

**71st Meeting of the National Cancer Institute (NCI)
NCI Council of Research Advocates (NCRA)
National Institutes of Health (NIH)**

**Webinar and Teleconference
Building 31, Conference Room 10A03
NIH Campus
Bethesda, Maryland**

Monday, August 22, 2016

The NCI Council of Research Advocates (NCRA) convened for its 71st meeting on 22 August 2016. NCRA members attended virtually, and National Cancer Institute (NCI) staff attended in Conference Room 10A03, National Institutes of Health (NIH), Bethesda, Maryland, or virtually. The meeting was open to the public. NCRA Chair, Mr. David Arons, and Ms. Amy Williams, NCRA Executive Secretary, and Director, NCI Office of Advocacy Relations (OAR), presided.

Members Present

Mr. David Arons, Chair
Dr. Gregory Aune
Ms. Mary Ann Battles
Dr. Sue Friedman

Ms. Shelley Fuld Nasso
Ms. Martha Gaines
Dr. June McKoy
Ms. Heather Ortner

Speakers

Mr. David Arons, Chair, NCRA; Chief Executive Officer, National Brain Tumor Society
Ms. Amy Williams, Director, NCI OAR; Executive Secretary, NCRA

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Welcome and Opening Remarks

Mr. Arons, Ms. Williams

Ms. Williams welcomed the attendees and explained that the meeting was designed to provide an update to NCRA regarding the progress and status of the Vice President's National Cancer (Moonshot) Initiative, particularly the development of the scientific recommendations. For the benefit of those less familiar with NCRA, Ms. Williams explained that NCRA is a federal advisory committee to NCI that focuses on matters that facilitate research, and is composed of advocate leaders.

Ms. Williams reviewed meeting logistics and explained that questions would be solicited via the webinar platform's chat feature. Participants were also invited to send their questions/comments to nciadvocacy@nih.gov. Ms. Williams then introduced Mr. Arons.

Mr. Arons welcomed NCRA members and guests. Mr. Arons explained that a great deal of work has been done since NCRA last met in April and that this meeting was designed to provide members with an update on the work in order to set the stage for the September 26, 2016, face-to-face NCRA meeting, during which specific recommendations endorsed by the Blue Ribbon Panel (BRP) will be discussed. During the meeting, NCRA will also have a chance to hear about advocate experiences from BRP Working Group members and will learn more about the timeline for finalizing and disseminating the Blue Ribbon Panel's report. Mr. Arons also committed to taking time for questions and comments during the meeting.

Cancer Moonshot Recap and Blue Ribbon Panel Work to Date

Mr. Arons

Mr. Arons reviewed the overall goals of the Cancer Moonshot:

- Accelerate progress toward a cure for cancer, including prevention and screening;
- Encourage greater cooperation and collaboration; and
- Enhance data sharing.

Mr. Arons specifically stressed the importance of data sharing. He also reviewed the remit of the Cancer Moonshot Task Force, a federal task force composed of federal agency leaders and led by Greg Simon. The task force is charged with producing a detailed set of findings and recommendations to further the Cancer Moonshot. The scientific agenda of the Cancer Moonshot was delegated to a new BRP working under the auspices of the National Cancer Advisory Board (NCAB). In turn, seven BRP working groups were formed to facilitate the panel's work. Mr. Arons reviewed the working groups: Expanding Clinical Trials, Enhanced Data Sharing, Cancer Immunology and Prevention, Implementation Sciences, Pediatric Cancer, Precision Prevention and Early Detection, and Tumor Evolution and Progression.

Mr. Arons explained that each working group was composed of 12 to 20 researchers, patient advocates, and nonprofit and private-sector representatives with expertise in each topic area. The groups were charged with generating two to three recommendations on major scientific opportunities that are poised for acceleration. Each working group was co-chaired by experts in their fields and held weekly meetings throughout the summer. Each working group considered, among other things, the hundreds of ideas submitted through the Cancer Research Platform from researchers, scientists, philanthropists, advocates, students, data scientists, members of the public, and anyone with a scientific idea or suggestion for addressing cancer research challenges. The Cancer Research Platform

went live this spring and served as a vehicle for the public to share scientific ideas for bringing about a decade's worth of advances in five years, making more therapies available to more patients and spurring progress in cancer prevention, treatment, and care.

Each working group was challenged to identify opportunities that were truly transformative and had the potential to accelerate the progress of cancer research. In the process, the working groups discussed a number of cross-cutting themes, some of which were shared with NCAB at their June 2016 meeting. These themes included prevention; quality-of-life and survivorship issues; the need for new data sharing platforms, analytics, and predictive computational modeling; and the opportunity to advance collaboration through public-private partnerships.

In addition to looking at the science, each working group was asked to identify policy and implementation challenges associated with its recommendations. While the BRP was not charged with identifying or endorsing specific policy solutions, it is important to recognize that policy directly influences the environment in which cancer research is done. Some of the initial issues identified highlighted at the June 2016 NCAB meeting included matters associated with coverage and reimbursement, privacy issues and other barriers to data sharing, and the need for greater coordination across the patient care continuum. Mr. Arons invited participants who have not already done so to listen to the June 23 NCAB meeting. Meeting materials and recordings are available online (<http://deainfo.nci.nih.gov/advisory/joint/0615/index.htm>). The information will provide useful context for the September meeting. OAR staff are also happy to provide assistance accessing the NCAB meeting materials.

