



National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

April 17, 2007

John E. Niederhuber, M.D.
Director, National Cancer Institute
31 Center Drive
Building 31, Room 11A48, MSC 2590
Bethesda, MD 20892-2590

Dear Dr. Niederhuber

On behalf of the members of the Director's Consumer Liaison Group, thank you for your time and for your participation at our March 29-30, 2007 meeting. We appreciated your Director's update, and your discussion of the priorities that you have asked the DCLG to consider.

The March meeting was devoted to learning more about the three priorities of: Minority Recruitment and Clinical Trials; Eliminating Cancer Health Disparities; and Cancer Care Delivery through the NCCCP Pilot. We heard presentations from NCI scientists on each of these areas. Here is a summary of recommendations we made as the outcome of this meeting:

Eliminating Cancer Health Disparities

The Centers to Reduce Cancer Health Disparities: Dr. Springfield presented information about the scope of the Center's programs. Members were particularly interested in the CURE (Continuing Umbrella Research Experiences) Program providing opportunities for influencing high school students to consider careers in biomedical sciences.

The NIH Centers for Population Health and Health Disparities: Dr. Tim Rebbeck presented the work of this trans-NIH effort to Reduce Cancer Health Disparities in 8 communities across the country. The Centers program will be reviewed by the BSA in June 2007. The DCLG members felt that they could support a program that has the goal of reducing health disparities including cancer health disparities. The DCLG members agreed to send a letter of support to the Division of Cancer Control and Population Sciences.

Cancer.gov en español:

The members agreed to give Ms. Nelvis Castro feedback on the website. They also agreed, as a first step, to promote the new website with their constituents. It is the DCLG's feeling that the website adequately addresses a gap between cancer information and the Spanish-speaking consumer audiences. We applauded NCI's addressing such a critical issue in communication with patients, family members, caregivers and survivors.

National Cancer Institute Community Cancer Clinic Pilot

DCLG Vice-Chair Dr. Beverly Laird and Dr. Maureen Johnson, Project Director for the NCCCP presented an update to the members on the progress of, planning for and selecting the community clinic sites and for evaluating the effectiveness of the pilot. The members agreed to give Dr. Laird their suggestions for good outcomes from the advocate/patient perspective for the NCCCP for the April 2007 meeting.

In addition to specific recommendations related to the charge, DCLG recognized key opportunities to provide input and recommendations for NCI/OLA activities that continue to support consumer involvement in NCI:

1. The *NCI Listens and Learns* Website Pilot: The Evaluation Report of the *NCI Listens and Learns Pilot* was presented and discussed. We agreed to recommend that the website continue with modifications. The *NCI Listens and Learns* Working Group will draft the specifics of the recommendations, which you will receive in a separate communication.
2. The Consumer Advocates Summit: The Summit Working Group concluded its work with this meeting, and recommends that the OLA and the NCI Director host a second Summit within the next 2-3 years.
3. The caBIG™: The DCLG member who is a liaison with the CARRA representative to caBIG™, has asked that the Enterprise Project continue the involvement of advocates, now that the demonstration phase of the project is over.
4. The CARRA Program: The DCLG members recommended that the NCI Director encourage all offices, centers and divisions to use CARRA members when they need advocacy participation in their programs.

We covered a range of topics at this meeting, but the goal is to consider your charge as an integrated effort on behalf of patients, survivors and advocates dealing with cancer. We look forward to our next meeting, and will be pleased to have a continuing dialogue with you about these efforts.

Sincerely,

Doug Ulman
Chair
NCI Director's Consumer Liaison Group

Dr. Beverly Laird
Vice Chair
NCI Director's Consumer Liaison Group