

Bridging advocacy, scientific, and government communities in the progress of cancer research

## NCI's Cancer Control Academy Emphasizes the Role of Community Partners in Research

---

### Contents

CCA Emphasizes Role of Community	1
DCLG Appointees	2
From the DCLG	3
NCI Increases Consumer Advocate Involvement!	4
From the Consumer Perspective	5
Lessons in Survivorship	6
Clinical Trial Series	7
New Screening Materials	8
Research at Your Fingertips!	9

In July, the NCI hosted its second annual Cancer Control Academy in Washington, DC. The importance of community partners emerged as an important theme during this meeting. The 3-day CCA (Cancer Control Academy) meets annually to present the principles and practices of cancer control in a way that directly benefits the Special Populations Networks (SPNs). The SPNs are groups of researchers who have been awarded grants to address important questions about the burden of cancer in minority and underserved communities. The SPNs were created in order to build relationships between large research institutions and community-based programs.

One of the central themes of this meeting was Community-Based Participatory Research (CBPR). CBPR recognizes that there should be equal participation in all aspects of all research activities by researchers, staff, and community members. **CBPR allows all of those involved to acknowledge and utilize different areas of expertise in order to create and improve community health.** The NCI's Division of Cancer Control and Population Sciences (DCCPS) Director Barbara Rimer explained that researchers must "develop a shared vision for health at the level of the community."

As more researchers begin to incorporate the principles of CBPR into their own work, the involvement of advocacy groups in the research process will increase. As Assistant Deputy Director of DCCPS Dr. Jon Kerner added, "Advocates can be critical to the dissemination of evidence-based practice,

because they tell the stories about what happens when real people are helped by science and are not helped when evidence-based approaches are ignored."

For more information on SPNs and the CCA, please visit these Web sites:

Special Population Networks:  
<http://cancercontrol.cancer.gov/spn/index.html>

Cancer Control Academy:  
<http://cancercontrol.cancer.gov/spn/about/overview.html>

*Written by Brooke Hamilton  
Liaison Activities Branch*

This issue of *The NEALON Report* is dedicated to the memory of Yvonne Andejas, M.D., who passed away October 30, 2001. In 1995, Dr. Andejas was appointed program director for the Department of Defense's (DoD) Breast Cancer Research Program. In this role, she was instrumental in coordinating an advocacy program there that gave advocates a larger say in DoD cancer research and clinical trials. Dr. Andejas took the framework of that program and used it as a starting point for creating the Consumer Advocates in Research and Related Activities (CARRA) program at the National Cancer Institute. During her tenure as program director of the National Cancer Institute's Liaison Activities Branch, she was instrumental in the implementation of the CARRA program in a remarkably short time. Her vision, leadership, dedication, and commitment to advocate involvement will be greatly missed.

## THE NEALON REPORT

*The NEALON Report* is dedicated to Ms. Eleanor O'Donoghue Nealon, first director of the NCI Liaison Activities Branch. Ms. Nealon passed away in 1999 from breast cancer.

### **Editor-in-Chief**

Nina Ghanem, M.Ed., *CHES*

### **Editorial Board**

Tracy Kilmer Clagett, M.A.

Elisabeth Handley, M.P.A.

Mike Katz, M.B.A.

Elaine C. Lee

Rosalyn Lemak, M.P.H., C.F.L.E.

Julie Tu, M.S.

### **Liaison Activities Staff**

Elaine C. Lee, Branch Chief

Elisabeth Handley, Associate Director,  
Outreach and Partnerships

Tracy Kilmer Clagett, Advocacy Program  
Manager

Nina Ghanem, Communications  
Coordinator

Rosalyn Lemak, Profession Society  
Liaison

Keisha Martin, Program Assistant

Julie Tu, Technology Transfer Fellow

Brooke Hamilton, Health  
Communications Intern

### **Contact Information**

Liaison Activities

National Cancer Institute

6116 Executive Boulevard

Room 3068A, MSC 8324

Bethesda, MD 20892-8324

Tel: 301-594-3194

Fax: 301-480-7558

E-mail: [liaison@od.nci.nih.gov](mailto:liaison@od.nci.nih.gov)

