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In this issue:

[Director's Update...1](#)

NCI's CIS Celebrates
30 Years

[International CIS
Group Helping to
Spread the Word...1](#)

[Highlights of the
CIS Program...3](#)

[Map of CIS Regional
Offices...4](#)

[More CIS Facts...5](#)

[CIS Publications
Ordering Service Delivers
Needed Materials...6](#)

[CIS Partners with CNP...6](#)

[RFA Released for CIS
Research Grant...6](#)

[A Conversation with...7](#)
Mary Anne Bright

[Why I Am an Information
Specialist...8](#)

Director's Update

Guest Director's Update by Dr. John E. Niederhuber

NCI's CIS Celebrates 30 Years

In 1971, the National Cancer Act greatly broadened NCI's scope and responsibilities. In addition to conducting and supporting research and training the next generation of investigators, NCI was also tasked with providing patients and health professionals with comprehensive, accurate information on the most recent advances in cancer treatment and prevention.

This mandate led to the establishment of NCI's Cancer Information Service (CIS) in 1975. CIS provides education and information to cancer



NCI's CIS program staff

patients and the public, partners with organizations that reach minority and underserved communities, and collaborates on health communications research. Today, there are 15 regional CIS offices funded by NCI through competitively awarded contracts.

(continued on page 2)

International CIS Group Helping to Spread the Word

NCI's CIS will join the [International Cancer Information Service Group \(ICISG\)](#) and [International Union Against Cancer \(UICC\)](#) to host a full-day workshop this summer to help other nations, including some developing countries, learn "How to Start a CIS."

The workshop will take place July 8, a day before UICC's [World Cancer Congress 2006](#) meeting starts in Washington, D.C. Ten years ago at UICC's annual meeting in Australia, NCI and leaders from several other nations formed ICISG to foster development of high-quality cancer information services and resources on all aspects of cancer for those

concerned with or affected by cancer throughout the world. In addition to the pre-Congress workshop, ICISG is also contributing to several workshops and a plenary session on CIS programs at UICC's July meeting.

ICISG has grown exponentially over the past decade and now comprises 44 member organizations and 30 countries, which includes several developing nations—such as Bangladesh, India, and South Africa—which are all striving, with ICISG's assistance, to develop full-fledged CIS programs to help their citizens.

(continued on page 2)



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(Director's Update continued from page 1)

The early CIS comprised a mix of paid staff and volunteers, and each call center served only a specific geographic area. Over the following decade, efforts were made to establish the central, toll-free number used today, 1-800-4-CANCER, as well as to implement specialized services such as Spanish-language assistance and a smoking cessation quitline. Today, the voices answering these lines belong to highly trained cancer information specialists, who tailor information to meet each user's needs.

In addition to calling 1-800-4-CANCER, anyone with an Internet connection now can reach CIS through LiveHelp, an instant messaging service provided through NCI's Web site, Cancer.gov. However, the phone service continues to play a vital role. According to Dr. Thomas Fahey, principal investigator of the CIS contract at Memorial Sloan-Kettering Cancer Center, the public still sees the telephone service as very valuable, specifically to get cancer information that is not immediately available to them over the Web.

A vital component of the modern CIS is its Partnership Program, through which CIS reaches out to minority and other medically underserved populations. As explained by Mary Anne Bright, director of CIS, the regional CIS offices identify communities that suffer an unequal burden of cancer and lack access to services, and work with organizations trusted by these communities to try to address those gaps.

The CIS Partnership Program has worked extensively to increase the

rates of breast and cervical cancer screening in underserved communities and also leads educational programs to increase the awareness of clinical trials in underrepresented populations. The regional CIS offices, with their firsthand knowledge of the needs of the regional populations and the long-term partnerships they have developed and nurtured, are vital to the success of the Partnership Program. And in turn, explains Dr. Jon Kerner, deputy director for Research Dissemination and Diffusion in NCI's Division of Cancer Control and Population Sciences, CIS has supplied critical support to its community partners during the formulation and implementation of state comprehensive cancer control plans.

Since the 1980s, CIS has also collaborated on research to advance health communications, and in 2003 launched an official research agenda focusing on four research priorities: testing innovative cancer communication and education interventions; increasing access to and promoting appropriate use of cancer-related information and education; discovering effective models for disseminating successful cancer communication and education interventions; and understanding information seeking—who needs, looks for, and obtains cancer-related information.

