



# NetworkNews

Research Advocacy Network  
Advancing Patient-Focused Research

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## Research Advocacy Network Launches Advocate Institute™ with Focus on Research™ Course

Fifteen advocates and supporting faculty helped Research Advocacy Network launch the Advocate Institute with a course called Focus on Research. The course started in May with preparatory webconferences focusing on Targeted Therapies, the Drug Safety and Approval Process and Statistics and Logistics for Advocates to aid their understanding of presentations at the American Society of Clinical Oncology (ASCO) Annual Meeting, May 13-17 2005 in Orlando, FL. Followup webconferences and discussion groups are focusing on mechanisms for the advocates to influence the research system and serve their patient constituency by disseminating research results that will influence patient care.

The program is directed to advocates at the entry level of research advocacy and advocates who want to improve their effectiveness and refresh their knowledge. Materials and coursework were designed to allow advocates to: 1) have a greater understanding of the common concepts in oncology; 2) be able to relate these

common concepts to site specific research, and; 3) be more effective in disseminating research results that will change community practice.

The true test of the program will be how these advocates apply the knowledge they have gained. With the energy, passion and motivation of these few – many will gain!

From the participants:

*.....I followed the Sarcoma Track. Some presentations were hard to follow, but I can access them on-line to keep learning. So much was valuable! I have to say that my favorite part of ASCO was learning from the other advocates and what they have accomplished within their groups.*

*.....My favorite session was the discussion on angiogenesis led by Dr. Roy Herbst. Avastin is heralded as the greatest drug ever but if you listen to Folkman, VEGF is ONE growth factor. In late stage breast cancer there maybe five or six growth factors present besides VEGF. At least it is a start. I really liked meeting with my SPORE Lymphoma Pls at a three hour session one night. Extremely eye opening.*

*.... I felt like a kid at Disneyland. I wanted to go to everything. The exhibits, posters, discussions, and plenary sessions were good information. Loved the networking with everyone, especially the other advocates. I found the educational sessions really interesting. I went to 'How to write a successful manuscript' and 'How to write a clinical trial'. This will come in handy reading pilot research projects and reviewing returned manuscripts from IRB and FDA.*

*.....There is another science that I have been out of my mind enthusiastic about for the last eight years and that is the science of angiogenesis - targeting the blood supply - like Avastin does. Of course, we all dream of molecular level cures using the cancer Genome or getting the body's immune system to fight off the disease, bone marrow transplants, radioimmunotherapy etc....BUT it may be prudent to take a closer look at the blood side of the equation since.. we are pretty good at shrinking most tumors, or getting a patient into a remission, whether it is partial or complete. What we are awful at are durable remissions, I won't even say the word cure since low grade lymphoma patients can never turn their back on their disease. HOWEVER, I do believe we will turn cancer into a chronic disease, much like diabetes if we do a combination approach of targeting the GRAPES (tumors) and the VINES (blood). We are really good at targeting the grapes but lousy at targeting the vine. This was the theme I took with me as a patient advocate to ASCO 2005 in Orlando, Florida and I made a point to ask every lymphoma or cancer expert this very question, "why are we so good at targeting the grapes and not the vine?"*

If you would like more information on the Advocate Institute™, Focus on Research™ courses or to contact any of the participants from the program, please contact Research Advocacy Network ([info@researchadvocacy.org](mailto:info@researchadvocacy.org)).

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## **Reports from The American Society of Clinical Oncology 2005 Annual Meeting**

The American Society of Clinical Oncology (ASCO) held their annual meeting in Orlando, Florida May 13 to 17. ASCO is considered the premier oncology meeting of

the year and this year had an attendance of over 28,000 healthcare professionals, researchers and advocates. The excitement of this years meeting was the emergence of targeted therapies in the treatment of multiple cancers. Below are links to articles from various sources that report on highlights of the meeting.

