



# Roadmap to Research Advocacy

**Research Advocacy Network**

*Advancing Patient-Focused Research*

# Roadmap to Research Advocacy

## Table of Contents

- What is research advocacy? ..... 1
- What have research advocates done to support research? ..... 1
- What can research advocates do in their communities to support research? ..... 2
- What skills do research advocates need to advance research? ..... 2
- Are you ready to be a research advocate? ..... 3
- Protocol and Etiquette for Research Advocates ..... 5
- Protocol and Etiquette for Research Advocates ..... 5
- Advocacy Types and Styles ..... 6
- Interest Assessment ..... 7
- Opportunities for Research Advocates ..... 8
  - Grant review ..... 9
  - Institutional Review Board Community (Non-Affiliated) Member ..... 11
  - Peer Support for Potential Clinical Trial Participants ..... 12
  - Protocol Review/ Study Design Development ..... 13
  - Public-speaking About Clinical Trials ..... 15
  - SPORE Patient Advocates ..... 17
- Training and Resources ..... 19



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## Roadmap to Research Advocacy

Advocating for the advancement of research is crucial to finding new and better treatments for cancer patients. Cancer survivors, their caregivers and families are uniquely positioned to support cancer research in new and innovative ways. If you are a cancer survivor, caregiver or family member, you may find the following Q & A helpful in exploring this new and dynamic way that you can help cancer patients now and in the future.

### ***What is research advocacy?***

Research advocacy infuses the patient perspective into research making scientific and medical advances more timely and effective for people with cancer. Research advocates help provide a “face” to the science – as researchers focus on new approaches to cancer treatment, research advocates work alongside them and remind them of the human element. This partnership ensures clinical trials ask questions important to patients, eligibility criteria allow diversity of participation, and trial designs attract potential participants. Research advocates support conducting ethical, well-designed research and work to disseminate the results of that research so that new and better treatments are available in communities throughout the United States.

### ***What have research advocates done to support research?***

Research advocates support research by enhancing trial/study design. They review protocols, serve on study sections and conduct or participate in focus groups providing input into specific trial designs.

Research advocates serve on Institutional Review Boards (IRB) at academic medical centers and their local hospitals. Research conducted at an institution that is federally funded must have IRB approval. Each IRB is required to have a voting member from outside the institution or non-affiliated with the institution. This person may be called a community member and provide the perspective of his or her community to the board’s discussions.

Research advocates review proposals for research projects and help decide who will be funded. Both the Department of Defense Cancer Research Program and the Susan G. Komen for the Cure include research advocates on their review panels.

Research advocates participate in formal programs sponsored by the federal government. These federal agencies include the National Cancer Institute’s CARRA (Cancer Advocates in Research and Related Activities) and Director’s Consumer Liaison Group, the Food and Drug Administration’s consultant program and the Institute of Medicine (IOM) panels.

### ***What can research advocates do in their communities to support research?***

Research advocates can support research in their communities in a number of important ways. We have listed some activities here but it does not represent an exhaustive list. These activities may need the sponsorship of a local hospital or Cancer Center. They can:

- Serve on their local hospital Institutional Review Board
- Review educational materials for patients interested in participating in clinical trials
- Conduct support groups for patients participating in clinical trials and their family members
- Act as an advisor to their local hospital or clinic about accessibility and support for clinical trial participants
- Raise dollars for cancer research and to offset costs for people participating in clinical trials
- Be available in the clinic to talk to patients about their experience participating in a clinical trial
- Talk to patients and the public about clinical trials
- Work with state legislators to enact laws and regulations that support patients' participation in cancer research

### ***What skills do research advocates need to advance research?***

Survivors, caregivers and friends need:

- Desire to make things better
- Communication skills
- Ability to represent all patients and not just their personal "story"
- Willingness to learn the basics of science/treatments
- Ability to work collaboratively with others

## ***Are you ready to be a research advocate?***

### **Purpose:**

The Research Advocacy Network has developed the following template for advocates and researchers to use in reaching an understanding about the work and the responsibilities of each in accomplishing the objectives of the organization or agency.

