

STATEMENT

BY

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CANDLELIGHTERS (PARENTS OF CHILDREN WITH CANCER)

BEFORE THE

LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND
RELATED AGENCIES APPROPRIATIONS SUBCOMMITTEE
UNITED STATES SENATE COMMITTEE ON APPROPRIATIONS

APRIL 24, 1986

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco. I am National Liaison Chairman of the Metropolitan Washington Area Candlelighters. This association serves as the legislative arm of an international volunteer coalition of 225 groups of parents whose children have or have had cancer in 50 states and Australia, Canada, Chile, Denmark, England, Finland, France, Germany, Greece, Guatemala, Holland, India, Indonesia, Ireland, Israel, Italy, Mexico, New Zealand, Sweden, South Africa, Spain and East Africa.

When I first testified before this Committee in 1970 this nation was in a crisis point in federal cancer research funding. At that time we were only projecting the ability to fund research project grants at 50%. Today in 1986, that funding rate for peer reviewed and ranked research grants is only 27%. With the ripple effect, this Committee can anticipate how far the proposed budget will set back cancer research and its application in treatment and prevention. This is dismal as the prospect of such diminished research grant funding is made even more dismal by a hooker thrown at National Institutes of Health by Office of Management and Budget fiat regarding the apportionment process.

Until 1985, OMB distributed or apportioned funds appropriated by Congress directly to each of the NIH Institutes. Under this approach the Directors of the Institutes had the flexibility to make do within the budgetary restraints by shifting funds among program mechanisms to

accommodate promising or new avenues of opportunity.

This is no longer possible. OMB now apportions all 16 NIH appropriations to NIH as a whole and specifies the amounts to be distributed by time period, by major categories of NIH expenditure or mechanism, such as grant, contract, centers etc. and by numbers of awards within selected categories.

The Congress tells NCI what funds it will get, makes a few suggestions on special areas of emphasis if needed and say--get on with it, best good use of your countries money. OMB says you are bound by every nitpicking line in your proposed budget, if you find a way to cut A, your can't shift it to immediately start on implementing research in new breakthrough B, you have to give us that money back. Good for their bottom line, bad for the patients looking for survival from cancer.

Please tell OMB to get their noses out of the tent and give the Directors the flexibility to make the best use of our money as their scientific knowledge dictates.

Dr. De Vita's testimony before this Committee well portrayed the exciting scientific times ahead for cancer research and treatment. He omitted reference however to the most important laboratory for the discovery, development and implementation of curative cancer therapy - the pediatric cancer patient.

At the President's Cancer Panel meeting in Memphis on April 11 at St. Jude Children's Research Hospital which addressed "the molecular characterization of childhood cancers and its application to innovative

approaches to cancer therapy" Director De Vita remedied that omission. Dr. De Vita stated that pediatric researchers had initiated work on the cytogenetic problems in cancer in an orderly fashion ahead of their peers working in adult cancer. This comes as no surprise.

It was this population that was the guinea pig for the combination therapies that are now translated into increasing cure and survival rates in adults. 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.

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

It is this group that now serves as the guinea pigs for progress in fine tuning treatment programs and in attacking resistant cancers and residual tumors. Our children are the tabula rosa of cancer

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

** American Cancer Society Statistics 1984

research unsullied by the bad habits and exposures of adult life, giving a clear view to the genetic and chromosomal contributors to failures or success.

The magnificent work of Dr. Janet Rowley and colleagues presented at the President's Cancer Panel has targeted chromosomal defects and changes in Acute nonlymphocytic leukemia. Due to this ground breaking work knowledge of where and why chromosomal translocations and the like take place, what they mean and what they do is laying the groundwork to target defective genes in treatment and spare healthy genes.

In childhood neuroblastoma, identification of c-myc gene amplification helps target poor prognosis cancers and single those out for more aggressive treatment as well as pick up the disease progress earlier for special attention.

This hallmark work will increase our knowledge of who may have predispositions to certain cancer to permit earlier diagnosis, treatment and potentially prevention.

Further, in selective productive therapies, research in proto-oncogene expression has revealed the genetic similarities between neuroepithelioma and Ewings sarcoma. Prior to this discovery children with neuroepithelioma were treated under a neuroblastoma protocol.

Treatment under Ewings sarcoma protocol has lead to superior treatment results. Before treatment substitution neuorepithelioma was considered an usually lethal condition. Now these children are enjoying a 93% response rate and a 60% projected cure rate.

The cyto-genetic characterization of tumors is in its infancy but it is the key to matching treatment to disease with the best hope of success. Once again, our children are the laboratory and in collegiality these pediatric cancer researchers are sharing skills, probes, tumors across institutional lines to a common purpose.

It is anticipated that the work on proto-oncogenes which has gone forward in our unique pediatric cancer projects will soon be applied to identify treatable subsets of lung and colon cancer hitherto impossible.

From basic research to bedside to long term follow-up, our children are the unique laboratory for pediatric cancer centers of excellence, joined through cooperative clinical trial relationships including the pace setting efforts of the National Cancer Institute's intramural and clinical center programs in pediatric cancer. The efforts of these professionals are enhanced by the patient and family coping and education materials conceived by the Office of Cancer Communications.

The proposed budget would compromise the continued effectiveness of all these programs which have spelled the difference between cure and merely long term survival for many of our children.

Under the proposed budget:

Our clinical cooperative programs, pediatric and adult would be reduced 20%,

Our centers programs 25% and

The functions of the Office of Cancer Communications to directly translate survival skills during cancer to the patient and family populations would be amputated.

Our please to this Committee is:

To fully fund the cooperative and centers programs, at the level that peer review has found warranted,

To retain the financial base to permit Office of Cancer Communications to do the job needed and

To fully fund and support NCI's intramural research and trial activities.

Further, fully fund PO1's the mechanism to translate research advances to the bedside.

Cooperative Clinical Research should be fully funded at \$50,204,000

National Cancer Institute Intramural program should be fully funded at \$194,847,000

Clinical Centers programs should be funded at \$135,627,000

Office of Cancer Communications should be fully funded at \$900,000.

Cancer biology should be fully funded at \$258,686

Pre-Clinical Research should be fully funded at \$176,801

Clinical treatment research should be fully funded at \$180,807.

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 the Committee for this 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.