



National Institutes of Health  
National Cancer Institute  
Bethesda, Maryland 20892

April 28, 2006

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

Dear Dr. Niederhuber:

*John*

The NCI's Director's Consumer Liaison Group (DCLG), an important link between the NCI Director and the patient-survivor community, is gravely concerned about the current debate around funding and future direction for the Specialized Programs of Research Excellence (SPOREs). Before Dr. von Eschenbach publicized his intention to resign as Director of the NCI, he announced a planned reduction in SPORE funding and changes in funding procedures. The SPOREs, which account for less than 3% of the overall NCI budget, are unique in that they are currently the only formal NCI disease-specific research programs. These programs have made such discoveries as seminal molecular pathways, and are applying these findings directly to cancer treatments. SPORE, as a program that accounts for meaningful patient-oriented results, needs to be maintained so that disease-specific, patient-oriented research is not put in jeopardy.

At the April 6 hearing on the NIH budget held by the U.S. House of Representatives, Committee on Appropriations, Subcommittee on Labor, HHS/Education and Related Agencies, you confirmed your support for the SPOREs by stating that "I am not shifting any money out of the program; I am going to do my best to put more money into the program." We are encouraged by your verbal commitment to continue the important work of the SPOREs. On behalf of our joint constituents—the cancer advocacy community, and all cancer survivors and family members—the DCLG would like to outline its primary concerns both for the record and for your use in maintaining, and possibly increasing, funding for the SPORE.

SPOREs foster organ-specific translational research targeted for delivery to the patient within five years, promoting research team movement within the bench to bedside pipeline that can provide practical gains for patients during the research process. Proposed changes to SPORE funding procedures may damage, perhaps irreparably, the pipeline that moves discoveries from basic bench

The perception is that the reviews do not:

- provide clear scoring criteria for unique scientific discoveries and developments
- create objective approaches to globally score each grant
- clearly state how portfolios for different diseases will be balanced
- include enough peer reviewers (e.g., those experienced in performing translational research)

Recent NCI key initiatives, such as the Alliance for Nanotechnology in Cancer, The Cancer Biomedical Informatics Grid, and The Cancer Genome Atlas, reflect a trend away from the high priority given to organ-specific programs. Additionally, non-organ-specific research moves the momentum away from the ultimate endpoint—the patient. Although these new initiatives are exciting, in reality, they are years away from having an actual impact on patients' lives, and the return on investment from the patient-survivor perspective is far less than that which can be realized by maintaining and/or increasing SPORE funding.

Via this letter, the DCLG requests clarification on the NCI's plans for SPOREs. In addition to other information on which we have not been consulted or advised, we request answers to the following specific questions:

1. Will SPORE funding be protected as is, or increased? If increased, by what amount?
2. What level of funding for organ-specific translational research can we expect?
3. What does the NCI propose to do about systems changes to make peer review a fairer process that ensures that the best science will be funded?
4. How can the DCLG support your efforts to retain and increase SPORE funding and to prevent a shift in funding procedures?

The DCLG recommends no cuts in SPORE funding and cannot support cuts. We look forward to a written response to these questions by no later than May 15, 2006.

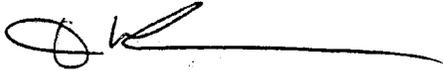
Finally, an urgent need exists for the DCLG to have clearer, more substantial input in developing NCI strategies and priorities. Among other concerns, the members believe the issuance of important announcements such as those regarding the SPOREs without prior consultation with or notification to the DCLG was a significant oversight. The failure to invite DCLG participation in such deliberations leaves the group with little purpose and function. Additionally the credibility of individual members and the group is greatly diminished with our patient advocate communities and legislative contacts that have supported NCI and who have enormous, collective capabilities to influence funding decisions on the Hill.

Page 4 - John E. Niederhuber, M.D.

We request a meeting with you at the next DCLG meeting on October 25-26, 2006 where we will be able to discuss the purpose, value and function of the DCLG as well as other issues of mutual interest to both advocates and the leadership of the NCI. We expect and look forward to the opportunity to participate actively and productively as the liaison between the NCI Director's office and the advocacy and patient-survivor community. Our constituents expect and deserve nothing less.

Again, thank you for your commitment to the SPOREs. We look forward to receiving your response to our specific questions, and to meeting with you in October.

Respectfully,



Doug Ulman,  
Chair  
Director's Consumer Liaison Group

*I look forward  
to speaking with you*

research to new methods of early prevention, detection, treatment, and palliative care.

These proposed changes include:

- A reduction of guaranteed research funding from five to three years
- Elimination of bridge funding if a grant is not renewed immediately
- Prohibition against grant reapplications during the next cycle of funding
- Reduction in overall SPORE numbers

Diminished support and sporadic rule changes may jeopardize the delicate balance between basic and applied research that SPOREs nurture, and will threaten key collaborations on research that is on the verge of helping cancer patients *today*. We are pleased that you support the DCLG's position that these changes are unacceptable from the perspective of patients and survivors.

A reduction in short term funding will discourage researchers from applying for SPORE grants, and a prohibition against immediate grant reapplication may result in the loss of vital tissue banks, as well as the disruption of biomarker studies and clinical trials. Research teams could be disbanded and patients may be left with less viable options.

These significant changes could, in fact, be perceived as a waste of taxpayer investment, especially at a time when many SPORE projects are poised for a return on that investment. Any one of these changes would cause concern. Together, they destroy the very foundation of this key translational research program—an action that runs counter to the NCI 2015 Goal of eliminating the suffering and death caused by cancer.

The Translational Research Working Group (TRWG) recently established to address concerns about translational research in general and the SPORE program specifically, is on the record stating that it will be at least five years before it can devise, recommend, and implement an alternative to the current translational research program. Even if the TRWG's new program structure is an improvement, a two-year gap exists between the current three-year funded SPOREs and this new program. This gap in continuity may destroy the infrastructure of SPORES at a critical point when their work is translating to patient care.

It is our hope that the TRWG will immediately address some of the systemic changes that are needed in the SPORE peer review process. Specifically, some DCLG constituents report disturbing trends in the SPORE peer review process.