LA Web site: <http://la.cancer.gov>

NCI Web site: [www.cancer.gov](http://www.cancer.gov)

**Articles may be reprinted without permission unless they have been reprinted here from another source. Contact the Liaison Activities Branch staff for more information.**

## **NCI Appoints Five New Members to the National Cancer Institute Director's Consumer Liaison Group**

The National Cancer Institute appointed five new members to the NCI Director's Consumer Liaison Group (DCLG). The DCLG helps the NCI develop programs and helps set research priorities as well as find new ways to increase consumer representation at the NCI, creating a forum for exchange between the cancer advocacy and scientific communities.

The new members and their represented groups are: Vernal Branch, Fremont, CA, Y-Me National Breast Cancer Organization; Kathy Giusti, New Canaan, CT, Multiple Myeloma Research Foundation; Karen Packer, Marshalltown, IA, Marshalltown Cancer Resource Center; Chris Pablo, Honolulu, HI, Leukemia and Lymphoma Society; and Doug Ulman, Austin, TX, Lance Armstrong Foundation.

The DCLG members serve 3-year terms.

## From the NCI Director's Consumer Liaison Group (DCLG) Chair

Established in 1997, the Director's Consumer Liaison Group (DCLG) advises and makes recommendations to the director of the National Cancer Institute from the perspective and viewpoint of cancer consumer advocates on a wide variety of issues, programs, and research priorities. The DCLG serves as a channel for consumer advocates to voice their views and concerns. To achieve these ends, the DCLG has worked, and continues to work, to establish strong collaborations between the NCI and the cancer advocacy community.

To enhance the involvement and influence of consumer advocates in various NCI programs and policy committees, the DCLG was instrumental in creating the Consumer Advocates in Research and Related Activities (CARRA) program. The over 200 advocates selected from nearly 500 applications received were chosen not only for their competency but also for their ability to represent various cancer types, ethnic backgrounds and cultural heritages, geographic regions, and age groups. These members of the CARRA program will be involved in NCI activities such as scientific peer review of research proposals submitted to the NCI for funding or the development of educational and informational materials. The DCLG is currently working with the NCI's Liaison Activities Branch to assure mutual support and ongoing orientation and education for advocates participating in NCI programs as well as the best use of consumer advocates within the NCI.

The DCLG also has served as a primary forum for discussing issues of relevance to cancer patients and survivors and their families, and for exchanging viewpoints with the NCI director and key division heads. Last April 2001, the DCLG sponsored a public forum on "Promoting

NCI/Advocacy Partnerships to Reduce Health Disparities." Dr. Harold Freeman, chair of the NCI's new Center to Reduce Cancer Health Disparities, opened the forum by emphasizing the moral and ethical imperatives for discovering the causes of health disparities in cancer outcomes. Dr. Freeman emphasized the importance of the NCI's working in partnership with the advocacy community to identify critical issues and establish a research agenda. Guest speakers representing national and local community-based advocacy organizations and organizations that address cancer issues specific to minority and underserved populations suggested ways in which the NCI can work with the advocacy community to address mutual concerns.

At its most recent meeting in October 2001, the DCLG hosted a forum on Cancer Survivorship. Along with the director of the NCI's Office of Cancer Survivorship Dr. Julia Rowland, the DCLG reviewed the current scope of NCI-sponsored survivorship research and identified both its strengths and its gaps. This forum was an opportunity for the advocacy community to influence the direction of an important area of cancer research. As a product of this forum, the DCLG has submitted to the director of the National Cancer Institute a declaration of cancer survivorship as a critically important area of focus for the institute. If accepted under the aegis of an "Extraordinary Opportunity for Investment," cancer survivorship will officially become a priority area of research for the NCI, subject to specially targeted funding and program development.

