

STATEMENT

BY

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BEFORE THE

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION
SUBCOMMITTEE
UNITED STATES HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS

APRIL 30, 1984

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco. I am National Liaison Chairman of the Metropolitan Washington Candlelighters. This association serves as the legislative arm of an international volunteer coalition of 218 groups of parents whose children have or have had cancer in 50 states and Australia, Canada, Chile, Denmark, England, France, Germany, Greece, Guatemala, Holland, India, Indonesia, Ireland, Italy, Mexico, Sweden, South Africa, East Africa, and New Zealand.

Children's cancer treatment successes have led the good news in cancer treatment for this decade. When my daughter was diagnosed in 1968, the possible cure rate for her cancer was less than 10%. Today the cure rate for acute lymphoblastic leukemia is 50% nationwide and 80% at centers of excellence in treating pediatric cancers.

A study by Dr. Robert W. Miller and Frank W. McKay published in the Journal of the American Medical Association* tracked deaths from cancer among children under age 15 from 1950 to 1979. It showed in that period:

80% fewer deaths from Hodgkin's disease, a type of blood cell cancer;

68% fewer deaths from kidney cancer;

50% fewer deaths from leukemia and bone cancer;

32% fewer deaths from other immune system cancers; and

31% fewer deaths from all other cancers.

The 1970 survival rate overall for childhood cancers was 39%. Now over 54% are surviving their disease.**

Data from 1980 show the mortality rates for leukemia and non-Hodgkin's lymphoma are still declining. But rates for Hodgkin's disease, bone sarcomas, kidney and other cancers seem to have reached a plateau.

Will the good news in childhood cancer continue? There is grave doubt if this Committee doesn't instruct NCI to stop its destructive, short sighted budgetary treatment of the mainstay of the progress in our children's cancers--the pediatric/adolescent clinical cooperative groups.

*JAMA:251-(12) 156-7-70) March 1984

**American Cancer Society Statistics 1984

Dr. DeVita was asked by Chairman Natcher if he intended to fund the cooperative groups at the amounts recommended by the peer review process. He said No--unequivocally.

In real dollars, a static budget, not tied to peer review supported amounts, means that the pediatric clinical cooperative trials are suffering cuts of 20% a year or more.

What will this do to progress against childhood cancers? It is rather like our worries over the Social Security system - it is robbing the future of its promise.

To understand the damage posed by not fully funding pediatric cancer clinical cooperative programs, you have to understand the unique position of pediatric and adolescent cancers in the United States. We represent about 7,000 new cancers a year, only about 1% of the total number of cases of cancer.

Because of the small numbers of children and adolescents with cancer, this country does not have the resources to have treatment facilities and programs in every child's backyard.

COOPs, the exciting new NCI initiative to make more widespread the benefits of front line cancer treatment is fine for adults.

CCOPs are not, however, appropriate to pediatric/adolescent cancer due to our numbers. A radiotherapist in a community might be called on to treat a young child with Hodgkin's disease about once every 5 years, or a surgeon to remove an abdominal tumor once every 5 years. This is not the level of expertise needed to deal with pediatric cancer.

In contrast, the clinical cooperative groups serve as the hub of the wheel. Through these groups children with cancer are referred to research centers usually less than 150 miles from small communities for initial definitive therapy. Much of the subsequent chemotherapy is given by the referring physician in close consultation with the regional pediatric oncology expert.

The close communication, cooperation, conferences and coordination of these groups give us the benefit of a truly national program. Their efforts have made access to to excellent major research and clinical programs, outreach and supportive care a reality to 2/3 of children and adolescents with cancer. In reality, these groups are the equal in pediatric/adolescent cancer to COOP. They are already delivering to the pediatric and adolescent cancer population the promise of access to first quality treatment and an expanded research base which it the premise and promise of CCOPs to the adult populations.

If their approved clinical cooperative group grants and their separate but equally essential cancer control programs are fully funded at the levels recommended by the peer review process, we should be able to expand the number of children enrolled in clinical studies so that over time we draw closer to 100% of our children are tied into the communication, cooperation, trial, outreach and support programs of these groups.

These groups are the equivalent of our COOPs. They are the proven and tested answer to progress and excellence in pediatric and adolescent cancer treatment. They are being slowly strangled. Without the information and insight supplied by these clinical programs, research progress and its clinical application would be slowed and new approaches to cancer cure may remain undiscovered, unthought, unexpressed.

It is the fervent hope of families of children with cancer that eventually medical school based pediatric oncology programs would be members of clinical coop trials. This will assure that all students, residents, ancillary personnel are made aware of some of the problems of children with cancer and allow them to conceptualize working with a childhood cancer center if they are one of the "local" doctors. The exceptions to this rule would be the existence of the excellent categorical institutions such as St. Jude Research Institute and Hospital.

Pediatric cooperative research should be fully funded in the amount of \$8 million.

Pediatric cooperative groups cancer control programs should be funded at \$4 million.

Mr. Chairman, Members of the Committee, on behalf of all these parents across the country, I should like again to commend the Chairman and the members of this Committee for their many efforts and their understanding of our problems. Your dedication to the cause, the cure and the prevention of cancer encourages us to face the future with a greater degree of hope and peace of mind. Those of us who have lost children are grateful that your efforts to adequately fund the cancer research will be a memorial to them. And, those of us whose children are under treatment are grateful for the hope which research gives us in maintaining their well-being.

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