



NetworkNews

Research Advocacy Network

Advancing Patient-Focused Research

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Dear Elda Railey,

A previous copy of the July August issue was sent to you today. After sending that issue to you we discovered that some of the links in that version did not work properly. We apologize and hope you find this version with corrected links easier to navigate.

*Elda Railey
Editor, Network News*

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Advancing Advocacy in the Genetic Disorder Community

RAN Co-Founder receives Art of Advocacy Award

The Genetic Alliance – an international coalition comprised of more than 600 advocacy, research, and healthcare organizations representing millions of individuals with genetic conditions – recently convened its annual conference in North Bethesda, Maryland. Held from July 29th – 31st, the 2005 “Leadership in Alliance” conference brought together advocates, researchers, healthcare providers, and patients for three dynamic days to focus on capacity-building within this community serving the patients and families living with genetic disorders and rare diseases.

Many genetic conditions have very small patient populations, and as a result, the resources required to advance research are frequently limited or nonexistent. To combat this obstacle, the Genetic Alliance has created an effective model for equipping advocates with the skills they need to drive the

research agenda for these diseases: leveraging the communities' varied expertise and voices to effect change for patients.

Workshop sessions, presentations, and speakers at the conference all echoed this theme of bringing the community together to learn from each other, share best practices, and support one another in advocacy efforts that can at times feel overwhelming given the limited amount of resources or public attention currently focused on genetic disorders and rare diseases. Specifically, sessions were offered on working with the FDA throughout the drug development process; effective lobbying and understanding public policy; driving research from the laboratory to patients; creating and leading successful advocacy organizations; and contributing effectively to research and advisory committees. These sessions all focused on providing concrete information and tools to the advocates at the conference, in a supportive atmosphere that fostered active discussion, idea-sharing, and learning among the participants. For more information about the Genetic Alliance or to download presentations from the conference go to: <http://www.geneticalliance.org>.

The Genetic Alliance's focus on capacity-building and resource-sharing among its network of members has given these organizations an opportunity to drive the research agenda for their specific diseases and conditions, achieving success through collaboration that could seem unreachable if these groups worked individually.

This model also embraces collaboration and learning through the recognition of significant contributions made by individual advocates. At this year's conference, the Genetic Alliance celebrated the achievements of Elda Railey by honoring her with the "Art of Advocacy" award. Previous recipients of the prestigious "Art of Advocacy" award have included Nancy Wexler and Patricia Barr, underscoring the Genetic Alliance's dedication to acknowledging the advocate community's current momentum and accomplishments, while paving the way for future advances.

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Issues in the Ongoing Biospecimens Debate

NCI's Biospecimen Coordinating Committee convened two workshops this summer to gather input on key issues surrounding efforts to systematize and regulate the collection of patients' tissue.

The first workshop, entitled "Biospecimen Access and Ethical, Legal and Policy Issues" was held in North Bethesda, Maryland on June 23rd and 24th, 2005. This workshop was chaired by Dr. Arthur Caplan of the University of Pennsylvania, and its focus was on providing an overview of the ethical, legal and policy issues associated with the collection and use of human biospecimen samples. By providing solid background information on these considerations, this workshop primed participants for the follow-up workshop in July, when they could then make specific recommendations on the management of patients' tissue. Mary Lou Smith and Judy Perotti, co-founders of Research Advocacy Network participated in this workshop.

Held on July 18th – 20th, 2005 in Washington, D.C., the follow-up workshop on "Best Practices and Recommendations for Establishing and Maintaining Biorepositories that Support Cancer Research" was chaired by Dr. Mark A. Rubin of Dana-Farber Cancer Institute. During this workshop, participants including Mary Lou Smith of Research Advocacy Network had the opportunity to discuss specific infrastructural, operational and procedural concerns surrounding biospecimens.

At both workshops, several key themes emerged that need the attention and input of advocates, to ensure that the patient perspective is clearly represented as NCI, researchers, and industry continue to grapple with the most ethical – yet efficient – ways to manage biospecimens in order to streamline research and hasten results.