### **Method**

This template applies to those instances when the research community has invited an advocate to “sit at the table” where research activities or processes are being discussed. These instances include Cooperative Group meeting, grant review, IRB review, study sections, etc. The template should be adapted to each activity. The research activity can be divided into three time limited components: pre-work, meeting and post-work.

### **Process**

#### Pre-work

- ✓ Request information from chair or sponsor’s office
  - What is the purpose of the committee or organization/agency?
  - What is the purpose of the meeting?
  - Agenda, handouts, previous reports from this committee, roles and responsibilities of the committee.
  - Any topics or issues chair expects the advocate to discuss at the meeting?
  - Any other advocates invited and/or attending?
- ✓ Visit organization’s web site to gain background information on mission and activities of the organization or agency
- ✓ If sponsor is paying for your travel expenses, make reservations in a timely manner to reduce costs
- ✓ Use internet to gain more information on topic area
  - Understand science – high level information
  - Understand system – Is it NCI supported? Who are the players? Who regulates the activity and how?
  - Understand the issues from the researcher and patient perspectives – issues such as: lack of communication across research community, funding, lack of expertise and/or resources, impact on patients, importance of issues to patients
  - Gain input from advocate community, if you are unfamiliar with the issues and/or the impact and importance for patients
- ✓ Contact other advocate(s), if invited and attending
  - What is their background?
  - Which patient community do they represent?
  - How are they planning to gain input from that community on the issue to be addressed?
  - How can we coordinate our efforts?

### Meeting

- ✓ Be on time and stay until the scheduled time of adjournment
- ✓ Introduce yourself to the chair, if you do not already know her/him
- ✓ Ask her/him what they expect or hope the advocate to provide at this meeting
- ✓ Let the chair know that if s/he would like your input at any point in the discussion they can request it
- ✓ If this is the first time you are attending the meeting and there will not be a time for the participants to introduce themselves, ask the chair to introduce you providing a summary of your role and responsibilities as a new member of/consultant to this committee or effort.
- ✓ State that you will contact the chair either at the end of the meeting or afterwards by phone or email to discuss next steps
- ✓ During the discussions note issues important to patients and either address them at the meeting or provide input in a discussion with chair
- ✓ Report the outcomes of the discussions to the advocate community, if acceptable to the Chair and sponsoring organization

### Post-meeting

- ✓ Communicate outcomes of the discussions to the advocate community and/or patients and public, if acceptable to the Chair and sponsoring organizations
  - Seek approval of report document from Chair before sending
  - Ask for any official documents (press releases, talking points, reports, links for the web site) the Chair would like disseminated with the report
  - Copy Chair on the report to advocates and/or patients and public
- ✓ If other advocates were involved, discuss next steps and reach consensus on who will do what
- ✓ Have a discussion by email or phone with Chair
  - Did we meet our objectives?
  - Is there any other input s/he would find helpful in going forward?
  - What are the next steps?
- ✓ Submit expenses in a timely manner

## ***Protocol and Etiquette for Research Advocates***

- Be respectful to all – researchers, professionals and other advocates.
- Be on time for scheduled meetings and stay for the entire meeting. If you do arrive late, enter quietly and try not to disturb the proceedings.
- Be assertive, but not confrontational.
- Consider materials and proceedings to be confidential and do not share with others unless you first check with the PI or someone in authority on the project.
- Be attentive.
- Ask questions when appropriate. It may be helpful to write down your question during the presentation and then ask when questions are called for.
- Writing down your question will help you be clear will avoid rambling and be sure your question is answered.
- Personal medical questions or agendas are inappropriate.
- Be responsible and dependable. If you make a commitment be sure to follow up.
- Side conversations can be very important and effective, but should be between meetings and not during a session.
- Dress appropriately and as much as possible in context with the setting.
- Try to understand the issues today, not just at the time of your treatment or experience.
- Ask the researchers what they expect or need from you as an advocate.
- Acknowledge the work of the researchers. Everyone appreciates recognition of the hard work they do. Thank you notes leave a very favorable impression.

## **Advocacy Types and Styles**

There are different types of advocacy and different activities included under the heading of advocacy. Most activities fall under one of four categories: 1) patient services or education; 2) public policy or political advocacy; 3) fund-raising events with the proceeds going to research and the fund-raisers granting out the dollars to specific research projects, and; 4) research advocacy where the advocates provide the patient perspective to the research process.

