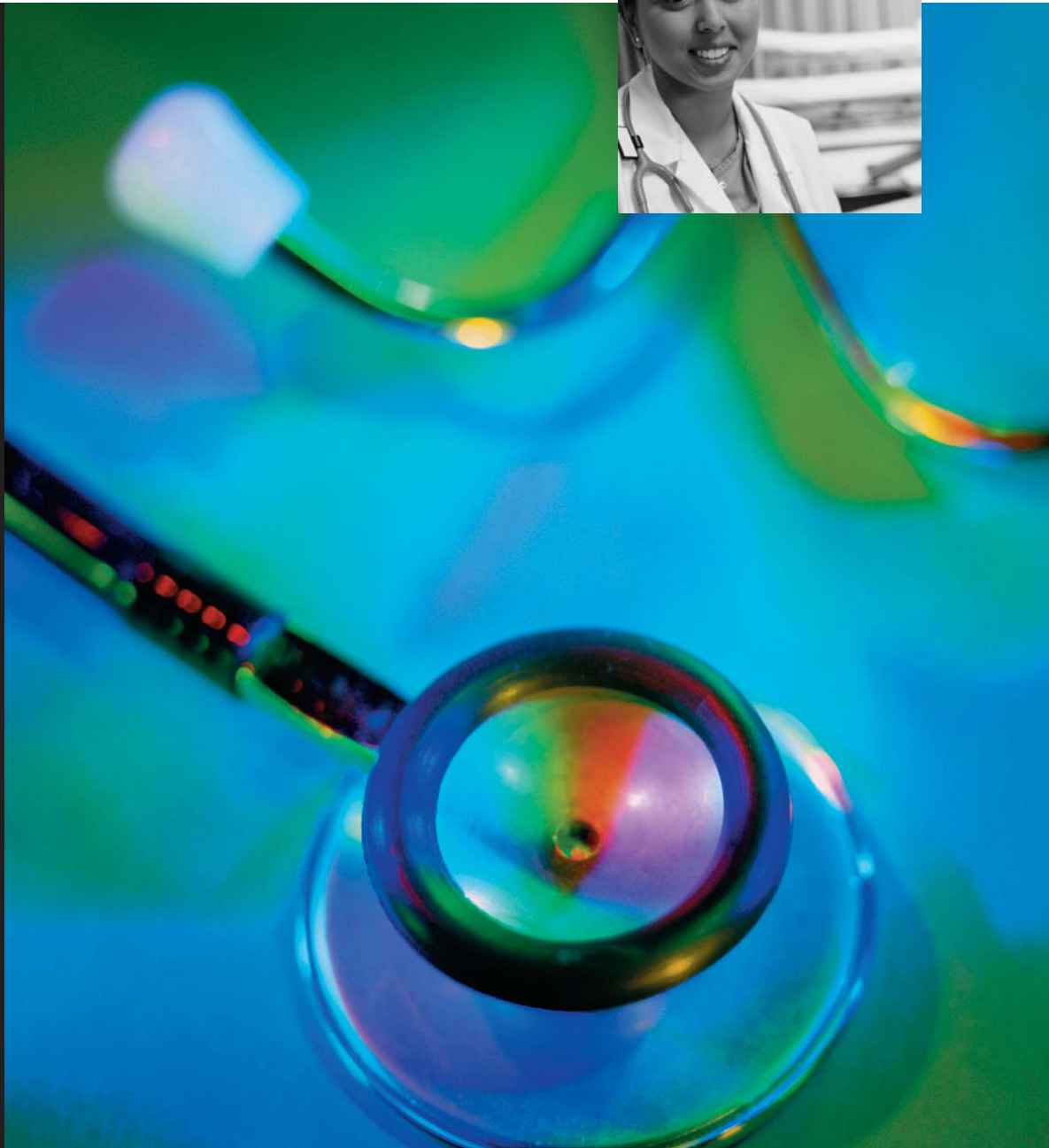




CANCER CLINICAL TRIAL **PARTNERSHIPS**
FOR RESEARCHERS AND ADVOCATES



RESEARCHERS



Introduction

According to a recent Harris Poll, 85 percent of cancer patients were unaware that they could participate in a clinical trial as part of their treatment. Over the past 20 years, cancer clinical trials have made a direct impact in the advancement of science and the treatment of cancer.

- Breast saving treatments, such as lumpectomy and radiation therapy, have been proven as effective as radical mastectomy.
- Treatment after surgery for colorectal cancer and malignant melanoma may increase a patient's survival rate.
- Many cancers in children can be cured.
- Prevention strategies can inhibit certain cancers from developing.

This progress in cancer treatment is an outcome of clinical trials. Cancer clinical trials are beginning to be recognized as an important treatment option for many patients.

The Eastern Cooperative Oncology Group (ECOG) is one of the largest clinical cancer research organizations in the United States. It conducts clinical trials in all types of adult cancers and performs multi-center cancer clinical trials. ECOG, like other groups and organizations is aggressively working to increase participation in clinical trials. Today, only three to five percent of adult cancer patients participate in clinical trials. In order to increase participation, patients need to be aware of the clinical trials in their community. One way to help your patients become aware of clinical trials at your institution is to work with patient advocate organizations. Patient advocates are prepared to help **you and your trial**. They share with you a common purpose — to find answers that will help cancer patients live with or conquer cancer. They are equipped with knowledge, information, influence, resources and support. They are in touch with the patients who could benefit from your trial.

