

STATEMENT OF THE CANDLELIGHTERS

Before the

Subcommittee on Health

Senate Committee on Labor and Public Welfare

January 30, 1974

We represent the Candlelighters, a group of Washington area parents whose children have - or had - cancer. There are similar groups in 16 states. My name is Richard J. Sullivan, and with me is Mrs. Grace Anne Monoco. One of the chief aims of our group is to improve federal cancer research programs. We know that the lives of our own children have been extended and, in some cases, saved through cancer research efforts funded primarily by the federal government. In the ultimate sense, we speak for the consumers of cancer research. Since our children's lives depend upon cancer research we have become sensitive to deficiencies in the program as well as the needs to expand it.

Under the leadership of this Committee, and particularly of the distinguished Chairman, Senator Kennedy, as well as his colleague in the other body, Mr. Rogers, the Congress enacted the National Cancer Act of 1971 which the President signed into law on December 23, 1971. This "war on cancer" was a Christmas gift to the nation and all of us are profoundly grateful to you, to the Congress and the Chief Executive for this initiative in an area that touches the lives of every American family. As is true for all initiatives, this one, too, has had some of its bright hopes unrealized, and we wish to discuss some of these deficiencies in this testimony and perhaps suggest some improvements.

The first and foremost item which we wish to raise for the consideration of the Committee is resources. The National Cancer Act of 1971 authorized appropriations of \$400 million for FY 1972, \$500 million for FY 1973, and \$600 million for FY 1974. The actual amounts appropriated fell far short of this goal principally because the President requested less, and repeatedly vetoed appropriations which came close to the authorized amounts. Added to the problem raised by these lesser amounts was the impoundment of funds which aggravated an already tight situation with respect to research, and which has seriously retarded the national cancer program. It must be clear to anyone that cancer research is not something that can be turned on and off. Impoundment has without a doubt a very long negative effect on the progress of the research projects. Our children profited from the cancer research investment made in years gone by, but the loss of momentum resulting from underfunding or impoundment will seriously affect the millions of Americans who will develop cancer in the years ahead, as well as those presently suffering from the disease. The Administration has compounded the funding problems related to research by impounding positions as well as actual resources. It was only a public outcry which caused the Office of Management and Budget to release 107 positions for the National Cancer Institute required not only for research projects, but also for the cancer treatment, itself.

The \$1.5 billion which you authorized in PL 92-218 did materialize in lesser amounts, and then only grudgingly. The 60 million impounded from the FY 1974 has allegedly now been released under conditions which

make it questionable that the maximum research yield will be obtained promptly. We find it very difficult to obtain adequate information on funding and we hope that this Committee will press the Administration with vigor to determine whether or not the FY 1974 appropriations have already been released.

Despite the budget shortfalls, and despite the impoundment and despite the bureaucratic harassment, the National Cancer Act of 1971 has been a good and wise investment in the wellbeing of our country and our people.

We sincerely believe that real and concrete strides have been made which have benefited our children. We must not stop or falter. The legislation must be extended. In terms of resources, we would propose to Congress to authorize \$2.7 billion for the next three-year period. We would further propose that the language presently contained in Section 601 of Public Law 91-296 forbidding the Chief Executive to impound public health funds should be carried into the new legislation, and meanwhile this provision should be extended beyond the June 30 expiration date. We feel that \$2.7 billion divided over a three-year period is a realistic amount, given the base of the first three-year period and the high rate of inflation which has lessened the value of the amounts initially proposed in the 1971 Act.

We further ask that the limit of 15 national cancer research centers be stricken, and that the legislation leave the number to the discretion of the Director of the National Cancer Institute. If this is not possible, we would ask that the number be raised to 33. We know

from our own groups around the country of the hardship it places on many patients to drive very long distances for the frequent treatments necessary to abate the course of the disease. Unless such centers are within a one day's drive for a patient, it will place out of reach the absolutely essential elements of treatment for a very large number of Americans who are so affected. We must enable the largest number of Americans possible to benefit from cancer research. A larger number of centers are essential for this purpose.