Just as there are different types of advocacy (political, support) there are different styles. All styles have their place in representing the patient perspective. These predominant styles can be classified as Activist or Collaborator. Advocates may utilize a "blended" style in some situations.

A predominant advocacy style can be adjusted to achieve the results desired but be aware there may be unintended consequences. Since we all need to fit people and situations into our previous experience, others may want to stereotype an advocate as one or the other. Your voice, manner and words may be seen as representative of one style or the other to your audience.

### **Characteristics of Predominant Advocacy Styles**

<b>Collaborator</b>	<b>Activist</b>
<ul style="list-style-type: none"> <li>▪ doesn't always say yes</li> </ul>	<ul style="list-style-type: none"> <li>▪ doesn't always say no</li> </ul>
<ul style="list-style-type: none"> <li>▪ bridge builder</li> </ul>	<ul style="list-style-type: none"> <li>▪ action oriented</li> </ul>
<ul style="list-style-type: none"> <li>▪ works from within the system on mutually agreed upon projects/problems</li> </ul>	<ul style="list-style-type: none"> <li>▪ works from outside the system on self-identified projects/problems</li> </ul>
<ul style="list-style-type: none"> <li>▪ conciliatory</li> </ul>	<ul style="list-style-type: none"> <li>▪ strident</li> </ul>
<ul style="list-style-type: none"> <li>▪ may be seen as a positive force for change</li> </ul>	<ul style="list-style-type: none"> <li>▪ may be seen as a negative force for change</li> </ul>

### Interest Assessment

This self assessment is offered to help you determine your main area of interest. Many research advocates participate in several varied activities so don't feel limited by this assessment let it serve as a guide to a starting place.

Medical, Scientific		
		<i>Rate your interest on a scale of 1-10 (10 being MOST interested)</i>
	I like to know of new medical discoveries	
	Science concepts are easy for me to grasp.	
	I like to research issues and understand the concepts.	

Ethics, Protections		
		<i>Rate your interest on a scale of 1-10 (10 being MOST interested)</i>
	I am interested in medical ethics and therapeutic safety.	
	I am not intimidated by legal wording.	
	I like rules to be followed.	

Communication		
	YES	NO
I prefer one on one interactions		
I prefer to read material and give written feedback		
I prefer to work in committees/ groups		
I like to do presentations in front of groups/ public speaking		
I prefer talking to other patients/families		

Time/ Availability		
	YES	NO
I prefer to volunteer for assignments on a regular basis		
I can devote ___ hours per ___ week /month for advocacy activities		
I prefer to volunteer for special events/ projects on occasional basis		

#### Analysis:

A high interest score in **Medical, Scientific** and a preference to read material and give written feedback consider volunteering to **review grants**.

A high interest score in **Ethics, Protections** and a preference to work in groups, consider volunteering for an **IRB**. (Each IRB has different time requirements).

A high interest score in **Medical, Scientific**, a preference to work in groups and the availability to travel to meetings consider volunteering for **cooperative group patient representative**.

A preference for one on one **Communication** and work with patients and families consider volunteering for **peer support**. If you are comfortable with public speaking consider **public speaking about clinical trials**.

## ***Opportunities for Research Advocates***

Opportunities for advocates to be “at the table” when research is being discussed and planned has increased over the past decade. This is due in large part to volunteers being available, vocal and efficient in providing the patient perspective to the research process. In each interaction and opportunity, the individual has a tremendous responsibility to make the most of the experience by being prepared and engaged. We have listed a few opportunities to help get you started. This is not an exhaustive list. Help us add to these opportunities as you find new and creative ways to advocate in research.

