



NetworkNews

Research Advocacy Network

Advancing Patient-Focused Research

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Research Advocacy Network

Celebrates Second Anniversary

Research Advocacy Network (RAN) was founded two years ago to focus on research advocates and their role in the medical research enterprise. In these two years we met advocates, researchers, people working for government agencies and advocate organizations that share our mission, concerns and passions. We believe the mission statement; "Advance patient focused research by fostering interactions among advocates, researchers, and organizations" captures the values and focus of RAN.

During our first two years many people wanted to know more about RAN programs and how RAN fit into the existing categories of advocacy. The struggles to answer these questions led to the conclusion that RAN was not like any other advocacy organization.

Research Advocacy Network:

- focuses on research advocacy
- is not disease site specific

- constituency is not patient based but advocate based
- functions as a bridge or interface between people who want to improve and advance medical research
- supports all individual and organizational efforts that reflect our mission

RAN is open to new ideas and ways of doing things. Four of the methods used in reaching RAN's goals are:

- Innovation - uses innovative approaches to change the system for the patient.
- Collaboration – collaborates with all stake holders in the medical research community to enhance the effectiveness of advocates and advocate organizations.
- Technology – uses the latest technology to reach a larger audience of advocates.
- Best practices from other industries – applies best practices from other industries to address system problems.

Accomplishments in the past two years include:

- Fast Fact Sheet Series "What it Means for Me™" to provide clinicians with communication aids for patients on research results
- Tissue Education Materials
- Publication of print companion newsletters "Options™" (for patients and families and caregivers) and "UpDate™" (for healthcare professionals) on recent research results in Breast Cancer and Colon Cancer
- Communications Module
- Publication of Network News
- Development of research advocacy awareness and training model in collaboration with the St. Louis Affiliate of the Susan G. Komen Breast Cancer Foundation and Siteman Cancer Center
- Posters at San Antonio Breast Cancer Symposium and DoD Era of Hope
- Launching the Advocate Institute™ with the course entitled Focus on Research™ at ASCO 2005
- Advocate Core at Indiana University Breast Cancer Research Centers of Excellence
- Focus Groups for PACCT-1 trial
- Focus Groups for Community Members of IRBs leading to collaboration with PRIMR for Community IRB training
- Collaboration with Coalition of National Cancer Cooperative Groups Patient Advocate Training

Thank you to all the advocates, sponsors, and supporters for making these two years successful. We look forward to working together in the future to "advance patient-focused research."

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Ask and You Shall Receive
Friends for Life—A Model for Tissue Collection

Article by Connie Rufenbarger, Catherine Peachey Fund

The Amelia Project is a project of the Catherine Peachey Fund devoted to bringing basic scientists and clinicians working on breast cancer together from across Indiana. Its yearly one-day conference is free to attendees through the support of the Indianapolis Affiliate of the Susan G. Komen Breast Cancer Foundation.

Three years ago at the Amelia Project, Dr. Wortia McCaskill Stevens of the National Cancer Institute was asked about a researcher receiving normal breast tissue samples needed to complete a funded project. Dr. Stevens stated that receiving the rare and sought after samples was not likely to happen. There was a silent drop of shoulders in the room.

It became a challenge. Mary Ellen's Tissue Bank was created through the Catherine Peachey Breast Cancer Prevention Program at the Indiana University Cancer Center. Dr. Anna Maria Storniolo is the Director of both the Prevention Program and the tissue bank. A research project evaluating the role of polymorphisms in candidate genes on angiogenesis and breast cancer in women who have and have not had a history of breast cancer became the impetus for creating a model for the first collection project.

"Friends for Life" was the product of great ambition and the goal of establishing a new model for tissue collection. The project was designed to collect informed consent, a 5-10 minute questionnaire and one 9ml tube of blood from 1,000 women. An oncology fellow, a research nurse coordinator from the Indiana University Cancer Center and an advocate from the Catherine Peachey Fund designed the project in January of 2005. The Indianapolis Affiliate of the Susan G. Komen Breast Cancer Foundation allowed the project to take place on the same day as their Race for the Cure®. One hundred and sixty volunteers including doctors, nurses, lab technicians, secretaries, nursing students, high school students, medical students, fellows and consumers manned the stations. Informed consent, questionnaire and phlebotomy workstations were located in the lobby of the Cancer Center. Flyers, public service announcements and newspaper coverage were the tools to promote the event.

On Saturday, April 16, 2005, participants walked into the Cancer Center and completed the project in 5.5 hours. During the last 2 hours of the event, the volunteer team moved approximately 600 women through the process. Data was collected from each woman including personal demographics, current and past medications, menopausal status, breast cancer history and other information. Of the 855 women sampled that day, 1% were Asian, 2% Other, 5% African American and 92% Caucasian. The median age of subjects with no history of breast cancer was 41.41 and the median age of subjects with a personal history of breast cancer was 52.64. Recruitment of breast cancer survivors continues in the breast cancer clinics.

At the end of the day, there were 855 signed consents with completed questionnaires and invaluable blood samples in the freezer for the benefit of research. A new model for tissue collection was designed. Ask and you shall receive.

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RAN Exhibits Poster at Era of Hope Conference

Era of Hope 2005 Department of Defense (DoD) Breast Cancer Research Program (BCRP) Meeting was held in Philadelphia June 8-11. This meeting is held every two or three years to review and report on breast cancer research funded through the BCRP.

The major topics addressed were: Risk and Prevention, Who Needs Treatment, and Focus on Treatment and Clinical Trials. The meeting had plenary sessions, innovator sessions, symposia and more than 1000 posters. Acceptance of DoD BCRP funding requires reporting of all findings, whether they are positive, negative, or inconclusive.

