

Research Advocacy Network Publishes Educational Series "The Importance of Tissue in Research"

The study of tissue and biospecimens in research is more important in today's world of genomics, genetics and rapidly developing science and is critical to the shift to targeted treatments. The supply of tissue needed for research comes almost exclusively from patients and non-patients who have consented to donate their archived tissue samples for study. The need for advocates, patients and the general public to understand the importance of tissue is critical if medical science is to continue making progress by using donated tissue. The Research Advocacy Network is pleased to announce the publishing of an educational series entitled "The Importance of Tissue in Research." The entire body of material was developed by the Research Advocacy Network and reviewed by experts. In order to meet the needs of different audiences (patients, advocates, and healthcare professionals) we provided the information in components that focus on different topics. The topics /components offered are:

- ***What is Tissue? Why is it Important?*** - The definition of tissue and how it is used in research is covered in *What is Tissue? Why is it Important?* This topic is covered in a short concept paper and longer booklet for printing. A PowerPoint Presentation is also offered in two lengths. This component explains and gives examples of how tissue is used to understand the causes of cancer, identify targets for treatment, discover biomarkers and develop treatments.
- ***The Treatment Development Process: The Role of Tissue*** focuses on how tissue is used in the scientific drug development process. It also covers the approval and regulatory process for developing drug and biologic cancer therapies. This component is available in a PowerPoint Presentation and a concept paper.
- ***Why is it important for me to consider donating my tissue for research?*** Helping advocates and patients understand why donating their tissue is important and what mechanisms are in place to protect them are the focus of *Why is it important for me to consider donating my tissue for research?* This component covers what can be learned from donated tissue, the risks of donating tissue, protections to ensure privacy and confidentiality and the informed consent process. Available to print in a short concept paper and longer booklet form.

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Our mission: To develop a network of advocates and researchers who can influence medical research from concept to patient care through education, support and collaborations.

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In addition to the three main components, there is additional material offered consisting of a *Glossary of Terms*, *How to Use this Material*, and stand alone slides. The registration process for access to these materials will be completed shortly. If you would like access to these materials before formally available on our website, please send an email to info@researchadvocacy.org.

We believe this material will help patients, advocates and healthcare professionals to increase understanding and raise awareness of the importance of tissue in research. What we learn from research will lead to better treatments and ultimately to improved patient care.

The Issue of Open Access to Scientific Publications

Have you ever been alerted to the release of an article reporting the results from a significant clinical trial or study and then not been able to read the article because the full text was not available without a subscription?

Have you ever checked out the prices of the Journals that publish the information you're looking for? It has been, and still is, very difficult for the consumer, patient or advocate to gain access to vital information.

More and more of the stakeholders in the transmission of information, such as libraries, publishers, scientists, scientific societies, institutions, funding agencies and advocate organizations are addressing the issue of Open Access. Open Access has been discussed since the late 1960s; however, in the beginning of 2000 the Open Access movement has received much wider support and attention.

In Open Access copyright holders "consent in advance to the unrestricted reading, downloading, copying, sharing, storing, printing, searching, and linking of the full-text of the work. Most authors choose to retain the right to block the distribution of mangled or misattributed copies. Essentially, these conditions block plagiarism, misrepresentation, and sometimes commercial re-use, and authorize all the uses required by legitimate scholarship, including those required by the tech-

nologies that facilitate online scholarly research."

There have been three major meetings that issued statements or initiatives:

- Budapest Open Access Initiative, February 14, 2002
- Bethesda Statement on Open Access Publishing, June 20, 2003
- Berlin Declaration, Oct 2003

Each of these meetings developed a slightly different definition of Open Access but all concluded that the time for Open Access has come.

On July 16, 2004 the House of Representatives Appropriations committee recommended to the NIH that it provide free public access to research articles resulting from NIH funded research. In addition they recommended that NIH offer access to authors' final manuscripts and supplemental materials through PubMed six months after publication and that if NIH funds were used to pay any publication charges PubMed, access should be immediate. While not everything Open Access proponents are calling for, this is a beginning. A check of the Directory of Open Access Journals showed there were sixteen Open Access journals for oncology.