<b>Grant review</b>	
Description of opportunity:	<p>Consumers participate in the scientific review process as representatives of the disease that has touched their lives. Advocates offer the patient perspective on applications for grant funding from the scientific community. Agencies that involve consumers (or advocates) set the parameters of review and method. Applications usually involve basic, translational or clinical research and can include quality of life, psychosocial needs and ethical issues.</p> <p>Agencies offering consumer/advocate review positions:</p> <ul style="list-style-type: none"> <li>• Susan G. Komen for the Cure Advocate Reviewer.</li> <li>• Dept of Defense: Consumers are nominated by their advocacy, outreach or support organization to serve as Consumer Reviewers in Peer Review. Participation on the Integration Panel <sup>1</sup> and Consumer Working Group <sup>2</sup> requires first participating in Peer Review.</li> </ul>
Time required:	Dependent on agency and volume of proposals expected to review
Travel required:	Possible
Equipment:	<ul style="list-style-type: none"> <li>• If review is to be done online, internet access</li> <li>• Fax availability is helpful</li> <li>• If conference calls are involved it is helpful to have a headset for a land line phone so you can be hands free to make notes. Cell phones are not the best method for conference calls as calls may be dropped and background noise may be distracting.</li> </ul>
Skills:	<ul style="list-style-type: none"> <li>• Basic understanding of scientific process / disease or condition being studied</li> <li>• Good communication skills both verbal and written</li> <li>• Critical thinking skills to formulate questions and respectful, confident approach to ask questions</li> </ul>
Training offered:	<ul style="list-style-type: none"> <li>• Program dependent</li> </ul>

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<sup>1</sup> Integration Panel—an expert panel of scientists, clinicians, and consumer advocates—meets to deliberate issues and concerns unique to the individual program and establishes a vision and an investment strategy for the coming year. Source: [http://cdmrp.army.mil/annreports/2006annrep/pdf/1\\_overview.pdf](http://cdmrp.army.mil/annreports/2006annrep/pdf/1_overview.pdf), p 16 2/9/2009

<sup>2</sup> Consumers on the CWG play a role in Program improvements, recruitment activities, and promote the benefits of consumer involvement. <http://cdmrp.army.mil/cwg/who.htm> 2/9/2008

<b>Grant review</b>	
Resources:	<ul style="list-style-type: none"><li>• Medical Dictionary, Encyclopedia, some tutorials <a href="http://medlineplus.gov/">http://medlineplus.gov/</a></li><li>• NCI Consumer Guide to Peer Review <a href="http://deainfo.nci.nih.gov/PeerReview/GuideCompleteBook.pdf">http://deainfo.nci.nih.gov/PeerReview/GuideCompleteBook.pdf</a></li><li>• NCI Consumers' Cancer Dictionary for Peer Review <a href="http://deainfo.nci.nih.gov/PeerReview/DictionaryCompleteBook.pdf">http://deainfo.nci.nih.gov/PeerReview/DictionaryCompleteBook.pdf</a></li><li>• Oncology Nursing Society Continuing Education Series Online Cancer Biology (\$40 non member registration fee) <a href="http://onsopcontent.ons.org/Education/DistanceEducation/CancerBiology/index.shtml">http://onsopcontent.ons.org/Education/DistanceEducation/CancerBiology/index.shtml</a></li><li>• Oncology Nursing Society Continuing Education Series Online Cancer Basics (\$40 non member registration) <a href="http://onsopcontent.ons.org/education/distanceeducation/cancerbasics/">http://onsopcontent.ons.org/education/distanceeducation/cancerbasics/</a></li></ul>
Opportunity contacts:	<ul style="list-style-type: none"><li>• Komen for the Cure <a href="http://www.komen.org">www.komen.org</a> Grants Section, email <a href="mailto:grantsreview@komen.org">grantsreview@komen.org</a> or call, toll-free, 1-888-300-5582.</li><li>• Department of Defense Breast Cancer Research Program Application for Consumer Reviewer <a href="http://cdmrp.army.mil/cwg/apply.htm">http://cdmrp.army.mil/cwg/apply.htm</a></li></ul>

