SUMMARY OF STATEMENT BY GRACE POWERS MONACO, J.D., CANDLELIGHTERS. BEFORE THE COMMITTEE ON FINANCE, SUBCOMMITTEE ON TAXATION AND DEBT MANAGEMENT, UNITED STATES SENATE, ON S. 474, TO AMEND THE INTERNAL REVENUE CODE OF 1954, ETC. APRIL 23, 1982

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

A Candlelighters survey indicates the importance of and cost of transportation in the treatment of a child with cancer.

Our families in States like Nevada where there are not treatment facilities for pediatric cancer pay plane fare to distant centers which may amount to as much as $8,000 yearly. In other states, families must drive 200-500 miles for treatment. Gas, car upkeep, meals away from home, lost hours of work can devastate cash holding. We are certainly in favor of raising the deductible for all travel.

Specialized cancer care facilities are not right around the corner for children as they are for adults. 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.

Without providing catastrophic coverage for pediatric and adolescent cancer families which will aid transportation and indirect expense burdens to parents, we are bankrupting families or depriving children of care of the excellence they need.

STATEMENT

BY

GRACE POWERS MONACO, J.D.

PRESIDENT

CANDLELIGHTERS

BEFORE THE

COMMITTEE ON FINANCE

SUBCOMMITTEE ON TAXATION & DEBT MANAGEMENT

OF THE

UNITED STATES SENATE

ON

S. 474

TO AMEND THE INTERNAL REVENUE CODE OF 1954

APRIL 23, 1982

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.

The legislation before this Committee seeks to raise the amount of deductions for the operation of an automobile available as a medical expense. I reproduce below tables from a survey done by Candlelighter families by Public Research Associates in New Jersey in 1980 which should indicate to this Committee the importance of and cost of transportation in the treatment of a child with cancer:

DISTANCE FROM MEDICAL CENTER (Miles)	
1 - 25	35%
26 - 50	20%
51 - 75	9%
76 - 100	9%
101 - 125	1%
126 - 150	3%
151 - 175	1%
176 - 200	2%
Over 200	13%
No Response	7%

MODE OF TRAVEL TO CENTER	
Car	82%
Bus	6%
Plane	7%
Other	4%
No Response	1%

COST OF TRANSPORTATION TO CENTER

\$ 1 - \$ 100	10%
\$ 101 - \$ 300	18%
\$ 301 - \$ 650	13%
\$ 651 - \$1,000	12%
\$1,001 - \$2,000	10%
\$2,001 - \$4,000	6%
\$4,001 - \$8,000	3%
Over \$8,000	1%
No Response	27%

The most telling financial impact on our families is the plane fare needed to transport families from states like Nevada where there are no facilities for the treatment of cancer in children to California which may amount to $6-8,000 a year per family. However, in other states such as Arkansas, New Mexico, and Washington, families may have to drive 240 - 500 miles for treatment. Gas, car upkeep, meals away from home can gut a family's cash money.

The biggest problem is the cash money needed for transportation when you have to drive 140 miles to the treatment center. When you have a family of 7 to feed, there isn't any money left for extras. Insurance pays for the hospital bills, but the added expenses are catastrophic. A Mother in Wisconsin.

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 $2,350 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.

For this reason we are certainly in favor of raising the deductible for all travel.

However, let me leave another thought for the future with this Committee. Although cancer is the second leading cause of death for our children, children acount 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.

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 remaining 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.

It is obvious that catastrophic coverage for 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.

Candlelighters suggests that catastrophic coverage for pediatric cancer must include transportation costs.

If it does not, we are bankrupting families or depriving children of the care of excellence they need.