

STATEMENT OF GRACE POWERS MONACO, J.D.  
NATIONAL LIAISON CHAIRPERSON - CANDLELIGHTERS  
SUBCOMMITTEE ON HEALTH  
COMMITTEE ON WAYS AND MEANS  
NATIONAL HEALTH INSURANCE  
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Ms. Monaco. Mr. Chairman, I would like to take the opportunity to have our full statement in the record.

Mr. Rangel. It is so ordered.

Ms. Monaco. I would also like to ask you if we could have permission to include in our statement sometime within the next month the results of a financial survey that we have done across the country on parents of children with cancer indicating the real financial impact on those families with catastrophic illness.

Mr. Rangel. I do not know whether we can keep the record open that long. Yes, we will be able to accommodate you.

Ms. Monaco. Thank you, Mr. Chairman.

I would like to concentrate on what Representative Sabo this morning acknowledged is an undeserved class, and that is the children that are affected with catastrophic illness. That category of client shall we say, for catastrophic health insurance, is dependent upon the foresight of their own parents for providing for their care or the goodwill of state or national organizations.

Too often both of these elements are lacking. It is understandable. Although cancer is the largest killer of children in this country next to accidents there are very few people that enter upon the state of matrimony in anticipation that they are going to have a child that has cancer or some other catastrophic illness.

The impact of cancer on the family, what it does to it emotionally and financially, are the kinds of things I would like to explore with you and to concentrate on the two aspects that you indicated you were most interested in listening to.

The first is the impact of the disease on a particular class and the other thing is the way of improving the system so that we can meet the needs of that class without blowing financial commitment sky high.

Children with cancer are only one percent of the cancer community and for that reason we cannot, as can the adult cancer sufferers or those that have heart disease or stroke, count on having a center of excellence within spitting distance of our front door.

We can count on that if we live in D.C. or New York City. We can count on that if we live in Memphis, Tennessee. We can count on that if we live in Boston or Minnesota or Los Angeles, and a few other places like Houston, Texas, and Seattle, Washington, but for the most part the parents that have children with lifethreatening illnesses like cancer have to travel from 250 to 500 miles one way for their child to receive treatment.

For that reason I would like to bring to your attention that even if we were able to receive medical reimbursement for every single medical procedure that our children experiences, still we would not be able to assure in any way that the financial catastrophic impact of disease on this class of families is going to be met.

First, I want to address the types of medical coverage that we feel any national health insurance program would have to include and then the deficiencies remaining even if we do have all of those medical procedures covered.

What is needed, - (1) hospital coverage, (2) out-patient costs, when you have a child with cancer that child may only be hospitalized twice, at diagnostic time and at demise. Most of the time is spent and most of the treatment is received on an out-patient basis. (3) Drug costs, (4) radiotherapy, (5) blood products, not just that whole red stuff that we have but also white cells,

plateletpheresis, things of that nature that help us avoid infection and go on to a better survival opportunity, (6) prosthesis, (7) nursing home care, very few nursing homes can accommodate children. For the most part they do not need to but this is not something readily available. (8) Counseling, which can be covered in most circumstances; (9) Home care, -home care is one of the glaring gaps in the way the whole national health insurance is proceeding with respect to the pediatric cancer patient. Although HEW is funding 26 hospice demonstration programs all over the country, none of them include a program, as far as we know, in which home care outreach services, a home care outreach team, is going to be available for pediatric patients that are going to die at home, particularly in our reference, patients that have cancer.

New Jersey has started a program that deals with this. Minneapolis has a program that deals with this. Washington, D.C. fingers crossed, is starting the same thing, and Virginia and Michigan. But this particular type of benefit which, in Ida Martinson's program out of University of Minnesota, has shown it can deliver the best tupe care to the pediatric patient at one-third or less the cost of a terminal illness in a hospital is something which the people that are putting the hospice programs together are brushing aside.

We are only one percent of the cancer population but it is important to keep costs down for all clients of the National health insurance system and not just the adult population.

Mr. Rangel. Are you not saying something else besides keeping costs down for home care?

Ms. Monaco. I am saying also, of course, the benefits that are available to the family, certainly. The lack of family disruption, dying in the bosom of the family which so many of us had the opportunity to experience growing up, which is not available for a lot of our children to be a part of today. The emotional toll, the financial toll, the entire impact on the family is so much better served and handled when we can let our children die at home where we want to have them, if they have to die at all.