<b>Institutional Review Board Community (Non-Affiliated) Member</b>	
Description of opportunity:	Research conducted at an institution that is federally funded must have IRB approval – each IRB is required to have a non-affiliated member, someone who does not work for the institution. This individual may represent the community perspective and reviews and votes on research that is proposed to be conducted at that institution including but not limited to oncology research studies. IRBs also conduct a continuing review during the duration of the study and review adverse events.
Time required:	Dependent on each board, usually one to two meetings per month. Preparation time (to review protocols) also varies but can be 4-6 hours for each meeting.
Travel required:	Local travel to/from IRB meetings
Skills:	<ul style="list-style-type: none"> <li>• Good verbal and written communication skills</li> <li>• Basic understanding of regulations and scientific process.</li> <li>• Time to participate in board meetings and prepare reviews.</li> </ul>
Compensation/ Expenses:	Most IRB community members are volunteer positions but this depends on the board. Out of pocket (parking, etc.) may be reimbursed.
Resources:	<ul style="list-style-type: none"> <li>• Medical Dictionary</li> <li>• <a href="http://www.hhs.gov/ohrp/irb/irb_guidebook.htm">http://www.hhs.gov/ohrp/irb/irb_guidebook.htm</a></li> <li>• <a href="http://www.primr.org/resources/human.html">http://www.primr.org/resources/human.html</a></li> <li>• <a href="http://www.irbforum.org/forum/read/6/205/205">http://www.irbforum.org/forum/read/6/205/205</a></li> <li>• <a href="http://www.fda.gov/oc/ohrt/irbs/faqs.html#IRBOrg">http://www.fda.gov/oc/ohrt/irbs/faqs.html#IRBOrg</a></li> <li>• <a href="http://humansubjects.stanford.edu/hrpp/Chapter1.html">http://humansubjects.stanford.edu/hrpp/Chapter1.html</a></li> </ul>
Opportunity contacts:	IRB administrator at local hospital, research institution or academic medical center.

<b>Peer Support for Potential Clinical Trial Participants</b>	
Description of opportunity:	Patients who are considering enrolling in a clinical trial may benefit from sharing their questions and concerns with a cancer survivor and hearing the experiences of another person who has participated in a clinical trial. This type of peer support can be provided face-to-face in the clinic or by phone.
Time required:	Dependent on the needs of the potential participant, usually at least one face-to-face meeting or telephone call which may last around an hour. Follow-up visits and calls on an as needed basis and timing will be mutually agreed upon. Time to participate in face-to-face meetings or telephone calls.
Travel required:	Local travel to/from face-to-face meetings
Skills:	<ul style="list-style-type: none"> <li>• Good listening skills and willingness to arrange schedules to accommodate patient's needs.</li> <li>• Basic understanding of clinical trials, patient confidentiality and standards of care for specific cancers.</li> <li>• Must be able to listen and not provide medical advice.</li> </ul>
Compensation/ Expenses:	Peer support is a volunteer activity. Out of pocket (parking, etc.) may be reimbursed.
Resources:	<ul style="list-style-type: none"> <li>• Orientation/ training provided by volunteer services</li> <li>• Listening skills: <a href="http://www.mindtools.com/CommSkill/Mind%20Tools%20Listening.pdf">http://www.mindtools.com/CommSkill/Mind%20Tools%20Listening.pdf</a></li> <li>• Medical Dictionary</li> <li>• National Comprehensive Cancer Network Patient Guidelines at <a href="http://www.nccn.org">www.nccn.org</a></li> <li>• National Cancer Institute <a href="http://www.cancer.gov">www.cancer.gov</a></li> </ul>
Opportunity contacts:	Research nurse at local hospital, research institution or academic medical center, volunteer services manager at the hospital.