As the NCI welcomes a new director, the DCLG seeks to enhance its ability to articulate the needs and desires of the advocacy community. We are looking to communicate directly with representatives of national and local advocacy organizations to establish the priorities that we can and will act upon together, working

*Continued on page 10*

## NCI Increases Consumer Advocate Involvement!

The National Cancer Institute announced a new program to increase cancer advocate involvement in its activities. The Consumer Advocates in Research and Related Activities (CARRA) program is a landmark initiative—it convenes a large network of dedicated advocates who bring the viewpoints of those affected by cancer to the NCI.

This fall, the NCI selected more than 200 advocates to serve as CARRA members. Each member was appointed for a 3-year term. Together, they represent a wide range of key perspectives such as cancer diagnosis, ethnicity, geographic region, and age. “CARRA members serve as critical, two-way links between the NCI and their communities,” said the late CARRA

Program Director Dr. Yvonne Andejas. “They strengthen and enhance NCI programs. For example, they help establish research priorities and assist in design and implementation for many programs. Without question, the NCI values the unique perspectives of advocates and is committed to including diverse perspectives in research.”

CARRA offers a solid infrastructure to support both advocates and researchers. Integral parts of the CARRA program include training, mentoring, orientation, and an interactive Web site to help advocates and NCI staff obtain a more in-depth understanding of the advocate’s role in NCI research and the research process. The program also helps NCI staff identify and select appropriate consumer advocates for projects. Because CARRA allows the NCI

*Continued on page 10*



### Information Resources

#### Liaison Activities (LA) Web Site

<http://la.cancer.gov>

This Web site provides NCI information and links for advocacy and professional societies.

#### NCI’s Cancer Information Service

1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

The Cancer Information Service (CIS) is a nationwide information and education network for cancer patients and their families and friends, the public, and health professionals. The CIS can provide information from the NCI’s PDQ® (Physician Data Query) database. This toll-free number connects English- and Spanish-speaking callers all over the country with the office that serves their area.

### NCI Web Sites

#### [www.cancer.gov](http://www.cancer.gov)

This NCI home page provides links to *CancerNet*® for NCI material for health professionals, patients, and the public; *cancerTrials* for cancer clinical trials information; and the NCI’s online publications locator and ordering service.

#### CancerMail

This service includes NCI information about cancer treatment, screening, prevention, and supportive care via computer E-mail. To obtain a contents list, send an E-mail with the word “help” in the body of the message to [cancermail@icicc.nci.nih.gov](mailto:cancermail@icicc.nci.nih.gov).

#### CancerFax®

This service provides cancer information by fax. To use CancerFax®, dial 301-402-5874 from the telephone on a fax machine and listen to the recorded instructions to receive a faxed list of available documents and instructions for having documents faxed to you.

## From the Consumer Perspective

For most Americans, a cancer diagnosis is traumatic. However, for many Native Americans, including the Pueblo people of New Mexico, the news might once have been received as a death sentence. Native Americans diagnosed with cancer have lower survival rates than other ethnic groups. For the most common cancers (breast, cervical, and prostate), the survival rates fall even further behind those of the majority population. Cancer survivors still experience social isolation in many Native American communities, and because survivors often hide their illness they may not receive the support of extended family, clans, and villages. This stigmatization and social isolation help to perpetuate the myth that a cancer diagnosis is always fatal. However, in New Mexico, a unique collaboration has been working to change this reality and promote the idea of survivorship among Native peoples.