Mission/Purpose of Patient Advocacy Organizations

Cancer patient advocate groups are typically founded or staffed by people who either have had cancer or whose loved ones have had cancer. Most have experienced the turbulent emotions that follow a diagnosis of cancer.

They share in the common goal — to eliminate the terrible disease called cancer. However, all advocate groups are not alike in the way they pursue this common goal. They work in many different ways.

Different Types of Patient Advocacy Organizations

Some groups work with a constituency broader than patients. They may focus on making policy or procedural changes by working with legislators, insurance companies and physicians. Some focus on specific types of cancers by providing support. Other groups work to make the medical and scientific information understandable to cancer patients and their families.

Research Advocacy: Clinical research and basic research are crucial to developing new drugs and new treatments for cancer. Some patient advocacy groups play a critical role by bringing the patient perspective into research and ensuring that patients have the continued opportunity to participate in innovative, high-quality clinical trials.

“When it comes to clinical trials, patient advocates, researchers and clinicians have the same goals. We want well-designed trials that will accrue in a timely manner so we can find answers to important treatment, detection, diagnosis and prevention questions. Patient advocates can and want to provide input at every step in the clinical trial process.”

— Judy Perotti,
Director of Patient Services at
Y-ME National Breast Cancer Organization



Here's How Patient Advocates Can Help You

Enhance Accrual Efforts

- *Connect research site and patients with study chair:* Act as a liaison to communicate concerns and information to each party.
- *Develop communication strategies:* Recommend communication strategies; review developing publications; participate in community education programs.
- *Hold focus and support groups:* Meet with people and discuss their feelings and opinions about a trial. Discover if they are willing or not willing to join a trial and why.
- *Distribute newsletters and publications:* Inform sites and patients of news and developments, create patient education materials, and disseminate information.
- *Put clinical trials on advocate Web sites:* Provide listing of trials.
- *Raise trial awareness:* Give general information about clinical trials.

“Y-ME is conducting a pilot program with ECOG, evaluating the effects of advocates’ site interactions on accrual to protocols. As chair of one of those protocols, E2193, I have found them to be extremely helpful.”

— Melody Cobleigh, MD,
Associate Professor of Medicine,
Rush Medical College

Navigate the Clinical Trial System

- *Provide information to researchers and patients:* Accept calls through a toll-free number, inform and support callers and prescreen them for trials.
- *Support patients through trial:* Address issues and concerns; provide emotional and psychological support; call sites on behalf of patients to get information; provide patient educational materials about the trial or protocol.
- *Match patients with others who have gone through a similar trial:* Arrange for patients to talk with peer counselors who have a similar profile or background as the patient.

Research Design

- *IRB Review:* Sit on institutional review boards as a non-scientific representative. Represent patient perspective and make sure that risks to participants do not outweigh the benefits.
- *Protocol Review:* Evaluate the design of a trial from patient's view, review eligibility criteria and informed consent documents. Patient advocates will make sure that the informed consent document has enough information in it for potential participants to make a reasonable decision about participation and that they fully understand their rights.

Funding Research

- *Awards:* Give money for researchers and investigators at different stages in their research career.
- *Grant programs:* A number of organizations have basic, clinical, training and translational grants at various levels for investigators and research projects.

You can get information on specific patient advocacy programs by going to the Web site of the Coalition of National Cancer Cooperative Groups, of which ECOG is a founding member. Visit www.cancertrials-help.org/researchadvocacy.jsp

About the "Team" at PanCAN:

"Against incredible odds you never give up, and thus, give hope to those of us with this disease. Never in the history of cancer have so few done so much for so many against overwhelming odds."

— Joy McCully,
Patient Diagnosed January 2000,
Woodside, California

Patient Advocate Organizations

Alliance for Lung Cancer Advocacy,
Support & Education
Alliance for Prostate Cancer Prevention
Cancer Care, Inc.
Cancer Research Foundation of America
Colon Cancer Alliance
Colorectal Cancer Network
International Myeloma Foundation
Kidney Cancer Association
Lance Armstrong Foundation
Lymphoma Research Foundation
Multiple Myeloma Research Foundation
National Alliance of Breast Cancer
Organizations
National Coalition for Cancer Survivorship
National Lymphedema Network
National Melanoma Foundation
National Ovarian Cancer Coalition
National Prostate Cancer Coalition
North American Brain Tumor Coalition
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Patient Advocate Foundation
Patient Advocates In Research
Susan G. Komen Breast Cancer Foundation
The Children's Cause
The Leukemia & Lymphoma Society
The Lustgarten Foundation for Pancreatic
Cancer Research
The Wellness Community
US Too! International, Inc.
Vital Options Tele-Support Cancer Network
Y-ME National Breast Cancer Organization
Yul Brynner Head & Neck Cancer
Foundation, Inc.



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