

STATEMENT OF THE CANDLELIGHTERS
BEFORE THE SUBCOMMITTEE ON
LABOR, HEALTH, EDUCATION AND WELFARE
OF THE COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE
March 30, 1979

Mr. Chairman and Members of the Committee:

My name is Grace Powers Monaco, I am representing Candlelighters an international volunteer coalition of families of children effected by cancer in 45 states, Canada, Australia and Europe. We wish to bring to your attention those areas in which the National Cancer Institute's efforts have had the most notable impact on our children's lives and those which we feel merit your further attention through program redirection or emphasis through the appropriation process.

Let me first extend on behalf of all of us, our deepest gratitude and appreciation to you, Mr. Chairman, and the members of this committee for your continuing efforts on behalf of all persons afflicted with cancer. Your unflinching interest in cancer research and the translation of this research into tangible programs for the detection, treatment and rehabilitation of cancer patients throughout the country has widened the benefits of the whole cancer effort. We know that the lives of the 6100 children a year affected by cancer have been and are continually being extended, and in a growing number of cases preserved, through the cancer research efforts and their clinical application which this Committee has supported through the National Cancer Institute.

The National Cancer Institute has responded to most of the needs articulated by families to them since Candlelighters initiated its programs and testimony nine years ago. The support of psycho-social research and its implementation, dedication to providing quality public and physician information and education materials are particularly deserving of praise. We also note with pride the intensified interest and multi-institute collaboration approach which the institute is adopting in the area of the diet, cancer and nutrition program which was initiated at Candlelighters urging by the 1974 Cancer Act Amendments. We note with approval the informal collaborative effort

between the National Cancer Institute and other institutes in the area of eye tumors and brain tumors. We believe that a special commendation should be made for the National Institute of Health Clinical Center which is the intramural arm of the federally funded cancer research effort. The aggressive but sensitive treatment received by the children in the pediatric oncology section of this program and the supportive nature of the program towards the families who travel to receive aid through the federal research program as well as the excellent outreach program to permit children to receive their follow-up treatment in the community demonstrates collaborative efforts of a high caliber with a proven effect rate in prolonging the survival and assuring a higher percentage of cure in those children whose cancers can be managed effectively at this time.

Summary of the Main Points of Candlelighters Testimony

The main focus of Candlelighters testimony is as follows:

1. Expansion of the federally funded research and clinical trial effort to translate the successes in the acute leukemias, lymphatic cancer, Hodgkins, bone cancers, wilms tumors, retinoblastoma, rhabdomysarcoma with 50 to 85 percent five year survival rate at centers of excellence in pediatric and adolescent cancer treatment to the non-acute leukemias, brain and central nervous system tumors and neuroblastomas which have not shown the sensitivity to treatment which these other cancers have.
2. Expansion of the consortium approach to pediatric and adolescent cancer supported by a network, tumor registry and computer access system which will permit children with cancer wherever they are found to experience the same opportunities for long term survival and possible cure that are experienced at the centers of excellence in the research and clinical application of pediatric cancer.
3. Expansion of the efforts to develop less toxic therapies.

4. Initiation of research into pain assessment and management in pediatric and adolescent cancer patients.
5. Funding for a study to determine how to provide parent access across the country to programs that will assist families of children with cancer to let their children die at home where this is the option the family selects.
6. Increased funding for blood component support programs.
7. Inquiry into discrimination against pediatric and adolescent cancer patients in state vocational education and rehabilitation programs.
8. Increased funding and positions for the Office of Cancer Communications to provide expanded efforts in the development of materials for the use of families, physicians, nurses and social workers for dealing with the psychological pressures of cancer and providing for development and dissemination of materials relating to rehabilitation.
9. Increased funding for the National Institutes of Health Clinical Center program in pediatric oncology to permit initiation or expansion of existing programs within the intramural program as pertains, for example, to long term physical, behavioral and psychological impacts of cancer on pediatric and adolescent patients and their families, pain assessment and management, and the development of less toxic therapy.
10. Continued support by this Committee for the nutrition program and additional funding to provide the development of physician and medical student education program in the area of nutritional support as applied to cancer.

Candlelighters specific requests for funding are contained in a table appended to this testimony.

Justification for the Requests Summarized Above

Although children and adolescents with cancer constitute only one percent of the cancer affected population in this country, cancer, except for accidents is still the cause responsible for the most deaths in children.

Ten years ago when Candlelighters began monitoring the federally supported cancer programs that affect the lives of our children there were few long-term survivors of cancer, but there was much hope for lengthening or saving the lives of these children and teenagers. Ten years ago, at most, ten to twenty percent of children with cancer treated aggressively in the centers of excellence were alive five years after diagnosis. Today, the overall nationwide survival rate in pediatric cancers for children is, according to the End Results Section, the Biometry Branch of the Division of Cancer Cause and Prevention at NCI, thirty-three percent. However, 60 to 65 percent five year life expectancies for childhood and adolescent cancer cases pertain to those treated in centers adequately staffed and equipped to manage childhood cancer. Specifically, with respect to treatment at centers that are recognized for excellence in treating pediatric and adolescent cancers, Hodgkins (80 percent five year survival rates), lymphatic cancer (70 percent), acute leukemias (50-70 percent), bone cancers (50-60 percent), retinoblastoma (83-85 percent), rhabdomyosarcoma (80 percent).

Development of Less Toxic Therapies

These figures represent a dramatic improvement, but it has not been without cost to our children. Additional emphasis must be placed on the need to develop less toxic therapies to avoid adverse complications in children with cancers which can now be successfully treated. One mother's comments are allusive:

"For the longevity of life, we pay dearly. He lived for a long time (7 years) but the result of his living with this disease caused extensive damage to his lungs and cataracts in his eyes. The children are living longer but the drugs are still as toxic as ever. It becomes a serious question of the deterioration in quality of life."

These problems were not important when our children had no real hope of long term survival or cure. These problems assume increasing importance as our children live longer. Parents report specific learning disabilities resulting from

the treatment they have received. These disabilities give rise to special tutoring needs. Physical disabilities, temporary or permanent, give rise to special needs for vocational, occupational, and rehabilitation therapy for this special class of children. Children with cancer who have these needs often fall between the cracks. The cost of caring for these children far outweighs the cost of providing rehabilitation services, if those services can be avoided by the development of less toxic therapy.

The National Cancer Institute's budget justification at pages 42-44 speaks of clinical evaluation of new therapeutic agents, and the development of more conservative surgical and radiological approaches it also clearly commits itself to the development of less toxic second generation chemotherapeutic agents. Such a commitment and the funding for it are required so that we can assure our children who are survivors that they will not be blind, sterile, retarded, paralyzed or otherwise crippled.

Further, to support the long-term evaluation of children which is an essential component of the drug refinement process, there needs to be developed standard assessment forms both from the medical and psychological approaches which assure that the children receive the same initial base line assessments and later comparisons.

Cancers Requiring Additional Research Emphasis

The figures quoted above represent a dramatic improvement for some cancers, but the picture is not so rosy for others. The efforts and funding levels that achieve the results in the leukemias, for example in the early 70's, should be directed towards producing the same results in other cancers hitherto resistant to success.

In contrast to the encouraging results in the acute leukemias, a discouraging area is that of acute non-lymphocytic leukemia (ANLL). The progress with this malignancy is nowhere near the strides seen in the acute leukemias which was such an encouragement several years ago.

The one single tumor system that does not appear to have been influenced to any degree by modern treatment modality is neuroblastoma. Continued research in this particular tumor system is critical not only in order to improve treatment but certain clues to the nature and spontaneous curability of cancer lie hidden within the neuroblastoma maze.

Brain and central nervous system tumors also require additional research emphasis. The survival rate, for example of medulloblastoma, is only 32 percent.

Mechanisms to Assure That All Children Have the Same Opportunities for Long Term Survival and Eventual Cure

The figures cited at the beginning of this section demonstrated a dramatic improvement in survival rates relating to many classes of pediatric and adolescent cancer. However, a comparison of the nationwide averages against the averages obtained from institutions considered comprehensive centers in the treatment of pediatric and adolescent cancer, that is, centers marked by intensive and aggressive research programs and the aggressive clinical application of approaches to cancer, show a deficiency in the program. That deficiency lies in the absence of effective ongoing dependable linkages within the system of federally supported pediatric and adolescent cancer research and its clinical application to those treated outside the system to assure that the results achieved from by the insiders can be achieved outside.

The importance of these linkages is demonstrated by the success of several federally funded network programs. One example was the demonstration out-reach program funded by the Division of Cancer Control and Rehabilitation pertaining to leukemia and lymphoma. This program called the Leukemia and Lymphoma Network Program linked centers of excellence in pediatric and adolescent cancer in an out-reach program with community hospitals and pediatric oncologists. The program was funded in Childrens Hospital in Los Angeles, Childrens Hospital in Cincinnati, Childrens Hospital in Denver, The Dartmouth Medical School, the University of Alabama, New York-Cornell, and the Mount Sinai School of Medicine. The result coming out of these programs established that when using a consortium approach with a center of excellence as the evaluation and re-evaluation and out-reach point, in excessive of 50 percent

of those children would be probably obtain a five year survival. Another example of the consortium approach that link the centers with aggressive research and clinical application programs with other facilities in the community is present right here at the National Institute of Health. The National Institute of Health intramural research program into childhood cancer has its clinical application on site at the National Institute of Health Clinical Center. The ways of managing the burdens of transportation costs, costs of lodging and board away from home, and particularly coordination of care with local physicians or childrens hospitals are all contained in the blueprints that already exist within this intramural federal program.

The consortium approach, outlined above, provides linkages of the three conventional defined levels of pediatric and adolescent health care. It should be expanded to relate to all pediatric and adolescent cancer patients:

Primary (Level I) - Located in the child's community, and providing home and outpatient/office health supervision with particular regard to normal growth and development, prevention of infectious disease, treatment of minor infections, liaison with school and community, and family counseling by professional and peer group. This would be provided by a pediatrician, a family practitioner, internist or pediatric oncologist.

Secondary (Level II) - The pediatric cancer care facility usually connected with the childrens hospital located close to the child's community and providing outpatient and inpatient care for the particular disease and its complications. This would include: administering anti-cancer drugs according to protocol; maintaining treatment records, managing moderate severe infections, bleeding episodes, anemia, nutritional and metabolic disorders. This would be provided by a pediatric hematologist/oncologist or someone with additional training or experience in pediatric oncology. Also, this facility should provide access to child life specialist, psycho-social support by professional or peer group as well as undertaking an education program directed to medical and nursing students, graduate trainees, and practitioners.

Tertiary (Level III) - The regional children's cancer center. These centers of excellence in treatment already exist. All they need is to be designated and pointed at their appropriate out-reach program group. These centers would be accessible to provide confirmation or correction of initial diagnosis, subcategorization and staging, complete evaluation of the child's needs through discussion among team members and with child and family, assignment to protocol study with consent of child and parent, initiation of therapy, conduct of Phase I experimental treatment, basic and clinical research relevant to childrens cancer and training of an oncologist in research and practice. The child and/or his specimens and findings would be periodically sent to the center for reassessment, change in therapy, investigative studies not available at the secondary level and documentation of disease course.

Secondary care personnel might provide primary care as well, and tertiary regional centers could provide primary and secondary care also. This would be decided in accordance with the residence of the child, the particular cancer and its treatment, the wishes of child and family, and of course whether there are any qualified supportive personnel of the primary or secondary care variety available in the geographic area of the family.

This consortium approach forming a communication network with a pediatric/adolescent center at the core with out-reach to childrens hospitals and pediatric oncologists which serve as the primary treating radials, needs to be initiated for the areas which do not possess such a center out-reach program and to be expanded in the areas which do. But this alone is not enough. The communications and information systems which provide the support to the treating physician are at best informal and are not sufficient to permit the type of out-reach program to the treating physicians which at this point in time is necessary to achieve uniform results in survival for children across the country. For example, let me recount a story that graphically shows the deficiency in the existing system. This example involves a child who has been in treatment in cancer for over ten years. She developed bladder complications last fall which were unknown to the literature and unknown in terms of treatment to the very excellent physicians who were treating her in an aggressive research and trial program.

The mother of the child requested that the physician place a call to every major cancer research center and inquire whether any child that they were treating had the same condition that her daughter had and how they were addressing that condition. The physicians did so, and one of the major cancer treatment centers which they did call indeed had a child who had the same condition and they advised the manner in which they were proceeding to treat. After two applications of the treatment which they advocated, the child's condition was completely corrected. The point of this illustration is that the child had a condition which had not been reported in the literature. There was no means available to these excellent clinicians to check on recent cases of similar appearance or if a side effect was involved, recent reportage of such side effects except the telephone.

How can the problem of stale data and access to recent data primarily by telephone be overcome. The means whereby it can be overcome already exist within the federally supported data base system and merely need to be expanded. What we are talking about is the use of information on health care "outcome" or the expected results of a particular care procedure whether it is related to an unusual phenomenon in the care of cancer in a child or the side effect for treatment which has not been reported in the literature so far, etc. The use of this type of information is not new and is used by physicians today. However, all too often, as the example given above illustrates, such information must be gleaned from the physicians personal experience or taken piecemeal from what literature the physician has had time to personally access. With the peer review procedure utilized for most of the reporting journals, the information that finally reaches these journals or other literary sources may indeed be old data by the time it is made available to the general run of physicians who could utilize it. Yet, the data collection procedures already followed in hospitals and health care facilities have a ready capability to provide that same physician information on the collective experiences of large numbers of other physicians and patients, information which could then lead to more effective and efficacious care for the patients, hopefully with results of longer term survivals and if properly utilized, lower cost. Then let us examine the health care data systems which are presently available within the federal system and indicate the ones that would seem most readily adaptable to the purposes that I have just described.

The National Library of Medicine includes within its computerized retrieval and data base systems, a system known as CLINPROT which stands for Clinical Cancer Protocols. This is an NCI sponsored data base which contains summaries of clinical investigations of new cancer agents and treatment techniques. Candlelighters, therefore, requests that a study be made of how this CLINPROT system can be adapted, made more current and utilized to provide the types of information that the physicians in the examples above exchange by telephone and to make this type of information access available to all physicians across the country who are actively engaged in treating pediatric and adolescent cancers through the vehicle of their closest tertiary or secondary care system. This goal is realistic and workable. At the present time almost 4800 of the anticipated 6100 new pediatric and adolescent cancer cases each year in the United States are accessible to a data retrieval system of some type through their inclusion in one of the children's cancer study groups or existing pediatric comprehensive centers. The center related out-reach program which we have requested above, should make the community based or childrens hospital based cancer programs which are not now included in this number accessible to such data base systems.

As additional support for this increase in data access capability, Candlelighters recommends that the research efforts at those centers designated to be the core center for out-reach network to the secondary and primary care radial treatment centers be supported by the establishment, supervision and utilization of a nationwide comprehensive childhood cancer registry. Again, the workability of this support mechanisms is evident from the facts set forth above namely that almost 4800 of the anticipated 6100 cases of pediatric and adolescent cancer each year are already a part of a federally supported data collection system which merely would need to be expanded. One model that we can suggest for this national registry is the "Delaware Valley Pediatric Oncology Program and Central Tumor Registry" which is a Division of Cancer Control and Rehabilitation Program originating from Childrens Hospital in Philadelphia under the direction of Dr. Audrey Evans.

Research Into Pain Management and Assessment

Regretfully, we report that in the area of pain research which was the subject of a recent National Cancer Institute Conference, pediatric pain was not mentioned and we are aware of no study into the assessment and management of pain in the pediatric cancer patient which are ongoing at the National Cancer Institute at this time. The problems of pain in a child

results from the effects of the disease as well as pain associated with the procedures which are used in treating the disease (anticipatory pain). This is a matter of great concern to families of children with cancer and is a matter which should receive research effort from the National Cancer Institute. A recent study of the University of Iowa showed that most hospitalized children between the ages of 4 and 10 have pain killer indicated on their charts after painful procedures such as surgery, but do not in fact receive them. The two major reasons given for this is a "old nurses tale" that because children's nervous systems are immature, children do not experience pain with the intensity that adults do and the other reason is that children do not ask for them.

Care of the Terminal Child

Finally, although the National Cancer Institute has funded an excellent program in Minnesota which involves research into the team approach, particularly nursing support, to permit parents who choose to have their children die in comfortable surroundings to reach that goal at home with dignity and comfort and far less cost than hospital death, and although the Hospice leaders in this country are aware of and supportive of this type of program, we have not seen any indication that the federally funded effort in Hospice through the National Cancer Institute will build into its death support capability at home and home care out-reach programs for adults, a capability to provide the team support to families of pediatric patients to permit these patients to die at home if that is the family decision. The results of the University of Minnesota study showed that in the median range with comparison between the home care group of children and those that died in the hospital, the cost estimates for the duration were \$633 for the home base program for 21 days of care as opposed to \$4,300 for 21.5 days of care in the hospital.

Based on the positive support, supportive and financially less exhaustive results of the University of Minnesota study, Candlelighters request that the National Cancer Institute be directed to study the means whereby this type of supportive care can most effectively be accessible to parents seeking to have their children die at home. For example, should this type of care emanate from a university cancer center, from a local children's hospital, or if none of the above are available, should it emanate from a planned adult Hospice program. Candlelighters reminds the Committee that there are states in which there are no pediatric cancer care facilities for example, the State of Nevada, in which the parents have to travel to California for treatment. Clearly in a case like this the out-reach could not be achieved through a centers program but other means would have to be explored to make this type of supportive service available.

Blood Component Programs

As this Committee is aware, NCI and ten additional centers have a national donor pool in the platelet pheresis area with computerized donor files totalling about 60,000 people. To permit maximum utilization and most effective utilization of this program, there are several needs for increased research emphasis. There needs to be additional research into better ways to maximize the use of platelets, for example, study of platelet migration, and inhibition assays in conjunction with HLA. There need to be studies on the best utilization of platelets, for example, whether they are most effectively used when specifically matched at the first instances of transfer or with a specific matching should wait until the later stages of need. Of particular promise is the work being done stem cell reconstruction which involves infusing with the patients own bone marrow.

Discrimination Against Children and Adolescents With Cancer

There is a real need for an inquiry into the discriminatory treatment of our children who are long-term survivors in the area of vocational and educational rehabilitation assistance provided by the states with federal funds. The HEW regulations covering access to such programs include children with cancer in the definition of the handicapped. However, assistance appears to be withheld from our children in many instances, unless those children can prove that they won't eventually die from the cancer that has caused them to lose a limb or require compensating assistance for other disabilities. A case in point involves a mother from Irving, Texas. She writes,

"I am writing in despair. Please allow me to tell you a little about my family and I.

I am the mother of an 18 year old osteogenic sarcoma patient who is presently a patient at the University of Texas, (M.D. Anderson Cancer Institute in Houston, Texas) and who also is a first year college student at Blinn Junior College in Bryan, Texas. Hopefully, in September she will attend Texas A&M in College Station.

Becky had her leg amputated in March of 1972 and in February of 1973 she had three parts of one lung removed due to a metastasis and in January of 1978, another metastasis occurred and she had lung surgery on the other lung in February. She is taking high doses of methotrexate and leukovorin shots.

I work for X Company as a supervisor and my gross pay is \$1700 a month. I use all my vacation each year going back and forth to the hospital. My pay is deducted after I use my vacation, for the week at a time that we go to Anderson for treatment and we go every third week.

My mother moved in with me when Becky was first diagnosed so I could continue to work as I have four other children, two of which are in college also. [My mother contracted cancer and expired in 1978 and my husband filed for divorce after 22 years of marriage and we were divorced last October, he contributes \$200 a month for my younger children but none towards Becky or the two older youngsters who are in college].

Becky wants to teach special children. My problem is I am having a very difficult time in securing any help from Social Security or Texas Rehabilitation Commission. Social Security just asked for my monthly salary and said no and Texas Rehabilitation will not help with her education or prothesis because she is an osteogenic sarcoma patient and they assume that she will die.

I feel her chances for survival are just as good as mine, she's a fighter and we've come a long way. She wants an education and if I could only get a little help, we could do it.

If I had to replace her prothesis right now, I could not do it. I am financially wiped out and it costs a great deal just going back and forth to Houston from my home in Irving, Texas. All the rehabilitation people sent me was a financial aid form which I could have gotten myself.

I don't understand why they help some handicapped persons but children with cancer are discriminated against. They are not God and at this time many children with cancer are living longer and some are cured due to new drugs, etc. Yet our society treats them as though they don't exist. We have met many fine youngsters at Anderson and I am also speaking for them."

Further, this problem seems to also be present in another program which receives federal funds - the crippled childrens program. I will not address the direct medical assistance components of that program because that is the sort of testimony which should be addressed to the Catastrophic Illness Coverage Hearings. What concerns us in the context of discrimination is that there are many states with provisions that require a child to have a good prognosis for cure before they will be accepted in a program. Others have provisions for dropping children when their outlook turns from good to poor. Since the crippled childrens program is an outgrowth of the Social Security system, we think that there should be minimal national standards setting minimum coverage ratios for all children with cancer.

National Institutes of Health Clinical Center

Candlelighters requests that the support for the pediatric oncology division of the center be increased by at least one-half million dollars. This division serves a prototype and demonstration unit for innovative cancer research and its application. The additional funds requested will enable it to perform this role more effectively. We specifically direct the Committee's attention to programs initiated in the center and the evaluation of psychological and neurological problems in long term survivors of pediatric cancers and its interest in the refinement of the existing protocols for the treatment of cancer to reduce the toxicity which may cause these problems. We believe that the NIH Clinical Center through its intramural program with the National Cancer Institute should be in the vanguard of assessment and management of pain relief for pediatric cancer patients.

Cancer Communications

The Office of Cancer Communications has initiated a variety of programs including a clearinghouse of cancer information services through the centers to implement the mandate of this

Committee 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 demands on OCC by the scientific and lay public are great. They had been both scientific and sensitive in attempting to meet these demands. Candlelighters can attest to the value of the information services provided and their usefulness to parents and front line physicians. They are bridging the information gap but they need additional resources and personnel in order to do so. We therefore request an additional 6 job slots and 1.5 million dollars over the level in the NCI budget for this program. Part of this information development and dissemination process should include the development of more specific site pamphlets relating to pediatric cancer and the involvement in the rehabilitation information and information resource area.

Mr. Chairman, Members of the Committee, on behalf of all of these parents across the country, I would like to commend the Chairman and 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 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 program will be a memorial to them. And those of us whose children are under treatment or who are off drugs and hopefully cured of cancer 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 cancer. Thank you for permitting us to appear before you.

CANDLELIGHTERS RECOMMENDATIONS
FOR FUNDING INCREASES

National Cancer Institute

The \$936.958 million for fiscal 1980 requested by President Carter is only 1/32 of 1% more than the fiscal 1979 appropriation. Considering inflationary factors, the Institute requires an additional 98 million just to stay even. At the Carter figure, less than 20% of approved priority one grant applications would be funded. Candlelighters reminds the Committee that in 1970 the crisis indicator for increased funding was whether less than 50% of such grant applications would be funded.

Specific Funding Requests

<u>Program</u>	<u>1980 Request</u>	<u>Candlelighters Request</u>
Pre-clinical treatment research (development of less toxic therapies included)	123,110,000	125,110,000
<u>Clinical Treatment</u> (pain assessment/management; improvement of information network)	138,000,000	139,500,000
<u>Intramural Research</u> (pain assessment/management, less toxic therapies; blood programs; study on expansion of data system to support consortium cancer treatment; study on nationwide pediatric/adolescent tumor registry)	103,606,000	105,000,000
<u>Rehabilitation Research</u> pediatric pain assessment/management; pediatric/adolescent cancer network programs (leukemia, lymphoma, etc.); study on methods of delivering home care to a family with a terminal child	24,940,000	26,250,000
<u>Office of Cancer Communications</u> (expansion of efforts in providing public/physician education materials particularly in rehabilitation); (physician, medical school nutrition education program development)	increase of	1,500,000

SUMMARY: CANDLELIGHTERS POSITION ON
1980 APPROPRIATION FOR THE NATIONAL CANCER INSTITUTE

1. Expansion of the federally funded research and clinical trial effort to translate the successes in the acute leukemias, lymphatic cancer, Hodgkins, bone cancers, wilms tumors, retinoblastoma, rhabdomyosarcoma with 50 to 85 percent five year survival rate at centers of excellence in pediatric and adolescent cancer treatment to the non-acute leukemias, brain and central nervous system tumors and neuroblastomas which have not shown the sensitivity to treatment which these other cancers have.
2. Expansion of the consortium approach to pediatric and adolescent cancer supported by a network, tumor registry and computer access system which will permit children with cancer wherever they are found to experience the same opportunities for long term survival and possible cure that are experienced at the centers of excellence in the research and clinical application of pediatric cancer.
3. Expansion of the efforts to develop less toxic therapies.
4. Initiation of research into pain assessment and management in pediatric and adolescent cancer patients.
5. Funding for a study to determine how to provide parent access across the country to programs that will assist families of children with cancer to let their children die at home where this is the option the family selects.
6. Increased funding for blood component support programs.
7. Inquiry into discrimination against pediatric and adolescent cancer patients in state vocational education and rehabilitation programs.
8. Increased funding and positions for the Office of Cancer Communications to provide expanded efforts in the development of materials for the use of families, physicians, nurses and social workers for dealing with the psychological pressures of cancer and providing for development and dissemination of materials relating to rehabilitation.
9. Increased funding for the National Institutes of Health Clinical Center program in pediatric oncology to permit initiation or expansion of existing programs within the intramural program as pertains, for example, to long term physical, behavioral and psychological impacts of cancer on pediatric and adolescent patients and their families, pain assessment and management, and the development of less toxic therapy.
10. Continued support by this Committee for the nutrition program and additional funding to provide the development of physician and medical student education program in the area of nutritional support as applied to cancer.