

RESEARCH ADVOCACY NETWORK



Harnessing *Passion*  
to Advance *Research*

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

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# The Power of *Passion*



## You already know the sobering cancer statistics:

- Some 1.4 million new cases are diagnosed each year.
- Only 5% of adult patients participate in clinical trials.
- It takes from 5 to 8 years to develop a new drug.
- The estimated cost of a new drug exceeds \$800 million.

At Research Advocacy Network (RAN), we believe that infusing the research process with the patient experience will dramatically improve these figures, and the National Academy of Sciences is in agreement.

Advocates channel the passion they have for making a difference for cancer patients into the research process by:

- Driving the questions research tries to answer
- Protecting the patients who participate in research
- Disseminating research results

More and more grant-making organizations are looking to see whether research programs incorporate the patient perspective into their work. Decision makers are recognizing that infusing the research process with the patient viewpoint makes research more relevant and can help increase the rate of clinical trial participation. Whether or not your organization is awarded a grant could hinge on how well you integrate that perspective into your program.

## Early Success

The patient advocacy movement has already changed the face of research by doubling the National Institutes of Health's funding; assisting in the development of the Department of Defense's (DoD) innovative Congressionally Directed Medical Research Programs; and successfully lobbying federal and state governments for insurance coverage for routine patient care costs in clinical trials, new drugs and treatment appeals mechanisms. Patient advocates have also provided invaluable input into a variety of selected research processes.

The DoD's Breast Cancer Research Program represents just one success story of collaboration among all research stakeholders. The DoD worked with the National Breast Cancer Coalition to invite research advocates to participate in every aspect of the program, including initial advocacy training, participation in peer reviews and integration panels, and involvement in ongoing consumer working groups.

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***Patient engagement should inform and saturate every aspect of research, from formulating a research agenda to study design, to study review, to oversight at all levels, to dissemination and to translation to practice.***



2003 National Academy of Sciences

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## The Many Roles of Research Advocates

Cancer patients, survivors, family members and other committed supporters draw on their unique experiences and contribute their invaluable viewpoints to ensure that research programs reflect the patient perspective. Research advocacy gives them the opportunity to channel their zeal into activities that lead to meaningful outcomes.

Research advocates enhance trial/study design by reviewing protocols, serving on study sections and committees, and

conducting or participating in focus groups to provide specific input on design.

Research advocates serve on Institutional Review Boards (IRB) at academic medical centers and their local hospitals to bolster the ethics of research conducted in those institutions.

**Discussions with the advocates provide a perspective that affects my research in very positive ways.**

...  
Researcher, Melissa Troester, PhD  
(5/2009)

Research advocates review proposals for research projects and help determine which research projects receive funding. Both the DoD Cancer Research Program and the Susan G. Komen for the Cure include research advocates on their review panels.

Research advocates can also take on a wide range of active roles in their communities. They may:

- Educate patients and the public about clinical trials
- Review educational materials intended 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 money for cancer research and to offset costs for people participating in clinical trials
- Be available in the clinic to counsel clinical trial participants
- Work with state legislators to enact laws related to research.

As advocates become more deeply involved in the research process, however, they will need more training and support to integrate fully into the research community. The Research Advocacy Network provides the education and resources they need to effectively bring the patient perspective into the research equation.

If you want to integrate advocates into your work, please register with our advocate/researcher matching service at [www.advocatelink.org](http://www.advocatelink.org).

At RAN, we harness advocates' passion to advance scientific research. Our mission is to advance patient-focused research by fostering interactions among advocates, researchers and related organizations.

Our goals are to:

- Develop a network of advocates and researchers who influence the design and conduct of research
- Equip advocates to affect change in the medical research system
- Mobilize a network of people around issues of patient-focused research.

While there are many organizations that address the needs of patients with specific diseases, political advocacy, cancer education and fundraising, RAN is the only nonprofit organization dedicated to advancing research through advocacy.

## Partnership Models

We promote more effective communication between the research and patient communities and deliver consulting services that foster partnerships between these groups. We understand the specific needs and desires of both communities and focus on their shared goals of getting treatments into patients' hands faster and more cost effectively.

