

# ONCOLOGY TIMES

Publishing for 30 Years

Lippincott Williams & Wilkins  
Wolters Kluwer Health

The Oncology & Hematology Source



## NCI Hangs Up on Cancer Information Service: Will End Partnership & Research Programs, Consolidate Phone Service

BY ERIC ROSENTHAL

**K**ey components of NCI's CIS were created to help medically underserved populations overcome the emerging digital divide. Now, some of those parts are facing termination due to what may be philosophical differences about NCI's mission. There is concern that NCI's decision to end two-thirds of the CIS program in January 2010 by not re-competing bids on its existing five-year contracts may not adequately serve the 700+ partnerships built on mutual trust over many years by the regional CIS offices.

See Page 21



**JOE SIMONE: My Favorite Great Ancient Physician**

p. 4



**In Wake of Economic Downturn, Dire Predictions for Future of Biotech Discoveries**

p. 13



**President's Cancer Panel Recommends New White House Cancer Position**

p. 26



**New Cancer-Related Biotechnology Medicines in Development**

p. 33

## [ ALSO ]

MICHAEL CALIGIURI: Get Insurance Coverage for Routine Care in Cancer Trials Now! . . . . . 12

NSCLC: Added Cetuximab Extends Survival . . . . . 16

Building a Cancer Center in the Middle East . . . . . 52

WENDY HARPAM: 'Crapshoot' . . . . . 55

High-Risk Myeloma: Use of Novel Agents with and without Transplant . . . . . 57

POETRY by Cancer Caregivers . . . . . 64

## Eric Rosenthal reports

## NCI Hangs Up on Cancer Information Service

## Plans to End Partnership &amp; Research Programs, Consolidate Phone Service in 2010

BY ERIC T. ROSENTHAL

Critical components of the National Cancer Institute's Cancer Information Service (CIS) were created over the years to help various medically underserved populations overcome the emerging digital divide. Now, some of those very components are facing termination because of what may be a philosophical divide regarding NCI's mission to disseminate information.

For more than three decades the CIS and its well-known 1-800-4-CANCER toll-free telephone hotline and allied but less-publicized partnership and health communications research programs have been an integral and evolving part of the 1971 National Cancer Act's mandate that NCI provide a program to disseminate and interpret scientific and other information regarding the causes, prevention, detection, and treatment of cancer to practitioners and other health professionals, scientists, and the general public.

The three parts have worked synergistically to provide information, outreach through partnerships, and a better understanding of health communications.

According to a former CIS official who requested anonymity, "CIS has always been more than a service program. Dissemination is the last step in the research process."

That statement raises an interesting question regarding what might be a fundamental philosophical difference between NCI Director John E. Niederhuber, MD's vision of the Institute and that of many others working on some of the Institute's programs to fulfill the longstanding Congressional mandate.

This article was prompted by a concern shared by some in the cancer community that NCI's decision to end two-thirds of the CIS program in January 2010 by not re-competing bids on its existing five-year contracts was arbitrary and made behind closed doors by the Executive Committee in August, and, among other things, did not make adequate provisions to continue serving the more than 700 partnerships built on mutual trust over many years by the nation's 15 regional CIS offices.

### Now Just 3 Call Centers

The telephone service, which at one time had as many as 34 local toll-free lines, has gradually been consolidated into three call centers located at CIS offices at Memorial Sloan-Kettering Cancer Center, the University of Miami Sylvester Comprehensive Cancer Center, and Fred Hutchinson Cancer Research Center.

NCI plans to continue this service under one competitively bid contract after 2010.

OT contacted numerous individuals either currently or formerly involved in both the intramural and extramural programs of the CIS for comment. Several did not respond at all to e-mails or phone calls; several others agreed to speak only off the record for fear they might be jeopardizing their grants or positions; and a few agreed to comment publicly, with one asking later

for a retraction of all statements made for attribution.

Two requests for an interview directly with Dr. Niederhuber were passed along instead to the Director of NCI's Office of Communications and Education, Lenora E. Johnson, who responded only with an e-mail message that was mainly a statement that had been posted on the CIS's Web site the day before under the title "NCI's Decision About the Partnership Program" (<http://cis.nci.nih.gov>).

In summary, the information on the Web site says that although NCI is not renewing the CIS Partnership Program contracts it still "remains committed to the communities being served through this Program and to reducing the burden of cancer by providing the latest, most accurate information to the general public and health professionals."

