STATEMENT OF THE CANDLELIGHTERS BEFORE THE SUBCOMMITTEE
ON LABOR, HEALTH, EDUCATION AND WELFARE

COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE
JULY 1974

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco, Chairman of the National Liaison Committee of the Candlelighters. This statement is the product of Candlelighter groups and their affiliates in 16 states, most notably the Washington Metropolitan area group, South Florida, Pittsburg, and a Candlelighter affiliate, IMPACT, in New Jersey. I am accompanied by Bob Bogorff, Co-founder of the South Florida Candlelighters and Mr. and Mrs. Lester Naegle, founders of IMPACT.

As the members of this Committee know, Candlelighters is an organization of parents in 16 states whose children have died from or are currently under treatment for cancer. As we have indicated in previous appearances before this Committee, we feel that we are in a good position to inform the Committee on the effect and results of the funding efforts on the consumer level. As in the past, we wish to bring to your attention those areas which we feel merit further attention or where increased funding levels or new funding is required.

Before entering into a discussion of the various aspects, I would be remiss if I did not extend on behalf of all of us our deep gratitude and appreciation to you, Mr. Chairman, and the members of this Committee for the efforts on behalf of the afflicted and, in particular, for the unflagging interest which this Committee has shown towards cancer research and treatment. We know that the lives of our children have been extended and, in some cases, preserved through cancer research efforts which this Committee allocated to the various elements of the National Cancer Institute and in conjunction with some private sources. We know, as I am sure you do, the importance of building on the great progress already made in this field so that the aspirations contained in the National Cancer Act may be realized.

Since our children's lives and the lives of future cancer victims depend upon cancer research progress, and the translation of the results of this progress into improved methods of

diagnosis, treatment and rehabilitation, we have made it our business to become informed about the various facets of the various different programs so that we might be in a position to inform you.

In preparing our testimony for this Hearing, we have related to the provisions of the National Cancer Amendments of 1974 as approved by the House and which are presently awaiting action on the Conference Report.

With respect to the overall amounts, the $600 million requested by the President for the 1975 budget would appear substantially below the amount necessary to carry forward the program along the lines contemplated in the Authorizing Legislation. If one looks to the inflationary factor alone, the small increase from the 1974 budget would be retrogression rather than an increase. An interesting table is contained in the House Report No. 93954 accompanying the National Cancer Amendments of 1974, which shows the appropriation in terms of the value of the 1965 dollar. Even without taking account of the inflation which has taken place since that table was compiled, the amount specified in the President's budget request would be less than $400 million in terms of the deflation to which I have referred.

If one takes account of the built-in increases, including those for salaries and for the higher costs of construction, the amount available for research in this sector, which is of such vital interest to us, might suffer material reduction. This, we believe should be avoided at all costs and we urge this Committee to take appropriate action on the line items regarding the NCI so that the amount set aside for research and other elements discussed in this testimony will not be adversely affected.

It would appear to us that the total amount which should be appropriated for NCI for FY 1975 should be the authorized amount of $800 million. There are a number of specific areas which we would like to bring to your attention, including two which we recommended to the Authorizing Committee. These deal with "nutrition" and "information services".

Comprehensive Cancer Centers

The amendments to the National Cancer Act provide for an expansion of the number of comprehensive cancer centers to 35. This expansion, which will take 5 to 10 years to implement, may go a long way toward insuring the best quality care to most of our population. However, the effect of the

comprehensive cancer center toward meeting this goal depends upon those centers not being centers in name only but truly centers of excellence, which the name would suggest, in all areas of cancer care.

