

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTITUTES OF HEALTH
NATIONAL CANCER INSTITUTE
26th MEETING
DIRECTOR'S CONSUMER LIAISON GROUP
TELECONFERENCE MEETING
June 28, 2004**

SUMMARY

The 26th meeting of the National Cancer Institute (NCI) Director's Consumer Liaison Group (DCLG) was convened as a teleconference. Mr. Hank Porterfield presided as Acting Chair.

Members Present:

Ms. Susan Butler
Ms. Kathy Giusti
Ms. Karen Packer
Mr. Henry Porterfield (Acting Chair)
Ms. Nyrvah Richard
Mr. Doug Ulman
Dr. Marisa Weiss

NCI Staff:

Ms. Elisabeth Handley
Dr. Edward Maibach

1. OPENING REMARKS

Ms. Elisabeth Handley explained that the purpose of this meeting was to discuss the progress on the "NCI Listens and Learns" website.

2. UPDATE ON THE NCI LISTENS AND LEARNS

Dr. Marisa Weiss explained that at its September 2003 face-to-face meeting, the DCLG was seeking a way to make a real difference in its ability to advise NCI Director Dr. Andrew von Eschenbach concerning the needs and interests of people affected by cancer. During the September meeting, Dr. Edward Maibach suggested that the DCLG help him address one of Dr. von Eschenbach's key priorities—establishing a dialogue with the cancer advocacy community.

The DCLG formed the Working Group to Facilitate Dialogue, chaired by Dr. Weiss. The group developed a Web-based platform to initiate a dialogue between NCI and the organizations representing people affected by cancer. NCI will post questions or issues on which it wants feedback from the advocacy community. Registered advocacy groups will then provide feedback on NCI's question on the site. NCI and the DCLG will summarize the feedback and post the summary provided by the advocacy community on the site. The summary will be passed on to the appropriate division(s) within NCI. Individuals who are not affiliated with a nonprofit

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organization (i.e. members of the public) will also be able to participate in discussions on the new website. Eventually, the DCLG will help organize a summit meeting for NCI and the cancer advocacy community, possibly in June 2005. This summit will likely focus on survivorship.

Mr. Porterfield thanked Dr. Weiss and her committee for all their hard work.

3. QUESTIONS AND ANSWERS

Ms. Handley explained that the National Cancer Advisory Board and the NCI Executive Committee have been briefed on the website. Dr. von Eschenbach is very supportive of having the DCLG play the role of honest broker on the site. Some concerns were raised about giving the impression that NCI will do everything that is suggested by dialogue participants. Dr. von Eschenbach promised to listen to the community's comments, but he may not always agree with them.

Dr. Maibach emphasized that Dr. von Eschenbach will be very involved in all dialogue topics, especially those that focus on areas of particular importance to the Institute, such as the redesign of the clinical trials process. Dr. von Eschenbach will be eager to see the community's feedback on this and other issues.

Dr. Weiss noted that most people affected by cancer are not part of cancer advocacy organizations, so a communications plan is being developed to reach out to these individuals. Ms. Handley offered to share the plan developed by the Office of Communications with the DCLG members.

Dr. Maibach explained that NIH has formed the Public Trust Initiative to ensure that all Institutes and Centers act in ways that enhance the public's trust in NIH. This website can become an important element of NIH's effort and will be brought to Dr. Elias Zerhouni as an example of NCI's attempts to increase public trust. NIH will scrutinize this project closely for its value to NIH as a whole.

Mr. Porterfield suggested that NCI explain on the website why it chooses to act on some of the suggestions it receives and not others. This will prevent community members from complaining that NCI does not respond to their comments. Dr. Maibach said that NCI will explain what it plans to do on the basis of the community's comments.

Dr. Maibach noted that NCI program managers who are not ready to solicit community input will not be required to do so. This will ensure that all materials on the website come from NCI program managers who are prepared to listen to and act on community feedback.

Ms. Handley explained that the 150 organizations surveyed by the Future of the DCLG Working Group will be the first groups invited to participate in the website but the hope is that more organizations will join them. A single individual from each organization will be designated as the spokesperson for that organization, so that each group has a single voice. Individual members of the public will also be invited to register for the site.

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Dr. Weiss explained that the website will post guidelines on acceptable behavior to ensure that all of the dialogue is respectful.

4. NEXT STEPS ON WEBSITE

Dr. Weiss pointed out that the DCLG will need to participate in and manage the dialogue, help summarize the results, and ensure that the results are passed on to the appropriate NCI Division or Center. This will require a great deal of coordination among the DCLG, the Office of Liaison Activities (OLA), and Dr. Maibach.

Ms. Handley explained that the website will be tested in July first with Specialized Program of Research Excellence (SPORE) advocates at a meeting in Baltimore to obtain their reactions and suggestions. A newer version will be reviewed and tested in August by breastcancer.org and all Consumer Advocates in Research and Related Activities (CARRA) members. The site will probably be launched in October.

Mr. Doug Ulman noted that the DCLG is working to develop good relationships with Center directors who view this site as a viable source of feedback. He asked all DCLG members to submit additional feedback or questions.

Ms. Handley invited the departing DCLG members to attend the DCLG's next face-to-face meeting on September 13-15. Dr. von Eschenbach would like to recognize the departing members for their contributions. Ms. Handley also thanked Dr. Weiss and the committee for all their work in bringing the website to its current status. Finally, Ms. Handley invited each DCLG member and the organization he or she represents to be the first to join the new website.

Date

Acting Chair, Director's Consumer Liaison
Group

Date

Executive Secretary
Director's Consumer Liaison Group

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DCLG ACTION ITEMS

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- Ms. Handley will distribute the promotion plan to DCLG members.
- DCLG members will submit additional feedback or questions on the new website to OLA.
- OLA will invite all DCLG members and their organizations to be the first to join the new Web site.