<b>Protocol Review/ Study Design Development</b>	
Description of opportunity:	<p>Survivors/Advocates review protocols and give input into the design of studies by participating as members of a Cooperative Group. The Cooperative Groups have included advocates to represent the particular type of cancer that has touched their lives. The Cooperative Groups conduct Phase II and III clinical trials. The clinical trials study new therapies, quality of life and/or correlative science. Advocates offer the patient perspective to the research being designed and conducted by the Cooperative Group. Each Cooperative Group sets their research agenda and process for reviewing and recommending concepts and protocols. Each has their own staff, structure and procedures. All the Cooperative Groups are partially funded by the National Cancer Institute (NCI) and must have their protocols approved by that agency.</p> <p>The ten NCI Cooperative Groups located in the United States are:</p> <ul style="list-style-type: none"> <li>• American College of Radiology Imaging Network</li> <li>• American College of Surgeons Oncology Group</li> <li>• Cancer and Leukemia Group B</li> <li>• Children’s Oncology Group</li> <li>• Eastern Cooperative Oncology Group</li> <li>• Gynecologic Oncology Group</li> <li>• National Surgical Adjuvant Breast and Bowel Project</li> <li>• North Central Cancer Treatment Group</li> <li>• Radiation Therapy Oncology Group</li> <li>• Southwest Oncology Group</li> </ul> <p>Other opportunities may exist for advocates to serve on advisory boards or committees for the pharmaceutical industry or protocol review committees at their local cancer center.</p>
Time required:	Dependent on the number of meetings held by each committee or Cooperative Group, usually one to two per year
Travel required:	Yes
Equipment:	<ul style="list-style-type: none"> <li>• Fax availability is helpful</li> <li>• If conference calls are involved it is helpful to have a headset for a landline phone so you can be hands free to make notes. Cell phones are not the best method for conference calls as calls may be dropped and background noise may be distracting.</li> </ul>
Skills:	<ul style="list-style-type: none"> <li>• Basic understanding of scientific process / cancer being studied</li> <li>• Good communication skills both verbal and written</li> <li>• Critical thinking skills to formulate questions and respectful, confident approach to ask questions</li> </ul>

<b>Protocol Review/ Study Design Development</b>	
Resources:	<ul style="list-style-type: none"> <li>• Cancer Research: A Guide to Clinical Trials, <a href="http://cancertrialshelp.org">http://cancertrialshelp.org</a></li> <li>• Medical Dictionary, Encyclopedia, some tutorials <a href="http://medlineplus.gov/">http://medlineplus.gov/</a></li> <li>• Oncology Nursing Society Continuing Education Series Online Cancer Biology (\$40 non member registration fee) <a href="http://onsopcontent.ons.org/Education/DistanceEducation/CancerBiology/index.shtml">http://onsopcontent.ons.org/Education/DistanceEducation/CancerBiology/index.shtml</a></li> <li>• Oncology Nursing Society Continuing Education Series Online Cancer Basics (\$40 non member registration) <a href="http://onsopcontent.ons.org/education/distanceeducation/cancerbasics/">http://onsopcontent.ons.org/education/distanceeducation/cancerbasics/</a></li> </ul>
Opportunity contacts:	<p>For cooperative groups: Coalition of Cancer Cooperative Groups, <a href="http://www.cancertrialshelp.org">www.cancertrialshelp.org</a>            Contact Karen Creamer            Phone: 1-877-520-4457            Fax: 215-789-3655</p> <p>For industry studies: Industry contact (sometimes the company's advocacy or public relations person)</p> <p>For local cancer center committees: Cancer center director's office or institutional research office.</p>

<b>Public-speaking About Clinical Trials</b>	
Description of opportunity:	<p>Educate cancer patients and the general public about cancer clinical trials by speaking to community groups interested in better understanding how advances in cancer prevention, diagnosis and treatment happen.</p> <p>The information would include a slide presentation developed by the National Cancer Institute (NCI) that covers the basics about clinical trials--what they are, who takes part, different types of trials, protecting patients' safety, risks and benefits of trials, and where to find trials. This could be done as a team of an advocate and a health care professional. Written materials developed by the National Cancer Institute could be given to attendees to take home with them.</p>
Travel Required	Travel to meeting location
Time required:	Each talk and slides would take about 15 – 20 minutes with another 10 – 15 minutes for questions and answers. Allow time for preparation, travel to the location of the meeting and coordination with the meeting planners.
Skills:	<ul style="list-style-type: none"> <li>• Basic understanding of clinical trials</li> <li>• Good verbal communication skills</li> <li>• Community contacts are helpful</li> </ul>
Compensation/ Expenses	The meeting organizers may or may not reimburse for travel expenses of parking and mileage
Resources:	<ul style="list-style-type: none"> <li>• National Cancer Institute (NCI) Cancer Clinical Trials Education Series (CTES) CD  <a href="http://www.cancer.gov/clinicaltrials/learning/clinical-trials-education-series">http://www.cancer.gov/clinicaltrials/learning/clinical-trials-education-series</a></li> <li>• NCI Trainers Guide is available on the NCI web site, <a href="http://www.cancer.gov">www.cancer.gov</a>. If there are sufficient number of people interested in being trained the NCI will conduct a train the trainer program for the group.</li> </ul>

