

Focus on Research™

Research Advocacy Network Announces Pilot Course

The Research Advocacy Network announces a new program for patient advocates. **Focus on Research™** is a system of preparatory conference calls, virtual classroom (webinars), learning materials and mentoring to prepare advocates to learn more about common scientific and statistical concepts in cancer research, the clinical trial and drug approval system as well as providing tools and background information by utilizing the Research Advocacy Network SkillBuilder™ series.

This pilot program of **Focus on Research** will be for advocates attending the American Society of Clinical Oncology Annual Meeting, May 13-17 2005. Participants will have post conference teleconferences organized in cancer site specific workgroups that will focus on disseminating the research results that have the potential to change clinical practice presented at the conference to their respective patient constituencies. Applications for participation are available at www.researchadvocacy.org and are due by April 8, 2005.

Research Advocacy Network Publishes Newsletters for Colon Cancer Awareness Month

Making sure research that changes the standard of care moves quickly into clinical practice is a goal of the Research Advocacy Network. RAN believes that one way of reaching this goal is to put research results into the hands of advocates, patients and healthcare professionals. We are pleased to announce the publication of the second issue of *Options* and *UpDate* focusing on colon cancer.

Both 8-page companion newsletters cover the same important research information with *Options* aimed at advocates, patients and their families and friends and *UpDate* aimed at healthcare professionals, especially community oncologists.

Topics covered in this issue are:

- Report on ECOG trial 3200 showing Bevacizumab Plus FOLFOX Improves Survival In Advanced Colorectal Cancer
- Expert Panel Reports Routine Use of Adjuvant Chemotherapy in Stage II Disease Not Recommended, Although High-Risk Patients Might Benefit

(Continued on page 2)

Options and UpDate Newsletters—Colon Cancer Edition

(Continued from page 1)

- Careful Monitoring and Aggressive Treatment Key to Managing Diarrhea in Colon Cancer
- Making Sense of the Studies: Biologics May Offer Added Treatment Options

UpDate's article on communication in this issue is *Bringing Oncologists and Surgeons Together* by Axel Grothey, MD, Mayo Foundation Scholar, Rochester, MN. Dr. Grothey addresses the need for surgeons and oncologists to work together to provide the best treatment options to colon cancer patients.

Options features *Communication and Connection Is the Key to Maintaining Control in Colon Cancer*, an article to help patients, newly diagnosed and others, to negotiate through the decision-making process. Gail Imig, a newly diagnosed colon cancer patient, and Michael J. O'Connell, MD, associate chairman of the National Surgical Adjuvant Breast and Bowel Project give their thoughts on how to maintain control when dealing with a diagnosis of colon cancer.

Options also features *The Clinical Trials Option...And You*, a short overview of clinical trials and their importance in advancing treatment options, and *Drug Names*, a list of the generic and brand names of drugs used in the treatment of colon cancer.

Both newsletters are available in PDF files at www.researchadvocacy.org or if you wish to have a hard copy(s) send a fax with your name, address, phone, fax and the number of copies of each newsletter you are requesting to 877-276-2187.

National Cancer Institute Board of Scientific Advisors

What is the NCI BSA?

The Board of Scientific Advisors is a 35-member federally chartered advisory committee appointed by the National Cancer Institute (NCI) Director to a five-year term. The NCI website describes the BSA as comprised of authorities knowledgeable in the fields of laboratory, clinical and biometric research, clinical cancer treatment, cancer etiology, and cancer prevention and control, with emphasis on training and experience in the various disciplines and fields related to scientific areas relevant to all aspects of cancer research and care including patient advocacy representation. The BSA shall advise the Director and Deputy Director for Extramural Science, NCI, and the Director of each NCI Division on a wide variety of matters concerning scientific program policy, and progress and future direction of extra-

murals research programs of each of the Divisions. The BSA is currently chaired by Dr. Robert Young of Fox Chase Cancer Center in Philadelphia, PA.

What does the BSA advise on?

Along with advising on the future direction of extramural research programs, the BSA evaluates NCI awarded grants, cooperative agreements, contracts, and concept review of those activities which it considers meritorious and consistent with the Institute's programs. The advisory role of the Board is scientific and does not include deliberation on matters of public policy. The 30th Regular Meeting of the National Cancer Institute (NCI) Board of Scientific Advisors (BSA) was held at the NCI Campus in Bethesda, MD on March 7-8, 2005. The Director of the NCI, Dr. Andrew von Eschenbach presented the Director's Report and a budget overview.