Mr. Arons said that the working groups have now concluded their deliberations for the purposes of the BRP report and have submitted their recommendations. The recommendations are being fine-tuned and prepared for presentation to NCAB and for submission to the Cancer Moonshot Task Force in early September. NCRA will have the chance to discuss the recommendations in detail in September. While the recommendations are not yet public, Mr. Arons referred to a couple of recommendations that generated a lot of enthusiasm from the BRP, including developing new ways to make it easier for patients to find and participate in clinical trials (e.g., a national registry of patients with cancer who are interested in volunteering for clinical trials); targeted and improved uptake of proven prevention strategies for three highly preventable forms of cancer (cervical, colorectal, and lung); and implementing genetic testing on a wider scale in family members of people with Lynch syndrome and other inherited cancer-associated mutations. These specific recommendations were highlighted in NCI Acting Director Dr. Lowy's June 23, 2016, *Cancer Currents* blog post.

Reflections on Advocate Involvement: Blue Ribbon Panel and Working Groups

Mr. Arons, Ms. Fuld Nasso

Mr. Arons shared his perspective as both a member of the BRP and a member of the Expanding Clinical Trials Working Group. He noted that the working group was impressive in its ability to put aside personal perspectives and priorities and to consistently focus on matters that advance the whole cancer research enterprise. The group is truly focused on identifying transformative projects that could "lift all boats." He appreciated the inclusivity of the deliberations and explained that the scientific experts with whom he had a chance to work were committed to creating time and space to discuss issues most important to patient advocates and to ensuring the patient perspectives were heard.

Ms. Fuld Nasso was asked to share her experience as a member of the Implementation Sciences Working Group. She noted that it was a time challenge, given the focus on "shovel ready" scientific

projects, but said that the working group was inclusive and took care to ensure discussions included a focus on quality-of-life issues for patients, both during and after treatment. She appreciated the group's commitment to identifying projects that, if funded, have the potential to quickly and positively affect the quality of patients' lives.

Next Steps: NCI and the Cancer Moonshot

Ms. Williams

Ms. Williams commended the entire cancer research community for its active engagement in the Cancer Moonshot to date. The culmination of this effort will be a report to NCAB in early September. The report will include the most promising opportunities that, given additional funding and focus under the Cancer Moonshot, are poised to produce significant progress within a short period of time (a decade's progress in five years).

While the Cancer Moonshot is broad in scope, NCI was specifically charged with convening the cancer research community for the purpose of developing the scientific agenda. In that regard, community engagement has been unprecedented. Ms. Williams reinforced the importance of the policy issues identified by the BRP working groups. While solving policy challenges was not the core focus of the working groups, those issues are within the scope of the Cancer Moonshot Task Force.

As previously mentioned, the BRP report will be presented to NCAB in September, before going to the Cancer Moonshot Task Force. As soon as the report is public, it will be shared, along with any commentary and supporting materials, with NCRA members. NCAB will likely continue its scientific discussion of the BRP recommendations in December. Because NCI does not yet have a defined budget for fiscal year (FY) 2017 or beyond, NCAB will likely continue discussing partnerships and other ideas for implementation beginning in December and into 2017.

In summary, Ms. Williams reiterated that the BRP recommendations reflect significant community input. There will be more opportunities for engagement ahead, including the September NRCA meeting.

Next Steps: Comments and Questions

Ms. Williams

Ms. Williams invited NCRA members to share what they are hearing from their communities or in the course of their day-to-day work lives about the Cancer Moonshot. Their feedback will help to identify the types of issues and opportunities that should be discussed at the September meeting. Ms. Williams invited comments via the webinar chat tool and OAR email box, but no comments were submitted.

Ms. Williams then invited all participants, not just NCRA members, to ask questions or to comment. Dr. Aune asked whether the BRP report would include funding recommendations directed at specific cancers, such as pediatric cancers. Ms. Williams explained that the budget is currently in flux. While there will be funding directed at specific BRP recommendations, the exact amounts have not yet been determined and will not be detailed in the upcoming report.

Ms. Williams then opened the floor to questions from the phone. No questions were received.

Closing Comments and Wrap-Up

Mr. Arons, Ms. Williams

Mr. Arons thanked the participants for their time and said he hopes for a lively discussion of the BRP recommendations with NCRA in September. While not every recommendation will be groundbreaking, the recommendations have the collective potential to transform cancer research and make a meaningful difference to cancer patients, if implemented appropriately and with the right funding. NCRA has the opportunity to provide educated and informed advice to NCI relative to implementing and operationalizing the recommendations based on its unique position in the community. NCRA can also ensure patient advocates continue to have opportunities to engage in the research and that the patient perspective is infused into the research that results from the Cancer Moonshot.

Ms. Williams thanked participants for their time and adjourned the meeting.

Certification

I hereby certify that foregoing minutes are accurate and complete.

Date

David Arons, Chair
NCI Council of Research Advocates

Date

Amy Williams, Executive Secretary