**Public-speaking About Clinical Trials**

Opportunity  
contacts:

Rosemary Padberg, RN  
Office of Communications and Education  
Phone: 301-451-6879 Fax: 301-480-0518  
E-mail: [ncioc@mail.nih.gov](mailto:ncioc@mail.nih.gov)  
Office of Communications  
National Cancer Institute  
Building 31, Room 10A31  
Bethesda, Md. 20892

## SPORE Patient Advocates

Description of opportunity:

Patient advocates that are willing to focus their attention on helping the NCI-funded Specialized Program of Research Excellence (SPORE) research programs translate their research into practical use for people. There are 52 SPORE programs in specific diseases (brain, breast, colon, GI, GU, gynecologic, head & neck, leukemia, lung, lymphoma, myeloma, ovarian, pancreas, prostate, skin) located in academic institutions throughout the U.S. These SPOREs connect many disciplines, including basic, epidemiological, and clinical scientists, together to plan, design and implement research programs that have an impact on cancer prevention, detection, diagnosis, treatment and control.

SPORE Patient Advocates can become involved in many opportunities, depending on what the needs of their particular SPORE are, and the interests that each patient advocate has.

Some of the opportunities fall into these categories:

- Attend and participate in research discussions and strategy meetings
- Hold 2-way educational sessions for patient and research communities
- Brainstorm on ways to improve the clinical trial system for participants
- Help identify barriers that keep SPORE research from moving forward, and participate in steps to resolve these issues
- Learn why tissue is important to researchers and patients, and help researchers get more of what they need while respecting privacy issues
- Give input into clinical trial development and design
- Help review small, "seed" grants that SPOREs can fund
- Help spread the word about SPORE clinical trials in a variety of ways

The following list shows the SPOREs who have integrated patient advocates into their research operations<sup>3</sup>

[Baylor College of Medicine](#) Breast

[Duke University](#) Breast

[Fox Chase Cancer Center](#) Ovarian

[Fred Hutchinson Cancer Research Center](#) Ovarian, Prostate

[John Hopkins University](#) Prostate

[Mayo Clinical Cancer Center](#) Prostate

[University of California, San Francisco](#) Breast, Prostate

[University of Iowa](#) Lymphoma

<sup>3</sup> Source: [http://spores.nci.nih.gov/part/index\\_part.html#feedback](http://spores.nci.nih.gov/part/index_part.html#feedback) downloaded 3/ 4/2008

<b>SPORE Patient Advocates</b>	
	<a href="#">University of Michigan</a> Head & Neck, Prostate <a href="#">University of Nebraska</a> Pancreatic <a href="#">University of Pittsburgh</a> Lung <a href="#">UT MD Anderson Cancer Center</a> GU, Ovarian <a href="#">Vanderbilt-Ingram Cancer Center</a> Breast, GI, Lung <a href="#">Northwestern University</a> Prostate <a href="#">University of Alabama at Birmingham</a> Breast <a href="#">University of Arizona</a> GI <a href="#">University of California, Los Angeles</a> Prostate
Travel Required	Travel to meeting location
Time required:	Program/ assignment dependent
Skills:	<ul style="list-style-type: none"> <li>• Patient-focused approach</li> <li>• Willing to make a personal commitment to work directly with cancer researchers within a local SPORE program.</li> <li>• Basic understanding of scientific process / cancer being studied</li> <li>• Good communication skills both verbal and written</li> <li>• Critical thinking skills to formulate questions and respectful, confident approach to ask questions</li> </ul>
Training offered:	Program dependent
Compensation/ Expenses	Usually volunteer Out of pocket (parking, etc.) may be reimbursed.
Resources:	<ul style="list-style-type: none"> <li>• <a href="http://spores.nci.nih.gov/index.html">http://spores.nci.nih.gov/index.html</a></li> <li>• Genomics in Cancer Research <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a></li> <li>• Clinical Trial Design <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a></li> <li>• Others listed in the resources section of this book</li> </ul>
Opportunity contacts:	<a href="http://spores.nci.nih.gov/index.html">http://spores.nci.nih.gov/index.html</a> Staff or volunteers at SPORES at academic medical centers listed above and on the SPORE website Clinicians/Researchers at academic medical centers as well as SPORE PI's.