Ownership

The question of who owns the tissue once it has been donated – as well as who owns any commercial products that may result from research conducted with that tissue sample – continues to create debate. This also raises questions about whether patients have the right to ask for their tissue back or request that some be saved for them in case they need it in the future, and if so, how it has been tracked throughout the research process and whether it can be located. This can be problematic if the tissue has been transferred several times from patient to research institution to pathologist, or if it has been destroyed after the sample was used for research. And even if a sample is still intact to return to a patient, it is not useful to them or their physician if there isn't any accompanying data on the research outcomes from their sample.

Confidentiality

Confidentiality continues to be a major concern of patients, who worry about insurers or the government storing private genetic information when they only intended to donate their tissue to support research efforts. Some advocates recommend that genetic information related to a tissue sample be handled differently than any other information derived from that sample. This solution, however, is somewhat complex since more and more often there is already genetic information attached to a given sample when it is donated. However, if there is a process in place to ensure that samples are consistently de-identified at the time of donation, patient confidentiality could still be protected.

Findings

Patients considering the possibility of donating their tissue often ask how it will be used and whether they will be informed of the research's outcomes. These questions support the concept of developing well-documented, transparent tracking systems for all biorepositories to use. Although it may not be appropriate to provide patients with a detailed itinerary of how their tissue was utilized, the research community has an opportunity to build trust with patients and advocates by providing information on the overall research findings, such as whether new tumor markers were discovered.

Willingness to Donate

Frequently, researchers believe that patients won't consider donating their tissue for research because they may not understand the concept, or they are not willing to undergo the overwhelming process of deciphering and signing consent forms. Advocates, however, don't believe this is true. Their experiences with patients indicate that if the information is provided in an easy-to-understand manner and if their questions are answered thoroughly, that they are much more likely to consider donating tissue.

These issues and concerns underscore the need to establish better systems for tracking tissue, protecting confidentiality, and communicating with patients, in order to harness the potential of biospecimens research and to translate those learnings into improved patient care and outcomes.

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At the Forefront of Cancer's Future

The Emerging Field of Nanotechnology

The National Cancer Institute (NCI) is embarking upon a new area of research, in an effort to fight cancer at its very core by exploring the emerging field of nanotechnology.

But what is nanotechnology? According to the National Nanotechnology Initiative – a federally-funded R&D program to coordinate the multi-disciplinary and multi-agency efforts in this field – nanotechnology can be defined as the understanding and control of matter at dimensions of roughly 1 to 100 nanometers, where unique phenomena enable novel applications.

To put this in perspective, a single nanometer is just one-billionth of a meter, and a sheet of paper is about 100,000 nanometers thick. Nanotechnology encompasses nanoscale science, engineering, and technology, and involves the imaging, measuring, modeling, and manipulating of matter at this infinitesimal scale.

At this level, the physical, chemical, and biological properties of materials differ in fundamental and valuable ways from the properties of individual atoms, molecules, or bulk matter. Nanotechnology R&D is directed toward understanding and creating improved materials, devices, and systems that exploit these new properties.

One way in which cancer research is already reaping the benefits of nanotechnology is through the development of Abraxane, the only taxane without solvents, which has been approved for the treatment of breast cancer after failure of combination chemotherapy for metastatic disease or relapse within six months of adjuvant chemotherapy. Scientists developed a method of making nanoparticles (think of a tiny hollow ball) from the protein albumin and loading paclitaxel into these nanoparticles. This allows patients to safely receive 50 percent more paclitaxel per dose. With the advent of this new area of research, it is our hope that Abraxane will be just the first of many nanotechnology-based advances for those affected by cancer.

For its part in driving this research forward, NCI has created the Alliance for Nanotechnology in Cancer, an initiative that will use this new technology to change the ways in which cancer is diagnosed, treated, and even prevented. NCI's research will focus on the development of extremely sensitive devices constructed of nanoscale components – such as nanocantilevers, nanowires, and nanochannels – that have the potential to detect rare molecular signals associated with malignancy, find gene mutations and genome instability in their earliest stages, or even monitor patients "real-time" to track their exposure to environmental triggers and life-style risk factors for cancer.

