

## Research Advocacy Network Receives Grants

Since the founding of the Research Advocacy Network in June, 2003, we have clarified our goals and received funding for some of our most important projects.

- Genentech accepted our tissue collection grant proposal, “*Educational Tools To Increase Tissue Research Awareness.*” We are developing content aimed at increasing understanding of the importance of tissue samples for research and improving patient care; raise awareness and support efforts of healthcare staff who provide patient education; and improve dialogue about tissue collection between patients and physicians and other healthcare professionals.
- Lilly provided an unrestricted educational grant that will be used to develop on-line training for advocates. This first module will focus on communication skills and strategies.
- We are partnering with the St. Louis Affiliate of the Susan G. Komen Breast Cancer Foundation to conduct two workshops for people interested in research advocacy. The first workshop is set for March 13<sup>th</sup>. “*Research In Action: What is Research Advocacy*” will be open to the public. The second workshop, which will be held in April, will be limited to 20 participants. This all day workshop will provide basic training needed by those interested in research advocacy.
- Research Advocacy Network will facilitate the Advocacy Core for the Indiana University, 2003 Department of Defense Breast Cancer Research Program Grant, “Center of Excellence for Individualization of Therapy for Breast Cancer,” Dr. George Sledge is the Principal Investigator.

## University of North Carolina School of Public Health Sponsors Patient Advocacy Conference

In November 2003, University of North Carolina, Department of Health Behavior and Health Education (HBHE) sponsored a path-breaking, two-day national summit focused on patient advocacy. ***Patients, Families and Health Care Providers: Partners in Decision-Making, Advocates in Health Care*** brought together over 40 of the nation’s foremost patient advocacy organizations and researchers as well as legal experts, policy-makers, and health-care professionals.

Patient advocacy previously constituted uncharted territory in HBHE practice and research. In 2002, Clarence Pearson and his wife Laurie Norris made a substantial donation to honor the memory of Clarence’s son, Scott. Scott Pearson died in 2001 from malignant melanoma. Scott and his family suffered unneces-

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### 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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sarily from the effects of poor communication among his multiple health care providers, and was strongly discouraged from participating in his own health care decision-making.

Introductory talks by School of Public Health Dean, William Roper, and HBHE Chair, Jo Anne Earp helped frame the summit. Dr. Carolyn Clancy, director of the U.S. Agency for Healthcare Research and Quality, summarized the state of research regarding patient safety and discussed possible ways that patient advocacy could help curb medical error.

Together, this diverse group of professionals began work on:

- (1) developing a national research agenda to create an easily navigable patient-centered health care system with informed patients at the core
- (2) identifying immediate, substantive action steps the patient advocacy movement could take to improve patient-doctor (and health care team) communication using all the information-seeking and decision-sharing tools now available.

Dr. Earp and her conference team are currently drawing up a report based on the summit. For further information please contact Elizabeth French either by phone at 919-966-9208 or via email at [efrench@email.unc.edu](mailto:efrench@email.unc.edu).

*From the UNC HBHE website, by permission*

## **Pfizer Hosts Patient Advocacy Summit**

Pfizer, who recently merged with Pharmacia Pharmaceuticals, hosted a two-day Patient Advocacy Summit, January 20<sup>th</sup> to the 21<sup>st</sup>. Organizations that attended included: Cancercare, Oncology Nursing Society, The Wellness Community, VitalOptions, Y-ME National Breast Cancer Organization, National Alliance Of Breast Cancer Organizations, Colon Cancer Alliance, Colon Cancer Network, Hereditary Colon Cancer Alliance, Kidney Cancer Association, The Lustgarten Foundation For Pancreatic Cancer Research, National Brain Tumor Foundation, Sisters Network, Inc., Alliance For Lung Cancer Advocacy, Support, And Education (ALCASE), Coalition Of National Cancer Cooperative Groups, Inc, Angiogenesis Foundation, American Cancer Society, National Coalition of Cancer Survivorship, CancerVive, Rise, Sister, Rise, Breast Cancer Resource Committee and others. Most participants agreed that bringing together this wide variety of organizations was the most important factor in the success of the meeting.

The program allowed opportunities for lively discussion about issues important to all cancer patients and advocates. One discussion was focused on the impact of changes in Medicare reimbursement policies. Many advocates expressed concern that the policies could affect patient's choice of treatment, payment for supportive drugs, staffing of medical offices and enrollment in clinical trials. Advocates, healthcare providers, researchers, industry and patients will be watching closely to determine what changes the new policies will bring. Another valuable discussion evolved around the issue of getting accurate, timely announcements about clinical trial results to advocates and patients. Most organizations reported that advanced notice of findings were crucial to their ability to respond to their constituencies.

## **Patient Advocacy Committee Awarded Grant for Ambassador Program**

The ACOSOG Patient Advocacy Committee was recently awarded a \$10,000 grant from the Coalition of National Cancer Cooperative Groups (CNCCG) for a pilot project that integrates patient advocates into the clinical trial process. The ACOSOG Ambassador program will integrate patient advocates (Ambassadors) into the clinical trial process for ACOSOG Z0070, "A randomized trial of radical prostatectomy versus brachytherapy for patients with T1c or T2a N0 M0 prostate cancer." The program will provide patient advocates recruited from community based organizations as new members of three clinical site research teams. Each Ambassador will collaborate with the clinical research team in designing educational sessions for prospective patients. Ambassadors will also talk with patients about the clinical trial process, including the informed consent process, randomization and follow-up. Jim Williams, a member of the Patient Advocacy Committee, made the initial proposal for this idea and will coordinate the pilot project. Results from the program will be shared with ACOSOG members. The Committee members hope that similar programs can be integrated into future clinical trials. —From the ACOSOG quarterly newsletter

# Calendar-What is Research Advocacy Network Doing?

## 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			

## January 2004

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

## Network News

Network News is being sent to you as a courtesy. If you would like to continue receiving this publication, please subscribe by sending an email to [info@researchadvocacy.org](mailto:info@researchadvocacy.org) and typing "SUBSCRIBE" in the subject line. The newsletter is currently published monthly and will include articles on advocacy, research results and activities.

## Research Advocacy Network

*Advancing Patient-Focused Research*

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## Research Advocacy Network Activities

- December, 2003 San Antonio Breast Cancer Conference (see December *Network News* for report)
- January, 2004 ACOSOG Patient Advocate Committee
- January, 2004 Coalition of National Cancer Cooperative Groups, Patient Advisory Board
- January, 2004 ASCO committee representative
- January, 2004 RTOG Patient Advocate Committee
- January, 2004 Pfizer Patient Advocate Summit (see report, page 2)

*Do you have events you would like added to the calendar? Send an email to [info@researchadvocacy.org](mailto:info@researchadvocacy.org)*

**Research  
Advocacy Network  
New Phone Number  
877-276-2187**

## NEW Additions to [www.researchadvocacy.org](http://www.researchadvocacy.org)

Check out the addition of ADVOCATE OPPORTUNITIES on the Research Advocacy Network website [www.researchadvocacy.org](http://www.researchadvocacy.org). This listing presents opportunities and contact information for research advocates to become involved in programs. Currently the list includes information about the FDA Patient Consultant Program, NCI Director's Consumer Liaison Group, NCI Consumer Advocates in Research and Related Activities, Eastern Cooperative Oncology Group, North Central Cancer Treatment Group and more. Other programs are added as information is received and opportunities are identified.

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](http://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](mailto:info@researchadvocacy.org) or call 877-276-2187