*Cancer support programs, developed and administered by Native Americans, can dispel the myths that prevent people from seeking early diagnosis and effective treatment.*

People Living Through Cancer, Inc. (PLTC) was founded in 1983 by and for cancer survivors and their loved ones. Through support and educational programs, it helps its members make informed choices and improves the quality of their lives by sharing in a community of people who have “been there.” Its nationally recognized programs have helped thousands of families facing cancer. The organization serves the people of New Mexico, the country’s most diverse state—51 percent of the population are from Hispanic, Native American, and other minority communities. Within this context, PLTC has developed successful, award-winning outreach programs. In 1996 it received the National Cancer Institute’s award for Innovative Minority Outreach programs. Since helping to launch the National Coalition for Cancer Survivorship, PLTC has maintained its position as a national leader, recognized for its quality support and education services and its organizational stability. From this position of prominence, PLTC was uniquely qualified to develop “Standards of Excellence for

Cancer Peer-Support Programs,” which include mandated strategies to involve underrepresented populations in all levels of the program, including leadership and program development. In keeping with its philosophy, PLTC has nurtured the growth of several independent survivorship programs, each serving diverse segments of the survivorship community.

As one of the early survivorship groups, PLTC helped to define and promote some of the enduring standards within the survivorship movement. From the beginning, PLTC was committed to improving the quality of life for people with cancer by offering peer support, education, and companionship. Additionally, PLTC has always maintained an absolute commitment to reach underrepresented populations. Recognizing the need for survivorship programs among diverse Native American communities, PLTC partnered with the Indian Health Services in 1995 to offer a unique week-long training called “Cancer Survivorship in Indian Country.” The training was designed to help Native American cancer survivors develop programs tailored for the needs and sensitivities of their own communities. Based upon an innovative survivorship program begun in New Mexico’s Santo Domingo Pueblo, “Cancer Survivorship in Indian Country” has trained more than 100 Native American survivorship leaders from around the United States and Canada representing more than 27 distinct and diverse tribes. Trained leaders have developed peer support groups, lending libraries, and culturally appropriate education programs on cancer prevention, screening, and risk reduction. Many also provide essential services such as transportation and translation at medical appointments.

Cancer support programs, developed and administered by Native Americans, can dispel the myths that prevent people from seeking early diagnosis and effective treatment. These support programs can also

*Continued on page 11*

## Lessons in Survivorship

In the wake of the cataclysmic events of September 11th, the lives of all Americans were, in a few short hours, changed forever. For the more than 10 million cancer survivors living in this country alone, many found themselves revisiting what it meant to be a “survivor.” For some, this meant re-experiencing the trauma of threatened loss and death brought by their diagnosis. For others it brought a realization that, unlike thousands at the World Trade Center, they would have time to complete unfinished business, say goodbyes. Still others felt they no longer could or wanted to call themselves a “cancer survivor” as survivorship had taken on new meaning.

*...there is now a growing line of research exploring the phenomenon of resilience and positivism in cancer survivors.*

On September 13th, I went to the regular meeting of my favorite local cancer support group. This loose coalition of cancer survivors representing diverse backgrounds and ages, a spectrum of different cancer diagnoses from the newly diagnosed to seasoned veterans of the cancer wars, has met once a week for years providing peer support, wisdom, laughter, friendship, and food to one another in an ever-evolving but continuous chain of caring members. There we shared our collective grief at our loss of innocence, sense of invulnerability, and confidence in the future. But in that room, we all realized that it does not take an event to turn our worlds upside down; this happens to thousands of men and women daily when they hear the words, “You have cancer.” In that room, I also was keenly aware that each member already knew well what it meant to survive and, in the case of these typical yet remarkable support group members, live fully in the face of uncertainty.

We have much to learn from our cancer survivors. Curiously, the scientific community has been slow to pick up on this aspect of patient outcomes. For years, clinical research addressing the psychosocial and behavioral outcomes of cancer was conducted using a medical model; we were

intent on learning the extent to which the treatment of cancer resulted in the impairment, disability, or dysfunction of those diagnosed. In the last few years, however, this paradigm has shifted, largely in response to survivors themselves telling us we were asking them the wrong questions. Time and again on our surveys and in interviews, survivors and their loved ones would speak of the important and life-affirming changes they had made after cancer entered their lives. They reflected on the richness of meaning, purpose, and relationships that newly developed or they came to appreciate. The consequence of this is that there is now a growing line of research exploring the phenomenon of resilience and positivism in cancer survivors. What is most exciting about this area of investigation is that it holds the promise of helping us to determine what qualities, skills, and resources may enable someone with life-threatening disease not merely to survive their illness but to thrive in the face of cancer, to be healed if not always cured. Certainly Eleanor Nealon, whose life this newsletter celebrates, understood and exemplified what it meant to live fully in the face of impending death.

