STATEMENT OF GRACE POWERS MONACOJ.D., CANDLELIGHTERS, BEFORE THE COMMITTEE ON APPROPRIATIONS, SUBCOMMITTEE ON LABOR, HEALTH,EDUCATION AND WELFARE, UNITED STATES HOUSE OF REPRESENTATIVES, APRIL 26,1982 NATIONAL CANCER INSTITUTE BUDGET HEARINGS

GRACE POWERS MONACO,J.D., representing CANDLELIGHTERS, an international coalition of families of children with cancer in the United STates and 10 foreign countries.

Survival rates of children with cancer have improved but the majority of these occur in centers staffed and equipped to manage *childhood* cancer. Black children fare less well than whites. National CAncer Institute ongoing or planned programs will give children a better chance at long term survival or cure.

To achieve this, children must have treatment managed by specialists in *pediatric* hematology, oncology, surgery, radiology and their support teams, not by physicians who may see only one child with cancer or by adult oncologists, etc.

The welcome thrust of NCI's planned Community Clinical ONcology Paograms would provide benefits to hook local physicians into the pediatric specialized programs. They would continue care locally, but reap the benefits of supervision of pediatric cancer research programs.

Appropriations are needed to achieve support for the programs vital to our children's cure or long term survival. The decreased funding of cooperative and center outreach programs realted to pediatric and adolescent cancers will not only exacerbate the problems but will tend to siphon off patients to less directed programs, put increased financial burden on families by limiting access to drugs, force medical centers and academic departments to underwrite an increasing proportion of clinical pediatric cancer research when their resources are shrinking, eliminate many important studies because their expense may not be picked up by third party coverage, cutbacks in training grants leading to a shortage of well-trained academic researchers in clinical and basic science aspects of childhood cancer, force institutions to absorb the costs of increading demands for data documentation and review and finally limit the basic research into mechanism of cancer cause and prevention - the area most likely to lead to the eradication of cancer.

Full funding of Children's Cancer Study Group; Cancer CEnters Outreach Programs; Community Clinical ONcology Programs, when they become operational; and, increases in training grants would eliminate these deficiencies.

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE:

My name is Grace Powers Monaco, I am representing CANDLELIGHTERS an international coalition of families of children and adolescents affected by cancer in 49 States and 10 foreign countries.

In 1970- 35% of our children with acute lymphocytic leukemia could look forward to long term survival or cure. Ten years later that percentage nationally is up to 55%. However, 60 to 65% five year life expectancies for childhood and adolescent cancer cases apply to those treated in centers adequately staffed and equipped to manage childhood cancer. Specifically, with respect to treatment at centers that are recognized for excellence in treating pediatric and adolescent cancers, Hodgkins (80% -five year survival rates), lymphatic cancer (70%), acute leukemia (50-70%), bone cancers (50-60%), retinoblastoma (83-85%), rhabdomyosarcoma (80%).

Our black children fare less well. For example, in the early 1970's, studies indicated that 92% of white children attained a remission in Acute lymphocytic leukemia and live an average of 23 months. In our black children the % was 74 % and these children lived an average of 14 months.

The majority of our children have a chance for the gold ring on the merry-go-round, CURE. There are activities currently on-going at the National Cancer Institute or in the planning stages that, with your support can give our children, a better chance to achieve cure or long term survival.

Key to an understanding of what is needed for this chance is that the care of children with cancer is highly specialized and constantly changing to meet new knowledge. The pediatric hematologist/ oncologist, the pediatric surgeon, the pediatric radiologist and the support teams are the lfelines our chilren lean on.

Clearly, to achieve cure our children must have the staging, evaluation and re-evaluation of their cancers done by people whose life is pediatric cancer. Their total treatment cannot be managed by physicians who see one child with cancer in 10 years, or by adult oncologists.

We do not look to eliminate the hometown pediatric oncologist or the local family physician. Our approach would not close the local physician out of the process. He or she would remain the central primary care physician in the child's treatment. This is the welcome thrust of the existing pediatric clinical cooperative programs, the cancer center outreach programs and National Cancer Institute's planned Community Clinical ONcology Program which all encourage and support full involvement of the local physician has the counsel and a hookup to all that is best in pediatric cancer. The most promising medical decisions are made for the child and everyday treatment, in 90% or more of cases, is carried out at the local level. The key is getting the child through the local caregiver into a relationship with a center of excellence in treatment of childhood cancer. Through this approach patient accrual in protocols increases and with that increase the ability to meaningfully evaluate therapy increases. National Cancer Institute is providing under Community Clinical Oncology Programs that extra credit be given to local physicians entering children into cooperative or center protocols as an inducement to a relationship between the local treatment process and the specialized care center.

