Participating Organizations

AirLifeLine
American Academy of Pediatrics
American Brain Tumor Association
American Cancer Society
American Pediatric Surgical Association
American Society of Clinical Oncology
American Society of Pediatric Hematology/Oncology
American Society for Therapeutic Radiology and Oncology
Association of Pediatric Oncology Nurses
Association of Pediatric Oncology Social Workers
Bear Necessities Pediatric Cancer Foundation
Candlelighters Childhood Cancer Foundation
Centers for Disease Control and Prevention
Children's Cancer Group
Children's Cancer Foundation
The Children's Cause
Children's Oncology Group
Children's Oncology Camping Association International
Children's Oncology Group
Intergroup Rhabdomyosarcoma Study Group
Leukemia and Lymphoma Society
National Cancer Institute
National Childhood Cancer Foundation
National Children's Cancer Society, Inc.
National Coalition for Cancer Research
National Coalition for Cancer Survivorship
National Wilms Tumor Study Group
Pediatric Brain Tumor Foundation of the United States
Pediatric Oncology Group
Society of Pediatric Psychology
STARBRIGHT Foundation
The American Cancer Society convened the National Summit Meetings on Childhood Cancer because we believe that an organized, concerted effort involving all stakeholders is the most effective means of developing a unified strategy for reducing the suffering and death that childhood cancer imposes. For six days in the autumn of 1999 and spring of 2000, over 50 people representing 30 national organizations came together in Atlanta for two national meetings on the topic of childhood cancer. These organizations differed in their missions and methods, but they shared one common goal: improving outcomes in childhood cancer. The people who represented these organizations came from every profession and walk of life that plays a role in achieving this goal: physicians, psychologists, nurses, and social workers who treat children with cancer; researchers who study the causes and search for cures; volunteers who provide special services, such as the pilots of AirLifeLine and folks from Camp Ronald McDonald; and perhaps most importantly, people who have experienced the disease themselves, first-hand: childhood cancer survivors and family caregivers.

These meetings were a landmark event. This was the first time that virtually every national group involved in the fight against childhood cancer came together under one roof for the express purpose of developing a collaborative strategy for dealing with the disease. During the six days of these two meetings, participants worked tirelessly to identify key issues and to develop a comprehensive plan of action. The result of their work, presented here, is the National Action Plan for Childhood Cancer.

Nowhere else in the arena of cancer control are medical advances as dramatic as in childhood cancer. The remarkable advances that have occurred in the absence of any comprehensive plan suggest that a great deal more can be achieved under a coordinated, organized, and collaborative effort. However, medical progress is only one part of the equation. Equivalent advances are needed in dealing with the psychosocial, emotional, and economic aspects of these cancers, as well as with their late effects. The National Action Plan for Childhood Cancer addresses all these elements of the childhood cancer experience. The American Cancer Society and the organizations who developed this plan hope that it will serve as a blueprint for everyone involved in the fight — health care providers, researchers, educators, patient advocates, and cancer survivors — to use in working toward a common goal of ultimately eliminating childhood cancer as a threat to our nation’s children.

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American Cancer Society
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Overview

Despite the remarkable treatment advances of the past three decades, cancer remains the leading cause of death by disease in young persons between the ages of one and 14 years. The American Cancer Society's Cancer Facts and Figures estimates that in 2002, 9,100 children will be newly diagnosed with cancer and 1,400 will die.

The effects of cancer and its treatment during the young, formative years of life can be lasting. Cancer takes a toll even on those who are cured. Survivors of childhood cancer and their families face a broad range of physical and psychological challenges imposed by the disease, and some will suffer its long-term effects for the rest of their lives.

Even given the problems associated with long-term effects, there have been dramatic successes in treating some childhood cancers. Certain cancers that were almost invariably fatal 40 years ago, such as some of the childhood leukemias, now have cure rates upward of 80 percent. These remarkable gains in treatment have been made within a relatively dispersed infrastructure of laboratory and clinical research, which raises the question of how much more could be achieved if a more coordinated, organized effort were undertaken within a collaborative national action plan for childhood cancer.

It was to answer this question that the American Cancer Society undertook in June of 1999 to bring together representatives from all national organizations, both private and public, involved in childhood cancer. Many organizations serve the needs of children and adolescents with cancer, organizations of health care providers, researchers, and cancer survivors, as well as government agencies. However, these groups had not previously all come together to consider how they could join forces to achieve results. It was envisioned that such a meeting, under the umbrella of common interests, would enable groups to discuss the current state of treatment, how that could be improved, and how to deal with the key issues in treatment and survivorship. Together, these groups could develop a unified plan of action to improve the outcome of pediatric cancer in terms of reduced morbidity and mortality and improved quality of life. This would be a plan that everyone involved in the childhood cancer continuum – survivors, their families, their health care providers, and organizations serving them – could support and push forward. Such a coordinated approach would eliminate duplication and maximize effectiveness of effort. Appendix A provides background on the planning and implementation of the summit meetings. Appendix B provides a listing of members of the Summit Steering Committee, which planned the meetings and invited participants.

National Summit Meetings on Childhood Cancer

In 1999 and 2000, the American Cancer Society convened two meetings of representatives from 30 national organizations, both public and private, working in the field of childhood cancer. Appendix C lists participating organizations, and Appendix D lists participants and their affiliations. These representatives worked together to identify the issues that needed to be addressed in order to improve outcomes for children and adolescents with cancer and their families.
The group concentrated its efforts in five principal areas:

- Access to care and patterns of care
- Advocacy and professional issues
- Long-term care and survivorship
- Patient and family quality of life
- Research priorities

Participants identified issues for study for each of these five areas and assigned representatives from among the attendees to form a workgroup to study each area. (Appendix E lists workgroups and their members.)

Reports of the Workgroups

The five designated workgroups met throughout the two summit meetings to discuss the key issues in the area they were charged to consider and to develop specific recommendations for meeting their charge. Appendix F lists members of the Summit Implementation Task Force, whose members were elected by each workgroup and charged with developing plans to implement the recommendations of the summit meetings. A key part of their work revolved around developing specific strategies for achieving their recommendations, including identifying the organizations involved in childhood cancer that might wish to be involved in meeting goals. The reports provide an overview of the issues, recommendations for addressing them, and strategies for accomplishing the recommendations.

The report of each workgroup was developed independently, and each considered issues, problems, needs, and solutions from the perspective of its topic area. Thus, the issues considered important by each workgroup may overlap with those of others. For example, research was approached both from the standpoint of advocacy for increased funding and scientific priorities. The overlap has been preserved so that the views and recommendations of each workgroup are presented.

Following each recommendation is a listing of organizations that could potentially participate in achieving the recommended action. These lists do not indicate commitments from these organizations but rather that their organizational objectives and activities suggest that they might wish to play a role.

Summary of Workgroup Recommendations

Access to Care and Patterns of Care

- Assure that all children and adolescents suspected of having cancer are referred initially to a pediatric cancer center and have their care coordinated by the center.

- Establish national standards of quality care for children and adolescents with cancer, both medical and psychosocial, as defined by healthcare professionals and patient advocates.

- Quantify current patterns, quality, and outcomes of all phases of childhood and adolescent cancer care.

- Increase participation of children and adolescents in all phases of approved clinical trials.

Advocacy and Professional Issues

- Ensure access to comprehensive, multidisciplinary cancer care for children and adolescents with cancer.

- Assess the need for fellowships and scholarships for training in all disciplines of pediatric oncology.

- Accelerate the application of new therapeutic technologies to children with cancer.
Long-term Care and Survivorship

- Develop a comprehensive intervention strategy to provide screening and/or treatment for survivors at risk for specific late effects consisting of the following three components: (1) identification of the concerns of survivors of childhood and adolescent cancer, their families, and their health care providers about late effects; (2) development of educational materials designed to increase the knowledge of both survivors of childhood and adolescent cancer and their health care providers about these late effects; (3) evaluation of the ability of these educational materials to motivate survivors to self-advocate in order to receive care for the late effects of childhood cancer.

- Using evidence-based methodology, establish a national standard for health maintenance of childhood cancer survivors, including physical, neurocognitive, and psychosocial functioning.

- Develop a national pediatric cancer survivor database consisting of existing survivors and providing prospective enrollment.

Patient and Family Quality of Life

- Study the effects of childhood cancer on family function and quality of life (QOL) and develop appropriate culturally sensitive interventions for positive outcomes.

- Develop and implement QOL assessment tools that are specific for stages of disease and phases of care across the continuum of care.

- Define the required components of psychosocial support.

Research Priorities

- Develop the necessary infrastructure to support clinical research.

- Apply and develop efficient mechanisms for timely application of effective new treatments.

- Recruit, train, mentor, and retain skilled research professionals.

- Prioritize emerging research initiatives.
Following is the National Action Plan for Childhood Cancer consisting of the recommendations of the National Summit Meetings on Childhood Cancer as developed by each workgroup.

**Access to Care and Patterns of Care**

**Charge to the Workgroup:** The Access to Care and Patterns of Care workgroup concentrated on issues related to access to state-of-the-art treatment and follow-up care. Discussions included standards of care, navigating the health care system, insurance coverage for treatment, the roles of third-party payers, the interface between medical centers and community care, standards of childhood cancer centers, and the roles of government agencies and volunteer organizations.

**Overview**

Achieving the best outcomes for children and adolescents with cancer depends on their having access to quality comprehensive and coordinated care from the time of a suspected diagnosis of cancer and throughout the cancer continuum. A substantial body of medical and psychosocial research data indicates that lives are saved, side effects ameliorated, and quality of life enhanced when children and their families have access to such care. However, certain barriers frequently intervene. These include referral patterns for medical treatment, attitudes toward emotional and mental health problems, social and economic status, lack of medical insurance coverage, patient beliefs, and the difficulty of providing community-based comprehensive care. Further influencing access to care is an ongoing trend toward evidence-based medicine, which limits the types of treatments that many health insurance plans will cover.

Pediatric cancer centers offer state-of-the-art treatment within research protocols designed specifically for pediatric cancers. Children and adolescents treated in such research protocols have higher survival and cure rates than those who are not. However, not all children and adolescents with cancer have access to such treatment because of the barriers described. Furthermore, there is an under-representation of adolescents between the ages of 15 and 19 in such clinical trials, and thus, cure rates in this age group may be lower than what could be achieved.

**Recommendations**

The Access to Care and Patterns of Care workgroup made four recommendations for improving access to state-of-the-art care for children and adolescents with cancer:

- Assure that all children and adolescents suspected of having cancer are referred initially to a pediatric cancer center and have their care coordinated by the center.
- Establish national standards of quality care for children and adolescents with cancer, both medical and psychosocial, as defined by health care professionals and patient advocates.
- Quantify current patterns, quality, and outcomes of all phases of childhood and adolescent cancer care.
- Increase children and adolescent participation in all phases of approved clinical trials.
**Recommendation 1**

Assure that all children and adolescents suspected of having cancer are referred initially to a pediatric cancer center and have their care coordinated by the center.

Available evidence demonstrates that survival rates of children and adolescents with cancer are improved when they receive specialized care at pediatric cancer centers. Children and adolescents entered into clinical trials at pediatric cancer centers experience the best outcomes while those cared for outside of such centers and without the benefit of protocol-based therapy experience the worst. Early detection, accurate diagnosis and staging, appropriate risk stratification, and assignment of the most suitable treatment associated with the fewest acute and long-term toxicities all depend on the availability of specialists from multiple diagnostic and therapeutic disciplines expert in the diagnosis and treatment of the cancers that occur in children. Also critical to the management of the child or adolescent with cancer is the availability of appropriate supportive care, including psychosocial support and, where appropriate, end-of-life care focused on the child and his or her family and delivered by professionals trained in the special needs of children and adolescents. Nurses, psychologists, social workers, child life experts, and teachers play critical roles in supporting the child through therapy and assuring the best overall outcome.

The enormous progress in histopathology, immunology, cytogenetics, and molecular biology that has occurred during the past three decades has promoted the remarkable advances in outcome for children with cancer. This progress has led to improved diagnostic classification and better understanding of tumor behavior. Increasingly, appropriate diagnosis and risk stratification require specialized testing of tumor tissue incorporating the techniques of molecular biology. Further, properly handled tissues can serve as a substrate for laboratory investigations into the biology and pathogenesis of childhood cancers. Because often only limited amounts of tissue are available, considerable planning and coordination are required to maximize the information that may be obtained. Thus, it is most appropriate that the child or adolescent suspected of having cancer be referred prior to biopsy to a pediatric cancer center, where such studies are done routinely, to ensure that the most important diagnostic information is obtained. Improper handling of the biopsy material because of inexperience increases the likelihood that a second surgical procedure will be required or that information critical to the management of an individual patient will not be available.

The majority of children in North America are treated in pediatric cancer centers where they are enrolled in clinical trials. Controlled clinical trials have been a crucial tool for advancing our understanding and treatment of these diseases such that treatment of the child with cancer in a clinical trial is now the standard of care. Referral to a pediatric cancer center assures the patient access to state-of-the-art clinical trials and, thus, the best available therapy.

Comprehensive, multidisciplinary treatment has been instrumental to improving the outcome of children and adolescents with cancer. Such multidisciplinary expertise is seldom available outside of pediatric cancer centers. Thus, all children and adolescents suspected of having cancer should be referred initially to a pediatric cancer center and have their care coordinated by the center.

**Potential Organizations to Involve**

- American Academy of Pediatrics
- American Cancer Society
- American Society of Clinical Oncology
- American Society of Pediatric Hematology/Oncology
- Children’s Oncology Group
- National Childhood Cancer Foundation
- Leukemia and Lymphoma Society
- Pediatric Brain Tumor Foundation of the United States
References


Recommendation 2

Establish national standards of quality care, both medical and psychosocial, as defined by health care professionals and patient advocates.

The Institute of Medicine’s report on quality in cancer care, Ensuring Quality Cancer Care, notes that in the United States “the ad hoc and fragmented cancer care system does not ensure access to care, lacks coordination, and is inefficient in its use of resources.” (p. 2) It argues that “…issues related to quality cancer care have to be addressed at…national and state levels…. In addition, the report states that excellence in cancer care could be achieved if individuals had, among other things, “access to comprehensive and coordinated services” and “assurances that agreed-upon national standards of quality care are met at their site of care.” (pp. 1-2) The report’s Recommendation 4 (p. 7) lists the general elements of quality care that should be available to each individual with cancer.

In pediatric oncology centers, there is a history of commitment to multidisciplinary comprehensive care. However, what actually is available to patients and families, especially in terms of education and psychosocial support services and programs, is left to the discretion of particular centers. There are no data to indicate what the overall picture is in centers nationwide, nor is there any consensus on what constitutes the components of quality, comprehensive care.

Most centers participate in collaborative efforts through several national study groups (recently combined into the Children’s Oncology Group) to direct medical care and improve survival rates through widespread use of clinical trials. This organization and cooperation has achieved enormous success. The study groups also address quality of life issues related to treatment, such as treatment symptoms, procedures, and long term effects. However, there has not been the opportunity to consider research on some of the broader psychosocial and service delivery issues that affect quality of care, and the study groups have not developed quality-of-care standards.

A few years ago, the American Society of Pediatric Hematology/Oncology (ASPHO) issued a position statement defining pediatric hematology/oncology programs2 that reinforced the importance of offering comprehensive and coordinated care, but again, the emphasis was on medical care with only brief mention of the importance of psychosocial services and support.

There is obvious need for development of standards of care in pediatric oncology applicable to all illness phases and treatment settings. Such standards would capture the essential components of a truly integrated, comprehensive, and coordinated approach, facilitate research on outcomes of quality care, and drive support for commitment to improving the overall quality of pediatric cancer care nationwide.

Potential Organizations to Involve

- American Psychological Association
- American Society of Pediatric Hematology/Oncology
- Association of Pediatric Oncology Nurses
- Association of Pediatric Oncology Social Workers
- Children’s Oncology Group
- Patient Advocacy Foundation

References

Recommendation 3

Quantify current patterns, quality, and outcomes of all phases of childhood and adolescent cancer care.

Unlike cancer in adults, there are no sources of comprehensive information on pediatric cancer incidence, patterns of care, and outcomes. There are some data available on cancer incidence, five-year survival rates, and accrual of patients under 40 years of age into cooperative group trials through the Cancer Therapy Evaluation Program (CTEP) and NCI’s Surveillance, Epidemiology, and End Results program (SEER). However, there are no data to actually describe the reasons patients of appropriate age are not being referred to pediatric centers. It is presumed that there are barriers to such referral, but there has been no actual study to identify these barriers.

A first step in advancing the availability of quality care for children and adolescents with cancer will be determining how their cancer is currently being treated, where the care is being delivered, and what the outcomes are. The American Society for Clinical Oncology (ASCO) and the Rand Corporation (Santa Monica, CA) have accomplished some successful data collection in this area, but more remains to be done. It is recommended that the American Cancer Society, NCI, and ASCO collaborate with ASCO/RAND to conduct a quality-of-care survey on childhood and adolescent cancer. Such a survey could be supported through funding from these organizations and from others with an interest in such data.

Potential Organizations to Involve

- American Society of Clinical Oncology
- American Cancer Society
- Children’s Oncology Group
- National Cancer Institute

Recommendation 4

Increase participation of children and adolescents in all phases of approved clinical trials.

Because children and adolescents with cancer who are treated within clinical trials experience greater survival rates, increased accrual to clinical trials in these age groups would improve survival rates overall. In order to effect such an increase, existing barriers to participation in trials must be identified and addressed. Among these are problems of poor adherence to protocol in this age group, economic and insurance-based factors, provider bias, patient/family preferences, provider age policies, and cooperative group limitations. In order to overcome these barriers, it will be necessary to undertake an educational effort directed at patients, their families, and their health care providers. Such education will need to take into consideration the special needs unique to this age group in outlining the benefits of participation in clinical trials and addressing concerns regarding compliance and adherence to trial protocols.

A first step in the process of education will be to develop a plan to educate the public about the importance of clinical trials for treatment of childhood cancer. This could be accomplished through a partnership with the National Cancer Institute’s (NCI) Cancer Clinical Trials Education Program. Another avenue would be to encourage all childhood cancer advocacy organizations to promote clinical trials and to demand that such trials become the standard of care for children and adolescents with cancer. Finally, a media campaign could be undertaken to disseminate information on clinical trials, including how trials function and the benefits of participation.

Advocacy efforts will be required to overcome problems related to insurance coverage and other financial aspects of clinical trials. From the patient standpoint, insurance often functions as a barrier to participation. From a research standpoint, clinical trials are very costly to operate, and there is a backlog of promising agents awaiting testing. An advocacy effort needs to be undertaken to encourage third-party payers to include coverage for cost of routine care provid-
ed under clinical trials and to encourage increased financial support from government and private sources to move new treatments more rapidly to market.

Potential Organizations to Involve

- American Cancer Society
- American Society of Clinical Oncology
- Cancer Leadership Council
- National Childhood Cancer Foundation
- Leukemia and Lymphoma Society
- Pediatric Brain Tumor Foundation of the United States

Advocacy and Professional Issues

Charge to the Workgroup: The Advocacy and Professional Issues workgroup examined how the organizations participating in the summit meetings could best address advocacy and professional concerns to strengthen work in the area of childhood cancer. This includes funding for professional education and training in oncology, advocacy on behalf of patients and families, public advocacy on legislation and public policy, assessment of the adequacy of funding for institutional and agency staffing and programs, and bioethical issues (e.g., gene therapy, confidentiality).

Overview

In the United States, approximately 80 percent of children with cancer under the age of 10 are referred for diagnosis and care to childhood cancer treatment and research centers where they receive comprehensive care from multidisciplinary teams of professionals with specific expertise in childhood cancer. Such centers participate in high-quality, national clinical trials, which provide the best-known treatment for each diagnosis, stage, and prognosis. However, most children older than 14 years, particularly those with bone and brain tumors, are treated in hospitals in their local communities that do not provide comprehensive care and do not participate in national clinical trials. Consequently, the majority of adolescents and young adults do not currently have access to the best-known treatments or to care by specialists in the types of cancer that attack children.

Although many community hospitals participate in clinical trials for adults, many cannot participate in trials for children. This is because in order to participate in national cancer clinical trials for children, a hospital must have on staff specialists in all of the diagnostic, treatment, supportive care, and research disciplines in order to comply with the sophisticated requirements of state-of-the-art treatment protocols. A shortage of physicians, nurses, and social workers specializing in childhood cancer limits the availability of comprehensive, multidisciplinary team care in many hospitals. Children with cancer also require the care of specialists in the long-term effects of cancer, quality of life of survivors, and reintegration of the childhood cancer survivor into family, school, work, and social activities. Such specialists are not generally available in community hospitals. For all these reasons, most clinical trials in childhood cancer are conducted at childhood cancer and research centers.

Although childhood cancer centers and clinical trials offer the highest quality care for childhood cancer, changing trends in health insurance coverage work against treatment in these centers. The growth of managed health care plans and limitations in insured health services have led to more frequent denial of access to centers, denial of insurance benefits to children managed on clinical trials, and lack of access to new therapeutic agents. Treatment in state-of-the-art clinical trials produces the most favorable outcomes and cure rates, and those who do not have access to childhood cancer centers and comprehensive care are, therefore, denied the best treatment and supportive care and, thus, the best outcome for their cancer.
Recommendations

The following goals were identified in the area of advocacy and professional issues:

• Ensure access to comprehensive, multidisciplinary cancer care for children and adolescents with cancer.

• Assess the need for and availability of fellowships and scholarships for training in all disciplines of pediatric oncology.

• Accelerate the application of new therapeutic technologies to children with cancer.

Recommendation 1

Ensure access to comprehensive, multidisciplinary cancer care for children and adolescents with cancer.

Access to comprehensive, multidisciplinary cancer care is instrumental in improving outcomes in childhood cancer, and such care is not usually available outside of pediatric cancer centers. All children with cancer who are younger than age 15 should receive their treatment in pediatric cancer centers. The number of adolescents receiving care in these centers should be increased from its current level to 60 percent. Further, adolescents and young adults (ages 15 to 21) should have access to clinical trials that meet National Cancer Institute (NCI) peer review standards and are most appropriate for their cancer diagnosis and age.

In order to make such care accessible, third-party payers should develop policies and guidelines that assure that children, adolescents, and young adults have access to treatment in cancer centers so that they can receive treatment that is most appropriate for their type of cancer and their age. Assuring access to multidisciplinary care, which cancer centers provide, will mean that more children and adolescents with cancer will receive quality care. Making an accurate diagnosis, proper staging, and assigning optimal treatment depend on the collaboration of specialists from multiple diagnostic and therapeutic disciplines who have expertise in the cancers that occur in children. Diagnosis and treatment in a cancer center also permit the collection of more data on pediatric cancer.

Legislative action is required to guarantee that children and adolescents with cancer have access to multidisciplinary care. An assessment should be conducted to determine if this action should take the form of a National Childhood Cancer Act. Such legislation would include a requirement that third-party payers cover treatment provided in clinical trials. It could also include establishment of a national portal for referral of children with cancer to comprehensive cancer centers for initial diagnosis and treatment. Legislation could lead to creation of a cancer registry devoted to childhood and adolescent cancer.

Legislative action could include advocacy for increased federal funding of research related to causes, prevention, and treatment of childhood cancer. Health care provider education is critical to assuring multidisciplinary care for children with cancer. Principles should be developed to guide high-quality, comprehensive, multidisciplinary pediatric cancer programs, and a venue for educating providers and consumers about the value of multidisciplinary care should be created. Gaps in high-quality care and access to care should be identified in order to advocate for appropriate changes. Such changes include provision of psychosocial support services to bereaved family and friends.

In order to effect legislative changes and promote educational programs, a national coalition of organizations involved in childhood cancer should be formed. Such a coalition would function as a forum representing children with cancer, their families, medical professionals, and advocacy organizations. It would advocate for legislative changes, as well as respond to legislative and regulatory initiatives that have an impact on childhood cancer programs, and would assist in carrying out appropriate recommendations of all summit workgroups.
Potential Organizations to Involve

- American Academy of Pediatrics
- American Cancer Society
- American Society of Pediatric Hematology/Oncology
- Centers for Disease Control and Prevention
- Children’s Oncology Group
- National Childhood Cancer Foundation
- National Cancer Institute
- Pediatric Brain Tumor Foundation of the United States

Recommendation 2

Assess the need for and availability of fellowships and scholarships for training in all disciplines of pediatric oncology.

To provide state-of-the-art care to children and adolescents with cancer, health care professionals need access to and support for education, training, and certification as specialists in the disciplines that comprise comprehensive cancer care. Such specialists will have the skills needed in childhood cancer centers and community hospitals and will improve the quality of care provided to children and adolescents with cancer. A first step in assuring such education would be an assessment of both the required training and the fellowships and scholarships available to health care providers in all disciplines involved in childhood cancer care. Once the specific requirements and available resources are defined, advocacy can be undertaken for increased federal and private funding for such training.

Potential Organizations to Involve

- American Academy of Pediatrics
- American Cancer Society
- American Psychological Association (Society of Pediatric Psychology)
- American Society for Therapeutic Radiology and Oncology
- Association of Pediatric Oncology Nurses
- Association of Pediatric Oncology Social Workers
- Children’s Oncology Group

Recommendation 3

Accelerate the application of new therapeutic technologies to children with cancer.

As the promises inherent in the new era of molecular medicine translate into clinical applications that are more effective and have fewer side effects, it is critical that these new therapies be evaluated as safe and effective as rapidly as possible. Accelerating the evaluation process will make new forms of chemotherapy, immunologic therapy, and molecular therapy for children more widely available.

The process of implementing new therapies often entails an extended lag time between development and clinical application. This process should be scrutinized, and avoidable delays should be identified and eliminated in order to make promising new treatments more quickly available.

In order to implement new treatment technologies, funding for translational research with potential application to childhood cancer should be designated high priority. The level of both federal and private funding should be increased, and new incentives should be created for the implementation of pediatric clinical trials. Such incentives should include increased financial support for the infrastructure of cooperative national clinical trials for children and adolescents with cancer.

Potential Organizations to Involve

- American Association for Cancer Research
- American Cancer Society
- American Society of Clinical Oncology
- American Society of Pediatric Hematology/Oncology
- Children’s Oncology Group
- National Childhood Cancer Foundation
- National Cancer Institute
Long-term Care and Survivorship

Charge to the Workgroup: The Long-term Care and Survivorship workgroup focused on the assessment and management of late effects of childhood cancer. Areas of concern included treatment sequelae, neurocognitive assessments and interventions, planning for long-term multidisciplinary care, coordination between medical center and community care, complementary and alternative therapies, employability and insurability, sexuality and fertility, survivor lifestyle issues, and transition from pediatric to adult medical care.

Overview

Survival rates for some childhood cancers continue to improve and are among the best for any age group. However, the late effects of treatment, both physical and psychosocial, may seriously compromise the long-term health of childhood cancer survivors. Treatments can damage developing body systems, affecting a child’s growth and neurocognitive function, and sometimes result in second primary cancers. Treatment can be disfiguring, may impair sexual function, and in some instances may affect fertility.

The psychosocial impact of childhood cancer can be equally disruptive. Physical and neurocognitive disabilities resulting from treatment may prevent the survivor from participating in normal activities, which can cause depression and feelings of isolation. These late effects may also affect employability, which in turn affects social and economic well-being. Because of their medical history, childhood cancer survivors may have difficulty obtaining health and other types of personal insurance. Child and adolescent cancer survivors often require support and assistance in becoming reintegrated into social systems, including school, home, work, and community.

Currently, cancer care for children and adolescents focuses primarily on treatment, not on the effects of treatment and how these effects will affect patients’ lives in the future. No tools, such as questionnaires, are available for survivors, parents, and surrogates to use when discussing the late effects of cancer with their health care providers. Acknowledgment and understanding of the long-term effects of childhood cancer will enable survivors, caregivers, and health care providers to anticipate and deal with these effects. It will also enable legislation and insurance reform to assure that survivors receive appropriate follow-up care. A study of the late effects of childhood cancer, including data collection on survivors and dissemination of this information within the community of survivors, researchers, and health care providers, could facilitate development of interventions to address the long-term needs of survivors.

Major clinical trial groups and funding organizations do not always assign high priority to interventions and research related to the late effects of childhood cancer. There are few mechanisms for accessing the population of childhood cancer survivors in order to assess their status and design interventions for dealing with the effects of their treatment. Well-informed survivors and their family members, health care providers, and members of health care systems can advocate for system changes that provide for care and insurance coverage for the late effects of childhood cancer and also for additional research in these areas. Effective ways to communicate with these populations must be devised, so that they can be informed about any progress that is made in developing interventions for survivors of childhood cancer, as well as guidelines for their health maintenance. Comprehensive cancer centers would likely be in a good position to incorporate such mechanisms for the study and follow up of late effects.
Recommendations

The workgroup identified four objectives for meeting the long-term needs of childhood cancer survivors:

• Develop a comprehensive intervention strategy to provide screening and/or treatment for survivors at risk for specific late effects consisting of the following three components: (1) identification of the concerns of survivors of childhood and adolescent cancer, their families, and their health care providers about late effects; (2) development of educational materials designed to increase the knowledge of both survivors of childhood and adolescent cancer and their health care providers about these late effects; (3) evaluation of the ability of these educational materials to motivate survivors to self-advocate in order to receive care for the late effects of childhood cancer.

• Using evidence-based methodology, establish a national standard for health maintenance of childhood cancer survivors, including physical, neurocognitive, and psychosocial functioning.

• Develop a national pediatric cancer survivor database consisting of existing survivors and providing prospective enrollment.

Recommendation 1

Develop a comprehensive intervention strategy to provide screening and/or treatment for survivors at risk for specific late effects consisting of the following three components: (1) identification of the concerns of survivors of childhood and adolescent cancer, their families, and their health care providers about late effects; (2) development of educational materials designed to increase the knowledge of both survivors of childhood and adolescent cancer and their health care providers about these late effects; (3) evaluation of the ability of these educational materials to motivate survivors to self-advocate in order to receive care for the late effects of childhood cancer.

The number of survivors of pediatric cancer is growing. In order to plan for meeting their long-term needs, it is necessary to assess exactly what those needs are. However, there is limited documentation of late effects and little sharing of information about needs and concerns unique to this population of cancer survivors. As a result, few interventions have been developed to deal with late effects of cancer and the associated needs of survivors.

A first step in identifying needs will be to conduct a survivor needs assessment consisting of a review of the literature relating to survivors of pediatric cancer and the long-term physical, neurocognitive, and psychosocial effects of treatment. This review would determine the current state of knowledge and guide decisions about where gaps in that knowledge occur. A survey of childhood cancer survivors could then be conducted to fill the knowledge gaps. Focus groups of cancer survivors and their family members could further help in determining what their greatest concerns and needs are.

A national conference should be convened to enable collection of information on empirically effective and promising treatments for the long-term effects of cancer. Such a conference should bring together investigators from all fields dealing with the various aspects of childhood cancer and survivorship, as well as survivors and their families. This would facilitate sharing of information about the most effective interventions available, identifying new directions of study, and disseminating information (in the form of educational materials) to health care providers and survivors throughout the United States. These materials should be evaluated to determine their effectiveness in encouraging self-advocacy of survivors regarding care and treatment of late effects.

With the information obtained from surveys, focus groups, and conferences, it will be possible to develop and test new interventions for reducing morbidity, promoting positive adaptation, and improving the general health of childhood cancer survivors.
Potential Organizations to Involve

- American Cancer Society
- American Psychological Association (Society of Pediatric Psychology)
- Association of Pediatric Oncology Nurses
- Association of Pediatric Oncology Social Workers
- Candlelighters Childhood Cancer Foundation
- Centers for Disease Control and Prevention
- Children's Brain Tumor Foundation
- National Cancer Institute
- National Childhood Cancer Foundation
- Nursing Research Group within Children's Oncology Group
- Pediatric Brain Tumor Foundation of the United States

Recommendation 2

Using evidence-based methodology, establish a national standard for health maintenance of childhood cancer survivors, including physical, neurocognitive, and psychosocial functioning.

Three factors influencing health maintenance for child and adolescent cancer survivors support the need for a national standard. First, in current practice, childhood and adolescent cancer survivors receive their follow-up care from a broad spectrum of health care providers, many of whom do not have adequate knowledge regarding the risks of specific late effects. Second, when follow-up assessment is an option, the level and type of health insurance the patient has, rather than what the patient needs, generally dictate the level of medical assessment performed. Finally, exposure-based guidelines need to be developed for follow up rather than using a one-size-fits-all approach to a given disease. Use of such guidelines will ensure that an appropriate balance is reached between the recommended level of testing and the risk of adverse outcomes (i.e., a risk-versus-cost ratio).

In approaching the establishment of a national standard for health maintenance of childhood cancer survivors, guidelines should initially be restricted to survivors of Hodgkin's disease, acute lymphocytic leukemia, and medulloblastoma. Workgroups for each of these cancers should be established to study specific associated toxicities and develop guidelines for evaluating and monitoring each one. Insurers should participate in the process of developing and evaluating these guidelines. Once the guidelines are developed, they should be evaluated for effectiveness. After testing and evaluation, these guidelines can be incorporated into standard protocols and integrated into clinical trials.

Guidelines developed should ultimately become part of state and federal mandates for the insurance industry, Medicaid, and the state children's health insurance program. It is recognized that accomplishing such institutional changes will require years of effort. The process of developing guidelines and of institutionalizing them within the health care system will require educating health care providers, as well as cancer survivors and their families. This can be accomplished through development and dissemination of educational programs and materials.

Potential Organizations to Involve

- American Cancer Society
- American Society of Pediatric Hematology and Oncology
- Association of Pediatric Oncology Social Workers
- Children's Oncology Group
- National Childhood Cancer Foundation
- National Cancer Institute

Recommendation 3

Develop a national pediatric cancer survivor database consisting of existing survivors and providing prospective enrollment.

In order to reduce the physical, neurocognitive, and psychosocial late effects of childhood cancer
and to increase childhood cancer survival, better data describing these late effects are needed. These data can be used to identify areas in which intervention is required.

A first step in developing such a database is already underway through the initiative known as the Childhood Cancer Research Network (CCRN), which is supported by the NCI in collaboration with the Children’s Oncology Group. The CCRN, which is currently in a pilot phase, will prospectively register the majority of children and adolescents with cancer in the United States and Canada. For the retrospective component, it will be necessary to survey existing databases to determine what data are currently available. These databases include those from the Surveillance, Epidemiology, and End Results (SEER) program, the National Cancer Database of the Commission on Cancer of the American College of Surgeons, NCI-sponsored clinical trials groups, epidemiology groups of major universities, the Centers for Disease Control and Prevention, the International Bone Marrow Transplant Registry, and the Central Brain Tumor Registry. Once this survey is complete, a meeting should be convened to determine the requirements for establishing a national database, including (1) identifying legal and ethical issues regarding national registries, (2) delineating outcomes of interest, and (3) selecting strategic methodologies.

Development of the database can be accomplished in three phases. Phase 1 could include registration of all pediatric cancer patients enrolled in clinical trials. If phase 1 is successful, phase 2 would consist of expanding the database to register all patients currently included in existing databases. Once phases 1 and 2 are successfully completed, phase 3 would be devoted to expanding the database to include a special component on adolescent cancer patients, a particularly understudied group.

Potential Organizations to Involve

- American Cancer Society
- American College of Surgeons
- Centers for Disease Control and Prevention
- Children's Brain Tumor Foundation
- Children’s Oncology Group
- National Childhood Cancer Foundation
- National Bio-Ethics Advisory Committee
- National Cancer Institute
- Pediatric Brain Tumor Foundation of the United States
- SEER program of the National Cancer Institute

Patient and Family Quality of Life

Charge to the Workgroup: The Patient and Family Quality of Life workgroup focused on issues related to the quality of life of childhood cancer survivors and their families. Areas of concern included the periods during and immediately after treatment as well as end-of-life and bereavement. Discussions centered on the need to address social and emotional needs, family economic concerns, the roles of religious and cultural beliefs, the influence of ethnicity on access to treatment, school reentry issues, and access to psychosocial support programs.

