STATEMENT OF THE CANDLELIGHTERS
BEFORE THE SUBCOMMITTEE ON
LABOR,HEALTH, EDUCATION AND WELFARE
OF THE COMMITTEE ON APPROPRIATIONS
U.S. HOUSE OF REPRESENTATIVES
APRIL 17, 1980

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco, I am representing CANDLELIGHTERS an international volunteer coalition of families of children affected by cancer in 48 States, Canada, Australia and Europe. We wish to bring to you attention those areas in which the National Cancer Institute's efforts have had the most notalbe impact on our children's lives and those which we feel merit your further attention through program redirection or emphasis through the appropriation process.

Let me first extend on behalf of all of us, our deepest gratitude and apprecation to you, Mr. Chairman, and the members of this committee for your continuing efforts on behalf of all person afflicted with cancer. Your unflaging interest in cancer research and the translation of this research into tangible programs for the detection, treatment and rehabilitation of cancer patients throughout the country has widened the benefits of the whole cancer effort. We know that the lives of 6100 children a year affected by cancer have been and are continually being extended, and in a growing number of cases preserved, through the cancer research efforts and their clinical application which this Committee has supported through the National Cancer Institute.

Consensus Development

As the good news in the treatment of the leukemias grows more and more parents and front line physicians express concerns about whether it can be treated in the community, whether ties to a research facility program by community physician is needed to insure optimal treatment success. It is time to answer those questions and provide guidelines for treatment through the National Institute of Health consensus development process where care is possible, mere longer survival is not acceptable. Consensus will show the medical and parent communities where we are and what we can expect. It is needed now in acute lymphocytic leukemia (80% of children with null cell disease can be cured), Wilms tumor (90% can be cured), Rhabdomyosarcoma and Ewings sarcoma (60-70% can be cured)

Nutrition

At the request of CANDLELIGHTERS, the Diet, Nutrition and Cancer Program (DNCP) of the National Cancer Institute was mandated by Congress in 1974. Great Promise. For example, the intramural research program of the NCI compliments extramural efforts. Dr. Michael Sporn spearheads

a laboratory effort in chemo-prevention, which seeks to transfer to human application the experimental finding that doses of the synthetic vitamin A--13 -Cis-retinoic acid-- can prevent to some degree those cancers arising from tissues that line the body surfaces. Dr. Murray Brennan of the NCI Surgery Branch conducts both basic research and clinical research in nutrition. His laboratory studies focus on metabolic defects hindering nutrition in patients with cancer. At the same time, he is carrying out randomized, controlled traials to determine whether hyperalimentation will increase the cancer patient's ability to respond to treatment and his subsequent clinical course. Three populations of cancer patients who differ in the severity of malnutrition are participating: lymphoma patients, patients with advanced sarcomas, and patients with cancer of the esophagus.

However, the handbook on diet and nutrition: A Resource for Parents of Children with Cancer mentioned in Dr. Upton's testimony of October 2, 1979 before Senator McGovern's committee has not yet been released.

Also nutrition education for doctors/nurses in training must be expanded. More parents are driven into the arms of quacks touting cancer cures each year by the lack of attention, lack of education in and lack of responsiveness of treating physicians about the nutritional status of their children with cancer than from any other source. Nutrition including education shoudl receive no less than 33 million dollars.

NCI Intramural Program

Candlelighters is continually impressed with the sensitivity to people needs and research opportunities in the NCI Intramural research and information programs. The Office of Cancer Communications does a first rate job of discovery and developing publications of aid to patients, families/physicians and uses its intimediary program to gain new constituencies to disseminate these materials to a wide audience. The Clinical Center has long been operating under fiscal, building, personnel restraints which should not be imposed upon the federal cancer showpiece. The Pediatric Oncology, Clinical Oncology and Radiation Oncology programs should receive an additional 10% increase in funds.

Prevention

Families who have experienced cancer in a young child are particularly sensitive to need for prevention of disease. For this reason we support full funding of the cancer epidemiology and toxicology programs. We grow increasingly sensitive to in utero exposures, pesticides, herbicides, chemicals, pollutants, low level radiation and their effects on ourselves and our children. Epidemiology programs should be funded at no less than $44 million. National Toxicology should be fully funded.

Clinprot

The National Library of Medicine includes within its computerized retrieval and data base systems, a system known as CLINPROT which stands for Clinical Cancer protocols. This is an NCI sponsored data base which contains summarys of clinical investigations of new cancer agents and treatment techniques. CANDLELIGHTERS, therefore, requests that a study be made of how this CLINPROT system can be adapted, made more current and utilized to provide the types of information that the physicians may exchange by telephone and to make this type of information access available to all physicians across the country who are actively engaged in treating pediatric and adolescent cancers through the vehicle of their tertiary or secondary care system. This goal is realistic and workable. At the present time almost 4800 of the anticipated 6100 new pediatric and adolescent cancer cases each year in the United States are accessible to a data retrieval system of some type through their inclusion in one of the children's cancer study groups or existing pediatric comprehensive cneters. The center related out-reach program should make the community based or children's hospitals based cancer programs which are not now included in this number accessible to such data base systems.

As additional support for this increase in data access capability, CANDLELIGHTERS recommends that the research efforts at those centers designated to be the core center for out-reach network to the secondary and primary care radial treatments centers by supported by the establishment, supervision and utilization of a nationwide comprehensive childhood cancer registry. Again, the workability of this support mechanisms is evident from the fact that almost 4800 of the anticipated 6100 cases of pediatric and adolescent cancer each year are already a part of a federally supported data collection system which merely would need to be expanded. One model that we can suggest for this national registry is the "Delaware Valley Pediatric Oncology Program and Central Tumor Registry" which is a Division of Cancer Control and Rehabilitation Program originating from Children's Hospital in Philadelphia under the direction of Dr. Audrey Evans.

Long Term Effects

Additional emphasis should be placed on the need to develop less toxic therapies to avoid adverse complications in children with cancer which can now be successfully treated. One mother's comments is illustrative. "For the longevity of life, we pay dearly. He lived for a long time (seven years) but the result of his living with this disease caused extensive damage to his lungs and cataracts in his eyes. The children are living longer, but the drugs are still as toxic as ever." It becomes a serious question of the deterioration in quality of life.

These problems were not important when our children had no real hope for long term survival or cure. These problems assume increasing importance as our children live longer.

Parents report specific learning disabilities resulting from the treatment they have received. These disabilities give rise to special tutoring meeds. Physicial disabilities, temporary or permanent, give rise to special needs for vocational, occupational,and rehabilitation therapy for this special class of children. Children with cancer who have these needs often fall between the cracks. The cost of caring for these children far outweighs the cost of providing rehabilitation services, if those service can be avoided by the development of less toxic therapy.

The National Cancer Institute speaks of clinical evaluation of new therapeutic agents, and the development of more conservative surgical and radiological appraoches it also clearly commits itself to the development of less toxic second generation chemotherapeutic agents. Such a commitment and the funding for it are required so that we can assure our children who are survivors that they will not be blind, sterile, retarded, paralyzed or otherwise crippled.

Mr. Chairman, Members of the Committee, on behalf of all of these parents across the country, I would like to commend the Chairman and 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 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 program will be a memorial to them. And those of us whose children are under treatment or who are off drugs and hopefully cured of cancer 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 cancer. Thank you for permitting us to appear before you.