one paid a rate higher than 20%. The most common response given, from 16 of the 43 organizations, was that their indirect rate was 10%.

In making its decision about the level of an indirect rate to allow, Donaghue relies to a large degree on the rates set by its peer organizations. At 10%, we feel we're appropriately "in the pack" and don't have any plans to change that level.



# News from the **Donaghue Office**

#### Social Impact Exchange Summit

On June 18 - 20, the Social Impact Exchange (SIE) held its 2013 Conference on Scaling Impact in New York City and Nancy Yedlin, Donaghue Vice President, was there among the 400 foundations, philanthropists, philanthropy advisors, and sector leaders who attended.



The presentations and panel discussions were thought-provoking and well aligned with Donaghue's interests in seeing that health interventions shown to be effective in research settings are structured so they can be scaled up to improve health in real life settings. By attending the conference, we had an opportunity to meet and connect with others who share this

The Social Impact Exchange, launched by the Growth Philanthropy Network (GPN), in partnership with Duke University — Center for Strategic Philanthropy and Civil Society (CSPCS) nd its Center for the Advancement of Social Entrepreneurship (CASE), is a national association whose members are working in various ways to build a marketplace to scale-up solutions to significant social problems. The purpose of SIE is to make it easier for philanthropic giving to achieve major positive change by collectively creating and supporting strategies

that improve lives and change systems. This year's conference focused on how multi-sector collaborations can accelerate and enable the scaling-up and replication of high-impact nonprofits with an emphasis on how to leverage funder networks to finance scale. To learn more about the Social Impact Exchange and its past conferences on Scaling Impact, see www.socialimpactechange.org.

#### **Reviewing PCORI applications**

Lynne Garner, President and Trustee, was a stakeholder reviewer for the second round of PCORI grant applications in the Communication and Dissemination Research Review Panel. "It was a great opportunity to learn not only about PCORI but also about the review process from the other side of the table," said Garner.



"For several years, I've been responsible for ensuring a high-quality review of applications sent to Donaghue grant programs, so it was helpful to experience the process from the perspective of the reviewer. And I thoroughly enjoyed the in-person merit review where I could meet the other reviewers on the panel."

The purpose of SIE is to make it easier for philanthropic giving to achieve major positive change by collectively creating and supporting strategies that improve lives and change systems.

# Science Under the Microscope

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Cavalier is also the founder of Science Cheerleaders, a group of over 250 former and current NFL and NBA cheerleaders who work in science or engineering fields. They promote their love of science with children through participating in school science fairs, visiting schools, mentorship programs, and by promoting citizen science at a variety of public events.

Moving to a national platform, Cavalier described her work in getting citizen input into national science policy. She is currently working with other organizations to promote ECAST, Expert and Citizen Assessment of Science and

Technology, that would be a distributed network to create and evaluate mechanisms to inform the public and solicit input in matters of science and technology policy.

Through all of these efforts, the overall goal is to bring a strong voice of the public into science. "By helping people rediscover, do, and shape science, technology, engineering and math," Cavalier said, "we can better mobilize one of our greatest resources."

The third part of the conference was a panel discussion with the two keynote speakers and the panel moderator, Guy Fish, MD, MBA. Dr. Fish contrasted differences between the liberal-

individualist as compared to the civic-republican concepts of "citizen" and how each might be suited to our expectation that citizens be fully involved in our technological world. "Anyone who is inquisitive is a scientist," said Casadevall. "Whether someone is in their backyard looking for a new comet or someone in the lab, as long as they are trying to generate new knowledge that can be used by humanity" they are both scientists.

Both Casadevall's and Cavalier's presentations and the panel discussion are on Donaghue's YouTube channel. Check out our website soon for short video clips of the conference highlights.



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Nancy Yedlin and Lynne Garner help to sort through the many questions submitted to be addressed by the panel discussion.

Arturo Casadevall shakes hands with moderator Guy Fish at the end of the panel discussion.



Signing in at the start of the conference.



J Russo Productions has videoed the Beyond Eureka! conferences. Videos from past conferences are available on the Donaghue website.



Connecticut Science Center was one of Connecticut's major science museums in the state to participate in the Fair.



Cecilia Payne and Marlyn Davila worked the booth at the Health Career Opportunity Programs.

# Science Opportunities Fair

In conjunction with the Beyond Eureka conference, Donaghue sponsored a Science Opportunities Fair to highlight the exciting programs offered by some of Connecticut's science organizations. The Fair featured both well-established and newer organizations. All of the participating groups have a focus on engaging families, children and mentors to promote science, technology, engineering or math, and it was a way for them to see how their colleagues are introducing STEM into communities and to network and learn about new resources around the state.

— story continues on page 6



Noelia Bonilla takes microbe samples for the Science Cheerleaders for their Project MERCCURI.



Hank Gruner, Vice President of Programs at **Connecticut Science Center.** 



More than 350 people attend the 2013 conference.

