

Statement of the Candlelighters before
Subcommittee on Labor, Health, Education and Welfare

Committee on Appropriations

United States House of Representatives

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco; I am representing "Candlelighters," a national organization of families with children affected by cancer. We wish to bring to your attention those areas in which federal funding has had the most noticeable impact on our children's lives and those which we feel merit your further attention either through program re-direction, emphasis or increased funding levels or position allocation.

This statement is the product of the Candlelighters groups in 30 states. It also reflects information obtained from other parents' groups who have responded to questionnaires on the status of the cancer programs in their respective areas and the effect of federal funding efforts on those programs. I am accompanied by Mrs. Beverly McGaughy, President and co-founder of the Metropolitan Washington area Candlelighters group.

Let me first extend on behalf of all of us our deep gratitude and appreciation to you, Mr. Chairman, and the members of this Committee for your continuing efforts on behalf of all persons afflicted by cancer. Your unflagging interest in cancer research and the translation of this research into tangible programs for detection, treatment and rehabilitation of cancer victims throughout the country has widened the benefits of the whole cancer effort. We know that the lives of our children have been, and are continually being extended, and in some cases preserved, through the cancer research efforts which this Committee has supported through the National Cancer Institute.

Our testimony reflects the provisions of the National Cancer Act, as amended in 1974, and the positions taken by this Committee in terms of funding and program, in its appropriation for the National Cancer Institute for fiscal 1976.

Our testimony this year focuses upon the following areas of the cancer program -- nutrition and cancer; the cancer control program, which is the key to the translation of the results of the federally funded cancer effort into programs that reach the public at large; the problems of carcinogenesis; psycho-social support programs; the need for a strong toxic substances act; the continuing problem of impoundment of positions at the Institute; and the needs of the NIH Clinical Center that must be met if it is to fulfill its mission of acquiring knowledge through clinical research without sacrificing the highest quality of medical care to its research subjects.

With respect to overall amounts, the \$687.8 million requested by the President for fiscal 1977 is substantially below the amount necessary to sustain, and completely inadequate to carry forward, the National Cancer Program. In dollars it is \$75 million, or 10%, below the fiscal 1976 appropriation, and less than the current inflationary factor. Making proper allowance for the actual inflation rate, maintenance of the status quo in the cancer program requires an appropriation of \$880-900 million and the forward momentum of the program requires an appropriation of about \$965 million.

Diet and Nutrition. In our opinion, Dr. Gio Gori, head of the Diet and Nutrition in Cancer Program has done an excellent job of getting the program off the ground. We are very pleased with the program thrusts in both etiology and treatment of cancer patients. Obviously the American public needs to know as much as possible about the possible causes of cancer connected to their diet. In addition, all of us have known the malnutrition problems experienced by cancer patients during the course of their disease which impair the quality of their remaining life, their ability to tolerate the treatment, and contribute to their early death. Both of these areas need to be explored fully, and NCI's Diet and Nutrition has rightly decided on this two-pronged approach.

Now that they have defined the questions to be answered and delineated the promising areas of research to tackle, it is time to support them with more than words and the current 2 quarter-time, borrowed job slots. Therefore, we are requesting \$15 million for Diet and Nutrition for fiscal 1977 and three (3) full-time positions as a special line item in the budget. We realize that this line item designation is unusual, but in our opinion it is necessary to keep the other parts of NCI from dipping their fingers into this relatively small pie. Since this is such a new program, there is a great temptation by the much larger, established programs to ignore it and deprive it of needed funds. Thus, until it is also well established in the minds of everyone, we feel it must have the protection of this special line item designation.

Cancer Control: The Cancer Control and Rehabilitation Division was incorporated into the cancer program authorizing legislation in 1971 in order to provide for a real need recognized by Congress -- to bridge the gap between research and the application of that research in the practice of medicine and public health programs.

the seed money provided by control for demonstration of these research results is working to bridge the gap.

Some examples are the beginnings of a communication network (Controline) through the comprehensive centers developed with the assistance and involvement of local agencies, public and private, concerned with cancer, most prominent in this effort the American Cancer Society. Through these systems another link has been forged to close the gap in providing each U.S. citizen access to what is known about cancer.

Community-based cancer programs are in the planning stage which will demonstrate to communities, particularly those which do not lie within the ambit of a cancer center, how they can assess their needs in the cancer control area and provide for them, utilizing the best information and results available to them from federal research efforts. This program is another move toward the fulfillment of the concern of Congress that all segments of the population have access to the results of the federally-funded research and programs.

One very important effect of the control program has been its function as a catalyst to bring together all aspects of the public and private agencies dealing with cancer and encouraging them to work together so that input from the total community will be received in assessing the cancer control needs of each population involved and developing the ways to meet those needs through cooperative efforts decreasing fragmentation and costly duplication of cancer programs. A particularly notable example of this lies in the Detroit area implementation program under the community based cancer programs. The local press and medical community has heralded the cooperative effort of the American Cancer Society and the Michigan Cancer Foundation with widely divergent attitudes toward programming for cancer in this implementation effort.

