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National Cancer Institute and Depository Libraries: A Productive Partnership

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Hello! I am very pleased to be here at the Depository Library Conference. Because this is the first time we have had the opportunity to tell you about some of NCI's activities, programs, and products, I thought it might be productive for me to put things into perspective and give you a little history and background on the Institute itself before telling you about the communications program in which you, the depository libraries, participate.

First, we are a Government agency, the Government's primary organization for cancer research. As with every Government agency, we belong to a hierarchy, including the National Institutes of Health; the Public Health Service; and our parent agency, the Department of Health and Human Services.

The National Institutes of Health, of which we are a part, are located only two short blocks north of here on a large campus of laboratories and clinical facilities.

Two major pieces of legislation designed the cancer program as we know it today. The first was passed in 1937. The National Institute of Health (NIH) was originally one Federal institute doing basic biomedical research. But during the 1930s, the American public, concerned about the prevalence of cancer, exerted pressure on the Government to do something about it.

The public pressure resulted in Congress unanimously passing the National Cancer Institute Act in July 1937 and Franklin Roosevelt signing it shortly after.

This Act established the National Cancer Institute; established a targeted research program (up until that time NIH research was not targeted at any particular disease); and made the conquest of cancer a national goal.

Again, during the late 1960s, with cancer rates still rising, the conquest of cancer took on even more urgent significance and motivated an intense public campaign to target cancer more fiercely. Many of you may remember that the mantra of the period was that if Americans could go to the moon, they should be able to cure cancer. Thus, the campaign, spearheaded by philanthropist Mary Lasker and businessman Benno Schmidt, was fueled by a theory that the problem of cancer could be solved with a NASA-like approach.

President Richard Nixon proclaimed a "war on cancer" and signed the National Cancer Act in 1971.

The 1971 Act created a National Cancer Program; dramatically increased the cancer research budget; gave the institute more autonomy, including a presidentially-appointed director; and, most importantly for our purposes here today, mandated the NCI to communicate to the American public about cancer.

The Institute's major mission is, of course, research. In its laboratories on the NIH campus, NCI conducts its intramural research program. However, nearly 80 percent of its appropriated budget supports extramural cancer research at institutions across the country. NCI also provides support for cancer centers and the training and education of specialists and researchers.

Cancer research is, by need, multifaceted. But central to the investigation is the comprehension of the mechanisms at work within the human cell. Why do normal cells develop into cancerous ones? How does that transformation occur? And, how can this transformation be prevented, stopped, or reversed? These are the basic questions being studied by scientists at NCI and across the country.

Although research is our major responsibility, the mission that most concerns us here today is communications. The 1971 National Cancer Act clearly stated that we must provide helpful information to Americans coping with cancer. We must also provide the general public with information on the early detection and prevention of cancer and help the lay public understand the science behind the research. Thus, NCI target audiences include patients and their families; the general public; health professionals; and special and ethnic populations.

How do we reach these target audiences? Often we reach them directly, but more often we reach them indirectly, through intermediaries.

One way we reach these audiences directly is through the Cancer Information Service (CIS). The CIS is a nationwide, toll-free cancer hotline with regional offices across the country. Specialists answer questions, in English and Spanish, about the latest cancer treatments and provide tips for early detection and prevention. It's also a source for NCI publications and for information about community services.

We also reach our audiences directly through the Internet. As you might expect, the Internet is a valuable tool not only for the public, but for scientist-to-scientist communications. Over the last several years with the rush to use the Internet, the NCI Web site virtually exploded into dozens of individual sites with a variety of purposes and target audiences. Because it is currently undergoing a major renovation, collapsing it into one integrated site, I won't emphasize our Web site today.

Most of our communications are accomplished indirectly, through intermediaries.

One important channel is the mass media. In addition to the usual press releases, backgrounders and fact sheets, NCI has a press office to answer questions from the media and to encourage media coverage of cancer-related stories. The media can also be very

useful in helping to translate complex scientific concepts into lay language. Recent studies have shown that most Americans get their medical information from the media, mostly television. So you can see why this channel is an important one.