#### Science Opportunities Fair

— continued from page 5

Some of the activities conducted at the Fair by the participating organizations included collecting swabs of microbes for Project MERCCURI that will compare microbial communities on the space station and at various locations on Earth, a demonstration of a robot built out of everyday materials by schoolchildren, and an opportunity for conference attendees to sign up to participate in one of SciStarter.Com's science projects.

The Science Opportunities Fair was organized and managed by Ivonne Padilla of ImagineINK!. "I learned a lot working with the twelve organizations together; although they all represented science, they were each quite different," Padilla said about her experience with the Fair. "It was a lot of fun seeing the Fair come together."



Organizations participating in the Fair were:

**Connecticut Science Center** 

**Connecticut Science and Engineering Festival** 

The Connecticut Technology Council's Girls of Innovation Science Challenge

Connecticut Women's Education & Legal Fund's G20 Expo

**Peabody Museum of Natural History** 

**Robotics & Beyond** 

Science Cheerleader

SciStarter.com

Solar Youth, Inc

**STARBASE Connecticut** 

**UConn School of Engineering** 

Department of Health Career Opportunity **Programs Aetna Health Professions** Partnership

# Donaghue **Grant News**

#### Status of "Another Look"

As this newsletter goes to press, applications for Another Look: Better Health for Elders in Care Facilities have recently arrived at the Foundation office and are being sent to the review committee. Another Look provides funding for researchers to use existing data sources to answer a research question that has the near term potential to improve health. In 2013, the focus is on improving quality of care and quality of life for the elderly



population in care facilities. Donaghue expects to make four grants from the program in its first year for a total of \$450,000 of funding. For the application review process, Donaghue has established a committee chaired by Mary Jane Koren, MD, Vice President for the Picker/ Commonwealth Fund Long-Term Care Quality Improvement Program at the Commonwealth Fund. The committee includes researchers and practitioners in the areas of gerontology, preventing functional decline in older adults, quality of care and patient experiences, and biostatistics.

#### How'd those blinded reviews go?

In our last issue, we discussed our new way of reviewing letters of intent that came into the Another Look program; applicants' names and their institutions were not seen by the Donaghue staff and science review committee members who participated in this phase of the review process. When the full applications are reviewed, however, all information contained in the application including applicants' bios and their institutions will be a part of the review process.

We knew that we would have to change our internal administrative process for accepting, logging in, and distributing the letters of intent not to mention changing the review process itself. Until you do something once, though, it's difficult to fully anticipate the extent of needed changes. The adjustments weren't onerous, and now that we've been through it once it will be easier the next time.

Our reviewers said that not knowing the person or the institution did make it easier to focus on the idea. Donaghue plans on continuing to use the blinded process in reviewing letters of intent for future grant cycles.

A blinded review process was also used for the second cycle of the RWJF-Donaghue Applying Behavioral Economics to Perplexing Health and

Health Care Challenges grant program. Given the large number of brief ideas that were submitted, it was particularly challenging for staff that provided the administrative support for this program at the Center for Health Incentives and Behavioral Economics at the Leonard Davis Institute, University of Pennsylvania, to make the adaptations required to facilitate this method of review. The review phase went without a hitch, though, and nineteen ideas were selected to proceed to the full application stage.

#### Round 2 for R3

Donaghue grantees take note: Donaghue will be offering a second round of its R3-Making Research Relevant & Ready award program later this year. An announcement will go out to all Donaghue grantees about the program, but you can get a snapshot of the awards made during the first cycle of the program by going to www.donaghue.org

#### Public access requirement for Donaghue grantees

Donaghue has recently established a policy that requires Donaghue grantees to make their peerreviewed articles supported in whole or in part by its grants available in the PubMed Central online archive. Donaghue adopted this policy when the Health Research Alliance, a membership organization of non-profit, non-governmental medical research funders, developed its own PubMed Central portal with the National Library of Medicine, the National Institutes of Health agency that implements PubMed Central.

PubMed Central is a database of full-text biomedical journal articles available online without a fee. It is hosted by the National Library of Medicine in the National Institutes of Health. Once posted in PubMed Central, results of research become more accessible, prominent, and integrated within the context of other research findings, making it easier for scientists worldwide to pursue their research. Equally important, families, clinicians, patients, educators, funders, and students reap the benefits of information arising from funding by accessing publications on PubMed Central at no charge.

An author must acknowledge The Patrick and Catherine Weldon Donaghue Medical Research Foundation support in every article arising from such funding. The acknowledgement statement must include the applicable Donaghue Foundation grant numbers. This will enable Donaghue Foundation to link the published outputs of research to the support it has provided.

Detailed instructions on how to do this will be available from the Foundation by the end of the summer. In the meantime, please contact the Donaghue office if you have questions.

