

NETWORK NEWS

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INSIDE THIS ISSUE:

Research Advocacy Activities	2
Meet the Founders	2
We Want to Hear From You	2
Calendar of RAN Activities	3
Contact RAN	3
Website URL	3

New Organization

The Research Advocacy Network is a newly formed organization that will bring together participants in the research process with a focus on educating, supporting, and connecting patient advocates with the larger research community. Many individuals pioneered, and have worked tirelessly for many years in, research advocacy. We believe it is time to move the work forward with an organization focused entirely on advancing research.

Research Advocacy Network

Advancing Patient-Focused Research

The patient advocacy movement has changed the face of research. Patient advocates have provided invaluable input into selected research processes. However, as the involvement of advocates in research grows, there is an increase in the need for training and support, to educate and empower advocates and to increase their effectiveness.

What is Research Advocacy?

The broadest possible answer is any activity performed by an advocate or advocate organization associated with medical research. The reason for such a broad definition is to include as many organizations and individuals as possible in bringing the patient perspective to research.

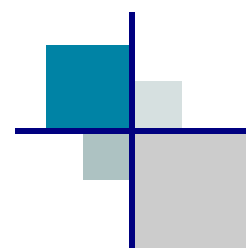
Many advocacy organizations have a mission, such as addressing the needs of patients with specific diseases, political advocacy, cancer education and fund raising, which does not focus on research advocacy. These organizations, however, often engage in activities that significantly influence research. Individuals, some associated with organizations, have also had a significant impact on research through a variety of activities.

- Reviewing protocols and informed consents for research studies
- Developing and/or reviewing trial specific patient education material

RESEARCH ADVOCACY NETWORK MISSION:

Our mission is to enable advocates and researchers to advance science and improve patient care through education, support, collaboration and the measurement and dissemination of research results and advocate interventions.

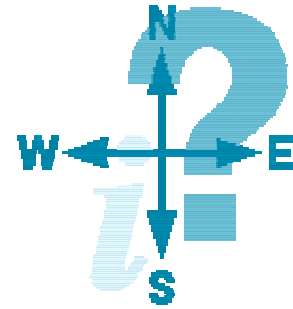
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Research Advocacy Activities

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- Giving input on trial design for private and public trials
- Serving as community representative on an Institutional Review Board (IRB)
- Talking to a patient about clinical trials
- Organizing an event to raise money for research
- Serving on a committee, panel or working group that addresses issues related to research
- Raising awareness and educating people about research and clinical trials
- Educating legislators at the state and national level to increase the amount of money spent on research and to support policies affecting patients.
- Working with government agencies to set research priorities



“Patient advocates are needed to provide a sense of urgency to the research process”

Meet the Founders

Judy Perotti, Elda Railey and Mary Lou Smith came together in June 2003 to found the Research Advocacy Network. All three are long time patient advocates who believe the time was right to form an organization entirely focused on research advocacy.

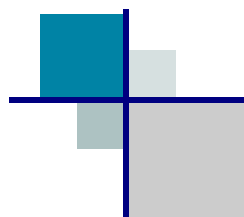
For full bios go to www.researchadvocacy.org.

Focus on Research Newsletter

This initial edition of Focus on Research newsletter is being sent to you as a courtesy. If you would like to continue receiving this publication, please subscribe at www.researchadvocacy.org. The newsletter is currently published monthly and will include articles on advocacy, research results and activities.

We Want to Hear From You

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 www.researchadvocacy.org 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 Elda Railey at 214-683-9937.



Calendar-What is Research Advocacy Network Doing?

October 2003

Sun	Mon	Tue	Wed	Thu	Fri	Sat
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

November 2003

Sun	Mon	Tue	Wed	Thu	Fri	Sat
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30						

December 2003

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

Research Advocacy Network Activities

- September, 2003 Presentation: "Patient Advocacy in the Cancer Community: Influencing Patient Outcomes" at Northwestern University's Outcomes Conference
- September, 2003 Panelist at the Lynn Sage Breast Cancer Conference Town Hall Meeting
- September, 2003 Participation at the Clinical Trials Summit VII
- October, 2003 Presentation "Cancer Research: A Guide to Clinical Trials," at the Pennsylvania Breast Cancer Coalition Scientific Training (Sponsored by the Coalition of National Cancer Cooperative Groups)
- October 2003 Attended the North Central Cancer Treatment Group as members of the Patient Advocate Committee
- October, 2003 Training "Patient Advocacy in Research" Michigan Breast Cancer Center
- November, 2003 Training "Drug Development" and "Protecting Research Participants" NSABP Patient Advocate meeting (Sponsored by the Coalition of National Cancer Cooperative Groups)
- November, 2003, Advisory Board University of North Carolina School of Public Health Conference "Patients, Families and Healthcare Providers: Partners in Decision-Making, Advocates in Health Care"
- November, 2003 InterSPORE meeting, Patient Advocate representative of Northwestern's Breast Cancer SPORE
- November, 2003 Patient Representative Committee ECOG Meeting
- December, 2003 San Antonio Breast Cancer Conference

Have events you would like added to the calendar????
Send an email to info@researchadvocacy.org

Research Advocacy Network

Advancing Patient-Focused Research

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Visit our web site:
www.researchadvocacy.org

Research Advocacy Network web site at www.researchadvocacy.org will be the place to find a wide variety of information about research advocacy.