## Training and Resources

The following materials are available from Research Advocacy Network. To obtain contact [info@researchadvocacy.org](mailto:info@researchadvocacy.org) or go to [www.researchadvocacy.org](http://www.researchadvocacy.org).

	Topic	Method of delivery
1.	Communications module- Talking to Researchers	Animated powerpoint
2.	Focus Research 2005- Drug Safety and Approval, Dr. David Banks of the FDA	Web lecture
3.	Web lectures- Focus Research 2005- Targeted Therapies – Dr. Richard Schilsky	Web lecture
4.	Web lectures- Focus Research 2005- NCCN Guidelines, Statistics (Cirincione), ASCO Logistics (Salamone)	Web lecture
5.	Web lectures- Focus Research 2006- Drug Approval Discussion	Web lecture
6.	Web lectures- Focus Research 2006- Statistics Discussion (Cirincione)	Web lecture
7.	NCCN Lecture series for advocates on practice guideline development	Web lecture
8.	Advocate lecture series Breast Cancer Centers of Excellence – Genomics, Pharmacogenetics	Web lecture(s) available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
9.	Genomics – Lecture 1	Web lecture available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
10.	Genomics – Lecture 2	Web lecture available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
11.	Genomics – Lecture 3	Web lecture available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
12.	Genomics – Lecture 4	Web lecture available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
13.	Clinical Trial Design –Lecture 1	Web lecture available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
14.	Clinical Trial Design – Lecture 2	Web lecture available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
<b>Publications</b>		
1.	"Why is important for me to consider donating tissue for research? - English	PDF and order hard copies at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
2.	"Why is important for me to consider donating tissue for research? -Spanish	PDF and order hard copies at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
3.	"The Importance of Tissue for Research" Booklets –(For IRBs) - English	PDF and order hard copies at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
4.	"The Importance of Tissue for Research" Booklets –(For IRBs) - Spanish	PDF and order hard copies at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
5.	Other Education materials about the "Tissue Issue" Concept sheets	
6.	Genomics in Cancer: A Guide for Advocates	Order hard copies at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>

	Topic	Method of delivery
7.	Clinical Trials Design: Tutorial for Research Advocates	PDF and order hard copies at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
8.	Glossary of Terms	
9.	Listing of Acronyms	
10.	Core Competencies for Advocates	
11.	Shortcut sheet – Evidenced Based Medicine	
12.	Drug Naming	
13.	Options/UpDate – Breast Cancer	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
14.	Options/ UpDate – Colon Cancer	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
15.	Network News Subscription and Archived Issues	
16.	Fact sheet – Her2 neu testing	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
17.	Fact sheet – Letrozole	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
18.	Fact sheet –Exemestane	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
19.	Fact sheet – Herceptin	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>
20.	Fact sheet – Avastin	PDF available at <a href="http://www.researchadvocacy.org">www.researchadvocacy.org</a>

**Other training / self-learning opportunities:**

- Alamo Breast Cancer Foundation Advocate Program at San Antonio Breast Cancer Symposium <http://www.alamobreastcancer.org/>
- American Association for Cancer Research (AACR) Scientist/Survivor Program [www.aacr.org](http://www.aacr.org)
- Coalition of National Cancer Cooperative Groups “A Guide to Cancer Clinical Trials” [www.clinicaltrialshelp.org](http://www.clinicaltrialshelp.org)
- DNA Interactive DVD and Inside Cancer Module available at <http://www.dnai.org/>. A Howard Hughes Medical Institute site developed by Cold Springs Harbor
- National Cancer Institute Education Series [www.cancer.gov](http://www.cancer.gov)
- National Institute of General Medical Sciences Publications series <http://www.nigms.nih.gov/Publications/> includes “Medicines by Design” and other biomedical and research findings publications
- Oncology Nursing Society Continuing Education Series Online (some fees apply for non members) <http://www.ons.org/ceCentral/more/web.shtml>
- Project LEAD <http://www.natlbcc.org>