The NCI’s Office of Cancer Survivorship plans to host, in collaboration with the American Cancer Society, what we hope will become a biennial survivorship conference. In recognition of this new theme in our survivorship research, the title of the first conference is: “Cancer Survivorship: Resilience Across the Life Span.” The conference will be held in Washington, DC on June 2 to 4, 2002, and will begin on the evening of June 2 with a Town Hall for cancer survivors, their families, and care givers. I am certain that the lessons we learn will have implications far beyond surviving cancer and may help all of us look with renewed hope to the future.

*Written by Julia H. Rowland, Ph.D.  
Director, Office of Cancer Survivorship*

# NCI's New Cancer Clinical Trial Education Series Launched in November

A new Cancer Clinical Trials Education Series, developed by the NCI's Office of Education and Special Initiatives (OESI), became available in November 2001. Developed through a comprehensive needs assessment, the series is designed to address the varied educational needs of the public, patient groups, and health care professionals about clinical trials.

## Why This Series?

Clinical trials help to move basic scientific research from the laboratory into treatments for people. By evaluating the results of these trials, scientists can find better ways to prevent, detect, and treat cancer. The more people who participate in clinical trials, the faster critical research questions can be answered—answers that will lead to better treatment and prevention options for all cancers. But very few adults with cancer—less than 5 percent—participate in clinical trials.

NCI research has shown that the general public is either unaware of clinical trials as a treatment/prevention option or misinformed about the clinical trial process. The reasons for this lack of understanding are complex, and there is no simple solution. However, there are many barriers that discourage both physicians and potential participants from taking part in clinical trials.

By using the NCI's new Cancer Clinical Trial Education Series, advocacy, patient service, and health professional organizations can begin to overcome some of these barriers. With the information, activities, and resources in the series, organizations can help people in their communities make informed decisions about their cancer treatment and prevention options, including the option of participating in a clinical trial.

## What Are the Parts of the Series?

The versatile series can be adapted in numerous ways. The series includes the following:

### ***Cancer Clinical Trials: The Basic Workbook***

The self-modulated workbook, with its accompanying activities, is designed for those who want to develop a basic understanding of clinical trials.

### ***Cancer Clinical Trials: The In-depth Program***

The textbook expands on the subjects outlined in *The Basic Workbook*. It is designed for health care professionals and others who seek a more in-depth understanding of clinical trials.

### ***Cancer Clinical Trials: A Resource Guide for Outreach, Education, and Advocacy***

The interactive workbook provides direction and guidance for individuals and organizations interested in developing clinical trial outreach and education activities. It also features a section on specific strategies for educating ethnic and culturally diverse populations about clinical trials.

### ***Trainer's Guide for Cancer Education***

A manual for planning and conducting educational sessions on any cancer-related topic.

**The following new resources will help support cancer clinical trials education and outreach efforts.**

## **Publications**

Low literacy **brochure** on cancer clinical trials (in English and Spanish):

*If You Have Cancer...What You Should Know About Clinical Trials* (for potential participants)

## **Videos**

A clinical trial awareness video and speaker's guide, "Cancer Trials: Because Lives Depend on It"

*Continued on page 11*

## NCI Releases New Cervical Cancer Screening Materials

### *Health Professionals Pap Test Packet*

Due to recent Medicare changes to pay for Pap tests more frequently and because many women incorrectly believe they no longer need a Pap test after age 65, the NCI's Outreach and Partnerships Program, in partnership with the Centers for Medicare and Medicaid (formerly HCFA), has developed a new Pap Test Packet.

