

NCI Cancer Bulletin

Eliminating the Suffering and Death Due to Cancer

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http://www.cancer.gov

The Rewards and Challenges of Cancer Communication

At first glance, the phrase "cancer communication" seems deceptively simple. But when you consider the huge amount of information generated about the long list of malignancies that make up the singular term "cancer," and couple that with the size and diversity of the audience affected by cancer, it becomes quite complex.

Despite this complexity, we know that there are effective ways to communicate about cancer—methods that differ depending on the audience involved. A cancer researcher who wants to collaborate with colleagues, for example, has different communication needs than a health educator who is trying to implement a cancer prevention program in a disadvantaged community.

This special issue of the *NCI Cancer Bulletin* discusses just a few examples of new and effective ways for different audiences to communicate about cancer, and some of the NCI-funded research on effective communication. It also provides resources to help those in the cancer community to communicate with colleagues, health care providers, family, and community members. *(continued on page 2)*

Special Report

SPORE Program Key in NCI's Translational Research Review and Planning

At the National Cancer Advisory Board meeting in early June, NCI Director Dr. Andrew C. von Eschenbach announced the formation of the Translational Research Work Group (TRWG). The TRWG will follow the model set by the Clinical Trials Working Group, undertaking an open and inclusive approach to reviewing NCI's translational research portfolio and identifying ways to synergize, integrate, and coordinate efforts. The review will draw heavily upon

the expertise and experience of members of the Institute's successful SPORE (Specialized Programs of Research Excellence) program, Dr. von Eschenbach told attendees at the SPORE annual investigators workshop on July 10.

"The TRWG, led by Dr. Ernie Hawk, will bring together members of the broader research community, including those participants in the SPORE program, to focus on the opportuni-(continued on page 2)

(Director's Update continued from page 1)

NCI's communication efforts are rooted in the National Cancer Act of 1971, which initially directed NCI to develop programs for rapid dissemination of cancer research knowledge to the scientific community. This was later broadened to include cancer patients and their families, health professionals, and the public.

Indeed, the remarkable pace of change and advancement in cancer research has made our stake in communication vitally important.

Researchers, community oncologists, and other providers face a constantly changing landscape of cancer prevention, diagnosis, treatment, and survivorship. And the public is regularly bombarded with news about cancer that they often must interpret on their own.

Clearly, NCI and the cancer community have an important role in disseminating accurate and helpful information, and also in making resources available to our partners who do the same. This is a huge task that NCI takes very seriously.

Since its launch in 1976, for example, NCI's Cancer Information Service (CIS) has answered more than 10 million calls from the public, patients, and health care providers about everything from clinical trials to new treatments. And the Physician Data Query (PDQ®) was launched in 1983 to provide peerreviewed, regularly updated summaries on important cancer topics for physicians and patients.

Of course, the Internet has dramatically altered how we develop and disseminate information about

cancer—a trend exemplified by the increasing number of individuals who have launched "blogs" to capture their experiences as cancer patients and share them with millions of people. In fact, cancer researchers are studying how blogs, such as those hosted by the Association of Cancer Online Resources (www.acor. org/support.html), are being used by and ultimately how they affect cancer patients. And NCI continues to find new ways to harness the communications advantages offered by the Internet, such as the recent launch of NCI Listens and Learns (http://ncilistens.cancer.gov/) to collect feedback directly from the cancer community on some of our most pressing issues.

We have vigorously responded to the communication mandate of the National Cancer Act. But, as several studies of public attitudes and beliefs about cancer indicate, we still have work to do. At NCI, we are committed to working with the cancer community to educate and inform all those with a stake in eliminating the suffering and death due to cancer. And that includes just about everybody. •

Dr. Andrew C. von Eschenbach Director, National Cancer Institute

(SPORE Program continued from page 1) ties and changes that must occur in translational research at NCI," Dr. von Eschenbach explained. "By its very nature, the SPORE program will be a critically important part of that assessment process." However, Dr. von Eschenbach emphasized, the TRWG is not simply a review of SPORE: "The definition of translational research and the mandate of the working group are broad—to

consider programs across the entire NCI portfolio, both extramural and intramural.