### Targeted Therapies

- [Targeted Treatment Takes Aim at Cancer](#), Peggy Peck, WebMD Medical News

### Breast Cancer

- [Herceptin® — New Standard of Care in Early Breast Cancer](#)
- [Avastin® Improves Outcomes in Advanced Breast Cancer](#)
- [Letrozole Better than Tamoxifen at Keeping Breast Cancer from Returning](#)
- [Drugs that Lower Cholesterol May Also Help Lower Breast Cancer Risk](#)
- [Eating Less Fat Can Lower the Risk that Breast Cancer Will Return](#)
- [Care Delayed for Black Women with Breast Cancer](#)
- [Chemotherapy Dose Does Not Differ Between Black Women and White Women with Breast Cancer](#)

### Colorectal Cancer

- [Taking Aspirin Regularly Lowers the Risk of Colorectal Cancer Returning and Improves Survival](#)
- [Two Studies Assess Benefit of Two Different Drugs Used to Lower the Risk of Colorectal Cancer Returning](#)

### Gastrointestinal Cancer

- [Too Few Lymph Nodes Are Being Removed During Stomach Cancer Surgery in the United States](#)
- [Chemotherapy Helps People with Cancer of the Stomach and Lower Esophagus Live Longer](#)

### Kidney Cancer

- [New Drug Shows Promise in Advanced Kidney Cancer](#)
- [Sorafenib Improves Outcome of Metastatic Renal Cell Carcinoma](#)

### Lung Cancer

- [New Drug Helps People with Non-Small Cell Lung Cancer Live Longer](#)

## Lymphoma

- [New Drug Regimen Doubles Remission Time for Lymphoma](#)

## Pancreatic Cancer

- [Addition of Tarceva™ to Gemzar® Improves Survival in Pancreatic Cancer](#)

## Prostate Cancer

- [Drug May Lower Risk of Developing Prostate Cancer](#)

## Survivorship

- [Most Survivors of Childhood Cancer Have Significant Health Problems by Age 45](#)
- [Many Cancer Survivors Say Their Nonmedical Needs Are Not Met](#)

## Uterine Cancer

- [Raloxifene May Protect Against Uterine Cancer](#)

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**Follow up to the article**  
**"Harnessing Advocacy Relationships To Deal With Serious Safety Issues"**  
**by Mike Katz, International Myeloma Foundation that appeared in the**  
**April issue of Network News**

The information is quoted from MedWatch, the FDA Safety Information and Adverse Event Reporting Program.

"Novartis and FDA notified dental healthcare professionals of revisions to the prescribing information to describe the occurrence of osteonecrosis of the jaw (ONJ) observed in cancer patients receiving treatment with intravenous bisphosphonates, Aredia (pamidronate disodium) and Zometa (zoledronic acid). The prescribing information recommends that cancer patients receive a dental examination prior to initiating therapy with intravenous bisphosphonates (Aredia and Zometa), and avoid invasive dental procedures while receiving bisphosphonate treatment. For patients who develop ONJ while on bisphosphonate therapy, dental surgery may exacerbate the condition."

Additional information can be found at: May 05, 2005 - [Dear Dentist Letter](#) – Novartis

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## **News from Redes En Acción: The National Latino Cancer Research Network**

Over the past five years, Redes En Acción has formed the most extensive collaboration of organizations ever assembled to address cancer disparities in Latino populations. Now, under the National Cancer Institute's new Community Networks Program initiative, Redes En Acción (Networks in Action) will receive funding to expand its efforts to fight cancer in Latino communities throughout the United States. The Redes En Acción program is supported by a new five-year, \$7.2 million National Cancer Institute grant. For more information, please see the news releases in English and Spanish at [www.redesenaccion.org](http://www.redesenaccion.org).

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### **Funding available:**

ENACCT The Education Network to Advance Cancer Clinical Trials (ENACCT) is pleased to announce the launch of its Pilot Education Program (PEP)—a new funding opportunity for cancer clinical trials education efforts.

With funding from the Lance Armstrong Foundation, ENACCT will award a total of \$450,000 to 3 community based Partnerships to develop unique approaches to

- Foster awareness about cancer treatment clinical trials,
- Enhance their acceptability, and
- Improve access to them.

The Partnerships will receive ongoing technical assistance, evaluation and training services provided by ENACCT staff. The preliminary application, as well as promotional material about the grant program can be found at <http://www.enacct.org/appguide>. The application deadline is July 11, 2005.

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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

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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](http://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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