Research Advocacy Network's poster, *Use of Focus Groups to Inform Clinical Trial Design*, was accepted for exhibit. The poster described RAN's use of focus groups to give input into the design of the PACCT-1 trial. PACCT stand for the Program for the Assessment of Clinical Cancer Tests and is a part of the Cancer Diagnosis Program at the National Cancer Institute.

The PACCT-1 trial is the first in the PACCT program and will be led by the Eastern Cooperative Oncology Group (ECOG) phase III, prospective, randomized, clinical trial to evaluate the use of a genomic test to determine treatment.

Dr. George Sledge, Chair of the ECOG Breast Committee commented, "This was the first time a cooperative group used focus groups during the design stage. It influenced the design and informed the conversation about eligibility and how the trial would be presented to potential participants."

RAN conducted two focus groups, one consisting of patients and the other advocates. The Illinois Affiliate of Y-ME National Breast Cancer Organization played a crucial role in identifying and recruiting participants. They also hosted the meeting.

The report submitted to ECOG contained information researchers found helpful in considering the design of this trial. Dr. Sledge stated, "It (the market research) did have an effect. Not on the basic question but on how we thought about the design. We broadened our criteria and became more realistic about our accrual goals."

Poster available at www.researchadvocacy.org

For more information

- Era of Hope <http://cdmrp.army.mil/bcrp/era/default.htm>

- National Breast Cancer Coalition <http://www.stopbreastcancer.org/bin/index.asp?strid=749&depid=20>
- PACCT program <http://www.cancerdiagnosis.nci.nih.gov/assessment/>
- Eastern Cooperative Oncology Group <http://www.ecog.org>

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AACR Scientist↔Survivor Program® Educational Workshop

Survivor advocates and scientific faculty met in Bethesda, Maryland for the first inaugural Scientist↔Survivor Program® Educational Workshop. Participants were introduced and guided through basic scientific concepts, discussed issues surrounding cancer research and strategized on ways to affect the progress in cancer research. Research Advocacy Network co-founder Elda Railey was honored to be a participant in this inaugural group.

The AACR Scientist↔Survivor Program® is a unique program designed to build bridges and unity among the leaders of the scientific, cancer survivor and patient advocacy communities worldwide. AACR hopes to accomplish these goals by fostering mutually beneficial and enduring partnerships among these important groups and promoting the exchange of information on key aspects of cancer research, survivorship, advocacy and public policy. For more information about the program, please go to www.aacr.org

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Cancer Clinical Trials, Recruitment of Underrepresented Populations AHRQ publishes new report June 2005

The Agency for Healthcare Research and Quality (www.ahrq.gov) recently published a report on the Recruitment of Underrepresented Populations in Cancer Clinical Trials. From the report....."Since enactment of the National Institutes of Health (NIH) Revitalization Act in 1993, cancer researchers have made significant efforts to develop evidence regarding barriers to participation in clinical trials, especially for ethnic minority populations. While some advances have been made in defining these barriers, significant gaps remain in the available evidence in regard to efficacious and/or effective interventions to improve enrollment to cancer clinical trials. It is essential to address these gaps in the evidence, in order to fulfill the intent of the NIH Revitalization Act. Only a small proportion of cancer patients are enrolled in clinical trials, and recent evidence indicates that racial and ethnic minorities, adolescents, the elderly, rural populations and individuals of low socioeconomic status in general, are underrepresented in cancer clinical trials funded by the National Cancer Institute (NCI). At the request and with the financial support of the NCI, the Agency for Healthcare Research and Quality commissioned a systematic review of the existing evidence on the recruitment of underrepresented populations into cancer clinical trials, to be performed by the Johns Hopkins University Evidence-based Practice

Center (EPC)."

The report can be downloaded in .pdf form from

<http://www.ahrq.gov/downloads/pub/evidence/pdf/recruitcantrials/recruit.pdf>.

Other links to resources on Evidence-based Medicine

Evidence-based Practice Center, Johns Hopkins University

Agency for Healthcare Research and Quality, Evidence-based Practice,

<http://www.ahrq.gov/clinic/epcix.htm>

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Research Advocacy Network Activities:

May

- American Society of Colon and Rectal Surgeons (ASCRS) Research Foundation Board Meeting, May 1
- Research Advocacy Network Advocate Institute, Focus on Research Course prep webconferences, May 3-10
- American Society of Clinical Oncology (ASCO) annual meeting, May 12-17
- Radiation Therapy Oncology Group (RTOG) Outcomes Committee Retreat, May 23

June

- Era of Hope Poster Presentation June 8-10
- Eastern Cooperative Oncology Group (ECOG) June 10-13
- American Association of Cancer Research (AACR) Survivor Scientist Workshop June 11-15
- North Central Cancer Treatment Group (NCCTG) Patient Advocate Symposium June 13-15
- American College of Surgeons Oncology Group (ACOSOG) June 22-24
- Biospecimen Access and Ethical, Legal, and Policy Issues Workshop June 22-24

July

- National Comprehensive Cancer Network (NCCN) Breast Cancer Treatment Guidelines Committee July 14-15
- BioSpecimen Collection, Processing and Storage, Quality Assurance, Quality Control, and Operational Issues including Bioinformatics Workshop July 18 -20
- Advocacy Symposium, Robert H. Lurie Medical Research Center July 21
- IRB Community Member Training, Rush University Medical Center July 27

Genetic Alliance 2005 Conference July 29-31

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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www.researchadvocacy.org

Exciting things are happening behind the scenes at researchadvocacy.org! We will be launching a brand new website soon!

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Network News is currently published 10 times per year and includes articles on advocacy, research results and activities.

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