A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS ADDRESSING PUBLIC POLICY ISSUES IN CANCER

February 7, 2000

Richard Klausner, M.D. Director, National Cancer Institute 31 Center Drive - MSC 2590 Bldg. 31 - Room 11-A-48 Bethesda, Maryland 20892-2590

Dear Dr. Klausner:

As organizations committed to securing ample federal funding for cancer research, we are frequently asked to review and support the recommendations of the "professional judgment" budget of the National Cancer Institute (NCI) or others urging increased funding for NCI or the National Institutes of Health generally. The budget for NCI has no more faithful supporters than the undersigned groups. However, we want our advocacy of the By-Pass Budget to be well informed and integral to our respective missions of advancing all aspects of cancer research, including cancer control, prevention, and treatment. More specifically, our support for your research recommendations will be facilitated greatly if we have been active participants in the development of those recommendations.

We are pleased to know of prospective enhancements to the current process for receiving input into the By-Pass Budget from the private sector. Under your leadership, we have confidence that you will find ways to be as inclusive as possible in order to manage this input. To assure the best result, we would like to make the following suggestions for your consideration as this planning process takes shape:

- Open up the process at an early phase by actively soliciting the views of interested parties at the outset i.e., as recommendations are being developed within your channels.
- Include meaningful representation from these outside interests the patient advocacy community, basic and clinical researchers, and academic health centers in the budget planning process within NCI.
- Provide an opportunity for public discussion of the rationale for recommendations included in NCI's final proposed budget submitted to the White House, and also for those suggested by interested parties but excluded from the budget after due consideration by NCI and its internal advisers.

It is because of your dynamic leadership in bringing diverse parties together around complex issues that we have confidence in your ability to recast the process for having input into the planning and budget process of the NCI. When the process is made even more inclusive and transparent, the advocacy of the cancer community for NCI funding increases will be strengthened.

We welcome the opportunity to meet with you to discuss ways in which reform of the budget process can become reality during your tenure.

Richard Klausner February 7, 2000 Page 2

The undersigned groups meet on a monthly basis to discuss issues related to assuring that high quality research is applied across all populations in a timely fashion. We would like very much for you to consider this letter an invitation to meet with us at our March 14 meeting. We believe additional dialogue will ensure that the positive interface you have created with members of our community will continue in the years to come.

Thank you and we look forward to hearing from you.

Sincerely,

Cancer Leadership Council

Alliance for Lung Cancer Advocacy, Support and Education American Society of Clinical Oncology Cancer Care, Inc. Cancer Research Foundation of America Cure For Lymphoma Foundation Kidney Cancer Association Leukemia Society of America, Inc. National Coalition for Cancer Survivorship National Patient Advocate Foundation North American Brain Tumor Coalition **Oncology Nursing Society** Ovarian Cancer National Alliance Susan G. Komen Breast Cancer Foundation US-TOO International, Inc. Y-ME National Breast Cancer Organization

Contact for CLC:

Ellen Stovall, Director National Coalition for Cancer Survivorship 1010 Wayne Avenue - Fifth Floor Silver Spring, Maryland 20910

Phone: 301/650-9127

Fax: 301/565-9670Contact for CLC: