

STATEMENT OF THE CANDLELIGHTERS BEFORE THE SUBCOMMITTEE
ON LABOR, HEALTH, EDUCATION AND WELFARE

SENATE COMMITTEE ON APPROPRIATIONS
FEBRUARY 1978

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco, National Liaison Chairperson of CANDLELIGHTERS, an organization of parents in 40 States whose children are under treatment for cancer, have died from cancer or have survived their experience with cancer.

As we have indicated in previous appearances before this Committee, we feel that we are in a good position to inform the Committee on the effect and results of the funding efforts on the consumer level. As in the past, we wish to bring to your attention those areas which we feel merit further attention or where increased funding levels or new funding is required.

Before entering into a discussion of the various aspects, I would be remiss if I did not extend on behalf of all of us our deep gratitude and appreciation to you, Mr. Chairman, and the Members of this Committee for the efforts on behalf of the afflicted and, in particular, for the unflagging interest which this Committee has shown towards cancer research and treatment. We know that the lives of our children have been extended and, in some cases, preserved through cancer research efforts which this Committee allocated to the various elements of the National Cancer Institute and in conjunction with some private sources. We know, as I am sure you do, the importance of building on the great progress already made in this field so that the aspirations contained in the National Cancer Act may be realized.

Since our children's lives and the lives of future cancer victims depend upon cancer research progress, and the translation of the results of this progress into improved methods of diagnosis, treatment and rehabilitation, we have made it our business to become informed about the various facets of the various different programs so that we might be in a position to inform you.

The \$878.8 million for fiscal 1979 requested by President Carter is only .7% more than the 1978 fiscal year appropriation. Considering inflationary factors, the Institute requires an additional \$50 million just to stay even. At this status quo figure less than 30% of the affirmed priority one grant applications would be funded.

For this reason, CANDLELIGHTERS requests an additional \$62 million for National Cancer Institute for fiscal 1979 and asks for specific line item treatment for the following programs:

SUMMARY OF SPECIFIC REQUESTS

CANCER CONTROL \$1.7 million for an expansion of the prototype demonstration clinical chemotherapy programs in cancer control (leukemia, lymphoma networks) and for the initiation of additional demonstration programs pertaining to the management of adolescent cancer patients.

CANCER COMMUNICATIONS \$1.5 million for an expansion of the clearinghouse and information dissemination programs of the Office of Cancer Communications.

NIH CLINICAL CENTER \$500,000 to the Division of Pediatric Oncology to provide additional program supports, with particular emphasis on its study of long term survivors and the psychological and neurological complications of such survivors.

NUTRITION \$9.5 million for the Diet, Nutrition and Cancer Program.

REASONS FOR SPECIFIC REQUESTS

Epidemiologic evidence continues to reinforce the observation that perhaps 60% of all cancer in women and over 40% of cancers in men may be related to diet and nutrition. Also, scientific evidence, as well as common sense indicates that nutritional support of cancer patients would increase their ability to withstand the rigors of aggressive therapy, perhaps the chance for better survival, and certainly their quality of life.

At the request of CANDLELIGHTERS, the Diet, Nutrition and Cancer Program (DNCP) of the National Cancer Institute was mandated by Congress in 1974; at that time amendments were introduced to Sec. 407(b)(4) of the National Cancer Act of 1971 which now authorizes the National Cancer Program to:

"collect, analyze, and disseminate information (including information respecting nutrition programs for cancer patients and the relationship between nutrition and cancer) useful in the prevention, diagnosis, and treatment of cancer..."

Appropriations for 1975 contained a \$6million item earmarked for various newly mandated activities including nutrition. Because specific program priorities could not be developed in time, it was not possible to utilize any of these monies for diet, nutrition, and cancer research.

The funds assigned to the DNCP during 12 months of 1976 were less than \$4 million, and the National Cancer Institute projections, as of late 1976, for DNCP funding during 1977 were less than \$3.5 million.

For Fiscal Year 1977, Congressional appropriation conferees suggested a funding level of \$7.5 million, but the DNCP still received less than \$3.5 million, and is scheduled by current projections of the National Cancer Institute to receive approximately the same amount during 1978, this is less than 1/2 of 1% of the NCI budget. Clearly a line item for nutrition is required to assure that the program will receive the funds which this Committee has supported for the program. The program could utilize up to \$15 million effectively, but given the limited amount of funds available this year, CANDLELIGHTERS requests a specific line item of \$9.5 million and 3 additional positions. The programs of DNCP clearly deserve such funding.

Up to the end of 1977, 31 projects have been initiated and a range of educational and informational documents has been developed. The program has established itself with the medical and scientific communities. This has been done with the funding and staffing that fall short of recommendations and requests, and that are very low in relation to the importance of nutrition in cancer prevention and treatment, and of the expected cost-effectiveness of nutrition research.

The DNCP informally coordinates its research activities with NIH programs as well as other government agencies. During 1976 and 1977, the NIH Nutrition Coordinating Committee (NCC) emerged as a trans-NIH entity for overall coordination of nutrition activities. It is likely that the NCC will develop an operational coordinating function during the next few years. At that time, the activities of the Diet, Nutrition and Cancer Program will be integrated in an overall set of NIH priorities in nutrition.

Some of the projects completed are nutritional handbooks for both adult and pediatric cancer patients, Review and Analysis of Categorical Citation Information Relevant to the DNCP; Literature Study on Indicators of Health and Nutritional Status with Emphasis on Primitive Populations; Literature Study on Primitive Populations in Relation to Diet; Literature Study to Evaluate Health Parameters in Various Human Populations in Relation to Diet.

Some ongoing projects include: Identification of Past, Ongoing, and Future Dietary and Nutritional Surveys and Cancer Epidemiology Studies; Development of a Guidebook for Inclusion of Dietary and Anthropometric Parameters in Cancer Epidemiology Studies; Survey of Dietetic Practices and Procedures Used in Feeding Cancer Patients; Evaluation of the Role of Learned Food Aversion in the Cancer Patient; Gustatory (Taste) Evaluation of Cancer Patients; Anorexia in Adult and Pediatric Cancer Patients;

Optimal Nutritional Support as an Adjunct to Cancer Therapy in the Pediatric Patient; Studies of Differential Nutritional Requirements by Host and Tumor as the Basis for Dietary Treatment of Cancer (Brain Tumors); Optimal Nutritional Support as an Adjunct to Cancer Therapy in the Adult; Environmental Stress and Tumorigenesis; Nutritive Quality of Dietary Fiber for Humans; Dietary Components and Cancer Development; Effect of Nutritional and Environmental Stress on Carcinogenesis; Effect of Nutritional Stress on Carcinogenesis.

Some of the New Programs include: Dietary Patterns, Nutritional Assessment, and Cancer Incidence of American Vegetarians; Quantification of Changes in Body Composition in Cancer Patients and Evaluation of Pharmacologic Agents for the Treatment of Anorexia in the Cancer Patient.

These programs speak from a scientific basis to the questions which American Public asks on the relationship of diet and nutrition to the cause, prevention and treatment of cancer. They deserve to be adequately funded.

CANCER CONTROL IN RELATION TO PEDIATRIC PATIENTS

Children with leukemia, lymphoma and Hodgkins can now be treated adequately in a community hospital setting. Demonstration outreach programs to community hospitals and pediatric oncologists treating children with leukemia and lymphoma funded by the Division of Cancer Control and Rehabilitation centering around Children's Hospital, Los Angeles; Children's Hospital, Cincinnati; Children's Hospital, Denver; Dartmouth Medical School; University of Alabama; New York Hospital- Cornell and Mount Sinai School of Medicine, have clearly established that using a Children's Hospital as the outreach center 84% of these children will probably attain a five year survival figure. The successes of this program provide the reason for funding demonstration programs for other geographic areas.

Further, the problems related to the management (rehabilitation research) of adolescent cancer patients are different from those of pediatric patients. Until recently, very little attention has been apid to the most effective ways of managing these patients. DCCR has thus far initiated a single program in this area. It is our request that additional funds be made available so that this program may be expanded to include a variety of geographic areas and treatment settings.

NIH CLINICAL CENTER We request that the support for the Pediatric oncology division of the Center be increased by at least \$500,000. This division serves as a prototype and demonstration unit for innovative cancer research and its application. The additional

funds requested will enable it to perform this role more effectively. We specifically direct the Committees attention to the programs initiated at the Center in the evaluation of physiological and neurological problems in long term survivors of pediatric cancers and its interest in the refinement of the existing protocols for the treatment of leukemia to reduce the toxicity which may cause these problems.

CANCER COMMUNICATIONS The Office of Cancer Communications has initiated a variety of programs including a clearinghouse and Cancer Information Services through the Centers to implement this the mandate of the 1974 Act to devise means to interpret and disseminate new and existing knowledge and information produced by the cancer program to researchers, practicing physicians and the general public. The demands on this office by the scientific and lay public are great. CANDLELIGHTERS can attest to the value of the information services provided and their usefulness to parents and front line physicians. They are indeed bridging the information gap. We request an additional 6 jobs slots and \$1.5 million over the level in the NCI budget for this program. Part of this information dissemination process, they have ready to go to press 24 new pamphlets for cancer patients dealing with specific cancers. 1977 alone printing costs for patient and physician related programs amounting to over \$1 million. This demonstrates the need for an additional \$1.5 million.

Mr. Chairman, Members of the Committee, on behalf of all these parents across the country, I should like to again commend the Chairman and the members of this Committee for their many efforts and their understanding of our problems. Your dedication to the cause, the cure and the prevention of cancer encourages us to face the future with a greater degree of hope and peace of mind. Those of us who have lost our children are grateful that your efforts to adequately fund the cancer research will be a memorial to them. And, those of us whose children are under treatment are grateful for the hope which research gives us in maintaining their well-being.

We gratefully acknowledge the part this Committee has played in this effort to conquer this dreaded disease. Thank you for permitting us to appear before you.