"The future will be framed by the fact that, during the lifetime of the SPORE program, we have gone through a metamorphosis from a macroscopic view of cancer to a molecular perspective," Dr. von Eschenbach continued. "The initiation of the era of molecular oncology has created a reality in which the future is not just an extrapolation of the past. We must create that new future—the opportunities for achieving the goal of eliminating the suffering and death due to cancer have never been greater."

Changes will result from that review process, the NCI Director acknowledged. "We're inviting you in the SPORE program and others in the research community to be part of the deliberation over the next year to help us define the future opportunities and direction of translational research."

The NCI leadership team is developing a funding plan for new and renewal SPORE applications for FY 2005 and FY 2006. As in past years, the plan is premised on peer assessments of scientific merit over 5-year project timelines. However, guaranteed funding will be for 3 years. This will allow NCI the flexibility to rapidly implement the TRWG's findings and recommendations.

"The history of SPORE is extraordinary and great," Dr. von Eschenbach affirmed. "What you have accomplished is in many ways beyond imagination. And yet I believe that the greatness of the SPORE program still lies ahead." •

NCI Office of Communications: Structured for Success

Guided by the 1971 National Cancer Act mandate to rapidly disseminate information about cancer research to the public and the scientific community, the NCI Office of Communications (OC) has long been committed to finding the most effective methods of communicating scientific findings. Today, OC stands as a trusted and valued resource for cancer communications strategies within NCI and among the larger cancer community. Utilizing consumer research, cuttingedge technology, and the latest information about health behavior, OC provides the highest level of expertise and services to the general public, the

media, health professionals, and partner organizations.

Just as NCI's overall cancer research has served as a catalyst for the advancement of broader scientific knowledge, so too have OC's innovations greatly enriched the vitality of communication efforts across the health care continuum. Since 1975, NCI has launched many ground-breaking communications programs such as the Cancer Information Service (1-800-4-CANCER) and the Physician Data Query (PDQ). In 1995, NCI was at the forefront of the World Wide Web explosion with the establishment of CancerNet, a computer-based infor-

mation service that ultimately evolved into the award-winning cancer.gov Web site. While innovative services such as CIS and online resources including cancer.gov and the *NCI Cancer Bulletin* are some of the more visible OC products, the success of these and other programs depends on a comprehensive, integrated, and technology-based organizational structure staffed by committed public servants.

The graphic below illustrates OC's integrated approach to effective communications, harnessing its many resources to maximize efficiency and rapidly develop future advances in communications technology. *



Notable Events in NCI Cancer Communications

1970

1973—Surveillance, Epidemiology, and End Results (SEER) Program begins, with collection of cancer incidence and survival data

1974—CANCERLINE, a national database of published cancer research, is established



1989—The Pink Book: Making Health Communications Programs Work is first published by NCI Office of Cancer Communications

1993—Age-adjusted mortality estimates decline, due largely to behavior changes



2000—Human genome completed, emphasis shifts to "tailored" interventions

2004—Call for electronic health records in the Presidential State of the Union address; Cancer.gov redesign; Cancer.gov wins Freddie Award



1975—NCI's Cancer Information Service (1-800-4-CANCER) opens

1977—First national cancer patient education program, I Can Cope, is founded

1983—PDQ (Physician Data Query®) database goes online

1991—The American Stop Smoking Intervention Study (ASSIST) is initiated; national 5 A Day for Better Health program launches

1998—Cancer is the third most popular health search on the Web



2003—Health Information
Trends National Survey (HINTS)
developed; Internet penetration
reaches 63 percent; NCI funds four
Centers of Excellence in Cancer
Communications Research

2005—Cancer.gov wins Webby Award

Did You Know That...

According to a 2005 Pew Internet & American Life Project report, 79 percent of Internet users—roughly 95 million adults—search online for health information. That's close to half of all Americans: 51 percent of women and 49 percent of men.