As you are well aware, NCI does not "fund" cancer centers as such, it provides some organizational seed money when the center is designated. But as recognized by the NCI, the core grants provide only a small part of the operational costs; the remainder of the operational costs are supplied through individual research grants, center grants contracts, and non federal sources. To become a comprehensive cancer center, the center must therefore compete for research grants, contracts, fellowships, training funds, etc. It is unusual if all areas of cancer treatment at a newly designated center would approach the same level or degree of excellence. For example, it might have an excellent and innovative radiotherapy staff but might need upgrading in neurology or pediatrics, or pharmacology. How do we bring the other areas of the center up to the standard of excellence envisioned by the term comprehensive cancer center, --how do we maintain the degree of excellence in the departments that are already excellent, through competition for federal moneys; to fund innovative programs.

That is where the "rub" is with respect to the goal of cancer centers of a uniform degree of excellence in the spectrum of programs offered. It is current NCI funding policy to give grants to investigators for programs. Well endowed medical schools and institutes which maintain large and prestigious staff continue to attract the bulk of program funding in both the basic research and clinical trial areas. The core support money appears to be insufficient to provide innovative investigative support to a staff which usually because of an overwhelming case load does not have the time and also lacks the specialized expertise to draft grantable programs. Therefore the established and prestigious centers which have the time and funds to support innovative staff investigators to draft programs, will continue, albeit on merit, to get the lions' share of federal funds. If the policy continues as it now exists, new centers will have to struggle along for years while slowly attracting and building up a quality staff necessary for a center's all around strength.

Obviously any sort of preferential or quota system is inappropriate to remedy this problem. The most excellent program responses should be the ones funded. However, we would urge this Committee to allocate the additional sum of

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Obviously any sort of preferential or quota system is inappropriate to remedy this problem. The most excellent program responses should be the ones funded. However, we would urge this Committee to allocate the additional sum of

$2,400,000 to provide for the support of additional innovative investigators for new centers. This will enable new centers to reach their goal--the goal promised by the Cancer Act and expected by the community--of all around excellence in cancer treatment sooner. By way of illustration of this problem, we cite as an example the current situation in South Florida. The Miami Comprehensive Cancer Center which has some excellent cancer programas received $2.9 of the $13 million requested for its first three years. The ten worthiest proposals were funded. However, there are some departments which have excellent staffs and good treatment facilities but because of an unbalanced patient/physician ratio are deficient in personnel who have the time and special expertise to devise and draft grantable programs. For example, the pediatrics, radiotherapy and pharmacology departments need assistance in this area. Fortunately, there was sufficient unearmarked money in the center's funding to bring in one investigator who will probably be assigned to assist pediatrics. However, this will not help the upgrading in other departments with similar problems.

The expansion of the number of comprehensive cancer centers in the next 5 to 10 years should alleviate one major problem connected with obtaining the best possible cancer treatment which we experience now,--distance. In New Mexico, to reach a comprehensive treatment center patients travel from 100 to 400 miles, even drawing from Arizona Indian Reservations. Also traveling a distance for treatment, when unnecessary, may be forced upon patients for economic reasons. New Jersey pediatric patients travel from only a few miles to over 75 miles one way. However, driving 75 miles for in-state cancer care is too far for a desperately ill child, at least for those patients situated in the northernmost or southernmost areas of the state who are closer to care in New York or Philadelphia than that which is available in New Jersey. Even if it is more convenient for a family so situated to go to New York or Philadelphia to receive care, there are economic reasons why they may not be able to go. For example, according to our experience, the State funded the Crippled Children's Program which reimburses some cancer care costs will not pay for any services out-of-state unless they are <u>totally</u> unavailable in New Jersey.

<u>Personnel Requirements</u>

The National Cancer Amendments of 1974 provide that the Director of the NCI include, in conjunction with his budget estimate, an estimate of the number and type of personnel needed for the implementation of the National Cancer Program. This

procedure was included in the amendments to isolate the real job slot requirements of the program and to enable the Congress to realistically provide for the meeting of those requirements through the appropriation process.

It is clear that without adequate personnel the program will falter. The following examples serve to illustrate that the personnel situation at the NCI is graver than any of us were previously aware of. For example, one of the senior scientists who runs an active laboratory is also responsible for the oversight of a six million dollar program in cancer prevention but has only one secretary to help him fulfill his obligations. Obviously the quality of either his on-campus lab work or his off-campus supervision has to suffer.

Another example with potentially frightening implications is the lack of personnel handling drug requests. In 1969 there were approximately 25 requests per day for a total of 50 drugs. In 1974 the average daily requests have doubled while the number of drugs requested has increased 150%. Unfortunately there are the same number of people handling the requests today as there were in 1969. When one stops to realize that these requests involve new drugs that must be monitored closely, the potentially explosive nature of this personnel situation is apparent. Therefore, we ask that this Committee give close attention to the very real personnel needs of the NCI and allocate financial support for at least 25 additional positions.

Psycho-social Support

This Committee has heard from us in the past about the importance of psycho-social support to the patient and the family group undergoing an experience with cancer. This type of supportive care, where available, has been shown to improve the quality of treatment and enable the family during and after crisis to function as a cohesive supporting family group instead of breaking up, with the resultant drain on themselves and on society, NCI has recognized the importance of this assistance in treatment and rehabilitation and has initiated a request for proposals dealing with this area.

This group counseling or psycho-social support should be made available not only to the patient and his family but also to the medical staff in dealing with the problem of the terminal patient. A common complaint of our groups both local and national is that many doctors were largely unable to deal with the terminally ill patient and his family. They tend to be mechanical, impersonal and curt and this problem becomes more severe when the child approaches death, when the support

should be the strongest from medical and nursing personnel. Unless medical personnel can cope and come to terms with their own feelings about death and dying, they cannot give the type of support required by the terminally ill child. Indeed, how can they appropriately monitor the child if they try to avoid him. It is an incredibly frightening experience for a parent to be left virtually alone with his dying child. For this reason we request that NCI be directed to include within the definition of cancer related subject in its clinical training program to advance the education given by medical schools in cancer related subjects, programs related to the training of the physician and nursing personnel in how to deal with death and the dying patient. We also request that these programs be expanded to permit inclusion of practicing physicians in the cancer area.

We realize that this Committee can go no further than provide the funds for demonstration projects in this area. However, we would ask you to talk to your colleagues who deal with national health insurance legislation to include coverage for all kinds of cancer rehabilitation programs, of which this is one type.

Neurologic Diagnostic Evaluation

As the survival statistics applied to cancer patients on chemotherapy and radiotherapy lengthen, problems arise which were unknown when the patient's lifespan was compressed into 2 or 3 years, e.g. an increasing number of neurologic disorders resulting from chemotherapy and radiotherapy. For example, nerve damage, paraplegia, meningistic impairment of cognitive function, muscle pain and atrophy are surfacing. Since one of the goals of the cancer control program is to focus on rehabilitation--the best quality of life as well as the ever lengthening life span--, it is imperative that evaluations of patients be done to assess the damage chemotherapy or radiotherapy is causing neurologically and to pinpoint its cause and take steps to correct it. Funds to support this type of evaluation work would not be included in most normal insurance coverage. We would ask this Committee to require NCI to initiate demonstration projects which would evaluate the new and existing patient neurologically as well as medically and hematologically and as part of these projects, to undertake to convince major insurers to include such evaluations in their insurance coverage.

Insurance Coverage

The area of insurance coverage is one which strikes hard at the parents whose children are under treatment. Even if you have taken a major medical policy and consider yourself well covered, you have not protected your family when cancer strikes. For example, some insurance carriers do not consider chemotherapy a recognized treatment for cancer and will not reimburse it; some will not pay for recognized rehabilitation needs; some will not pay for psychiatric or group counseling sessions or for experimental drugs, etc. If this Committee is to be assured that once the NCI has demonstrated the effectiveness of cancer diagnostic treatment and rehabilitation programs, that these programs are not dropped but continued; it is essential that the insurance community review and revise their coverage standards to reflect the up-to-date procedures which are the crux of cancer treatment and rehabilitation.

We hope that this Committee would utilize its good offices in bringing to the attention of your colleagues who are concerned with health insurance legislation the great and vital need for an early change in the attitude of the insurance industry with respect to the coverage of proven diagnostic, treatment and rehabilitative procedures connected with cancer.

Laminar Flow Facilities

One of the successes in the cancer program pointed to by NCI is the reduction of deaths due to infection related to acute leukemia through the use of protective environments and antibiotic therapy. The findings of NCI make it clear to us that every center or hospital employed in clinical trials for NCI should have laminar flow facilities. One of the reasons they are not being included in privately funded hospitals is that there are no funds available to sustain them. One reason may be lack of insurance carrier coverage for such facilities. For instance, the new Childrens Hospital here in Washington for lack of funds has not planned to put in any laminar flow room.

Cancer Control

Even after the expansion of Comprehensive Cancer Centers, we must still rely on local physicians for diagnosis and follow-up care. At present in the areas in which we have Candlelighter chapters or affiliates, there are no federal privately funded programs designed to educate the family physician or pediatrician on the best methods for detecting cancer. Early proper diagnosis

is often critical in determining the patient's chances of survival. Unfortunately, however, misdiagnosis of childhood cancers, from the experience of our members, is the rule rather than the exception. The experience of one of our local Candlelighters families is a case in point: Following a playground accident, they took their child to a local hospital where X-rays were taken and the child was examined by two staff physicians who concluded that it was merely a soft tissue injury. Two months later a prominent and thoroughly experienced orthopedist pronounced the child neurotic when he was not responding to the treatment he prescribed and in fact his condition was deteriorating. Two more months passed before the child was diagnosed as having acute lymphocytic leukemia. Four valuable months were lost. The symptoms and objective evidence was available from the time of the original hospital visit but the physicians were incapable or neglectful of interpreting them. Other examples are: Wilms tumor diagnosed as an impacted bowel; leukemia frequently diagnosed as flu or rheumatoid arthritis or even malingering. The importance of and need for full support of the cancer central program is further cogently demonstrated by an experience of a Candlelighter member. Ten years ago when the son of one of our members was being treated at Sloane-Hettering in New York, she was shown the equipment for breast mammography and had the procedure explained to her. Last week in the Washington papers she saw the breat mammography program heralded as the newest and most promising breakthrough in the detection of breast cancer. The approximate ten year log demonstrates the crying need for the cancer control program. For this reason we request the fullest support of the cancer control program so that through the expansion of information systems and demonstration projects, the facts on cancer diagnosis and treatment can be disseminated to all physicians. For this we request that the fullest authorized sum of $50,000,000 for fiscal year 1975 be appropriated for the Cancer Control Program.

Information Services

The Authorizing Committees included in the National Cancer Act Amendments of 1974 language suggested by Candlelighters which would require NCI to devise means to interpret and disseminate new and existing knowledge and information produced by the Cancer Program to researchers, practicing physicians and the general public. The outlay required to implement this program for fiscal 1975 is $3,000,000.

In this connection, pending implementation of cancer control information and education projects, and the information services provided for in the 1974 Cancer Act Amendments, the

information burden at NCI falls upon the Office of Cancer Communication. It was this office which was mentioned as the disseminator of information by Dr. Rauscher in his testimony before the Committee. It is this office which was given as the information access reference in a recent Public Broadcasting System special program on cancer. Also, it is this office which has responded fully and informatively to many inquiries made by Candlelighter families and their physicians with respect to materials available on a disease or its treatment, a medican contact within NCI to talk to and information on where there are comprehensive cancer care facilities available in their area. However, the personnel in this office has recently been cut back by 25% as part of an overall cutback in HEW public information offices. It is impossible to do the job expected of this office pending any Cancer Control Program or information services development without proper staffing. The Committee has demonstrated in the past that it is not content with paper tiger programs, --programs that look good on paper but cannot deliver. This Committee wants working programs,--programs that really are able to reach the people they are designed to help with information. We would suggest, therefore, that at least 6 additional job slots be provided to implement the function of the Office of Cancer Communication and return it to the level of its operating strength during 1973.

Training Grants and Fellowships

In connection with our testimony of last year, we pointed out that there are three definite purposes that training grants and fellowship programs serve in relation to the conquest of cancer:

A. They provide the economic support needed to encourage qualified young physicians to concentrate on the less lucrative cancer connected specialties.

B. They provide the increase in skilled manpower available to implement the cancer program on all levels.

1) They provide during training the additional personnel needed by the clinical trial centers to insure that those trials are carried out completely, the subjects monitores sufficiently and the results reported comprehensively.

2) And at the matrix of the cancer program, which is the National Cancer Institute, they provide

> the constant questioning needed by the older established researchers to spur them on in their creative efforts. Of course, as you all know, they also provide the lab support needed to permit them to carry out the research programs these ideas engender.
>
> Unfortunately, because the current level of staff fellow support is so low, there are very real fears on campus that several established NCI researchers may leave for universities where they will at least have graduate students available to them. Candlelighters considers this possibility a grave threat to the whole cancer program. We consider this possibility a grave threat to the whole cancer program 1/

We also indicated the experience of the clinical centers treating our children, namely, that the principal investigators had received their basic training through federal grants and had stayed in the field.

To provide a level of training and fellowship support which will not permit the above objectives is to short circuit the cancer program now and for the future. Without sufficient manpower to implement the programs, increased funding is useless.

One example of this folly is the current dilemma of the excellent clinical trial program at the University of New Mexico School of Medicine. Because of the cutbacks in fellowship training grants by NCI they will only be able to fund one fellow for fiscal year 1975, instead of two to three which they really need. If the level of support is not restored and increased, the additional medical personnel will have to come from private funds committed to other vital areas of the Department's cancer program.

1/ The authorizing legislation to remedy this problem by increasing the level of staff fellowship support,-H.R.7724, has passed both the House and Senate and awaits the President's signature. For this reason it will not be included in this appropriation but will be a part of the omnibus health supplemental appropriation bill planned for later in this session. However, we are including information on this problem and its proposed remedy in our testimony because it is necessary to a comprehensive overview of problems relating to training grants and fellowships.

For example, the Department has an excellent program in the area of rehabilitation for the cancer patient and his family. Group and individual counseling is available to children and adult cancer patients and their families. This program should be expanded but if funds for additional medical personnel are not forthcoming from private sources, there is therefore the possibility that the moneys used for the part-time social worker running the counseling programs which are contributed by the Leukemia-Lymphoma Society of New Mexico could be rerouted for medical personnel. The supportive care furnished by the University of New Mexico is the sort of program which NCI is now encouraging as part of the Cancer Control Program. This is the kind of program which parents know is essential to survive this scarring experience. This type of program helps the parent/child face their joint problems and give each other the support needed to make the best use of the treatment program and to emerge a whole, productive family unit after the experience. It is ironic that the level of support for fellowships and training could place UNM in a robbing Peter to pay Paul situation. Thus it could be necessary to de-emphasize a far reaching rehabilitation program to provide needed personnel for the clinical trial program. Another example is one reported by Candlelighters in Pittsburg in which the same procedure was followed at Childrens Hospital in Pittsburg. Because of a cutback in the level of federal funding, the part-time social worker which they made available for group counseling was terminated.

We have already pointed out the importance of adequate staffing for conducting the most intensive and productive clinical trials. At present, there does not seem to be any consideration given in the NCI funding process to the ratio of patients to clinician. Obviously there are only so many patients that a single physician can treat and monitor comprehensively at one time. Even if medical care does not suffer from an increased ratio, which is doubtful, the quality of monitoring and reporting, which is the function of the clinical trial, must suffer. Therefore, we request that the overall appropriation be increased to the level in terms of a percentage of the total appropriation of fiscal 1972 (5.4%), over the 1975 requested level of 4%. Further we request that NCI be directed to establish a patient/physician ratio for its clinical trial programs and to provide for additional clinical trial staff at trial centers where an unrealistic, overburdening patient/clinician ratio exists. For example, in the South Florida Center the ratio is 130 pediatric oncology patients for two hemotologists.

Nutrition Program

Our testimony before the Authorizing Committee with respect to nutrition programs as confirmed by the NCI indicated that the programs of support for nutrition were inadequate. In general, this program is concerned with the function of nutrition related to the wellbeing and survival time of cancer patients as well as the relation of nutrition to cancer causation. We have felt and Congress has concurred, that NCI has not maintained general programs of dissemination to people concerned with cancer or afflicted by it of information about the relationship between nutrition and cancer. For this reason the National Cancer Amendments of 1974 provided for language to encourage NCI to improve its performance in these areas. The amendment will require the Institute to gather information on the relationship between nutrition and cancer and the role of nutrition in the treatment of cancer patients and then make this information generally available to all those who would be interested in or aided by it. For this new program we would urge the Committee to appropriate $6.5 million for fiscal year 1975.

The Interrelationship of Cancer and Other Programs of the National Institutes of Health: A Question of Health Priorities.

The National Cancer Act of 1971 and the 1974 amendments to that Act have established definitive goals for the cancer program and have indicated the levels of support necessary to achieve those goals. This Committee has in the past supported the appropriations levels in the authorizing legislation, and this level of support has permitted the cancer program to build up considerable momentum toward the achievement of its goals.

Candlelighters greatly appreciate the impact of this Committee on the cancer program. Continuation of this momentum is necessary if the cancer effort is not to grind down to a mere holding operation.

However, we also understand that basic biomedical research and cancer research are inextricably interrelated. As you are well aware, there is a current controversy as to whether the increased cancer spending has caused an attendant slowdown in other areas of biomedical research financing. If this is the case, we suggest that the remedy for this problem does not lie in dismantling or slowing down the cancer program. Rather, we strongly support an overall increase in health research spending. We consider it a sad commentary on our national priorities

when our country's total health research budget is probably less than 1% of the total of our health expenditures. If the United States can afford to expend in excess of $50 billion for a space shuttle it can certainly affort to finance health research on all fronts.

It is a matter of considerable concern to Candlelighters that in the rush to find a fast answer to the cancer problem, some research programs, particularly in the areas of cause and prevention which hold the key to the ultimate resolution of this problem may be deemphasized. Candlelighters realize that the most effective use of our current knowledge of exam and treatment procedures holds the only real hope available to the present cancer patient. However, we know that in the long run it is basic research which will give us the final answer.

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Mr. Chairman, Members of the Committee, on behalf of all these parents across the country, I should like to again 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 our 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.

TABLE

NATIONAL CANCER INSTITUTE
APPROPRIATION FOR FISCAL 1975

Object	Administrative Request	Candlelighters*
Research		
(a) Cause and Prevention	--	--
(b) Detection and Diagnosis	--	--
(c) Treatment	203,128,000	211,028,000 (+6.5 million nutrition) (+1.4 million neurological evaluation)
(d) Cancer biology	--	--
Resource Development		
(a) Cancer Centers support	23,484,000	25,884,000 (+2,400,000 additional core support for investigations)
(b) Research Manpower Development	22,530,000	40,500,000 + 17,970,000 (fellowship & training at 1972 5.4%** level)
(c) Contractual	--	--
Cancer Control		
(a) Cancer Control	45,814,000	50,000,000 (+ 4,186,000)
(b) Information Services	--	3,000,000

* Candlelighters in this table only address themselves to the areas in which our particular knowledge of the cancer program gives us information on which to base requests for specific resources. In general we support the 800 million authorized for fiscal 1975 and particularly urge increase in funds for Research to at least 50% of the approved projects.

** This 5.4% figure should prevent erosion of this program, an ongoing program would appear to require 7%,-about a 30,000,000 increase.