

Research Advocacy Network Celebrates First Anniversary

A year of progress and refinement

A year ago, Elda Railey, Mary Lou Smith, and Judy Perotti came together to discuss a need. The need for an organization that would focus on the efforts of patient advocates who want to make a difference in medical research by providing the patient perspective and create energy within the research system to keep advances moving. With encouragement from the research community and after gathering input from many of you, the Research Advocacy Network was started. The combined passions of these three individuals coming from different functional aspects of the advocacy community (IRB, cooperative groups, grant review, education, support services, evidence based medicine, addressing disparities) and a deeply held belief that consumer advocates make a difference in the way that medical science advances was a powerful motivator. During this inaugural year, the organization has been very involved in defining the focus and methodology of the Network. The growth model of the Research Advocacy Network is intentionally innovative, non-traditional in management, and collaborative. It is the goal of the Network to raise the standard and effectiveness of advocates by collaborating with existing organizations, defining best practices and creating new tools for advocates.

RAN is working to create new opportunities while recognizing the past roles and successes of advocates in legislative, fundraising/grantmaking, awareness and support services. RAN works to equip advocates for more purposeful and effective advocacy interactions with the intent to collapse the amount of time it takes for research results to reach community practice. We have also identified three impact points on the research continuum (design, conduct and reporting results) and have developed programs to increase the influence of advocates in these activities. Our website <http://www.researchadvocacy.org> has a listing of accomplishments.

To celebrate this first year, the co-founders met in May to revisit the strategic plan and are pleased to announce the refined mission of the organization:

*To develop a network of advocates and researchers who
can influence medical research from concept to patient
care through education, support and collaborations.*

*Thanks to you for your help this year, we appreciate your input and anticipate
accomplishing great things together in the future!*

NBCAM celebrates 20 years of progress in breast cancer

Research Advocacy Network co-founder Mary Lou Smith honored

Events for Advocates

Leading breast cancer experts, physicians and patient advocates from around the country gathered to discuss the progress of breast cancer treatment over the past 20 years at the National Breast Cancer Awareness Month (NBCAM) National Summit. The summit, "20 Years of National Breast Cancer Awareness: The People, The Progress, The Future" was held on May 14, 2004 in New York.

"NBCAM was started at a time when few women received mammograms and public discussion of breast cancer was shunned," said Susan Nathanson, National Coordinator, National Breast Cancer Awareness Month Board of Sponsors. "This summit provided leaders in the breast cancer community an excellent opportunity to look back at how far we have come and discuss what the future may hold. The efforts of NBCAM over the past 20 years have significantly raised the awareness of the importance of early detection and have served as a model for other disease awareness initiatives."

The summit featured several key thought leaders including: Larry Norton, M.D., Deputy Physician-in-Chief for Breast Cancer Programs, Memorial Sloan-Kettering Cancer Center ; Daniel Kopans, M.D., Professor of Radiology, Harvard Medical School and Director of Breast Imaging, Massachusetts General Hospital; Robert Bazell, Chief Science Correspondent, NBC; Diane Blum, MSW, Executive Director, CancerCare, Inc.; Susan J. Blumenthal, M.D., M.P.A., U.S. Assistant Surgeon General and Rear Admiral in the U.S. Department of Health and Human Services; Susan Shinagawa, Co-founder/Co-coordinator, Asian Pacific Islander National Cancer Survivors Network.

The speakers discussed a variety of important issues including the progress that has been made over the last two decades and the impact this will have on the future of breast cancer diagnosis and treatment. Topics included developments in mammography, breast cancer in the media, the evolving role of the patient, breast cancer detection and treatment disparities in minorities and breast cancer as a critical women's health priority.

During the summit, NBCAM honored remarkable individuals from the medical community, patient advocate organizations and government bodies for their outstanding contributions to the fight against breast cancer over the last 20 years. Mary Lou Smith, co-founder of the Research Advocacy Network, was honored for her outstanding contributions in patient advocacy. Mary Lou was part of a select group being honored for accomplishments in raising awareness, encouraging women to understand their options, and advocating for greater achievement in eradicating breast cancer.

For a listing of all the honorees, go to <http://www.researchadvocacy.org>.

PRIM&R Conference

Conflicts of Interest, Privacy/Confidentiality, and Tissue Repositories: Protections, Policies, and Practical Strategies

Issues in Research

Conflicts of Interest, Privacy/Confidentiality, and Tissue Repositories/Tissue Banking are three of the most troubling and complex issues currently facing researchers, institutional administrators, human research protection programs, and Institutional Review Boards. Each of these topics was addressed at a unique conference held May 3-5 in Boston, sponsored by Public Responsibility in Medicine and Research (PRIM&R) and the Columbia University, College of Physicians and Surgeons in collaboration with the Association of American Medical Colleges (AAMC), the NIH, and Partners HealthCare System. The conference gave those who attended access to the latest information on regulatory requirements, best practices, participant protections, responsive and responsible policies, and effective strategies for implementation. Fundamental principles, regulations and guidelines, and current

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legal and ethical issues pertaining to three of the most contentious topics in research were addressed:

- **Conflicts of Interest:** When investigators, institutions, and IRBs are exposed to opportunities for profit and/or personal gain, bias and a loss of objectivity can result. There is growing concern that any loss of objectivity could influence decisions about study design, participant selection and recruitment, data collection and analysis, and publication. Bias in any of these areas could, and has on occasion, also resulted in increased risk to research participants. Such conflicts may be real or perceived, and they are never simple “black or white” issues. Resolution usually requires a case-by-case approach. This Conference focused on a range of complex conflicts — both financial and non-financial — involving individuals, institutions, and IRBs. The latest regulations, guidelines, and novel strategies that can be used to identify, manage, and reduce conflicts of interest was presented and discussed.
- **Privacy/Confidentiality:** Although privacy in the research realm is now mostly synonymous with “HIPAA,” this meeting explored both the “post HIPAA” and “pre-HIPAA” principles underlying privacy and confidentiality, and focused on specific areas that often present research challenges. Speakers discussed privacy/confidentiality issues not specifically covered by HIPAA, including genetic research and research with secondary subjects, and those aspects of privacy and confidentiality that are key ingredients of the informed consent process. Acknowledging that HIPAA is now “the law of the land” with respect to privacy, part of the conference served as a guide in the post-HIPAA era for those doing and reviewing research.
- **Tissue Repositories/Tissue Banking:** Human tissues — including solid tissue, blood, spinal fluid, etc. — are an important resource for research, but the obstacles to their collection and banking are often daunting. At this meeting, researchers, institutional officials, tissue repository managers, industry representatives, patient advocates, IRB members, and federal agency representatives addressed the challenges and current successful strategies for tissue banking and repositories. Please see the companion article about Research Advocacy Network co-founder, Judy Perotti’s presentation and involvement in this session.

The Conference attracted attendees from over 37 states and four countries (Canada, the Netherlands, Switzerland, and Australia). In response to numerous requests the PowerPoint presentations for the conference are available at :<http://www.columbia.edu/itc/hs/medical/bioethics/cire/conference/conferenceMay04.html>

An advocate’s involvement in the PRIM&R conference

By Judy Perotti, Co-Founder Research Advocacy Network

At this meeting, researchers, institutional officials, tissue repository managers, industry representatives, patient advocates, IRB members, and federal agency representatives addressed the challenges and current successful strategies for tissue banking and repositories. I was invited to co-lead a workshop session with Ruth Fischbach, Professor of Bioethics at Columbia University’s College of Physicians and Surgeons, entitled *Conflicts of Interest from the Research Participant’s Perspective: What Do Participants Want to Know?* In addition, I gave a short presentation and was a member of the panel discussion, *Perspectives From Those Who Want/Need Tissue Banks*. My presentation addressed the patient’s and advocate’s need to have high quality research proceed, while protecting patients. Areas needing improvement were identified such as the tissue consent forms, IRB confusion about differing sets of regulation, and the general public’s, patient’s and some advocate’s lack of knowledge of the importance of tissue in research and the complex system needed to collect, process and store samples.

“The response of attendees to a presentation on the patient perspective was overwhelmingly positive.”

One outcome of the conference was an invitation to be part of the HumanTissue/Specimen Banking Working Group, which will work to find ways of facilitating research using human specimens and data, while protecting the participants from whom the specimens and data were obtained. I will serve as co-chair of the Patient Attitude and Education sub-committee. The group is charged with drafting a white paper that will identify current legal and ethical questions related to the development of repositories and the use of specimens for research and developing practical approaches and solutions.

Link to presentation <http://www.columbia.edu/itc/hs/medical/bioethics/cire/conference/confMay04/wednesday/PanellI/Perotti.html>

Calendar-What is Research Advocacy Network Doing?

May 2004

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June 2004

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Network News

Network News is being sent to you as a courtesy. If you would like to discontinue receiving this publication, please send an email message to info@researchadvocacy.org and type "UNSUBSCRIBE" in the subject line. The newsletter is currently published monthly and includes articles on advocacy, research results and activities.

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Advancing Patient-Focused Research

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Research Advocacy Network Activities

- May 2-6 Invited panelist at PRIM&R Meeting
- May 9-13 Patient Advocate representative, American Society of Colon and Rectal Surgeons
- May 12-14 Representative attending American Oncology Social Work Meeting
- May 11,12 Member Executive Committee, Summit on Clinical Trials Work Groups 1,3
- May 14 National Breast Cancer Awareness Month (NBCAM) event, New York City
- May 14-16 Patient representative, Eastern Cooperative Oncology Group (ECOG)
- June 4-8 American Society of Clinical Oncologists, New Orleans
- June 14-18 NCCTG Patient Forum, Rochester MN
- June 17-18 Patient Advocate, ACOSOG Semi Annual Meeting
- June 23 Presentation at ECOG Coordinating Center on Patient Focused Research
- June 24-28 Patient Advocate, RTOG Semi Annual Meeting
- June 25-28 Patient Advocate, NSABP Semi Annual Meeting

Research Advocacy
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Features on <http://www.researchadvocacy.org>

- Advocate Opportunities
- RAN accomplishments
- Tools for advocates
 - Glossary
 - Drug naming article
- Archived newsletters

Research Advocacy Network is YOUR network. A part of our primary mission is to serve and support research advocates and in order to do that we want to hear from you. Please help us by going to <http://www.researchadvocacy.org/form.html> and completing the survey. If you prefer to have a print copy that you can fax back to us, just let us know via email to info@researchadvocacy.org or call 877-276-2187.

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