IU HEALTH ARNETT – ONCOLOGICAL SCIENCES CENTER MEDICAL RESEARCH ADVOCATE PROGRAM

INITIATIVE

Early detection is a key in significantly decreasing deaths from colon cancer. The Cancer Care Engineering (CCE) project seeks to identify molecular signatures (biomarkers) in blood and tissues that are predictive of disease onset and subsequent therapeutic response. The CCE project is managed through the Oncological Sciences Center (OSC) in Discovery Park in collaboration with the Indiana University Melvin and Bren Simon Cancer Center (IUSCC) and has been collecting blood and tissue samples from patients at the Indiana University hospitals in Indianapolis since 2010. To broaden the base of patients participating in the CCE project, a second site at IU Health Arnett (IUHA), a community hospital in Lafayette, Indiana, was opened in August, 2012. Historically, participation by patients at community/rural hospitals in medical research and clinical trials has been very low. In order to increase the participation levels, IUHA and OSC called upon the Research Advocacy Network (RAN), a nonprofit organization, to bring together participants in the research process with a focus on educating, supporting and connecting patient advocates with the medical research community. Together, RAN, IUHA and OSC contacted local and regional organizations and cancer patients to build a cohort of medical research advocates and provide them with information on the CCE project, advocate roles and opportunities. More than 30 people were participating as of fall 2012. This group of volunteers is very diverse, including cancer survivors, life science researchers and students, leaders of non-profit organizations, and medical personnel.

IMPACT

The advocates have had a major impact by accompanying the IUHA study personnel in discussing participation in the CCE study to provide a “lay” perspective and answer questions, making presentations about medical research benefits to local groups, and serving on institutional review boards overseeing clinical trial approval.

“Our goals are to get the results of research studies — new treatment — to patients more quickly, give those touched by the disease opportunities to give back to the cancer community, and help the medical community improve the design of research studies so that more people are willing to participate in clinical trials.” — Mary Lou Smith, co-founder of the Research Advocacy Network

“I have gained knowledge that will allow me to be a better consumer of cancer literature, cancer advocacy and cancer research. In turn, this knowledge will help me to support the Research Advocacy Program and those patients impacted by the programs efforts.” — Cezanne Elias, advocate

“An advocate who can answer patient’s questions is wonderful. It allows the patient and family to consider participating with research with the help of a peer and with less of the ‘I have to please this doctor’ barrier.” — Shannon Oates, healthcare provider, Chairman of the Board for St. Elizabeth Local IRB

“The Advocate Program has brought together a wide variety of people, all with the common goal of bringing quality research opportunities to the community as well as educating people about the value of participation in research to themselves and to others.” — Ginny Mason, Inflammatory Breast Cancer Research Foundation, advocate

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