

Patient Advocate Corner

Research Advocacy Network: Advancing Patient-Focused Research

By Mary Lou Smith and Elda Railey

Advocating for the advancement of research is crucial to finding new and better treatments for cancer patients. Cancer survivors and their caregivers and families are uniquely positioned to support cancer research in new and innovative ways. The Research Advocacy Network (RAN) was formed in 2003 to bring together participants in the research process with a focus on educating, supporting, and connecting patient advocates with the larger research community. While there are many organizations advocating on behalf of cancer patients, no organization has focused on advancing research through advocacy. RAN is committed to improving patient care through providing the patient perspective to research.

Why Research Advocacy?

Research advocates help provide a “face” for science and remind researchers of the human element. This partnership tries to ensure that clinical trials address questions that are important to patients, that eligibility criteria allow diversity of participation, and that trial designs are attractive to potential participants. Research advocates support conducting ethical, well-designed research and dissemination of research results so that new and better treatments are available in communities throughout the United States.

RAN's Advocate Institute

RAN helps advocates work effectively with the research community by providing members with training, educational materials, and opportunities to use their skills. RAN's Advocate Institute is the online portal that provides advocates with multiple learning modalities to better understand the medical research system and scientific concepts for more effective interactions with the research “world.” The newest web-based technologies are utilized in this process.

Focus on Research

The Advocate Institute course entitled Focus on Research is a new model to assist advocates in disseminating research results presented at major oncology-related conferences. This program helps advocates attending the ASCO Annual Meeting better understand the science presented at the Meeting. This preparatory program consists of web lectures led by outstanding professionals. The lectures occur both before and after the ASCO Annual Meeting. Networking, shared experiences, and mentoring are offered throughout the Meeting as the advocates

attend scientific sessions. Advocates are required to provide a written report of the results reported at the ASCO Annual Meeting, based on their particular cancer focus. These reports are compiled into a document that is shared with the larger advocate community. Response to this program from past participants has been overwhelmingly positive.

Mentor Program for Research Advocates

A new program of the Advocate Institute, the Mentor Program for Research Advocates, is being tested in 2007. The purpose of the Mentor Program is to equip experienced advocates to mentor people interested in working with the research community. The content will be focused on genomics, proteomics, and pharmacogenetics, and how this new science applies to research advocacy. The formal educational program will include both didactic and laboratory work. Experiential learning opportunities will be provided in order to reinforce and apply the knowledge acquired in the lectures.

Genomics in Cancer

Genomics in Cancer is a recent addition to the curriculum of the Advocate Institute and will be the cornerstone for much of RAN's programming in 2007. Topics included are an in-depth explanation of genomics; basics of DNA, the Human Genome Project; variation and mutation in DNA; gene assessment techniques; regulation of genetic tests; ethical, legal, and social implications of genomics; and how advocates can use information about genomics in their activities. Workbooks can be ordered through our Web site at www.researchadvocacy.org.

RAN's efforts have resulted in increased awareness of research advocacy as a new and important advocacy activity. Thanks in part to the work of RAN, the term “research advocate” is increasingly being used to describe advocates who participate in research activities both locally and nationally.

For more information, please visit our Web site www.researchadvocacy.org or call 877-276-2187.

Mary Lou Smith and Elda Railey are the cofounders of Research Advocacy Network. They have more than 30 combined years in patient advocacy and cancer research and represent various areas of expertise and backgrounds in nonprofit organization management, education, patient services, grants management, research programs, and facilitation and collaboration.

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