Overview

Maintaining a high quality of life is a vital objective of treatment for everyone with cancer. Cancer is a family disease in that it affects not only the patient but the entire family throughout the cancer continuum. All persons affected require psychosocial as well as medical support to assure that their quality of life is maintained and that long-term maintenance continues to be a goal.

The burden imposed by childhood cancer is immense. The child or adolescent with cancer faces the trauma of diagnosis and treatment, as well as the long-term effects of cancer, including fertility problems, second malignancies, and
posttraumatic stress disorder. The medical system that is evolving under the influence of managed care often requires shorter hospital stays, which in turn lead to complex home care needs.

Pediatric cancer imposes consequences on all family members and, potentially, on future generations. Family issues such as sibling responses to the crisis become a concern, as do future social issues, especially employment and insurance. Thus, treatment that is family centered, with the family acting in partnership with health care systems, achieves the best possible outcomes.

Addressing the entire family’s needs, including those of the person with cancer, will require defining what constitutes a high quality of life and developing tools for assessing it. A fuller understanding of the effects of cancer on family function will enable development of psychosocial support systems to assure attainment and maintenance of a high quality of life for everyone affected by childhood cancer.

**Recommendations**

The workgroup identified the following objectives:

- Study the effects of childhood cancer on family function and quality of life (QOL) and develop appropriate culturally sensitive interventions for positive outcomes.

- Develop and implement QOL assessment tools that are specific for stages of disease and phases of care across the continuum of care.

- Define the required components of psychosocial support.

**Recommendation 1**

Study the effects of childhood cancer on family function and quality of life (QOL) and develop appropriate culturally sensitive interventions for positive outcomes.

Maintaining an acceptable QOL, which comprises physical, psychological, social, emotional, and spiritual components, can be an outcome of cancer treatment that is as important as cure, particularly as survival rates continue to improve. To assure that QOL is emphasized in pediatric cancer treatment, it needs to become a prognostic factor for psychological outcomes, such as social adjustment and adaptation, in the design of new therapeutic trials. The diagnosis of cancer in a child deeply affects the functioning, and thus the QOL, of all family members. The level of family functioning is a strong predictor of the ability of the child with cancer to function appropriately. Therefore, further study is needed to better understand the effects of a cancer diagnosis on the functioning of family members and to develop effective interventions that will lessen the negative impact of this event and promote positive adaptation. Examples of study areas include growth and development, neurocognitive functioning, reintegration issues (school, community activities, work), capacity to develop and sustain intimate relationships (marital, peer, parent, and sexual relationships), and shifts in both technology and health care that are effecting changes in the responsibility for and provision of care.

To conduct further study in the area of QOL, several avenues of research are possible. Currently, health-related QOL is a measurement in some clinical trials. The Children's Oncology Group (COG) could expand its multidisciplinary research agenda to address these QOL issues in all clinical trials, including the role of the social worker in providing psychosocial support to families. This expansion could be encouraged via letters to the chairpersons of the Cancer Control Committee and Psychology and Nursing Committees of COG from a coalition of organizations working in the area of childhood cancer.

To support research, funding agencies, such as the National Cancer Institute and the American Cancer Society, could be urged to offer increased grant funding for research projects that address QOL issues.
Potential Organizations to Involve

- American Cancer Society
- Association of Pediatric Oncology Social Workers
- Children’s Oncology Group
- National Cancer Institute
- Pediatric Brain Tumor Foundation of the United States

**Recommendation 2**

**Develop and implement quality of life (QOL) assessment tools that are specific for stages of disease and phases of care across the continuum of care.**

During the past 10 years, measures for assessing QOL in pediatric cancer have been developed, and a great deal of research in this area is being conducted. However, more work needs to be done to determine the relevance of these measurement tools and their validity for use in different phases of active treatment, end of treatment, active follow up, and long-term survivorship. In addition, the utility of these tools needs to be defined in terms of the following:

- Use for prognostic stratification
- Utility in guiding the use of supportive care interventions
- Application to the design of new treatment protocols

Furthermore, QOL needs to be better understood in the context of the developmental changes occurring in children and adolescents undergoing treatment. Also needed is a better understanding of the unique perspectives of parents and children in their perception of health-related quality of life.

Because most of the treatment for pediatric cancer in the United States and Canada is conducted through the Children’s Oncology Group (COG), a survey of the COG would determine what QOL measures exist and how effectively they are being employed in studies related to clinical trials. Also, because a large body of research has been done in the adult cancer population, it would be advisable to survey the adult cooperative groups to assess their experience in use of such tools in clinical trials. Using information obtained from these surveys, assessment tools can be selected or developed for inclusion in childhood cancer protocols.

Potential Organizations to Involve

- Children’s Oncology Group, particularly its Psychology, Nursing, Outcomes, and Cancer Control committees
- Coalition of National Childhood Cancer Organizations

**Recommendation 3**

**Define the required components of psychosocial support.**

Psychosocial care is an extension of medical treatment. Based on the current medical model of national treatment protocols, developing requirements for psychosocial support in these trials is essential to providing consistent, comprehensive, state-of-the-art treatment for children and adolescents with cancer as well as their families. Addressing the emotional, psychological, and spiritual needs of patients and families enhances a positive response to treatment and enables healthy family functioning. A team approach that includes all disciplines is necessary to effectively address medical and psychosocial issues.

A first step in defining the required components of psychosocial support should be a review of existing guidelines and published position papers on comprehensive pediatric oncology care, including those of the American Academy of Pediatrics, the American Society of Pediatric Hematology and Oncology, the Children's Oncology Group, Blue Cross/Blue Shield, and the American Cancer Society. This review is now underway with representatives of various childhood cancer organizations, and efforts should be coordinated.
A second step should be to recommend and justify essential components of psychosocial support in order to obtain endorsement of organizations dedicated to childhood cancer. To promulgate these components and the rationale behind recommending them, organizations participating in the National Summit Meetings on Childhood Cancer must review and endorse them, as should the National Dialogue on Cancer. These groups can make recommendations to the National Coalition on Childhood Cancer and then conduct their own reviews and endorsements. With a consensus of these organizations, a position paper can be published stating the standards of psychosocial care in pediatric oncology. Support and endorsement of recommendations need to come from not only psychosocial and medical groups but also from other organizations in the Coalition. Such a process and final product will strengthen the likelihood of implementation of a national standard of psychosocial support and care.