The report also showed that the most popular search topics for Internet users include specific diseases or medical problems, treatments and procedures, diet and fitness, and drug information.

However, even with all of the information available about cancer, many Americans remain misinformed. A recent survey of 957 adults from across the country, published online by the journal *Cancer*, showed that:

- 41 percent believed treating cancer with surgery can cause it to spread
- 27 percent believed there is a cure for cancer, but the medical community is keeping it a secret
- 19 percent believed pain medications are not effective against cancer pain
- 7 percent believed cancer cannot be treated, while 6 percent were unsure.

The study showed that residents of particular regions in the United States are not more knowledgeable about cancer issues than others, but interestingly:

- People in the Northeast were more likely to believe that cancer pain can be controlled
- Those in the South were more likely to believe that a positive attitude can cure cancer
- Residents of the Midwest were most likely to believe that cancer can be treated effectively.

2005

A Conversation with Amy Dockser Marcus

Wall Street Journal reporter Amy Dockser Marcus received the 2005 Pulitzer Prize for Beat Re-



porting after writing a series of stories about cancer survivors.

Why did you choose to write these stories?

Cancer's impact is felt far beyond the 10 million survivors living with the disease—it touches every survivor's family, friends, and community. I knew that, thanks to new treat-

ments, many people were living longer with cancer. I was interested in exploring the challenges created by this phenomenon.

In writing these stories, what did you feel were the most important messages to communicate?

My goal was to allow the survivors to tell their own stories and to write them in a way that reflected how they told them—in an understated, simple style that was not maudlin or sentimental. I saw universal issues in their personal struggles that I knew would touch people, even if they did not know someone who had cancer.

What did you enjoy the most about writing these stories?

I enjoyed getting to know the people whom I was profiling. The relationships that I developed with them during the writing and reporting process were very meaningful to me. I came into their lives at a difficult time. Some of them were still in the middle of their treatments. And yet their willingness to share one of the worst things that ever happened to them because they thought it might help someone else was very inspiring.

How has telling these stories affected the cancer survivors you interviewed?

Andy Martin, the young medical student who studied his own rare tumor because no one else was, passed away 8 months after the story about him ran on the *Wall Street Journal's* front page. But a generous reader who was touched by his efforts provided funding for a researcher who continues to study SNUC, the cancer that Andy had. In that way, Andy lives on. I think the people whose stories I told understood that their experiences continue to touch and help other people in small and large—and often unforeseen—ways. *

Centers Explore New Communications Methods

NCI launched the Centers of Excellence in Cancer Communications Research (CECCR) initiative in 2003. The four centers provide the infrastructure for interdisciplinary teams to promote advances in cancer communications, develop interventions, translate theory into practice, and train health communicators. NCI awarded each center \$10 million over 5 years.

At the University of Michigan, Dr. Victor Strecher is developing a model for health behavior interventions that applies to all sociodemographic groups in the United States. One project explores ways of communicating risk about tamoxifen prophylaxis to women at high risk for breast cancer.

At the University of Pennsylvania, Dr. Robert Hornik is examining how people make sense of complex information and how that affects their health choices. One project is developing a descriptive model and specific measures of cancer-related information searching and scanning behavior in the general population, and determining whether this behavior is associated with post-diagnosis treatment choices, as well as with changes in cancer screening and prevention behavior.

At Saint Louis University, Dr. Matthew Kreuter is studying cancer communication among African Americans. One project is analyzing African American newspapers across the country to determine the frequency and nature of their coverage of cancer-related stories, and developing and testing a computer-based intervention to enhance cancer coverage in these newspapers by contributing community-specific stories and data on cancer.

And at the University of Wisconsin-Madison, Dr. David Gustafson is advancing interactive cancer communications to improve the quality of life of patients and families. Projects examine whether Comprehensive Health Enhancement Support Systems improve cancer outcomes and survivorship experiences. •

HINTS Web Site Provides Access to Health Information Trends

Researchers, health educators, and communication practitioners know that communicating effectively with the public is essential to realizing population-wide impacts in cancer prevention, early detection, and survivorship. But investigators, who study the relationship between how people get information about cancer and how that information influences health behavior, have been hindered in the past by a lack of nationally available data.