As I mentioned, even if we do have all of our medical needs met, if we are fortunate enough through state and federal programs and private health insurance to pick up those medical costs, there are studies, the primary one of which has come out of the University of Kansas, and others at Sloan-Kettering and at the University of Los Angeles, that show that between 15 and 25 percent of a families total income, goes to the tupes of costs that are directly related to the disease category we are talking about, pediatric cancer, namely transportation to a medical center, food and lodging for the family member that accompanies the child, child care for the children that remain at home, and homemaker assistance to the children that remain at home.

We cannot reinvent the wheel and duplicate Class A cancer treatment facilities all over the country to serve this one percent. But we can build upon the good children's hospital set-ups that treat cancer, although they are not major centers, clinical cooperative groups, pediatric oncologists in the community. We can leave this structure intact, assure that transportation costs be picked up for families that for one reason or another have to leave the bosom of their own community and travel to a major center for treatment, and by this avoid duplication of services. With transportation and lodging paid, we would be able to make the best use of the services that are available, resist the temptation to duplicate unnecessary and extraordinarily expensive services

in other places and meet the arguments on non-accessibility.

For the most part families would not have to use this transportation money. The fact that they were tied to a center and that those that were treating them could rely upon a center for evaluation and reevaluation while they were monitoring the care at home would be sufficient.

However, for families, for example, that live in Nevada who must travel to Los Angeles for the most part of treatment, their transportation costs can go over \$6000 a year. Nobody pays that.

I am thinking particularly of an example of a family from Michigan that transported itself to Sloan Kettering in New York for a very simple reason. If the child stayed at home she would have a limb amputated. If she went to Sloan Kettering they had the ability to replace, to utilize that limb, keep it in place and she would have a workable limb.

But in order to avail themselves of Sloan Kettering's fantastic reputation in this area the family, that was not a welfare family, that was not Medicare or Medicaid, had to come all the way across the country. The mother had to give her job up. Every single cent of their savings were spent in order to assure that their child would have a limb.

Families love their children but they are not always willing to make those sacrifices. We have a family right now in the Metro. Area that cannot afford the \$25,000 a year it is going to cost them to do what they need to do to their child with pediatric cancer and for that reason they have decided to discontinue treatment.

But even becoming destitute is no guarantee that you are going to receive the care that you need. There is an example of a family that is in New Orleans, Louisiana, that was a family whose income met State aid standards. They

petitioned the state health to pay for a Bone Marrow Transplant for their child. That Bone Marrow Transplant was the only thing that could be done for the particular type of cancer that this child had.

The state health said, "No. It is an experimental procedure. We will not do it." Our local parents group took them to court and the court decreed payment for the bone marrow procedure. But now they are looking towards legislation that will make this available to all other children.

Children are a very small bag in the area of catastrophic illness. But children have been where we have learned the best lessons in terms of cancer. The things that have happened to our children five years ago now save the lives of a lot of adults.

I think that we can say that the children are not only important then for the substantive medical progress that they have given us but also they are a small enough group, that they could prove to be an experimental unit whereby we might try some innovative ways of handling care, delivery and reimbursement that might later prove to be an excellent example for the entire adult community.

I trust, Mr. Chairman, Mr. Duncan, that with your concerns in these areas of health care and the way you have gone on the record, that you will consider strongly the particular needs of the catastrophically ill child in tailoring your response to national health insurance.

We certainly, as an organization that has groups in 48 States and many overseas, stand ready to be of whatever assistance we can in helping you to tailor your approach.

I would be happy to answer any questions you have.

Mr. Rangel. Thank you, Ms. Monaco. Mr. Duncan.

Mr. Duncan. Thank you, Mr. Chairman. I want to thank Ms Monaco for an excellent statement. The appts that I missed before I came in I read it and I want to compliment you on your persuasiveness and sincerity and

dedication.

How many children would you say that are affected by cancer are now living?

Ms. Monaco. Approximately 6000 children are diagnosed with cancer every year. Of this number, not quite 50 percent are leukemias and the rest are solid tumors and cancers of other description. Of course, now we can look forward to saving about 80 percent of our leukemia children, our Null Cell leukemia children, if they do receive the proper treatment, and we can look forward to saving a lot of our children that have solid tumors.