Board of Scientific Advisors (continued)

Updates, progress reports and presentations on:

- NCI activities and the Congress <http://www3.cancer.gov/legis/index.html>
- Food and Drug Administration (FDA)/NCI Task Force <http://cancer.gov/newscenter/pressreleases/NciFdaCollab>
- National Lung Screening Trial (NLST) <http://cancer.gov/NLST>
- Clinical Trials Working Group <http://integratedtrials.nci.nih.gov/ict/>
- Bioethics and the Future of Biorepositories
- BSA participation scheduled at “NCI Listens” sessions for upcoming national meetings of ASCO, AACR, and the Society of Behavioral Medicine and a report on the ASTRO 2004 session.

- Program Concept Renewals:

Program concept renewals were presented on the Blood and Marrow Transplant Clinical Trials Network (BMTCTN) from the Division of Cancer Treatment and Diagnosis <http://cancer.gov/dctd/> and the Breast Cancer Family Registries (B-CFR) from the Division of Cancer Control and Population Sciences. <http://dccps.nci.nih.gov/>

The BMTCTN <http://spitfire.emmes.com/study/bmt/> is a joint program funded by the NCI and the National Heart, Lung and Blood Institute. The program objective is to accelerate research in blood and marrow transplantation and improve outcome by comparing novel and existing treatment strategies and to improve transplant techniques and strategies.

The Breast Cancer Family Registries <http://epi.grants.cancer.gov/BCFR/> is designed to

- a) Identify and follow a cohort of individuals and their families spanning the whole spectrum of breast cancer risk
- b) Characterize diverse genetically susceptible populations
- c) Develop an informatics model to support studies based on the B-CFR infrastructure and
- d) Enable and expedite collaborative interdisciplinary investigator-initiated research.

- Proteomics:

Dr. Leland Hartwell presided over a mini-symposium titled: The Current State of Cancer Proteomics. Presentations included: Proteomic analysis in Cancer Research; Advances in Mass Spectrometry in Serum-based proteomics; Platform Technologies in Affinity Methodologies; and Considerations for Study Design and Technology Evaluation. Proteomics is an area of high interest in the research community, as they work to refine this technology to the point of practical and widespread clinical application for patients.

Researchers search for proteins in biospecimens such as blood, urine, or diseased tissue that can be used in early detection, response to therapy, risk, and diagnosis. Learn more about proteomics: <http://cancer.gov/cancerinfo/proteomics>

How can I find out more about the BSA?

The BSA meeting schedule is posted on its website and meetings are open to the public. You can also find BSA Information, roster, meeting minutes and agendas. NCI Website: www.cancer.gov. BSA Home Page: <http://deainfo.nci.nih.gov/advisory/bsa.htm>

.....Submitted by: Paula Kim, President- Paula Kim Consulting, *Translating Research Across Communities*SM
TRAC works to improve communication and outreach among all sectors focused on cancer research and care.

****Editor's note: Research Advocacy Network advocates for responsibility and accountability of all research advocates to report on activities and share outcomes. Network News offers a forum for reporting on participation in conferences and events. If you have articles you would like to submit, please contact Elda Railey at erailey@researchadvocacy.org.

Action Idea:

“NCI Listens” Sessions provide an opportunity to ask questions, share ideas, and viewpoints in an open forum setting with members of the BSA and NCI Staff. I encourage you to attend the “NCI Listens” sessions at the upcoming national meetings and use the opportunity to learn more about the BSA and to share your thoughts about cancer research.
 Paula Kim

Calendar-What is Research Advocacy Network Doing?

February 2005

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					

- February 5-Amelia Project
- February 8- NCCN Breast Cancer Screening Guidelines Committee Meeting
- February 11- NCCN Review of Breast Cancer Guidelines 2005
- February 14-RAN IRB Community Member Focus Group
- February 17-18-National Cancer Advisory Board Hearings

March 2005

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		

- March 16-17 -University of North Carolina, School of Public Health, Health Advocacy Conference
- March 18—ECOG Developmental Therapeutics Committee Retreat

April 2005

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

- April 11- UCSF Breast SPORE External Advisory Board
- April 14-15 NCI Understanding SEER Data Conference
- April 16-20 American Association of Cancer Research Annual Meeting
- April 18- Public Affairs Network Presentation
- April 18-21—NCCTG Patient Advisory Working Group
- April 30- Indiana University Center of Excellence Breast Cancer Advocate's Seminar

Features on

[http://
www.researchadvocacy.org](http://www.researchadvocacy.org)

- Advocate SkillBuilders
- Advocate Opportunities
- Fact Sheet Series: What It Means For Me
- RAN accomplishments
- Current and archived newsletters

Research Advocacy Network

Advancing Patient-Focused Research

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 10 times per year and includes articles on advocacy, research results and activities.

Editor and Authors: Elda Railey, Mary Lou Smith, Judy Perotti

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