CIS begins its next 30 years of providing help nationally and internationally with the continuing support of the cancer community. As summed up by a member of that community, Dr. Paul Engstrom, principal investigator of the CIS contract at Fox Chase Cancer Center, CIS keeps reinventing itself as needs change, continuing to meet defi-

nite needs and provide services that are not available anywhere else. ♦

(International CIS continued from page 1)

"I want to thank the leadership of UICC, which has been very supportive of ICISG in this important endeavor," said Mary Anne Bright, director of NCI's CIS. ICISG and UICC signed a Memorandum of Understanding to formalize the partnership toward the goal of establishing CIS programs worldwide, she explained.

At the upcoming workshop, ICISG will bring in 25 representatives from various countries, including some with scholarship assistance from UICC, who are interested in starting a CIS or enhancing an existing program. Topics to be covered include a basic needs assessment, scope of services, strategic plan, staffing, and financing a CIS. ICISG is also developing a comprehensive toolbox for workshop participants that provides examples of training plans, phone call record forms, data collection tools, training modules, and other items to get a CIS up and running. After the workshop, ICISG faculty will be available for individual consultations to provide technical assistance to the workshop participants. The toolbox will also be available on ICISG's Web site.

"Involvement of NCI's CIS with ICISG and UICC is part of our commitment, along with all other NCI divisions and offices, to help address the global burden of cancer," Ms. Bright noted. At 30 years old, NCI's CIS was the first cancer information program developed in the world, she added. "We remain unique—as part of an internationally preeminent

(continued on page 3)



(International CIS continued from page 2)

cancer research institute—in our experience and knowledge about successfully communicating with cancer patients, health professionals, and others with a keen interest in cancer.”

Over the years, NCI’s CIS worked directly with a number of nations to share its expertise and resources to help them start successful CIS programs, Ms. Bright pointed out. Most recently, under an agreement signed by NIH and the [Istituto Superiore di Sanità](#), the Italian NIH, NCI’s CIS and the [National Center for Complementary and Alternative Medicine \(NCCAM\)](#) have partnered with the Italian CIS to cosponsor a series of three workshops on the role of CIS programs in emerging issues, such as complementary and alternative medicine (CAM), clinical trials, and cancer survivorship.

The first full-day workshop in Rome last December focused on increasing awareness about the use of CAM by cancer patients. “Afterwards, we authorized the Italian CIS to translate and distribute a patient brochure on CAM developed by NCI and NCCAM,” Ms. Bright said. In addition, the Italian CIS has developed Italian translations of the “What You Need to Know...” series of booklets from NCI’s CIS.

“The mission of NCI’s CIS is to educate people about cancer prevention, risk factors, early detection, symptoms, diagnosis, treatment, and research and is an essential part of NCI’s cancer prevention and control efforts at home and abroad,” Ms. Bright commented. ♦

By Bill Robinson

Highlights of the CIS Program

1975

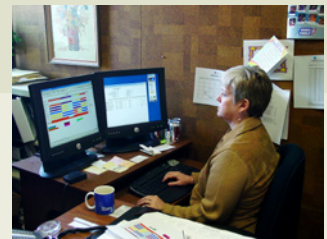
1975 – The first 17 CIS contracts are awarded to NCI-designated Cancer Centers

1983 – NCI establishes a CIS toll-free number, 1-800-4-CANCER, replacing the previous 34 local toll-free lines

1989 – The first national training on clinical trials is launched, as is the adoption of the first standardized clinical trials search tool that tailors CIS’ response to callers

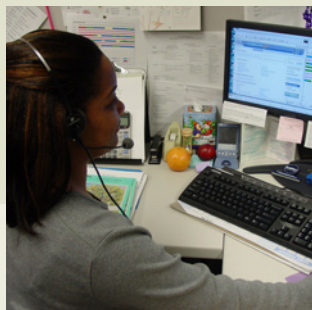
1996 – The International CIS Group is established, and the CIS e-mail response service for NCI’s Web site is launched

1997 – CIS Spanish call centers are inaugurated



1999 – New contracts are awarded to 14 offices; the CIS Web site is launched; and a new telephone system is implemented