Finally the cancer control program has demonstrated acute common sense in its approach to programming for cancer control. It has felt the Congress' concern with spiraling costs of hospital-based care and it has therefore initiated a series of projects to determine, for example, whether at home rehabilitation and continuing care programs can work and be cost effective. It has realized that the federal treasury is not a bottomless pit and has taken steps to begin the development of guidelines that will enable the community hospital or other agency participating as a grantee or contractor in a demonstration program to achieve financial self-support during the phasing out of federal funds, thus providing some certainty that these demonstration programs will be continued after withdrawal of federal funds.

The Administration's proposal for the cancer control program funding for fiscal 1977 would decrease this program's funding by

over \$5 million and eliminate needed position slots. The control program should be allocated at least \$75 million for fiscal 1977 and an additional ten (10) positions so that its mission of providing the transition of federal research results to the public at large can be pursued with vigor. This appropriation request includes 500,000 for the development of a strong cooperative program in conjunction with NIMH in developing studies in handling psychosocial support programs.

Cancer Prevention -- Carcinogenesis. During this past year, the NCI has performed a major service for us, and for the world, in assembling and publishing very detailed survey reports on the geographic distribution of cancer. Some of the most publicized portions of these reports have shown spectacularly high levels of cancer incidence in areas of chemical pollution, such as the heavily industrialized Northeast. Other areas show abnormally high incidence rates that indicate a relationship of cancer to diet.

With the release of this data, some of the localized causes of cancer become more apparent, and thereby avoidable. And the evidence increases that the major gains in the future fight against cancer lie in prevention rather than cure. If a chemical plant is releasing quantities of asbestos into the air or drinking water, this can be prevented. If our children and infants are being swathed with talcum, we should not tolerate any trace of asbestos in that talcum. If Red Dye #2 is carcinogenic, we can eliminate it from our food. And as we continue to identify carcinogenic agents in the air we breathe and the food we eat, we can eliminate them or minimize our contact with them.

This approach to reducing our exposure to carcinogenic agents can be simple to implement when we can clearly identify the agent and when we know that it is carcinogenic. However, there are many potentially carcinogenic foodstuffs, and environmental pollutants for which our knowledge of their effects on our bodies is not sufficiently known. For the future, knowledge of how our body reacts to the many chemicals to which we are exposed must be increased significantly so that our health can be protected.

The problem is vast. Each year new knowledge is gathered, and with that, a realization of how much remains to be grasped. As just one example, it was not so long ago that it was believed that most of the major metabolic pathways of our bodies were well understood, and now we find vastly greater unknowns than we imagined. This complexity of metabolic pathways is highlighted in two recent SCIENTIFIC AMERICAN articles on the liver. This organ, the liver, is a metabolic center of vastly greater complexity than we imagined just a short time ago. Relative to how the body treats ingested pollutants, the liver performs the major housekeeping function. It produces the enzymes to break down foreign substances and

provide a first line of defense against them. We know that the liver has enzyme systems that digest the many foods we eat --- it has enzyme systems that attack waste products within the body to prepare them for disposal, and it has enzyme systems that break down trace poisons that we have eaten or that have entered our body through the lungs in order to prepare such poisons for ultimate disposal. In performing these functions, which poisons get through these defenses? Which get through and lead to cancers? At what levels of exposure? And the most ironic question of all: Which non-carcinogenic substances does the liver turn into effective carcinogens as it attempts to treat them for disposal? We must take steps to answer these and other questions for the liver and for all of the body's cancer-related biochemistry. To prepare for this, now is the time to begin a new emphasis on the scientific studies that are to be the basis of a broader future understanding of the biochemistry of our bodies. This is particularly important for those biochemistries that are most active in metabolizing ingested pollutants, trace elements of heavy metals such as lead, arsenic, etc.

We recommend several immediate steps to set the basis for greater future gains:

1. In prevention, we recommend that \$20 million and fourteen (14) positions be added to the Research program of Cause and Prevention Research. This increased funding should be used in support of environmental carcinogenesis research.
2. We recommend that an added \$10 million and six (6) positions be spent on Cancer Biology to broaden our understanding of the body metabolism as it reacts to potentially carcinogenic agents and also to lay the basis for a broad future understanding of other potentially applicable areas of our biochemistry.
3. To better tie together and administer the above two efforts as a unity, we will recommend to the Committees considering the 1977 Cancer Act Amendments that a new Research area be established that would be based in the biochemistry of the body. This new area would include the current environmental carcinogenesis and nutritional programs from Cause and Prevention Research, as well as the research elements on chemical factors that contribute to induction of cancerous cells from the Cancer Biology program. This new Research area would be an administrative mechanism for the NCI to bring together those entities that are enabling it to establish a world-wide leadership role in developing the scientific understanding of the effects of trace elements, chemicals, etc., on our bodies and on our health.