There are some cancers like brain tumors in which we do not have such great hopes yet but we have come a long way in the last ten years.

Mr. Duncan. How many locations do we have in the country that specialize in cancer treatment for children?

Ms. Monaco. There are a lot of people that say they do, sir, but we only have seven or eight centers, real centers, of excellence in this country for the treatment of pediatric cancer. You are fortunate enough to be right around the corner from one.

Mr. Duncan. It is a long ways from east to west in Tennessee, but it is in our state. We are proud of the one in Memphis. Thank you very much. and thank you Mr. Chairman.

Mr. Rangel. Thank you, Mr. Duncan. The Candlelighters, do they concern themselves just with children and just with cancer?

Ms. Monaco. We are just concerned with pediatric and adolescent cancer and the effect that it has on our families, yes, sir, although we do serve as an organization that is a lead organization in helping parents with other disease site interests to get their own types of activities going that parallel ours.

Mr. Rangle. You are located in 48 states?

Ms. Monaco. We are indeed, sir.

Mr. Rangel. How do you identify the family, by going to the hospitals?

Ms. Monaco. The families usually identify us. We are usually a part of the information package that a family would receive upon diagnosis. So they would know the kind of self-help information and education programs that Candlelighters has available for them and they can participate in them.

We have five groups in the metropolitan New York area. We have different ones in New York State. There are about five groups on the island, Westchester County, Brooklyn, Staten Island and the city itself.

Mr. Rangel. Is it entirely privately funded?

Ms. Monaco. It is publicly funded insofar as it is funded by parents themselves. We do not do any fundraising. What we do is we steal a lot. We put our hands in the pockets of the people we know have the money, including organizations that are raising money generally in the community for the aid of cancer patients.

Mr. Rangel. But you do not receive public funding.

Mrs. Monaco. No, we do not. We have never had to worry about that.

Mr. Rangel. I hope you send me some literature concerning the Candlelighters. It is a very emotional subject and certainly people that are struck by this, families rather, need all the help they can get and I would like to see what I could do to help.

Ms. Monaco, Thank you, Mr. Chairman. I appreciate your interest.



SUMMARY: CANDLELIGHTERS POSITION ON  
1980 APPROPRIATION FOR THE NATIONAL CANCER INSTITUTE

1. Expansion of the federally funded research and clinical trial effort to translate the successes in the acute leukemias, lymphatic cancer, Hodgkins, bone cancers, wilms tumors, retinoblastoma, rhabdomyosarcoma with 50 to 85 percent five year survival rate at centers of excellence in pediatric and adolescent cancer treatment to the non-acute leukemias, brain and central nervous system tumors and neuroblastomas which have not shown the sensitivity to treatment which these other cancers have.
2. Expansion of the consortium approach to pediatric and adolescent cancer supported by a network, tumor registry and computer access system which will permit children with cancer wherever they are found to experience the same opportunities for long term survival and possible cure that are experienced at the centers of excellence in the research and clinical application of pediatric cancer.
3. Expansion of the efforts to develop less toxic therapies.
4. Initiation of research into pain assessment and management in pediatric and adolescent cancer patients.
5. Funding for a study to determine how to provide parent access across the country to programs that will assist families of children with cancer to let their children die at home where this is the option the family selects.
6. Increased funding for blood component support programs.
7. Inquiry into discrimination against pediatric and adolescent cancer patients in state vocational education and rehabilitation programs.
8. Increased funding and positions for the Office of Cancer Communications to provide expanded efforts in the development of materials for the use of families, physicians, nurses and social workers for dealing with the psychological pressures of cancer and providing for development and dissemination of materials relating to rehabilitation.
9. Increased funding for the National Institutes of Health Clinical Center program in pediatric oncology to permit initiation or expansion of existing programs within the intramural program as pertains, for example, to long term physical, behavioral and psychological impacts of cancer on pediatric and adolescent patients and their families, pain assessment and management, and the development of less toxic therapy.
10. Continued support by this Committee for the nutrition program and additional funding to provide the development of physician and medical student education program in the area of nutritional support as applied to cancer.