A Candlelighters canvas of respected authorities in the treatment of cancer in children and adolescents have revealed the following threats to cure for our children. The proliferation of medical oncologists and surgeons with some experience in oncology has made them all a bit "hungrier" for patients and less willing to refer them to the pediatric oncologists. The improved results in children's cancer therapy has also given them the impression that it must be easier.

The following example gives flesh to the threats to our children's chance of cure outlined above.

> "A black,single, medicaid mother in a metropolitan area where there is a wealth of pediatric specialists, including hematologists/oncologists. A child with a lump on her jaw. A pediatrician referral to an adult head and neck surgeon. No pediatric oncology or surgery consultations. Surgery. 'Mother, your daughter has terminal cancer, nothing can be done.' This child had a rhabdomyosarcoma. Raise your hands, all our children with rhabdomyosarcoma who are off drugs and doing fine. We encouraged her to seek a second opinion and provided her with names of institutions in her area which could be contacted. We also told her about the second opinion physician to physician service which the NIH Clinical Center has. NIH was studying this form of childhood cancer . The child has been accepted for treatment there. Without this information and guidance Candlelighters provided for this family, this child would be sitting home waiting to die."

APPROPORIATIONS NEEDED TO ACHIEVE SUPPORT FOR THE PROGRAMS VITAL TO OUR CHILDREN'S CURE OR LONG TERM SURVIVAL.

The decreased funding of cooperative and center outreach programs related to pediatric and adolescent cancers will not only exacerbate the problems noted above but will also have the following effects:

1) The decreased funding of cooperative groups coupled with the shifting emphasis to Clinical Community Oncology Programs will further limit the pediatric programs financially and tend to siphon off some patients, particularly adolescents, to less directed programs.

2) Decreased funding puts an increased financial burden on families due to limited access to drugs, etc.

3) The medical centers and academic departments are forced to underwrite an increasing proporation of clinical pediatric cancer research as the increased costs of performing good studies, data collection, etc. are really no longer being covered by study group budgets. This comes at a time of shrinking general resources to support other phases of our academic programs.

4) Many important studies cannot be included in protocols because of their expense which may not be picked up by third party coverage. An example is psychologic testing in leukemic children receiving CNS prophylaxis. At times these scientific questions are the most important part of a study. There is virtually no money available any longer to defray the expense for studies of purely research interest on protocol patients.

5) The cutback of training grants in all part of the NIH is leading to a shortage of well-trained academic researchers in clinical and basic science aspects of childhood cancer care (and most other pediatric specialists as well). Due to cutbacks, there has been a general reducation in clinical investigation and two very serious effects of reduced funding have been clinical training and clinical laboratory investigations training. Due to the lack of support for trainees there has been a marked reduction in the production of potential investigators for pediatric cancer. By "clinical laboratory investigation" I do not mean the kind of animal or drug testing which seems to have a priority for support by the Cancer Institute. I mean, the kind of studies that are being done between the bedside and the research laboratory. These kind of studies

are extremely important in understanding and being able to provide leads for more basic research. The trainees in the Childrens Cancer Study Group institutions are not only involved in clinical care, but also participate and are trained in the performance of clinical laboratory research investigations go hand-in-hand and desperately need support.

6) Increasing demands for quality control, data documentation and data review by the NCI has added a new area of expense for study groups which is not compensated for in the grant funding. Again, this will have to be absorbed by the institutions and study groups from their already limited budgets.

7) Basic research into mechanisms of cancer cause and prevention is being limited - these are the areas most likely to lead to the eradication of cancer.

Full funding of: Children's Cancer Study Group; Cancer Center Outreach Programs; Community Clinical Oncology Programs, when they become operational; and, increases in training grants would eliminate these deficiencies.

Cooperative Clinical Research is budgeted for fiscal 1983 at 36,000,000 of which 6,665,000 is for pediatric and adolescent cancer. To fully fund the pediatric and adolescent programs the amount should be increased by 1.2 million dollars.

Training awards restored to funding level for fiscal 1982 increase of 734,000 to 22,799,000.

Cancer Control. Full funding for all Centers and Community Clinical ONcology efforts to 28,344,000.