Toxic Substances Act. We realize that this Committee is not directly involved in toxic substances legislation. However, in line with your interest in carcinogenesis, we would urge all of you to support a strong toxic substances act. Because of the great expense associated with testing even a single substance, it is patently ridiculous to expect NCI to test all of the thousands of new substances that are introduced into our environment each year. Yet we know that more and more of these are posing threats to the health of all of us. The public is becoming increasingly suspicious of industry's current practices. Therefore, we believe that disinterested government-regulated laboratories must perform these bioassays before any new substances are introduced into the environment, with payment for these tests being made by the industry.

We believe that a strong toxic substances act could have prevented the current horrors of kepone, nitrosamines, polyvinyl chloride and the seemingly endless list of chemical abominations assailing the American public in their newspapers each morning and on the television news at night.

Psycho-Social Support. There is no worse destruction than the destruction of the human spirit. It is for this reason that Candlelighters have been talking about the need for psycho-social support for young cancer patients and their families for several years now. But little has been done in the area. In the meantime, 2,000 to 3,000 new patients are diagnosed each year and most are destined to live in a kind of purgatory, a delayed death sentence hanging over their heads. Traditionally, diseases are characterized as chronic or fatal. But our children's disease is usually both at the same time ---chronic because they live with it for a long time, but fatal because they eventually die from it. Ten or fifteen years ago most children with cancer lived a very short time, so the need of these children and their families for psycho-social support -- while undoubtedly intense -- was short lived. Now that they are living so much longer, but often with a great deal of both physical and psychological pain, we believe this problem must be addressed.

To start with, there have been very few studies of people in our position, but the results of those few have been quite frightening. Dr. Kaplan at Stanford came up with a family disintegration figure of 80-85%. This includes both parents and siblings, divorces and psychiatric problems. At St. Jude's, the family break-up rate was 70%. Therefore, when a child is diagnosed with cancer the family is also, in effect, diagnosed as heading for major, if not unsurmountable, problems.

We have even heard many doctors admit privately that children with cancer and their families take much more of the doctor's time than do adults. Indeed, the adult oncology branch at the NIH Clinical Center has only one more senior staff clinician than the pediatric oncology branch, even though it has twice as many patients. Presently this branch has one child psychiatrist who is there one half day a week to consult with the staff, but not with the patients or their families. Therefore, we are requesting one full-time position to remedy this situation.

It is an oft-repeated truism that in treating children with cancer the doctors are really treating the whole family. Yet there is so little known on how to prevent family breakup, that it is obvious that some well-thought-out studies must be conducted first.

The Cancer Control and Rehabilitation Division through its authority to conduct research in the area of the rehabilitation of the cancer patient has contracted out some studies dealing with the psycho-social impact of cancer. One of these studies deals with the impact of pediatric cancer on the family group, ways of dealing with it and ways of coping. It is being done by Dr. Shirley Lansky, psychiatrist, at the very excellent University of Kansas pediatric cancer program. However, Cancer Control has no in-house capabilities to conduct research in this area. For that reason we recommend that an inter-agency agreement be worked out with the National Institute of Mental Health, which has such in-house capability, to vigorously explore the impact of psycho-social support on the cancer patient and his family

NIH Clinical Center. The NIH Clinical Center was created by Congress as an institution whose primary mission is translating proven laboratory research into the most effective clinical research and care as quickly as possible. There are several obstacles currently standing in the way of the achievement of the goal of the continuation of a high caliber program. The most notable of these obstacles is the lack of positions. The impact of this lack of positions ranges from an inadequacy in the maintenance and housekeeping at the facility through the spectrum of supportive personnel for the clinical management and care of the cancer patient.

For example, our members have noticed that although the lobby is always bright and shiny, the less public areas leave a lot to be desired in terms of cleanliness which can be traced to a lack of housekeeping personnel. When some of our parents in great distress complained that they weren't getting the psycho-social support they needed, we learned that the social work program had been cut in half in the past two years. There is a clear need for three (3) additional social work positions. The Clinical Center does not have a non-surgical intensive care unit. Such a unit is needed, together with requisite supportive personnel. We therefore request a line item to provide for such a facility within the Cancer Institute's units at the Clinical Center, and twelve (12) positions to support it. Finally, the inadequacy of nursing coverage at the Clinical Center for in-house patients continues. This is particularly evident in the evenings and on weekends. Patients and their families often feel that they must serve the nursing function themselves even when the patient is terminal. We therefore request that fifty (50) job slots be provided for nursing services.

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Mr. Chairman, Members of the Committee, on behalf of all these parents across the country, I should like again to commend you for your many efforts and for your understanding of our problems. Your dedication to the discovery of 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 our children are grateful that your efforts to adequately fund cancer research will be a memorial to them. 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 that this Committee has played in this effort to conquer cancer. Thank you for permitting us to appear before you.