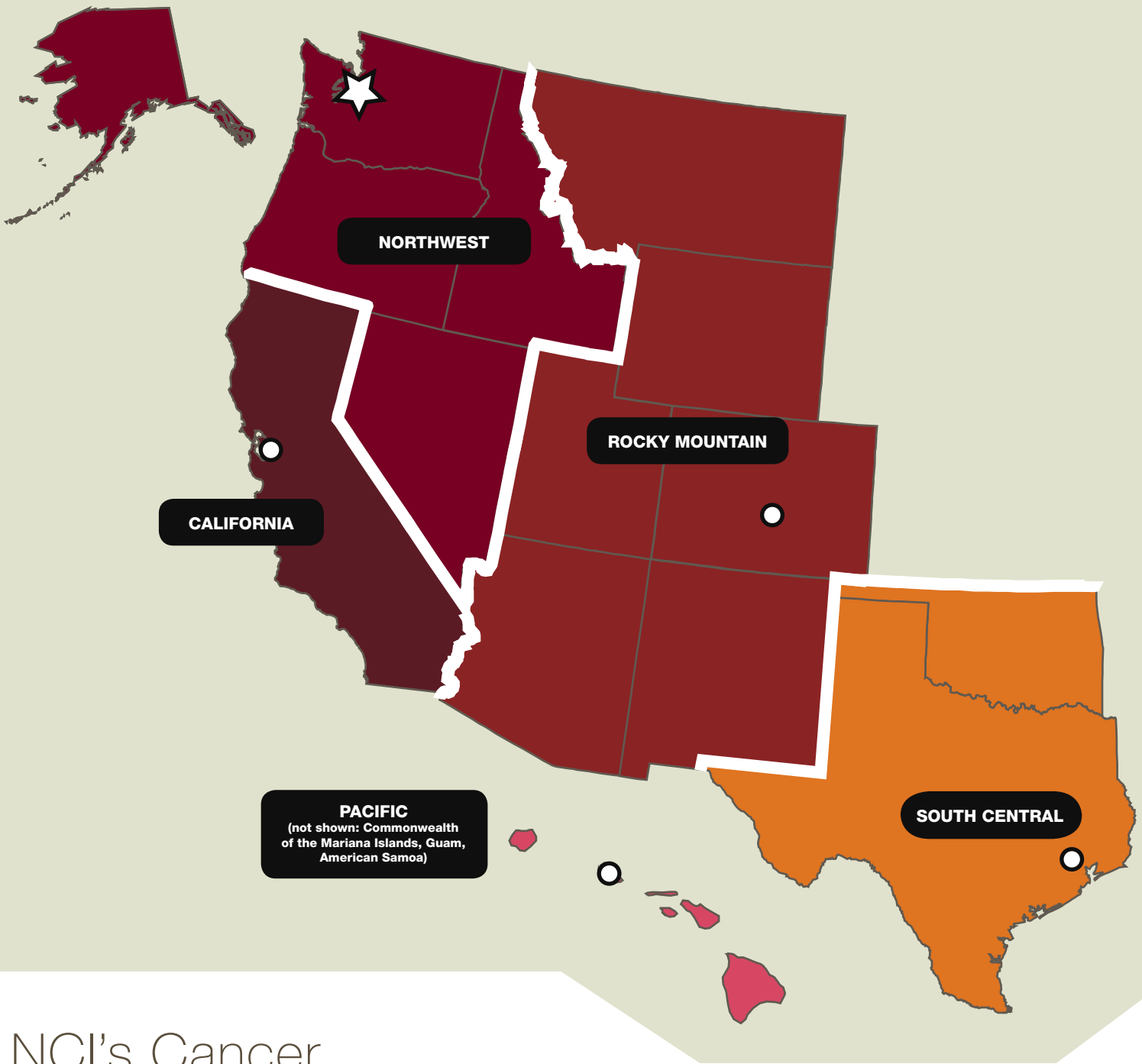
2001 – CIS celebrates its 25th anniversary; LiveHelp, an instant-messaging service, is launched



2004 – CIS takes its 10 millionth call

2006 – CIS celebrates its 30th anniversary

2006



NCI's Cancer Information Service

For more information on CIS regional offices, go to <http://cis.nci.nih.gov/community/Regions/regions.html>.

- Key
- ☆ Regional Partnership Offices with a Call Center
 - Regional Partnership Offices



More CIS Facts

February 1976: The first CIS call is taken (Florida)

Mid-1980s: CIS begins using Physician Data Query, NCI's comprehensive cancer database; the Publications Ordering Service is launched; e-mail is introduced into day-to-day operations; and CIS launches a community outreach component

2000: Smoking cessation call centers become a permanent service

2002: The NCI Smoking Quitline number, 1-877-44U-QUIT, is implemented

2004: In accordance with the National Network of Tobacco Cessation Quitlines Initiative, 1-800-QUITNOW is established

2005: CIS is awarded 15 base contracts to operate the CIS Partnership Program, and 4 of those contracts are also awarded call centers

In FY 2005, via all access channels to CIS, 4,256,912 inquiries were received.