The packet contains clear and useful cervical cancer information for health professionals to use with their patients. It features a new brochure on Pap tests aimed at older women and a resource guide that includes statistics and other available materials. The signature pieces to the packet are Pap Test Reminder Pads in English and Spanish. Similar to a prescription pad, this tool enables physicians to give patients a written reminder of when their next Pap test is due and reinforces the physician-patient dialogue by providing information about why a woman should have this test routinely.

Up to 20 packets can be ordered by visiting the NCI's Publications Locator Web site at <http://cancer.gov/publications>, searching under the key words "Pap test packet," and clicking on "Health Professionals Pap Test Packet."

### *Cervical Cancer Screening: What Vietnamese Women Should Know*

The NCI's Outreach and Partnership Program, in collaboration with the Vietnamese Community Health Promotion Project, has developed this new brochure. Written in Vietnamese, the brochure can help educate Vietnamese women about their high risk of cervical cancer and the importance of getting regular Pap tests, since more than half have never received a Pap test. The brochure can be viewed in Vietnamese at

<http://cancer.gov/hpb/vietnamese/cervical/>. Up to 20 copies can be ordered from the NCI's Publications Locator site at <http://cancer.gov/publications> (search under key word "Vietnamese"). Although a companion piece in English does not exist, an English translation is available online at <http://cervix.cancer.gov> (click on "Testing for Cervical Cancer").

*Written by Rhonda DeJoice  
NCI's Health Promotions Branch*

# NCI Research at Your Fingertips!

## *NCI Launches Public Web Site to View, Browse, and Search NCI-Supported Research*

“What research is the NCI supporting in pancreatic cancer?” “How much of this research is devoted to biology or etiology versus treatment or prevention?” These appear to be simple questions, but until recently not easily answered.

Questions such as these about what the NCI is supporting and how it breaks down across disease category and scientific area are routine questions for the NCI. Cancer research advocates, Congress, the administration, members of scientific professional associations, and researchers across the country all have an interest in the research programs of the NCI, and all can benefit by gaining access to information about the science that is being supported.

A new NCI Web site, launched in the spring of 2001, the **Cancer Research Portfolio** ([researchportfolio.cancer.gov](http://researchportfolio.cancer.gov)) is a comprehensive, easy-to-use source of information about current NCI-supported research. For the first time, grants, contracts, clinical trials, and the NCI’s intramural research are available in a single database and accessible on a public Web site. On this new site, the NCI’s research portfolio is organized by broad scientific areas (biology, etiology, treatment, prevention...) and by specific cancers for searching, browsing, and analyzing.

With this new site, advocates and researchers with an interest in breast cancer can click on “breast cancer” and immediately view a total of over 2500 research projects and/or clinical trials devoted to this disease. Those interested in prostate cancer prevention and screenings are able to see that there are over 200

studies devoted to prevention and over 350 on early detection out of approximately 2300 prostate cancer projects.

Scientists with an interest in cancer research related to early detection can more easily identify investigators doing similar work by sorting the NCI research portfolio by subcategory—technology development, marker discovery, or marker testing—within the broad scientific area of early detection, and find research abstracts of colleagues with similar research interests. Clinical investigators and the public can, with direct links to the NCI’s clinical trials and Physician Data Query databases, view and determine the total number of clinical trials under way in specific cancers such as leukemia or myeloma.

The Cancer Research Portfolio Web site will now make it possible for the leadership of other cancer funding organizations, Federal health policy analysts, and the NCI leadership to build a framework for analyzing cancer research by revealing areas of strong research commitment, identifying gaps in others, and helping to facilitate the identification of new, more focused research priorities.

*Written by the Health Promotion Branch*

Bookmark the site at **[researchportfolio.cancer.gov](http://researchportfolio.cancer.gov)**. While clicking on the type of cancer or type of research that you’re interested in, check out “About this Site” and “Frequently Asked Questions” for more information on the Cancer Research Portfolio’s offerings. Questions and comments can be directed to the NCI’s Office of Science Planning and Assessment at [CRP-R@mail.nih.gov](mailto:CRP-R@mail.nih.gov) or phone 301-496-5515.