Debuting in 2003 as the first survey of its kind, NCI's Health Information National Trends Survey (HINTS) assesses the American public's need for, access to, and use of cancer information. The data identify changing communication trends and practices; provide updates on changing information patterns, needs, and opportunities; assess cancer information access and usage; and provide insight about how cancer risks are perceived.

A HINTS article published in February's *Tobacco Control* reveals, for example, that smokers underestimate their relative risk of lung cancer compared with nonsmokers and, contrary to previous surveys, believe they personally have a lower risk of developing lung cancer than the average smoker. In addition, HINTS reveals that many current and former smokers incorrectly agree with several myths about smoking and

health—with more than half agreeing that exercise undoes most of tobacco's negative effects.

The HINTS Web site (http://hints. cancer.gov) was launched in February 2004. "Since then, we've been using our own advances in informatics technology to change the way that cancer control researchers are doing business," said Dr. Bradford W. Hesse, acting chief of NCI's Health Communication and Informatics Research Branch. In 2005, the site introduced a number of new tools to allow users easy, direct access to nationally representative data for every item on the survey. To date, more than 100 researchers have used HINTS data to conduct their own research.

CIS Partnership Program Builds Communication Inroads

NCI's Cancer Information Service (CIS) may be best known for its toll-free information line, but its cancer control efforts delve further into minority and medically underserved populations via its far-reaching partnership program. "We bring technical assistance and evidence-based program planning expertise and the partners give us access to populations most in need," said Madeline La Porta, deputy director of CIS.

Some 70 field staff in CIS's 15 regional offices establish and maintain partnerships across the country. They look to further the goals of NCI—eliminating cancer health disparities, recruiting for clinical trials, and

preventing cancer—according to the needs of their region. Comprehensive cancer control plans for states, tribes, and territories guide the process.

There are more than 1,000 CIS partners, including cancer control coalitions, state and local health departments, academic institutions, patient alliances, health professional organizations, insurance companies, nonprofit community groups, and labor unions. A sampling of specific projects that the partners have undertaken include:

- TEAM-UP: Cancer Screening
 Saves Lives—A regional partnership among several NCI divisions,
 the U.S. Department of Agriculture, the Centers for Disease
 Control and Prevention, and the
 American Cancer Society in eight
 Appalachian states that encourages
 breast and cervical cancer screening among women who have never
 been screened
- Ceru Humo Campaign—A partnership with the Clark County Health District and the Nevada Tobacco Users' Helpline to raise awareness of the risks of second-hand smoke among Latino adults in Las Vegas via displays in laundromats, barbershops, and supermarkets
- The Northwest Native American Navigator Program Pilot Project— A partnership with the Yakama Indian Health Center, the Spirit of EAGLES, the Seattle Cancer Care Alliance, and the Puyallup Tribal Health Authority, among others, to train nurses to help Native Americans overcome the unique barriers to cancer care that they experience. •

