

STATEMENT OF THE CANDLELIGHTERS ON OVERSIGHT  
HEARINGS FOR THE NATIONAL CANCER INSTITUTE

SUBCOMMITTEE ON HEALTH AND SCIENCE RESEARCH OF  
THE SENATE COMMITTEE ON HUMAN RESOURCES

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco; I am representing CANDLELIGHTERS an international coalition of families of children affected by cancer in 42 states, Canada and Europe. We wish to bring to your attention those areas in which the national cancer plan has had the most notable impact on our children's lives and those which we feel merit your further attention through programs redirection or initiation.

Let me first extend on behalf of all of us, our deep gratitude and appreciation to you, Mr. Chairman, and the members of this committee for your continuing efforts on behalf of all persons afflicted with cancer. Your unflagging interest in cancer research and the translation of this research into tangible programs for the detection, treatment and rehabilitation of cancer victims throughout the country has widened the benefits of the whole cancer effort. We know that the lives of children have been and are continually being extended, and in many cases, preserved, through the cancer research efforts which this committee has supported through the National Cancer Institute.

The focus of our testimony is as follows. Our initial concentration is on providing the committee with a profile of the financial problems which confront a family with a child or adolescent affected by cancer; our second area of emphasis is upon the collaborative efforts which the National Cancer Institute is undertaking in conjunction with other Institutes that deserve special commendation, the problems of the management of childhood and adolescent cancer that are not receiving any or adequate emphasis and our last area of emphasis springing from our practical observations of the research and clinical trial system as it works in application to pediatric and adolescent cancer. From these observations we suggest what we believe to be a way of increasing the quality of research and the consistency in delivery of that research to our children.

## The Financial Impact of Cancer on the Family Unit

The problems parents of children with cancer share is not a small one: after accidents, the second leading cause of death in American children is cancer. Although cancer is primarily an adult disease, it kills more children between the ages of three and fourteen than any other kind of illness. Although the incidence and mortality have declined slightly over the years, in 1979, cancer is expected to strike some 6,000 children and to kill about 2500. For all forms of cancer occurring in children under 15, the five year survival rate age-adjusted for normal life expectancy is 39 percent. For the most frequent forms of cancer, the rate ranges from nil for some leukemias to 84 percent for eye tumors. In centers that specialize in pediatric cancer, the five year survival rate rises to 50 percent for children with acute lymphocytic leukemia; these results reflect aggressive treatment.

The emotional burdens of cancer on a family unit that is faced with a child or adolescent with cancer are self evident and need not be stated here. However, the financial burden borne by each family is second only to the distress caused by the disease itself. A study of seventy families with children in treatment for cancer at the University of Kansas Medical Center, demonstrated that in addition to medical expenses (usually covered by third party coverage and installment payments, and in some cases helped also by the crippled childrens programs), the out-of-pocket for non-medical expenses usually averaged more than 15 percent of the family budget. For half of the families, the figure was over 25 percent. These non-medical expenses include loss of pay, transportation to different medical facilities, food and lodging while away from home, child care, special clothing and special food.

One illustration is the circumstances presented for pediatric cancer patients in Nevada. This child and the family unit has three treatment options. The closest oncology care centers are in California (San Diego, Los Angeles or San Francisco). They are from 250 to 460 miles away. Air transportation ranges from \$150-300 per person round trip and remember that a parent must always accompany the child. Visits to the clinic vary in frequency from once every two weeks to once every eight weeks. When a child is hospitalized, there are food and lodging costs for the parents and often lost wages.

One Nevada family spent over \$6000 in out-of-pocket expenses the first year their child was diagnosed. A few months ago they spent \$750 for a five day trip to San Diego for tests. When they have to stay several days, the family makes the trip across the desert in a camper to save on lodging.

Another Nevada family recently had to spend \$2350 dollars in just seven weeks for out-of-pocket expenses incurred during the treatment of their child's cancer. These expenses were for gas, lodging and food incidental to their needs when they were at their treatment facility.