Ms. Johnson also said in her e-mail message that information dissemination has changed since the start of the Partnership Program in 1984, and that "it is important that we consider these changes and their impact on NCI's outreach strategies and approaches."

### Why did NCI make this decision behind closed doors within its Executive Committee instead of using one of its advisory boards like the Board of Scientific Advisors or the National Cancer Advisory Board? And why were there no minutes or a reported summary of the discussion to end the Partnership Program?

"Rather than renew the Partnership Program as it has been defined for the last decade, we are taking this opportunity to determine how NCI can most effectively and efficiently disseminate important cancer information, and engage communities in order to realize an impact in the lives of those we serve," she wrote.

She said there were no plans to revisit this decision, and "as responsible stewards of public funds, NCI is constantly reevaluating needs against ever changing environments and scientific priorities. NCI is committed to making the best use of our resources to provide the most benefit to the cancer community."

The e-mail continued on about the importance of collaborations, noting that there are numerous efforts under way

involving many different partners, and that "between now and January 2010, NCI will consider these engagements and work as efficiently as possible to gain a better understanding of those relationships and how the Institute can best facilitate these and future activities."

Ms. Johnson concluded by writing that she hoped the information provided was helpful in addressing my questions, and said "please feel free to contact me or a member of my staff with further questions...."

I replied that I was disappointed that I did not have an opportunity to speak with Dr. Niederhuber, but would appreciate speaking with her about a few issues that had not as yet been addressed. She replied back two days later saying that she would try to return my call if I left a message the next day. I did, but that evening I received another e-mail that said: "Please understand that we are currently talking with the CIS regional offices and project managers about the recent decision and would like to first meet their information needs prior to holding discussions with the media....Please refer to my previous e-mail as a summary of the decision for your use."

### Dr. Niederhuber's Webcast with the Director's Consumer Liaison Group

Although I wasn't able to communicate directly with Dr. Niederhuber I was able to access the Webcast of his October 15 meeting with the Director's Consumer Liaison Group (DCLG), where he said in response to a question about his plans to end the Partnership Program that NCI's job "is to ask questions to create new knowledge."

"We are not a delivery organization," he said. "That's not the charge or the role of the National Cancer Institute. We bend that rule over and over again probably many times inappropriately, cheating over into that policy area or that delivery area, but our charge is to create new knowledge around these issues around these health care disparities. Our challenge is to find those facts to create the science so others can do the implementation."

### Passionate Disagreement

Nearly everyone I spoke with about this issue passionately disagreed with the Director—who had been principal investigator of the CIS office at the University of Wisconsin Cancer Center when he was the Director there—regarding the importance of the partnership and dissemination roles of the CIS, considering them essential parts of NCI's mandate.

Stephen Stuyck, Vice President for Public Affairs at the University of Texas M. D. Anderson Cancer Center and long-time Principal Investigator of its CIS program, told me during a telephone interview that he believed NCI should have local or regional voices in the community.

*continued on page 22*



ERIC T. ROSENTHAL  
is OT's Special  
Correspondent.

"The CIS has always been more than a service program. Dissemination is the last step in the research process."

→ CIS

*continued from page 21*

“NCI was established to create knowledge, but it also has a responsibility to disseminate that new information. We have a lot of examples throughout the federal government of education and outreach programs on behalf of citizens in this country, and I don’t think that NCI should give this up and leave it for other organizations to do,” he said.

**Said a community partner to one CIS PI:**  
**“If we’ve made so much progress in health disparities, why would they [NCI] abandon us now?”**

“Cancer is enough of an issue and problem that we all need to be involved, especially since CIS offices around the country have already established complex partnership networks that have been built over many years and are based on trust.”

A CIS PI from another region said that when a partner learned of NCI’s plans to end the program, he asked, “If we’ve made so much progress in health disparities, why would they [NCI] abandon us now?”

**Semantics & Mixed Messages**

This raises another issue that seems somewhat familiar to a similar situation involving semantics and mixed messages to the public by the NCI a few years ago when the Institute was strongly considering cutting patient accrual in NCI-sponsored clinical trials cooperative groups by 10%—following years of a concerted awareness effort to inform the public about cancer clinical trials to increase accrual (*OT*, 3/25/07 and 6/25/07).

The edict to cut was eventually rescinded, but many of the trials and programs involved had already been scaled back or eliminated.

Sharon Davis, Program Director of the California CIS based at the Northern California Cancer Center, asked a number of questions that reflected those of others interviewed for this article.