Cancer Communications Resources

For Everyone			For Health Pr	actitioners and Educa	aturs
	http://www.cancer.gov	The main NCI Web page with links to information, tools, and resources on cancer	Pink Book— Making Health Communications Programs Work	http://www.cancer. gov/pinkbook	A guide to communication program planning
NIH Plain Language Training	http://plainlanguage.nih. gov/CBTs/PlainLanguage/ login.asp	An online training module that reinforces simple, clear communication practices	ClinicalTrials.gov	http://www.clinicaltrials. gov/	A searchable database of NIH and industry-sponsored clinical trials
Health Communications Internship	http://internship.cancer. gov/whynci.cfm	A once-renewable 6-month program for graduate students to become involved in communications projects at NCI	NCI Clinical Trials Web site	http://www.cancer. gov/clinicaltrials	A database of cancer clinical trials, with background on the clinical trials process
Program Understanding	http://www.cancer.	Graphic tutorials in PDF and PowerPoint	HINTS	http://cancercontrol.can- cer.gov:0/hints/index.jsp	National data about how adults gather information on cancer
Cancer Series	gov/cancertopics/under- standingcancer	to instruct on various cancer topics; some modules available in Spanish	Risk Communication	http://cancercontrol. cancer.gov/DECC/risk-	References to documents addressing communication of
State Cancer Profiles	http://statecancerprofiles.cancer.gov	A searchable database of cancer statistics by state and cancer site	Bibliography Multimedia Health	commbib/ http://cancercontrol.	public health hazards An online directory of products
LiveHelp	https://cissecure.nci.nih. gov/livehelp/welcome.asp	An online portal to information about cancer and smoking cessation from information specialists at the NCI Cancer	Communication Products Showcase	cancer.gov/cgi-bin/sbir_ index_search.cgi	developed as a result of NCI- sponsored communication and behavior-change research
Publications	https://cissecure.nci.nih.	Information Service A searchable database for viewing	PDQ	http://www.cancer. gov/cancertopics/pdq	A database of cancer topics, clinical trials, and professional directories
Locator	gov/ncipubs/ http://www.cancer.	and ordering copies of NCI-developed publications A searchable database of information on	Office of Education and Special Iniatives	http://www.cancer. gov/aboutnci/oesi	NCI office responsible for the development, implementation, and evaluation of education programs
i bų	gov/cancertopics/pdq	cancer topics, closed and open clinical trials, and professional directories	Understanding Cancer Series	http://www.cancer. gov/cancertopics/under-	Tutorials on cancer topics; some modules available in Spanish
MedlinePlus	http://www.medlineplus. gov	The National Library of Medicine's portal to information sources on a variety of health topics	Cancer Control PLANET	standingcancer http://cancercontrolplanet. cancer.gov/	Resources for planning cancer awareness and behavior change
NCI Dictionary of Cancer Terms	http://www.cancer. gov/dictionary/	Contains more than 3,500 terms related to cancer and medicine	ILANLI	cancer.gov/	programs
ACS Cancer Survivors	http://www.acscsn.org/	An online forum sponsored by the American Cancer Society for sharing personal stories and discussing issues related to cancer	For Scientists	3	
Network®			CRISP	http://crisp.cit.nih.gov/	A database of federally funded biomedical research projects
For the Media	ı		HINTS	http://cancercontrol.cancer. gov:0/hints/index.jsp	National data on how adults gather cancer information
NCI NewsCenter	http://www.cancer. gov/newscenter/	Announcements of research and upcoming events, as well as online audio-visual materials	Health Communication and Informatics Research Branch	http://cancercontrol.cancer. gov/hcirb	Supports basic and translational research on communication practices and infrastructure
CRISP	http://crisp.cit.nih.gov/	A searchable database of federally funded biomedical research projects	Risk Communication	http://cancercontrol.cancer. gov/DECC/riskcommbib/	References to documents about communication of public health
BenchMarks	http://www.cancer. gov/newscenter/bench- marks/archive	NCl's online magazine, with multi- media background materials related to recent, high-profile cancer news	Bibliography NCI Liaison Activities	http://la.cancer.gov/index. html	hazards Fosters NCI's relationships with advocates, professional societies, scientific organizations, and federal agencies
NCI Entertainment Resources	http://www.cancer. gov/newscenter/enter- tainment-overview	Provides accurate information about issues related to cancer for screenwriters, producers, and other			
B-Roll Footage	http://www.cancer.	members of the entertainment media Online catalog of .MOV preview files	Cancer Biomedical Informatics Grid	http://cabig.nci.nih.gov	Network of individuals and institutions to enable sharing of data and tools
	gov/newscenter/pressre- leases/b-roll-general	for television cancer news coverage; beta tapes can be ordered by phone	(caBIG) Nanotechnology	http://nano.cancer. gov/resource_center/team- ing_site.asp	A venue for nanotech researchers to explore collaborative opportunities
Radio Broadcasts	http://www.cancer. gov/newscenter/pressre- leases/radio-broadcasts	Online catalog of MP3 files sampling interviews with NCl scientists on cancer topics	Teaming Site		
Visuals Online	http://visualsonline. cancer.gov/	Searchable database of photo- graphs, slides, and scanned docu- ments; images available in various			
		resolutions			7 NCI Cancer Bulletir