Another example involves a Michigan teenager with a cancerous bone in her right leg. Local doctors were ready to amputate but contacted a specialist in New York that led to a special operation at Memorial Sloan Kettering that saved the teenager's leg. Her mother had to quit her job in order to accompany the child to New York for treatment and to care for her. The mother's living expenses in New York, travel bills, and caring for five other children completely depleted the family's savings. Thus, even though the family's insurance covered most of the teenagers medical bills and the State Crippled Childrens Program paid remaining expenses the family was in effect destitute.

The Crippled Childrens Program presents a checkered pattern of assistance for families of children with cancer. Some states cover all childhood cancers while others limit coverage to but a few types. Some states cover diagnostic tests but not treatment and vice a versa. Some states have no coverage under the Crippled Childrens Program. In most cases, the coverage offered is very minimal especially in today's inflationary economy. Further, coverage varies widely from state to state. A few are generous. One or two will cover incomes of \$20,000 or more if there is a hardship. The eligibility requirements in almost all cases are very strict, so much so that many needy cases are not covered. What concerns us most is that those states with provisions that require the child to have a good prognosis for cure before they are accepted in a program. Others have the provision of dropping children when their outlook turns from good to poor. Since the Crippled Childrens Program is an outgrowth of the Social Security system, we think that minimum national standards ought to be the goal - standards setting crude coverage for all children with leukemia or cancer. If national health insurance at least for catastrophic illness coverage is not to become a reality in the near future, national uniform standards for crippled childrens program may be a way of assisting families while we are waiting for the type of relief we really need.

## National Cancer Institute Programs

The National Cancer Institute has responded to most of the needs articulated by families to them since Candlelighters initiation nine years ago. The support of psycho social research and its implementation, dedication to providing quality public and physician information and education materials are particularly deserving of praise. We also note with pride the intensified interest and the multi Institute collaboration approach which the Institute is adopting in the area of the diet, cancer and nutrition program which was created at Candlelighters urging by the 1974 Cancer Act Amendment and we also note with approval the informal collaborative efforts between the National Cancer Institute and other institutes in the area of eye and brain tumors.

Regretfully, we report that in the area of pain research which was the subject of a recent NCI conference, pediatric pain was not mentioned and we are aware of no study into the assessment and management of pain in the pediatric cancer patient which are ongoing at the National Cancer Institute at this time. The problems of pain in children resulting from the effects of the disease on the child as well as pain associated with procedures which are used in treating the disease is a matter of great concern to families and is a matter which should receive attention by the National Cancer Institute.

Further, additional emphasis should be placed on the need to develop less toxic therapies to avoid adverse complications in children with cancers 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 of long term survival or cure. These problems assume increasing importance as our children live longer. Parents report specific learning disabilities resulted with the treatment they have received. These disabilities give rise to special tutoring needs. Physical 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 requirements often fall between the cracks. State administration of federal vocational/occupational therapy programs like some of the crippled childrens programs are administered to discriminate against our children unless you can guarantee that you will be a survivor. You are, in light of these programs, stigmatized by your cancer and not considered worth the educational/vocational rehabilitation effort.

Finally, although the Institute has funded an excellent program in Minnesota which involves research into the team approach particularly nursing support to permit parents who choose to have their children die in comfortable surroundings to reach that goal with dignity, comfort and far less cost than hospital death, and although the Hospice leaders in this country are aware of and supportive of this type of program, we have not seen any indication that the federally funded Hospice effort through the National Cancer Institute will build into its death at home and home care outreach programs for adults, a capability to provide the team support to families of pediatric patients.

Better Ways of Meeting Our Children's Needs Through Research and the Clinical Application of that Research.

In view of the shrinking dollars allocated to health, it is important to develop an approach to cancer research in children and its application that produces excellence in research and provides an optimum in application of research for all children/adolescents with cancer at the lowest cost to families and to society. One suggestion growing out of observations by parents is the consortium approach to health care for children with cancer.