## Networking

We link trained advocates with research opportunities via a unique matching service ([www.advocatelink.org](http://www.advocatelink.org)), and we provide a communications center where advocates can interact with one another and with researchers to share successes and solve problems.

## Measurement and Evaluation

We evaluate and assess the effectiveness of advocate activities in basic, translational and clinical research.

## Education

We create in-depth training materials and news updates to keep advocates well informed.

## Research Dissemination

We integrate individual study results into the larger research context by providing models and tools to accelerate dissemination to improve patient care

## Advocate Institute

Advocates are often called upon to "translate" or "interpret" complex publications and research results. This daunting task is made all the more difficult because bias and inaccuracies in media coverage can color public perceptions.

Our Advocate Institute is designed to equip advocates with an understanding of the medical research system, scientific concepts and protections for research participants. We give them the tools and resources they need to comprehend research studies and communicate effectively with patients, researchers and other advocates. We offer on-site training, as well as online learning resources for advocates who are often geographically dispersed and come to RAN with varying degrees of knowledge. Our goal is to channel their passion into effective interactions with the research community.

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**FABULOUS learning experience... I've already shared quite a bit of information from the conference informally with my community of hereditary cancer high risk.**

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Advocate Institute participant, 2009

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RAN has demonstrated leadership in the patient advocacy movement by identifying core competencies and advocacy styles needed to advance research. With our understanding of both the research community's expectations and the skills necessary for effective advocacy, we can customize workshops and Webinars that meet your research program's specifications.

## Courses

The more advocates understand, the better prepared they are to influence the system in the name of advancing patient care. For that reason, we continue to develop a core curriculum that offers research advocates the opportunity for ongoing education. Organized by topic—including *Genomics in Cancer*, *Pathology and Tissue Research*, and *Critical Thinking Skills*—each module provides the information and addresses the skills advocates need to successfully advance research.



## AdvocateLink

AdvocateLink helps researchers and research advocates find each other. Modeled after career websites, this online resource is the first of its kind—it fills the previously unmet need of enabling trained volunteers to identify opportunities within the research community. RAN also provides a self-assessment tool for volunteers to help them determine the best avenues for their research advocacy.

Research organizations that want to include research advocates in their programs can register at [www.advocatelink.org](http://www.advocatelink.org) and post opportunities for advocates to get involved. Research advocates can use this resource to build their advocacy profiles and search for avenues to participate.

## Publications

Here is a partial list of our current educational guides, posters and newsletters.

### Advocate Education

- *Genomics in Cancer: An Advocate's Guide and Training Manual* – This 120-page illustrated guide explains the basic principles of genomics and the applications to cancer and other diseases.

- *Understanding Pathology and Tissue Research: An Advocate's Guide* – This guide was developed to help advocates understand pathology as it relates to cancer. It also explains tissue research and its importance in identifying causes, treatments and potential cures.
- *Understanding Clinical Trial Design: A Tutorial for Advocates* – This workbook was developed for advocates to better understand selected statistical methods of designing clinical trials.

### Posters

- *Influencing Patient Focused Research Through Advocate Interventions* (presented at the San Antonio Breast Cancer Symposium).
- *Use of Focus Groups to Inform Clinical Trial Design* (presented at the Department of Defense's Era of Hope meeting).
- *Adoption of Research Results in Community Oncology Practices* (presented at the American Society of Clinical Oncology).

### Newsletters

Our quarterly *NetworkNews* provides up-to-date information on happenings across the country that are relevant to research advocacy. We cover a wide range of topics—from drug trial opportunities to research results to advocacy training events.

## **SAY 'YES' TO RESEARCH ADVOCACY**

At RAN, we are ready to help you develop a robust advocacy program that will make your research even more relevant to patients and may help boost participation in your clinical trials.

Whether you want to bolster your existing efforts to include advocates in your work or are starting from scratch, we will apply our experience and resources to make sure the patient perspective informs your entire research process.

Contact us today at 877.276.2187 or [info@researchadvocacy.org](mailto:info@researchadvocacy.org) to find out what we've done for other research organizations and discuss what we can do for yours.

# RESEARCH ADVOCACY NETWORK

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