



ADVOCACY INSIGHT

NCI's Office of Liaison Activities: Enlisting Consumers to Improve Science



By Eric T. Rosenthal

Eric Rosenthal has worked in the world of medical and cancer communications in a variety of capacities, including founding and chairing the NCI-designated Cancer Centers

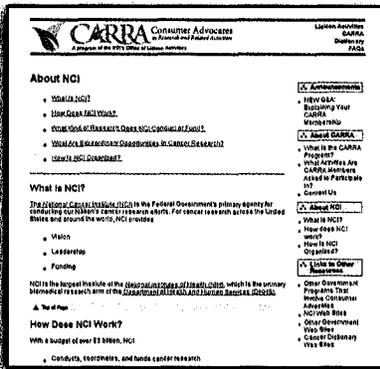
Public Affairs Network, serving as Senior Correspondent and News Features Editor for Vital Options/The Group Room; and organizing two national conferences about the media and medical/cancer communications issues.

The shift brought Liaison Activities back to where it was originally established in 1996 when Eleanor Nealon created the entity to help support NCI research and related programs by fostering strong communications and relationships with the cancer advocacy community, professional societies, scientific organizations, and federal agencies.

In many ways Ms. Nealon was the ideal person to take on the task. A consummate communicator and expert in cancer-

related information and programs who previously served in the number-two NCI cancer communications position, she was also a breast cancer survivor (who unfortunately ultimately succumbed to the disease the second time around).

Under Ms. Nealon's leadership, the Liaison Office helped pioneer the concept of integrating the consumer advocate's voice into the research process and subsequently served as a model for establishing other public liaison offices in each of the National Institutes of Health's various institutes and centers.



Nursing Society's Consumer Advisory Panel.)

Both Carolene and I found the experience rewarding and insightful, and it seemed the scientific members of the panel found our "consumer" perspectives to be of value in making decisions about which proposals should be submitted to the next level of review.

Asked for a comment for this article, Dr. von Eschenbach said he believes that "NCI has been very fortunate to have involved consumers in our activities over the years.

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NCI Director Andrew von Eschenbach, MD:
"NCI has been very fortunate to have involved consumers in our activities over the years. With the creation of the CARRA program, we now have a more effective pathway to systematically involve a number of experienced consumer advocates in the Institute's daily activities."

"CARRA members, for example, work directly alongside NCI scientists on peer-review panels, on site visits, reviewing educational materials, and in workshops. Their views help keep us focused on the core issues affecting cancer patients and

their families. Their work alongside us is vital to our common goal of eliminating the suffering and death caused by cancer by the year 2015."

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The inclusion of the consumer voice in cancer research got a hearty endorsement shortly after Andrew von Eschenbach, MD, started his tenure as the NCI's 12th Director in January 2002.

Dr. von Eschenbach relocated the office that handles advocacy relations—the Office of Liaison Activities (OLA)—from the Office of Cancer Communications to the Office of the Director under the oversight of Deputy Director Alan Rabson, MD.

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international family planning clinics.

The Bush administration had hoped to reach a compromise that would allow funding for organizations that offer abortions as well as HIV treatment and prevention as long as the programs were completely separated from each other and the money was accounted for.

But opponents say that this isn't good enough. Led by Sen. Sam Brownback (R-KS), they are insisting that more comprehensive language be written into the bill.

This could be a major stumbling block, because family-planning clinics care for so many pregnant women who are HIV positive. Also, in the 12 African nations plus Haiti and Guyana to which the funds are targeted, lack of money and resources force medical clinics to provide overlapping care.

Work is underway on a bipartisan bill that could win enough votes in Congress to pass. At press time, it was still far from completion. ■

The CARRA program has been so successful that NCI is now launching a promotional effort within the Institute to familiarize key NCI staff members about the specifics.

Two Main Programs

Through the years, Liaison Activities grew and took on additional responsibilities. Today, it has two primary programs: Consumer Advocates in Research and Related Activities or CARRA; and the Director's Consumer Liaison Group (DCLG), and also develops partnerships with cancer advocacy and voluntary groups and works with the leadership of professional societies and scientific organizations involved in

cancer research.

In 2000, when NCI introduced the CARRA program, Ms. Nealon's successor, Yvonne Andejeski, MD, was interviewed about the new venture on The Group Room radio show, for which I serve as news director. Dr. Andejeski was discussing the program that would bring more consumers into the NCI research process and in a follow-up conversation suggested that I apply as a CARRA member.

I submitted my application and was honored to be among the 220 selected as the first class of "consumer advocates" to start serving three-year terms. All CARRA members share the distinction of being a cancer survivor or patient; a family member or partner of a cancer survivor; or involved in cancer-related activities.

Most members are used to develop and review cancer education pamphlets, publications, or Web sites; serve on panels to evaluate the scientific merit of grant proposals submitted to the NCI for funding; or participate in meetings to represent cancer patients.

Surprise Assignment

I figured that with my background I would be asked to help as a "communications mentor," but my first assignment took me by surprise: I was asked to serve on a peer-review committee to evaluate international tobacco-control grants. I was one of two non-scientists to participate with full voting rights. (Small cancer world that it is, the other CARRA member, Carolene Marks, also served with me on the Oncology