CIS Publications Ordering Service Delivers Needed Materials

As part of its legislated mission, NCI actively supports information dissemination activities via CIS. Through its [Publications Ordering Service](#), CIS ensures that the public, as well as health care professionals, are given easy access to up-to-date information—in a variety of media formats—regarding cancer prevention, detection, diagnosis, and treatment measures.



sheets in English, with 81 of these materials also available in Spanish, through its Publications Ordering Service. NCI publications are designed to address a vast range of cancer-related topics—from encouraging screening for breast and cervical cancers to coping with the emotional burden of cancer and understanding the clinical trials process.

Despite the advent of the Internet information revolution in the 1990s, many Americans still rely on the printed word for health information. In response, CIS makes available nearly 360 NCI publications and fact

According to the NCI Office of Communications Annual Report, in 2005, the CIS Publications Ordering Service distributed 6.4 million publications, including 1.2 million booklets belonging to NCI's "What You Need to Know About Cancer" series.

Last year, 133,561 orders for printed material were received, comprising 32,808 phone orders, 69,294 online orders, and 31,459 orders from other sources. An average of 20 to 30 thousand copies of publications and other materials are distributed each day.

To handle this demand, the CIS Publications Ordering Service maintains an average monthly inventory of 27 to 28 million copies of NCI materials. Orders for cancer patients, families, and friends are shipped by priority mail for delivery within 3 business days after an order has been placed.

The CIS Publications Ordering Service has adopted new technologies, such as the bar code scanning system, to better serve the public through increased efficiency and accuracy. Current accuracy in shipping, fulfillment, and inventory management is nearly 100 percent. ♦

CIS Partners with CNP

In 2005, NCI's Center to Reduce Cancer Health Disparities awarded 25 [Community Networks Program \(CNP\)](#) grants. CIS and CNPs collaborate to reach communities and populations that experience a disproportionate share of the cancer burden (e.g., African Americans, American Indians/Alaska Natives, Hawaiian Natives and other Pacific Islanders, Asians, and Hispanics/Latinos) and reduce cancer health disparities by conducting community-based participatory education, training, and research among

racial/ethnic minorities and underserved populations.

CNPs build upon partnerships that were developed between CIS and the Special Populations Networks previously funded by NCI. These grantees have developed community-based infrastructures that provide expertise in culturally competent cancer awareness activities and training of researchers from racial and ethnic minorities and underserved populations to conduct community-based participatory research. ♦

RFA Released for CIS Research Grant

NCI released a Request for Applications (RFA) for "Exploratory Grants for Increasing the Utilization and Impact of NCI's CIS" to stimulate research that explores communication strategies to increase the use and effectiveness of existing cancer information sources by underserved populations. Formative research that examines how to engage health care providers in using and referring patients to CIS is of special interest. The deadline for applications is April 19. For more information, go to <http://grants.nih.gov/grants/guide/rfa-files/RFA-CA-06-015.html>. ♦



A Conversation with...Mary Anne Bright



Mary Anne Bright, director of NCI's CIS national program since 2002, has served in a variety of roles at CIS since 1989. Prior to working at CIS, Ms. Bright was an oncology nurse from 1978 to 1986 and an oncology clinical nurse specialist in NIH's Clinical Center from 1986 to 1989.

What is CIS?

CIS is a national network of 15 regional offices serving the United States, Puerto Rico, the U.S. Virgin Islands, and the Pacific Islands. The CIS program is a key effector arm of NCI and through its three core components disseminates evidence-based programs, products, and services to the public and partner organizations; operates call centers; and contributes to the science base of health communications research.

Can you elaborate on the three core components of CIS?

CIS is most well known for its call centers, but information dissemination is just one of the core components that make up CIS. In addition to providing information, CIS sup-

ports partnership programs and health communications research.

Information dissemination

Through CIS, information specialists respond to the public's questions about cancer via telephone in English and Spanish (1-800-4-CANCER), Web chat or instant messaging, e-mail, or written correspondence. TTY service is also available (1-800-332-8615). In addition to providing cancer information and education, CIS informs the public about the harmful effects of tobacco and offers smoking cessation counseling.