Primary care doctors, nurses and other health professionals are important intermediaries through whom we channel our information. Much of this work is done through exhibits at national professional meetings where we promote our materials and programs.

When the science calls for it, we develop special campaigns to reach a specific audience. For example, when it became evident that the use of spit tobacco among young boys was dramatically rising, we developed a video kit, Dangerous Game. The kit was promoted as a tool for teachers, scout leaders and others to reach this young target audience.

We frequently join with other organizations, both public and private. Our most recent examples of this include a joint campaign on prostate cancer with the group US-Too, and a campaign with the Health Care Financing Administration (HCFA) to raise awareness among older women of Medicare coverage of mammograms.

At times, it may take more than pamphlets and booklets to get information to the public. For example, a kit was designed to train health professionals who will then go out into the community and educate other professionals and the public about clinical trials.

And as you well know, we also reach our target audiences through libraries.

It is evident that in many communities, libraries are the first places people head when they want information, and community libraries across the country serve as a valuable resource for cancer information.

Now I'd like to tell you a little about the kinds of information we have available. The NCI is well known as the source for the most accurate and up-to-date cancer information. And we certainly have a wealth of information, both on the Internet and in print. Let's start with the Internet.

Clinical trials are a major priority for the Institute. In order to prove new and better treatment methods, each must go through clinical trial. A clinical trial might test a potentially superior chemotherapy drug, for example, against the standard treatment regimen. We develop information to help recruit patients to these clinical trials, to help patients locate appropriate clinical trials, and to answer questions for the patients who are participating.

CancerNet is a Web site that contains detection, diagnosis, and treatment information on all cancers, both for physicians and for patients. It is the best place to go for descriptions of the most current treatment protocols available.

This NCI Web site is the current home for patient education information. Information on how to cope with the side effects of cancer treatments; what are mammograms and who should get them; how to include five fruits and vegetables into your daily diet; tips on smoking cessation; and much, much more.

NCI also has a fledgling, but growing, science education site on the Web. The purpose of the site is to explain the "science behind the news" for students and the lay public, helping them better understand the scientific concepts behind the research. The information on all the sites that I've described will all be integrated into one new NCI Web site to be unveiled sometime this summer.

Printed materials have always been the basis of the NCI communications program.

It's hard to overemphasize how important our materials are for cancer patients. Just to give you some idea, we distribute about a half- million copies of each of these publications each year. Each booklet is reviewed and revised at each printing, so that NCI materials are always current. These booklets may help patients deal with radiation treatment or chemotherapy; provide advice for patients with eating problems; or simply help with some of the psychosocial issues involved in being a cancer patient.

One series of pamphlets is site specific and discusses the causes, detection, diagnosis and treatments for most cancers. The booklets are targeted to both cancer patients and the lay public.

Other materials are designed to promote mammography and breast cancer awareness among women over age 40 and in various ethnic communities. They include colorful posters, bookmarks, booklets, and easy-to-read brochures.

There are materials on smoking cessation, tips on quitting, and effects of secondhand smoke.

We try to produce many of our materials in easy-to-read formats, as well as large-print materials for the visually-impaired. These include information on mammograms, pap tests, and treatment issues.

Some of our most popular materials are targeted at special populations, including Hispanic, African-American, and Native American ethnic groups.

We also package our science education information as "speakers kits," sets of slides and scripts for teaching at almost any level. Our two most popular kits are "Understanding the Immune System" and "Understanding Gene Testing." There are more of these teaching kits in the works.

The National Cancer Institute and depository libraries are now a productive partnership, and we can make this partnership even stronger. We welcome your feedback to help us make our materials even better or to make your professional lives easier. We urge you to let us know about any special needs you might have, or collaborations you might want to suggest. For example, should you want extra mammography materials to distribute during breast cancer awareness month, or smoking booklets for the Great American Smokeout, or teaching kits for library lectures, we'll help whenever possible.

Who should you call? You can call your contacts at GPO, I'm sure they will relay the message. Or, call us directly. Thank you very much for letting me tell you about the National Cancer Institute today.