STATEMENT OF CANDLELIGHTERS ON CATASTROPHIC HEALTH INSURANCE (S.350,S.351) BEFORE THE

SENATE COMMITTEE ON FINANCE

APRIL 2, 1979

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 45 states, Canada, Australia and Europe. We wish to bring to your attention the unique problems of children affected by cancer and their needs in catastrophic health coverage.

CATASTROPHIC COVERAGE FOR PEDIATRIC CANCER MUST INCLUDE TRANSPORTATION COSTS

The problems families of children with cancer share is a large one: after accidents, the second leading cause of death in American children in cancer.

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. The burdens also include inability to change jobs because of loss of medical coverage for the affected child.

Although cancer is the second leading cause of death for our children, children account for only 1% of the population affected by cancer in this country. What this means is that specialized cancer care facilities to provide skilled treatment for children are not right around the corner as they are for the adult cancer population. What this means is that even if a family can be assured that all its direct medical expenses are paid, transportation costs to a care facility, board, lodging, child care for other children remaining at home, loss of work time must be borne by the family and indeed are as "direct" costs as the medical treatment itself.

Transportation and the related costs are necessary to assure receiving skilled medical treatment.

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 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 teenager's medical bills and the State Crippled Childrens Program paid remaing expenses the family was in effect destitute.

A further example involves a divorced mother with four children in Irving, Texas. Her daughter has had osteogenic sarcoma (amputee) since 1972. Every third week she goes to M.D. Anderson with her daughter for treatment for a week stay.

She works weekends to make up lost pay and after using her vacation time she has her pay docked. The Texas rehabilitation agency will not help with her daughter's prosthesis or education because they assume she will die.

A further example is the plight of families whose children need bone marrow transplants and must travel to one of the half dozen pediatric facilities in the country that can offer this service with the same indirect expenses covered above.

PROVISION FOR TRANSPORTATION AS PART OF A CONSORTIUM APPROACH TO PEDIATRIC CANCER

It is obvious that catastrophic coverage for pediatric/adolescent cancer patients requires more than reimbursement for direct medical expenses. It is also obvious that it would be impractical and not cost effective to multiply the number of skilled pediatric/adolescent cancer facilities to avoid the transportation and indirect expense burdens. Candlelighters suggests an approach to this problem which will provide optimum care to the child and true protection to the parent from catastrophic expenses.

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 patients 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 not 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 in breast cancer to prevent metastases; and, the combination chemotherapy in 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 committed 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 care 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 proceed viogorously.

There is already an example of the consortium approach that we suggest within the National Cancer Institute's intramural research program into childhood cancer which 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 accoring 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 childrens 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.

The tertiary center is the outreach program at the hub of the wheel and the secondary (usually a children's hospital) and primary (usually a pediatric oncologist) are the radials. In this consortium approach the primary and secondary levels of caregivers provide most of the care in concert and in collaboration with the tertiary center. Under such a cooperative approach, given the primary sentiment of families to achieve as much care as possible close to home if their child would not be endangered by that decision, the transportation and lodging requirement of the catastrophic coverage plan would not be abused.

WHAT SERVICES SHOULD BE COVERED IN A CATASTROPHIC INSURANCE PROGRAM

1. The cost of transportation and lodging as needed for evaluation, re-evaluation and specialized care at the tertiary research facility.

2. In-patient hospital costs.

3. Out-patient visits

4. All drugs, radiotherapy, blood components, prosthesis

5. Nursing home care for the child who no longer needs hospitalization but cannot be cared for at home.

6. Home care during terminal stages. A study at the University of Minnesota shows that home care for the terminal child with full team support costs less than a third of death in a hospital.

7. Counseling costs for the family during illness and after termination of care.

NEED FOR A NATIONAL STANDARD FOR CRIPPLED CHILDRENS PROGRAMS

The need for uniform catastrophic coverage is particularly apparent from the checkerboard coverage pattern of the Crippled Childrens Programs. Candlelighters of Connecticut has been acting as a task force in reviewing the pattern of coverage in the States. Most of the states provide full or partial coverage for treatment of childhood cancer or leukemia. Some States cover all childhood cancers while others limit coverage to but a few types. Some states cover diagnostic tests but not treatment and visa versa. Some states have no coverage under the Crippled Children's Programs but provide support from private or other sources. In most cases the coverage is very minimal, especially in today's inflationary economy. Further, it varies widely from state to state. A few are semi-generous. One or two will cover incomes of $20,000 or more, if there is hardship. The eligibility requirements in almost all cases are very strict, so much so that many needy cases are not covered. The requirements are generally so complicated or couched in such language that even the educated layman will find it difficult to understand.

What bothers us most is those states with provisions that require the child to have a good prognosis for cure before they are accepted in the program. Others have the inhumane provisions of dropping children when their outlook turns from good to poor. Since the Crippled Children's Program is an outgrowth of the Social Security Law, we think that minimum national standard ought to be the goal--standards that include coverage for all children with leukemia or cancer. See study appended for survey of states.

The difficulties caused by this checkerboard coverage can be resolved with uniform catastrophic coverage standards.