# News from Elizabeth Park

#### Concerts and Movies

Ethel Donaghue's legacy of philanthropy goes beyond medical research. She also created a trust for capital improvements in Elizabeth Park, a much-loved park in Hartford and West Hartford. So we believe Miss Donaghue would be delighted to see the summer concert series once again drawing so many people to Elizabeth Park each Wednesday in July and August. The concerts are free and begin at 6:30. For those who are going to one of the concerts, please consider parking in the St. Josephs' College parking lot and walking the four blocks to the concert; this will help to help keep car congestion out of the Park and off the lawns.

This year, Elizabeth Park will also feature movie nights on the East Lawn. For more information about the concert or movie series, please go to elizabethparkct.org/whats\_happening.html.

#### Ethel F. Donaghue Award

We also believe Miss Donaghue would be pleased to know that this year an award was created in her name to recognize an individual or organization for long-time service to the Elizabeth Park Conservancy. The Elizabeth Park Conservancy (used to be named Friends of Elizabeth Park) developed the award in the spirit of Ethel Donaghue, whose trust to support Elizabeth Park has helped to improve the park for the thousands of people who visit it each year. The inaugural award winner was Lisa Silvestri, former president of the board for the Friends of Elizabeth Park and a long-time champion of the park.



Lisa Silvestri (center) is the first recipient of the Ethel F. Donaghue award. With her are Kathy Kraczkowski, Elizabeth Park Conservancy board president, and Ray Andrews, former trustee of the Ethel F. Donaghue Trust for Elizabeth Park.

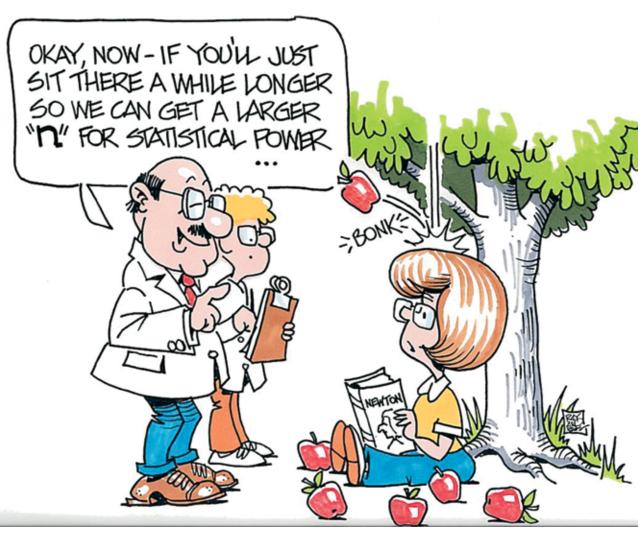
# Donaghue Dictionary

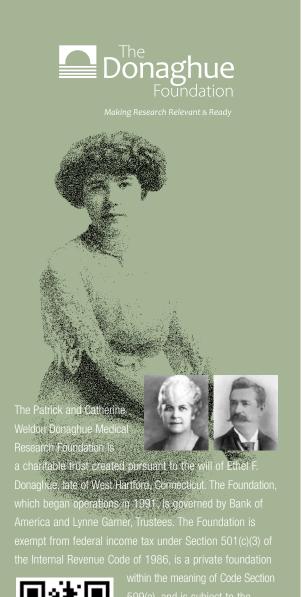
# Sci' ence

Science can be defined as intellectual and practical activity encompassing systematic, disciplined study of the structure and behavior of the natural and physical world, through observation, investigation and experiment. It is also a body of generalizable knowledge gained through the above activity.

A perspective on science can be gained by comparing it to art and religion, the former being based on imagination and expression of form, and the latter embodying untested beliefs, taith, and trust in unknowable truths.

Science is clearly distinguishable from the whimsy embodied in the illustration accompanying this text.





The Patrick and Catherine Weldon Donaghue Medical Research Foundation

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# Updates from some of **Donaghue's Grantees**

We love to keep in touch with our current and former grantees.

Please contact the Foundation if you have news about your work that you would like to share.



- Elizabeth H. Bradley, PhD has recently published The American Health Care Paradox: Why Spending More is Getting Us Less. Lauren A. Taylor is the co-author with Dr. Bradley. The book, scheduled to be released November 5, examines the levels of spending for health care asd well as areas outside of health care that are known or considered to be social determinants of health.
- The Hastings Center's newly reissued Guidelines for Decisions on Life-sustaining Treatment at the End of Life (partially funded by Donaghue) has been getting positive attention from a number of sources, including The New York Times and The Huffington Post. Nancy Berlinger, PhD, the lead author of the Guidelines, said "We wrote the new Guidelines for every health care professional responsible for the care of a patient facing decisions about life-sustaining treatment or approaching the end of life."
- Jennifer Prah Ruger, PhD, is now Associate Professor of Medical Ethics & Health Policy at the University of Pennsylvania. Congratulations to Jennifer and good luck to her and her family as they move to a new home.
- CARE has recently released the first in a series of videos about their New Haven Partners in Health. The first video features the Little Red Hen, a grass-root movement to transform a vacant, blighted lot into a common garden. Check it out on YouTube at http://bit.ly/1618V5t.