Partnership programs

With field representatives located at cancer centers and universities across the country, CIS works with state, regional, and national partners—such as the Centers for Disease Control and Prevention and the American Cancer Society—to eliminate cancer health disparities and to provide leadership and technical support for comprehensive cancer control planning and tobacco control efforts in states, tribes, and territories. Numerous regionally implemented evidence-informed projects reach populations most in need.

Health communications research

The CIS research agenda supports NCI's communications research priorities and programs. Regional research coordinators enhance support of quality research, establish targeted funding opportunities, and develop mutually beneficial col-

laborative health communications research partnerships. Dissemination of cancer communication messages, tested in research, is a primary goal of CIS.

What does it take to be a part of CIS?

The people who work in the CIS program are dedicated and talented communications and cancer control professionals who are committed to providing a quality service to the public. They play a key role in translating the complexity of ever-emerging scientific information so those inquiring can understand it in simple terms and apply it to their particular situation. The program comprises approximately 300 individuals who exemplify the spirit of caring and commitment. I am very proud of the CIS staff and the critically important work we do, and am honored that the CIS program is the cornerstone of NCI's public outreach efforts. ♦

How to Reach CIS

By telephone toll free:

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

By TTY toll free:

1-800-332-8615

Over the Internet (Instant Messaging):

Access LiveHelp by going to <http://www.cancer.gov>, clicking on "Need Help?" then "Connect to LiveHelp." ♦



Why I Am an Information Specialist



Samuel Montenegro, a bilingual information specialist at CIS for 5 years, started with the California regional CIS office, located at the Northern California Cancer Center in Fremont, Calif. In 2005, he relocated to Seattle to continue working with CIS.

NCI's mission to communicate about cancer is what CIS call centers are all about, and it's the human element that is so important to the call. It's true that we, as CIS Information Specialists (ISs), provide up-to-date scientific information, but CIS is much more than a library at the other end of your telephone. To do our job effectively, we need to tailor the information to meet the needs of each caller. Often that goes far beyond discussing a recent article or sending out a specific publication. Sometimes it means helping people deal with fears, or taking the next step in what may seem like a maze and perhaps finding the motivation to change their situation.

It also can mean just listening. Recently, a woman called who was so upset, she couldn't even talk. I had to

slow down and let her realize I was there to help her. We're under no pressure to cut a call short, and she wasn't ready to hear cancer statistics or research results, so the challenge was to try to make sure she knew that she could call us as many times as she needed and that we're here to help. So I let her know how CIS can help her navigate the resources available.

By contrast, many people want the medical context for their situation, but need help with interpreting the complex medical language and the "What does all this mean for me?" question. What almost every caller needs, and what we owe them, is a meaningful interaction, and I believe we can do that if we're motivated to engage them one at a time on a level that works.

In my experience, a successful interaction leaves callers feeling satisfied that they actually got what they needed. This may be in the form of specific information or answers they were looking for, or it could be more subtle by broadening their understanding of cancer to enhance their communication with their doctors, caregivers, and family. You have to be

ready for anything when you pick up the phone. This is why I find the job such an exhilarating challenge.

You obviously can't train for this work by just reading a manual because intuition and communication skills come into play. But all ISs receive comprehensive training. We learn to navigate the CIS intranet database, Cancer.gov, and other sources that we need to have at our fingertips to respond to calls.

Our call center is located at the Fred Hutchinson Cancer Center in Seattle, where almost every week I go to a seminar or lecture. It's a rich continuing-education opportunity that I'm often able to use right away. Friends and people from other call centers will come by our facility, and walk away amazed at what a powerfully supported and cohesive system CIS provides.

For me, it's become home—so much so that I left my Mexican American community in San Francisco and moved to Seattle. I have found the motivation to want to be the best IS I can possibly be. I think that gives me a special link with people who may be looking for the motivation themselves and the path, as well as the knowledge, to find their way through the challenge of cancer. ♦

The *NCI Cancer Bulletin* is produced by the National Cancer Institute (NCI). NCI, which was established in 1937, leads the national effort to eliminate the suffering and death due to cancer. Through basic, clinical, and population-based biomedical research and training, NCI conducts and supports research that will lead to a future in which we can identify the environmental and genetic causes of cancer, prevent cancer before it starts, identify cancers that do develop at the earliest stage, eliminate cancers through innovative treatment interventions, and biologically control those cancers that we cannot eliminate so they become manageable, chronic diseases.

For more information on cancer, call 1-800-4-CANCER or visit <http://www.cancer.gov>.

NCI Cancer Bulletin staff can be reached at ncicancerbulletin@mail.nih.gov.