If you or your organizations are interested in supporting Open Access the following resources will be helpful:

- OPEN ACCESS NEWS <http://www.earlham.edu/~peters/fos/fosblog.html>
- Open Access *now* <http://www.biomedcentral.com/openaccess/>
- Directory of Open Access Journals <http://www.doaj.org/ljbs?cpid=37>
- The Public Library of Science (PLOS) <http://www.plos.org/about/openaccess.html>
- PubMed Central <http://www.pubmedcentral.gov/about/openaccess.html>

St. Louis Komen Affiliate Workshop

Advocates in Action

A collaboration of the Komen St. Louis Affiliate, the Siteman Cancer Center and the Research Advocacy Network provided an educational program for local advocates in the St. Louis, Missouri area. Held in early spring 2004, the goal was to increase their awareness and understanding of the mission and objectives of the research process. The symposium was met with a great deal of enthusiasm. Twenty participants expressed interest in learning more about research advocacy.

On September 10th the St. Louis Komen Affiliate and the Research Advocacy Network conducted a day-long workshop on research advocacy at the Siteman Cancer Center. The purpose of the workshop was to prepare the participants to give their time and talent to the research efforts in the St. Louis area. The workshop focused on three major areas: understanding the medical research process and how therapies are developed; patient protections and the regulatory processes that are in place to protect participants in medical research; and the types of opportunities that exist for advocates to be successfully involved in the design and conduct of medical research. The aspect of the training that the participants most enjoyed was the lively discussions among the group. One of the highlights of the day was a visit to Dr. Katherine Weilbaecher's laboratory at Washington University. Dr. Weilbaecher's basic and clinical research focuses on the molecular mechanisms through which tumor cells metastasize to bone. She is specifically studying the role of beta 3 integrin which is critical in osteoclastic bone resorption, and tumor associated angiogenesis. Workshop participants were able to see a working laboratory with a mouse model of disease.

Each of the participants developed an action plan for their involvement in research activities. The action plans included goals, milestones and timelines. Each advocate identified barriers and what possible solutions and resources existed for them to address these barriers. The Komen Affiliate will support these advocates in meeting their goals and provide support for them as they work toward becoming effective research advocates. The Komen Affiliate plans to follow-up on the training with a session to review actual protocols and informed consent documents. The Research Advocacy Network believes in working with advocate organizations at the local level to maximize resources and establish the value of research advocacy to the community.

"Participating in the Research Advocacy Network Training session enhanced my understanding of the ways that I can become actively involved in the cancer research advocacy process. Inspired by all that I learned, I am submitting my application for Project LEAD training, and am actively networking with local research advocates to learn more about institutional review boards and how I can get involved in the future. Thank you for providing this opportunity!"

— Judy Johnson

Ohio Komen Presentation

RAN co-founder Judy Perotti was invited to present *Patient Advocacy: Understanding Clinical Trials* at **Committed to the Cure** at the Columbus Ohio Affiliate of the Susan G. Komen Breast Cancer Foundation. This was the second year for this event that attracted over 200 people. In addition to Perotti's presentation, the program consisted of *Living without Estrogen, Beauty: Inside and Out*, and Betty Rollin as the luncheon speaker.

Calendar-What is Research Advocacy Network Doing?

October 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						

November 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				

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 /yr and includes articles on advocacy, research results and activities.

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Advancing Patient-Focused Research

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Research Advocacy Network Activities

- **October 5**— Trainer at the Pennsylvania Breast Cancer Coalition Keystone Breast Cancer Conference Scientific Training
- **October 6**—GSK Advisory Board
- **October 12**—IRB Administrators Focus Group, Rush Presbyterian, Chicago, IL
- **October 16**—Presentation at Columbus Affiliate of The Susan G. Komen Breast Cancer Foundation
- **October 20-24**—Facilitators for Lymph Science Advocacy Program (LSAP), National Lymphedema Network Conference, Reno, NV
- **October 28-31**—PRIM&R and ARENA conference, presentation "Maximizing Community and Non Scientific Member Participation"
- **October 28-31**—Lynn Sage Breast Cancer Conference, Chicago, IL
- **November 4**—Trainers for Coalition of National Cancer Cooperative Groups Module 6: Tissue and Its Use at NSABP
- **November 4-8**—NSABP meeting, Patient Advisory Working Group
- **November 5**— 1:30 –2:30pm (Eastern) Telephone Education Workshop, Topic: Clinical Trials
Register online (free) at www.cancercare.org or call (800) 813-HOPE
- **November 10 - 12**— Breast SPORE Roundtable
- **November 10**— ASCO Patient Advocate Roundtable
- **November 19** Trainers for Coalition of National Cancer Cooperative Groups Module 6: Tissue and Its Use at ECOG

Research Advocacy
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Features on <http://www.researchadvocacy.org>

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

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