---

### **From the DCLG Chair**

*Continued from page 3*

in conjunction with the NCI director, NCI division heads, and staff. Our major objectives are to enhance the awareness of what advocates can bring to the National Cancer Institute and facilitate the work and influence of advocates within the NCI.

One of my personal goals this year as chair of the DCLG is to increase outreach to the leaders of advocacy organizations in order to enhance the NCI's and the DCLG's understanding of their organizational priorities and commitments. I wish to communicate to a broader advocacy community the DCLG's ability and willingness to work cooperatively to establish priorities and an advocacy community agenda that overlaps with the National Cancer Institute. I also hope to increase the broader advocacy community's understanding of the DCLG's role and position of influence within the Office of the Director of the National Cancer Institute. Finally, I'm looking to stimulate greater participation within the NCI among advocates representing issues of concern to traditionally underserved communities. If you would like to be contacted or are interested in information about applying for membership on the DCLG, contact the NCI Liaison Activities Branch at 301-594-3194. We look forward to hearing from you.

*Written by Barbara LeStage  
DCLG Chair*

---

### **Consumer Advocate Involvement**

*Continued from page 4*

to recruit and screen consumer advocates in advance, the program ensures that advocates are available and ready to participate in activities when needed by NCI program staff. CARRA then matches advocates' skills and interests with individual NCI program needs. CARRA members are selected for NCI activities based on a combination of their preferred area of interest and the NCI's emerging activity needs.

The NCI developed the CARRA program in consultation with consumer advocates and NCI staff. The new program replaces informal methods of advocate involvement with a clear and well-defined system. CARRA members may be asked to participate in a range of both science and communications activities. They may help develop and review cancer education pamphlets, videos, or Web sites, participate in meetings about NCI research plans and policies, or evaluate patient-oriented studies at cancer research centers.

The NCI's Liaison Activities (LA) provides support and coordination of the CARRA program in addition to other activities involving advocates. LA plans to continuously evaluate and refine the program over time. The NCI anticipates another call for applications within a year. In the meantime, please visit our Web site at <http://la.cancer.gov/carra>.

*Written by Tracy Kilmer Clagett, M.A.  
NCI's Liaison Activities Branch*

---

**From the Consumer Perspective**

*Continued from page 5*

reduce the social isolation and stigma Native Americans diagnosed with cancer sometimes experience in their own communities. Within New Mexico, results show more Native Americans are participating in screening and early detection programs. If diagnosed with cancer, a Native American may now find a trained survivor within his or her own community who can support, encourage, and advocate for the entire family affected by the diagnosis. Because of the unique collaboration among Native American cancer survivors, the Indian Health Service, and PLTC, the beginnings of the “metastasis of hope” among the pueblos can be seen.

*Written by Gena Love  
People Living Through Cancer, Inc.*

---

**Clinical Trial Education Series**

*Continued from page 7*

A video and discussion guide on deciding to take part in a clinical trial, “Cancer Clinical Trials: An Introduction for Patients and their Families”

**Slide Program**

Available in PowerPoint on CD-ROM, two slide programs (with talking points) are designed for those not familiar with cancer clinical trials. Another slide program is designed for those already familiar with cancer clinical trials.

**You’ve Convinced Me! How Do I Order?**

To order these publications, contact the Cancer Information Service at 1-800-4-CANCER or log onto **[www.cancer.gov/publications](http://www.cancer.gov/publications)**. Most materials will also be available as PDF files on this Web site.

*Written by Margo Michaels, M.P.H.  
NCI’s Office of Education and Special Initiatives*

---

NCI Liaison Activities  
Office of Communications  
6116 Executive Boulevard  
Room 3068A, MSC 8324  
Bethesda, MD 20892-8324  
Tel: 301-594-3194  
Fax: 301-480-7558  
E-mail: [liaison@od.nih.nci.gov](mailto:liaison@od.nih.nci.gov)

---



Media Mail Postage & Fees Paid NIH/NCI Permit No. G-806
--