We have alluded earlier in this testimony to the impoundment of positions. This is a very serious matter. Obviously additional resources cannot be effectively utilized if personnel positions remain frozen. Provision should be made in the legislation to free the Director of the National Cancer Institute from the bureaucratic restrictions placed upon them by the NIH and the Department of Health, Education and Welfare. It does not seem very logical to promise the American people a cancer control program and then not allow positions to be filled. We could tell some horror stories of cancer wards at NCI remaining empty because of lack of personnel, and laminar flow rooms, which could have prolonged a child's life, being un-utilized because of positions which could not be filled. We must not permit some faceless bureaucrat to superimpose his judgment on personnel over those of the Director of the National Cancer Institute.

We also believe that separate provisions should be made in the new Act for the funding of a cancer information clearing house which would provide to the physicians and the public current information on cancer treatment.

We hear from our members all too many stories of misdiagnosis and mis-information which has caused needless suffering and frequently has prevented timely and adequate treatment for this disease. There is a tremendous gap between what could be done for the cancer patients and the care that individual physicians are delivering. The following example might illustrate the point: children who have leukemia must undergo periodic bone marrow tests, a very painful procedure where a needle is inserted into the hip bone and the marrow is extracted in search of the leukemic cells. Some of the Florida Candlelighters told us of a new method whereby the parent can attach an anesthetic bandage to the hip three hours prior to the insertion of the needle, which relieves the patient of most of the pain.

We informed the NCI and, finally after a considerable period of urging, the NCI has now adopted this method of preparing the patient for a bone marrow test. The pain and suffering which could be avoided by the dissemination of just this little piece of information alone would make the insertion into the Act of a provision for the cancer information clearing house very worthwhile.

The present language of the Act, for an international research data bank, deals only with research, and we need to do so much more with respect to treatment, particularly information to the family physician or pediatrician who is usually the first doctor contacted with respect to the disease.

The family physician needs a central information center which can give him the most comprehensive and specific information on the

treatment of each specific cancer problem that he may encounter. Such information will also permit the parents of the stricken children and older cancer patients to cooperate completely with the physician in charge of their child or relative's treatment to provide the proper nutrition and supportive environment for the optimum success of the treatment program.

The knowledge in the data bank must constantly be updated and changed; and it seems to us that only the NCI itself can do this task. Cancer victims, their families, the parents of children suffering from the disease, should have the peace of mind that the treatment which is being given is the most up-to-date, and is the best that can be provided. We strongly feel that this is presently not the case, and it would be a wise investment to create a cancer treatment information center.

In the past few years, we have received many questions concerning nutrition, both from our Washington membership and from other parents around the country. We have learned that there are some isolated research projects in this area being carried out in various parts of the country supported by NCI funds. However, there is no coordinated nutrition effort at this time. With so many foods and food additives being declared carcinogenic by the FDA, it is very confusing for the average housewife to know what she should or should not feed her family. Furthermore, when you have a cancer patient on a sophisticated drug regimen, this problem is greatly compounded. Thus, an enlargement of the research effort in this area and a coordination and dissemination of the results of these efforts through the public data bank we have just discussed is greatly needed.

We hear again and again of the interference by the Department of Health, Education and Welfare and by OMB in the work of the National Cancer Institute. Despite the language presently in the Act, HEW regulations require that the head of the Cancer Institute must clear any public statements with HEW. We believe this to be totally wrong. The American public has every right to hear directly from the head of the NCI without clearances from the HEW hierarchy.

We further believe that OMB, HEW and NIH have illegally interfered in the allocation of positions and resources to the NCI, and feel that there should be new language in the extension of the law to prevent such interference in the future.

In the past three years, the bureaucratic interferences have negated specific authorization and appropriations for such items as training programs. The will of the Congress has been expressed by means of authorizations and appropriations, and the executive branch must be made to obey its constitutional mandate to faithfully execute the law. We leave it to the Committee to find the means of doing so.

Mr. Chairman, we are grateful to you and to the Committee for permitting us to appear before you. We want you to know that cancer research has been effective, not as effective as we would have hoped it would be, but, nevertheless, strides have been made and the lives of our children, in many cases, have been prolonged, and for this we are grateful.

The recommendations that we have made are intended to strengthen the program. Our criticism was not meant in any derogatory sense, but

is evidence of our desire to overcome the deficiencies which we have found. The war against cancer will not be won easily and cheaply. An advance has been made. We ask you to extend the Act for a second stage, during which we hope that the progress will be more rapid.

Thank you.