Her office covers the entire state of California and has relationships with some 75 partners representing populations as diverse as American Samoans, Filipinos, Hispanics, Native Americans, African Americans, native Hawaiians, Pacific Islanders, various Asian communities, and rural whites.

Ms. Davis wanted to know why NCI made this decision behind closed doors within its Executive Committee instead of using one of its advisory boards like the Board of Scientific Advisors or the National Cancer Advisory Board. And why were there no minutes or a reported summary of the discussion to end the Partnership Program?

“And if NCI finally announced on its Web site that it wanted to look at the outreach and dissemination needs and activities, then why wouldn’t the Institute keep up the current programs until it’s done that analysis so there can be a transfer between

the new system and the current Partnership Program?”

“We’ve taken 30 years to build relationships with partners in the community and it takes a lot of time to build trust with these organizations, and for some of them cancer was not a priority, but we’ve worked with them so that now it is.”

**‘You Lose Trust with People’**

“You lose trust with people if you just say, ‘sorry this will end in 2010 but maybe NCI will come around with another program to help you out.’ And there really aren’t any answers from NCI about who will work with those partners after 2010. We’ve been asking the project office, and they seem to be scrambling around to find something to say but there’s really no real substance to it.”

During his meeting with the DCLG, Dr. Niederhuber said that the telephone service would be “downsized, since technology would allow us to do that from India. So that’s been downsized in terms of technology, and so we are continuing that, although I must admit personally I’m not so sure that’s [the best] expenditure of our resources at the moment.

“We also recognize that this program had really been around a long time and...it was a decision we made really looking at the data we had, and it wasn’t clear to us that we needed to be in this business long term,” Dr. Niederhuber continued. “It would be nice if we could evolve out of it and let others pick it up as resource. I think some of the other programs we have are also effectively picking up this area as well. The National Community Cancer Centers Program [NCCCCP] is another investment that seems a little more timely and capable and is now doing a similar type of job.”

NCCCCP has long been a pet project of Dr. Niederhuber, and received some criticism two years ago when this pilot project was devised without benefit of formal review by any NCI advisory groups.

NCI’s communications process of notifying the regional offices about its decision was less than transparent.

A number of those interviewed said they first began to think things might be changing following the reorganization of the Office of Cancer Communications earlier this year into the NCI Office of Communications and Education, under Ms. Johnson’s direction.

The three CIS programs were separated under different offices, and CIS formally disappeared from the NCI organizational chart.

Even though the Executive Committee met in August there still has been no formal contact made about the decision by the NCI with the principal investigators overseeing the 15 regional CIS offices.

I learned that word of the decision was delivered via a hastily convened teleconference on October 1 to the program’s regional project directors by Mary Anne Bright, Director of NCI’s CIS national program since 2002 and a member of its staff since 1989.

**Project Directors Were Stunned by the News**

The project directors were stunned by the news, and were informed that notices were posted that day on FedBizOpps.Gov, the NIH’s federal business opportunities Web site.

One, under the title CIS Partnership Program, announced “The NCI does not intend to solicit offers for continued partnership program tasks” [when the CIS contracts expire in January 2010]. The other two dealt with NCI’s Contact Center, noting that the current three contracts would be handled by a single contractor after January 2010.

On Oct. 29, NCI’s Office of Advocacy Relations (OAR) hosted a teleconference for advocates on “NCI’s Cancer Information Service: Reaching the Community with Evidence-Based Resources.” Among the speakers were Ms. Johnson and Ms. Bright.

**“The CIS is not ending. The decision has been made to not re-compete the current contracts for some of the CIS services...which will continue through the end of their contract period, January 2010. Conversely, the decision was made to re-compete some of the current services within the current contract, and those services do include the NCI contact services center—the 800 number.”**

OAR’s James Hadley helped open the discussion, saying that the great work of the CIS should be celebrated before explaining about the changes to the Partnership Program.

A little later Ms. Johnson said she wanted to “take a few moments just to briefly clarify some of the discussions.”

“First thing,” she said, “The CIS is not ending. The decision has been made to not re-compete the current contracts for some of the CIS services...which will continue through the end of their contract period, which is January 2010. Conversely, the decision was made to re-compete some of the current services within the current contract, and those services do include the NCI contact services center—the 800 number.

“NCI will continue to provide the host of information products that are disseminated through the Cancer Information Service,” she concluded, adding that further information would be discussed on the next teleconference, which is scheduled for December 2. ☐

**“NCI will continue to provide the host of information products that are disseminated through the Cancer Information Service.”**