

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

January 21, 2005

Via Telecopy and Regular Mail

William T. McGivney, Ph.D. Chief Executive Officer National Comprehensive Cancer Network 500 Old York Road – Suite 250 Jenkintown, Pennsylvania 19046

Dear Dr. McGivney:

The Cancer Leadership Council (CLC) and the individual undersigned organizations share with the National Comprehensive Cancer Network (NCCN) the goal of quality cancer care, and we commend NCCN for its leading role in developing guidelines that help to achieve that goal. We are writing to support the recent petition from Fertile Hope encouraging NCCN to develop guidelines for disclosure of risks in connection with potential infertility from cancer treatment, as well as for discussion of the options available to help preserve fertility in patients undergoing treatment. Fertile Hope is a member of the CLC and has briefed the CLC membership on the request to NCCN.

Many oncologists understandably focus on their efforts to eradicate cancer in their patients while failing to discuss sufficiently the impact, particularly in younger patients, on the ability to have children following treatment. Since there are now options for preserving fertility in such patients, it would seem appropriate for discussion of risks and options to be a standard feature of physician-patient communication. To the extent that oncologists do not routinely raise these matters with their patients, an NCCN guideline would certainly help to correct that failure.

We urge NCCN to look favorably upon the Fertile Hope request and to undertake development of a fertility preservation guideline. Thank you for your consideration of this matter, which is of great importance to many people with cancer.

Sincerely,

Cancer Leadership Council

American Cancer Society
American Psychosocial Oncology Society
Cancer Care, Inc.
Cancer Research and Prevention Foundation
Coalition of National Cancer Cooperative
Groups
Fertile Hope
International Myeloma Foundation
Kidney Cancer Association
Lance Armstrong Foundation
Lymphoma Research Foundation

Multiple Myeloma Research Foundation
National Coalition for Cancer Survivorship
North American Brain Tumor Coalition
Ovarian Cancer National Alliance
Pancreatic Cancer Action Network
Sarcoma Foundation of America
The Susan G. Komen Breast Cancer Foundation
Us Too International Prostate Cancer Education
and Support Network
The Wellness Community
Y-ME National Breast Cancer Organization