Cancer Blogs: A New Way for Patients to Communicate



This photo of Dr.
Roberts was taken after she began chemotherapy in 2004.

Michigan, I was feeling rather painfully bloat-

June 4, 2005. The good, the bad, and the wonderful. The day after returning from our wonderful weekend in Grand Rapids, Michigan, I was feeling rather painfully bloat-

ed, but nonetheless decided that we would go as scheduled to a dear friend's house for dinner. We enjoyed a wonderful evening of gourmet food, fine wine, and lots of fun, but on returning home, I could sense that I was in trouble...As a result I spent all of Wednesday in the ER getting poked and scanned.

This day in the life of a cancer patient was written by NCI researcher Dr. Anita Roberts in her blog (short for "Web log"), an online tool she adopted after being diagnosed with gastric cancer in March 2004. Like other cancer patients and survivors, Dr. Roberts uses her blog (at http://www.anitaroberts.net) to communicate "how I'm doing, and what I'm thinking and feeling as I work through this difficult, and at times surreal, transition in my life."

Blogs provide the people who write them (also known as "bloggers") with a platform for sharing their thoughts and experiences with others. Dr. Bradford W. Hesse, acting chief of NCI's Health Communication and Informatics Research Branch, notes that 7 percent of Web users in the United States say they have created blogs. "Although we don't have any data on how many cancer patients or their caretakers are beginning to use blogs, we imagine that the number will begin growing as more Americans get used to blogging as a ubiquitous online activity," he says.

As a platform for online chronicling, many still consider blogs to be unfamiliar territory. Prior to her diagnosis, Dr. Roberts says she would never have considered becoming a blogger. "I was extremely reluctant to do it in the beginning," she recalls. "I have my private life and I don't always feel like sharing it." However, Dr. Roberts, a worldrenowned scientist who was chief of NCI's Laboratory of Cell Regulation and Carcinogenesis until last August, quickly became overwhelmed by the outpouring of e-mails and phone calls once news of her illness became known. Her son urged her to start a blog to keep her friends and colleagues informed of her journey with cancer.

"Gradually, I got more comfortable with it," she says. "It became very much of a therapeutic tool for me." Dr. Roberts finds it especially helpful in focusing her thoughts on what

upsets her about her situation, such as the side effects of her chemotherapy drugs. An entry from May 2004 begins: "Tonight is time for catharsis—why I hate Xeloda!"

Dr. Keith Bellizzi, a cancer prevention fellow working in NCI's Office of Cancer Survivorship, recently began a cancer blog "as a forum to track and discuss late-health effects of cancer treatment that I had 10 years ago." He notes that another benefit of blogging is that it creates a record of a patient's experience. "Reflecting back on your experience via journal entries can be quite therapeutic in seeing how far one has come."

The therapy comes not only from introspection, but also from reaching out to other people and helping them deal with cancer, whether it be their own or that of a loved one. "It's connected me to cancer patients who write to me and say, 'I found your site and have been reading it and it's been helping me," Dr. Roberts explains. "That has really been good for me." *

NCI Listens and Learns

Another Way to Communicate with NCI

NCI and the Director's Consumer Liaison Group have launched a pilot project called NCI Listens and Learns, an online forum that offers cancer advocacy groups and members of the public the chance to publicly communicate with NCI on key topics. Those who would like to participate in the discussion can go to http://ncilistens.cancer.gov/. Watch for *Bulletin* announcements of new discussion topics which will be posted on the site at the beginning of each month. *

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.