Specifically, the Alliance has secured \$144 million in federal funding to explore the role of nanotechnology in several aspects of cancer research, including:

- Researching tools to identify new biological targets
- Developing agents to monitor predictive molecular changes and prevent pre-cancerous cells from becoming malignant
- Creating imaging agents and diagnostics to detect cancer in the earliest, most easily treatable, pre-symptomatic stage
- Developing multi-functional targeted devices to deliver multiple therapeutic agents directly to cancer cells
- Coming up with systems to provide real-time assessments of therapeutic and surgical efficacy
- Discovering novel methods to manage symptoms that affect quality of life

Currently, the Alliance is reviewing grant proposals from researchers across the United States and will begin to award grants that it believes will further our understanding of nanotechnology and its ability to impact cancer care. Those grants will be awarded on a five- or six-year basis, with the possibility of ensuing clinical trials based on findings from the initial research.

It is the Alliance's hope that this focus on nanotechnology will help achieve NCI's overarching goal of eliminating death and suffering due to cancer by 2015. According to Wayland Eppard, co-chair of the North Central Cancer Treatment Group and consumer advocate to the Alliance, "As nanotechnology becomes even more sophisticated and as scientists understand it better, it will be truly powerful because it will be able to diagnose cancer at the cellular level and kill just that malignant cell – this technology has incredible potential."

Although the Alliance is just at the very beginning of this significant research, it is still important for advocates to follow this science as it develops. One way to do that is by subscribing to the weekly and monthly nanotechnology articles that are available online at the Alliance's News Center at <http://nano.cancer.gov>.

Stay tuned for further updates from the Research Advocacy Network on this exciting area of cancer research.

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New Fact Sheets Available

Two new fact sheets have been added to the "What it Means for Me" Fact Sheet Series. The new topics are on the results of the Avastin and Herceptin studies in breast cancer. These are available for download on the Research Advocacy Network Publications area of the website.

- [Avastin Studies: What It Means For Me](#)
- [Herceptin Studies: What It Means For Me](#)

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Research Advocacy Network Website www.researchadvocacy.org

Check out the first version of our new website at www.researchadvocacy.org. New areas have been added and more will come soon. Be sure to join Research Advocacy Network with the "Join" link. There is no charge for Network membership and this will assure that you receive all notices and have access to Network programs

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Research Advocacy Network Activities:

July

- **July 14-15**
National Comprehensive Cancer Network (NCCN) Breast Cancer Treatment Guidelines

Committee

- **July 18 -20**
BioSpecimen Collection, Processing and Storage, Quality Assurance, Quality Control and Operational Issues including Bioinformatics Workshop
- **July 21**
Advocacy Symposium, Robert H. Lurie Medical Research Center
- **July 29-31**
Genetic Alliance 2005 Conference

August

- **August 20**
National Lymphedema Network Presentation on Lymph Science Advocacy Program

September

- **Sept 16-18**
NSABP (National Surgical Adjuvant Breast and Bowel Project)
- **Sept 19-23**
NCCTG (North Central Cancer Treatment Group)
- **Sept 26-27**
Summit on Cancer Clinical Trials

October

- **Oct 1**
Presentation at Colon Cancer Alliance Conference
- **Oct 5**
Indiana Cancer Consortium
- **Oct 5**
IRB Community Member Training, Rush University Medical Center
- **Oct 6-9**
Lynn Sage Breast Cancer Conference

Do you know of conferences/meetings/ activities that you would like posted to the calendar?
Let us know at info@researchadvocacy.org.

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Your Two Cents Make a Difference!

If you believe in the hope of research and the power of advocacy, you can help the Research Advocacy Network just by shopping! Your two cents can make a difference – how do you make that happen? Just by buying your office supplies, books, sporting gear, CDs and everyday items at through the iGive Mall at www.iGive.com/ResearchAdvocacyNetwork. You can shop at 500+ stores and without even knowing it, you'll be helping Research Advocacy Network at the same time.

Of course, if you'd rather just send a check we would greatly appreciate that!!!! We are an exempt 501 c 3 organization and dependent on your support to keep going. Our mailing address is 309 East Rand Road, Suite 175, Arlington Heights, IL 60004. THANKS!!!!

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