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

STATE	COVERS THE MEDICAL TREATMENT OF ALL CHILDHOOD CANCER AND LEUKEMIA	COVERS THE MEDICAL TREATMENT OF SPECIFIC DIAGNOSES OF CHILDHOOD CANCER AND LEUKEMIA	ALTERNATIVE PROGRAMS WITHIN THE STATE	ELIGIBILITY REQUIREMENTS
Alabama		they do not routinely accept cases of leukemia or childhood cancer but will accept a very few cases of leukemia on a special per case basis		age diagnosis financial means test
Arizona		pays for some childhood cancer and leukemia but requires that the child have a pregnosis for cure or significant improvement toward rehabilitation		age diagnosis financial means test
Arkansas		covers certain operable cancers of the bone or skull		residency requirement age diagnosis financial means test
California	pays for the treatment of all childhood cancer and leukemia--includes in- and outpatient care, meds, blood products, lab work, psychosocial counseling and terminal home care			age diagnosis financial means test
Colorado	no coverage			none
Delaware	no		Alfred J. DuPont Institute (private) will handle crippling bone cancer	

STATE	COVERS THE MEDICAL TREATMENT OF ALL CHILDHOOD CANCER AND LEUKEMIA	COVERS THE MEDICAL TREATMENT OF SPECIFIC DIAGNOSES OF CHILDHOOD CANCER AND LEUKEMIA	ALTERNATIVE PROGRAMS WITHIN THE STATE	ELIGIBILITY REQUIREMENTS
Florida	medical care is covered only in certain designated clinics and hospitals in Florida			age diagnosis financial means test
Georgia	no		Cancer Control Program --managed through the Adult Health Unit, Division of Physical Health	
Hawaii	no coverage			
Idaho		offers very limited coverage --leukemia is not covered, only malignancies that require rehabilitation are served		age diagnosis financial means test
Illinois		covers medical care for cancer related to neurologic or orthopedic conditions		age diagnosis financial means test
Indiana	full coverage for treatment			age diagnosis financial means test
Iowa	no coverage			
Kansas		pays for the medical diagnosis and treatment of solid tumors but not leukemia		age diagnosis financial means test

STATE	COVERS THE MEDICAL TREATMENT OF ALL CHILDHOOD CANCER AND LEUKEMIA	COVERS THE MEDICAL TREATMENT OF SPECIFIC DIAGNOSES OF CHILDHOOD CANCER AND LEUKEMIA	ALTERNATIVE PROGRAMS WITHIN THE STATE	ELIGIBILITY REQUIREMENTS
Kentucky		covers the treatment of brain tumors and orthopedic (bone) cancer		age diagnosis financial means test
Maine	all diagnoses		catastrophic health insurance	age diagnosis financial means test
Maryland		diagnostic work-up both as in- or outpatient; medication provided by approved hospitals or M.D.		financial means test
Michigan	all diagnoses--only restriction is that the treatment must be rendered by a provider approved by the program			age diagnosis financial means test
Minnesota	all diagnoses		catastrophic health insurance	age diagnosis financial means test
Mississippi	no			
Montana		assist with diagnostic evaluations but not treatment		age financial means test
Nebraska	yes--all treatment			age diagnosis financial means test

STATE	COVERS THE MEDICAL TREATMENT OF ALL CHILDHOOD CANCER AND LEUKEMIA	COVERS THE MEDICAL TREATMENT OF SPECIFIC DIAGNOSES OF CHILDHOOD CANCER AND LEUKEMIA	ALTERNATIVE PROGRAMS WITHIN THE STATE	ELIGIBILITY REQUIREMENTS
Nevada	yes--pays for all or part of the costs of diagnosis and treatment of all childhood neoplastic diseases, malignant or benign			age diagnosis financial means tes
New Hampshire	no		treatment is covered by the New Hampshire Cancer Commission	
New Jersey	yes--all diagnoses			age diagnosis financial means tes
New Mexico	no			
New York	yes--all diagnoses: except two counties in N.Y. have elected to exclude malignancies			age financial means test
North Carolina	yes--all diagnoses			age financial means test
North Dakota	yes--includes cancer and leukemia; however, it does not cover supportive care, transportation, or out of hospital drugs; they will not go above $5000 hospitalization limit in 12 month period			age financial means test

STATE	COVERS THE MEDICAL TREATMENT OF ALL CHILDHOOD CANCER AND LEUKEMIA	COVERS THE MEDICAL TREATMENT OF SPECIFIC DIAGNOSES OF CHILDHOOD CANCER AND LEUKEMIA	ALTERNATIVE PROGRAMS WITHIN THE STATE	ELIGIBILITY REQUIREMENTS
Oklahoma	yes--includes all diagnoses			age financial means test
Oregon	no			
Pennsylvania	no			
Rhode Island	no		catastrophic health insurance to cover cost of treatment	
South Carolina		covers treatment of children who require orthopedic follow-up and/or appliances as a result of amputation, etc. because of bone tumors or other types of cancer	also the Division of DHEC cancer program provides diagnostic services, curative therapy and follow-up for all kinds of childhood cancer and leukemia	age diagnosis
Tennessee		children get initial diagnostic evaluation free of charge; cancer and leukemia are considered on an individual basis including: Wilm's, neuroblastoma, retinoblastoma, osteogenic sarcoma, Hodgkin's, multiple myeloma		age diagnosis financial means test
Texas	no			

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Vermont	no			
Virginia		has specialty programs for primary bone cancer, Wilm's tumor, brain tumors		age diagnosis financial means test
Washington		covers treatment of Wilm's tumor, rhabdomyosarcoma, Hodgkin's, lymphoblastic leukemia (may include osteogenic sarcoma and Ewing's sarcoma soon)		age diagnosis financial means test
West Virginia		covers only malignancies of the bone		age diagnosis financial means test
Wisconsin		covers neoplasms and chronic infections of the bone		age diagnosis financial means test