Childhood cancer research has proven to be the single most effective model for understanding and treating many forms of cancer. Pediatric cancers pioneered combined modality therapy utilizing surgery, radiotherapy and chemotherapy, various rescue factor approaches and adjuvant chemotherapy which have effectively arrested or retarded the development of many adult cancers. Dr. Emil J. Freireich of the University of Texas Systems Cancer Center in Houston has said that drug combinations pioneered in pediatric cancer are now producing remissions in a majority of adults with acute myelogenous leukemia and a "proportion of these patients are being cured. Five years ago if you asked me if we were producing cures, I could only say, 'rarely'." Additional specific examples include the development of and use of antifols in childhood leukemia which lead to curative measures in adult cancer, specifically the use of antifols in women with choriocarcinoma adjuvant chemotherapy and acute lymphocytic leukemia which is now being used successfully in adult Hodgkin's disease, finally, the total therapy concept used for childhood ALL is now being used successfully in cooperative study clinical trials involving adult lung cancers.

These applications of the results of research in pediatric and adolescent cancers underscores the importance of preserving, expanding and building upon the research efforts committee to childhood and adolescent cancer. The proposal Candlelighters suggest would work toward a guarantee that all children with cancer will have ready access to the most expeditious, safe and effective cure available as measured by national standards, but all will have responsible primary physician-advocates that no family will be economically constrained or burdened by the costs of care, that childrens cancer research will perceive vigorously.

The consortium approach that we suggest here is already occurring in regard to the federal research effort in regard to pediatric cancer. The National Cancer Institute's intramural research program into childhood cancer has its clinical application on site at the National Institutes of Health Clinical Center. The ways of managing the burdens of transportation costs, costs of lodging and board away from home, coordination of care with local physicians and the childrens hospital are all contained in the blueprint that already exists within the intramural federal program. The consortium approach as suggested by Candlelighters recognizes three conventionally defined levels of health care:

Primary (Level I) - located in the child's community, and providing home and outpatient/office health supervision with particular regard to normal growth and development, prevention of infectious disease, treatment of minor infections, liaison with school and community, and family counseling by professional and by peer group. This would be provided by a pediatrician, family practitioner, internist or pediatric oncologist.

Secondary (Level II) - The pediatric cancer care facility, usually connected with a children's hospital located close to the child's community and providing outpatient and inpatient care for the particular disease and its complications. This would include: administering anticancer drugs according to protocol; maintaining treatment records, and managing moderately severe infections, bleeding episodes, anemia, nutritional and metabolic disorders. This would be provided by a pediatric hematologist/oncologist or a pediatrician with additional training or experience in pediatric oncology. Also, this facility should provide access to childlife specialists, psychosocial support by professional or peer group as well as undertaking an education program directed to medical and nursing students, graduate trainees, and practitioners.

Tertiary (Level III) - A regional children's cancer center. This would be accessible to provide confirmation or correction of initial diagnosis, subcategorization and staging, complete evaluation of the child's needs through discussion among team members and with child and family, assignment to protocol study with consent of child and parents, initiation of therapy, conduct of any Phase I experimental treatment, basic and clinical research relevant to children's cancer, and training of oncologists in research and practice. The child and/or his specimens and findings would be periodically sent to the center for reassessment, change in therapy, investigative studies not available at the secondary level and documentation of disease course.

Secondary care persons might provide primary care as well, and tertiary regional centers could provide primary and secondary care also. This would be decided in accordance with the residence of the child, the particular cancer and its treatment, and the wishes of the child and family.

For child and adolescent patients not actively participating in a research program, a comprehensive registry of the data for childhood and adolescent cancer should be established. These patients could thus effectively participate in the research effort by providing data on effectiveness of treatment, toxicity of therapy and long term effects of childhood/adolescent cancer. Further, the cancer center and secondary care level should provide strong outreach services to the community physician. It goes without saying that due to the profile of pediatric cancer in this country (17% of all cancers) consortium treatment with its care and cost benefits requires that adequate transportation funds must be provided for those who must travel great distance for treatment.

Mr. Chairman, Members of the Committee, on behalf of parents across the country who have children affected by cancer, I should like to again commend you for your efforts and for your understanding of our problem.

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