Potential Organizations to Involve

- Children’s Oncology Group
- American Cancer Society
- Association of Pediatric Oncology Social Workers
- Association of Pediatric Oncology Nurses
- American Psychological Association (Society of Pediatric Psychology)

References


Research Priorities

Charge to the Workgroup: The Research Priorities workgroup was responsible for identifying the aspects of research related to childhood cancer that require improvement. These include adolescent accrual to clinical trials, expansion of research funding, evaluation of clinical outcomes, and novel therapeutic developments.

Overview

Through research efforts over the last half of the twentieth century, childhood cancer has been transformed from an almost universally fatal disease to one that is curable in approximately 75 percent of patients. This remarkable achievement has come about through the effort of laboratory scientists, clinical investigators, and the cooperative clinical trials groups. With this success has come the realization that the goal of curing all children with cancer is achievable.

However, cancer still continues to be the leading cause of death by disease in children and adolescents. Nearly a quarter of children with cancer continue to die of the disease, and many others experience serious short- and long-term side effects that negatively affect their quality of life. With the explosion of emerging research trends, especially in the areas of biotechnology, molecular biology, and immunobiology, there are unprecedented opportunities for developing more effective and less toxic curative therapies. The current merger of four cooperative clinical trials groups (Children’s Cancer Group, Pediatric Oncology Group, Intergroup Rhabdomyosarcoma Study Group, and the National Wilms Tumor Study Group) into the Children’s Oncology Group provides a unified clinical research engine for translating these new strategies into improved
clinical outcomes for children and adolescents with cancer. The overall goal of research should be to eliminate the personal, family, and societal burden of cancer in children and adolescents. To achieve the goal, it will be necessary to efficiently translate the exciting discoveries being made in laboratories to the bedside through clinical research. Research must focus on identifying the causes of childhood cancer in order to develop strategies for cure and prevention, and clinical research must be enhanced to define optimal treatments. Laboratory research that will translate into more effective treatments with fewer short- and long-term side effects must be augmented. Finally, it will be necessary to stimulate research to improve the quality of life for both children and adolescents with cancer and their families.

Recommendations

The Research Priorities workgroup evaluated research priorities that are theoretically achievable over the next three years. The group examined priorities related to research funding, clinical outcomes evaluation, novel therapeutic developments, the issue of adolescents and clinical trials, and other areas. Based on this review, the workgroup made four recommendations regarding research related to childhood cancer:

- Develop the necessary infrastructure to support clinical research.
- Apply and develop efficient mechanisms for timely application of effective new treatments.
- Recruit, train, mentor, and retain skilled research professionals.
- Prioritize emerging research initiatives.

Recommendation 1

Develop the necessary infrastructure to support clinical research.

The dramatic improvement in cancer survival for children and adolescents over the past 40 years has been achieved through national cooperative clinical research efforts of pediatric oncologists and other pediatric specialists working through the four NCI-funded childhood cancer cooperative groups – Children’s Cancer Group, Pediatric Oncology Group, Intergroup Rhabdomyosarcoma Study Group, and the National Wilms Tumor Study Group. The clinical trials and correlative research are conducted at academic medical centers throughout North America.

The recent unification of the four cooperative groups into the Children’s Oncology Group (COG) developed as a consequence of scientific, operational, statistical, and financial realities. COG represents an opportunity to efficiently test promising anticancer treatments and conduct clinical research while streamlining related operational efforts and expenses. This national childhood cancer cooperative group can also readily facilitate both the exchange of basic and clinical research ideas and the continuous refinement of contemporary standards for diagnostics and clinical treatments related to childhood cancer.

This unification of the four groups occurs amidst the explosion of advances in molecular biology that have the potential to transform the diagnosis and treatment of childhood cancer through genetic technology and molecularly targeted anticancer drugs. Simultaneously, the unification occurs as the academic medical environment in which childhood cancer treatments are developed and tested continues to suffer significant ongoing financial erosion. NCI support of the four cooperative groups has previously been supplemented by the academic medical center infrastructure. With the direct funding of COG by the NCI likely to remain at current levels, there may be deficits in funding for pediatric oncology programs that must be addressed if children with cancer are to benefit from contemporary scientific advances.

Establishment of a sufficient level of consistent funding for effective pediatric oncology clinical research requires assessment of future financial, technical, and human resource research needs as
well as appropriate prioritization to secure the necessary funds from private, pharmaceutical, and federal sources.

Current funding of the COG and funding for the next fiscal year is in large part provided by redistributed grant awards to the legacy cooperative groups in supporting a central Group Operations Center in Arcadia, California, as well as a Distributed Statistics Department centered in Arcadia, and a Research Data Center located at the University of Florida, Gainesville.

• Funding for the Children’s Oncology Group should be sufficient to support a single research data center as well as a single statistics department and operations center, which will be responsible for analysis of both study data and institutional performance, study registration, membership registration, protocol design and development, study conduct, study reports and performance, study implementation and publication of results, compliance with regulatory and reporting requirements, administration, meeting preparation, and member education and support.

• COG will require support to provide the mechanisms for prioritization in the establishment of its scientific agenda and the development and conduct of studies.

• COG will require support to use preclinical data, pilot data, and data from Phase I and II studies for appropriate study design and to facilitate correlative laboratory studies using biologic specimens from patients participating in studies.

• Funding support will be necessary to guarantee an effective clinical research infrastructure at member institutions, including support for data submission and management, compliance with regulatory procedures, and review of submitted protocols by institutional review boards.

• Funding will be needed to ensure scientific leadership, as well as appropriate salaries, for clinical investigators and ancillary professionals, including nursing, pharmacy, psychology, and clinical research associates; contribution to the clinical research enterprise is threatened at all academic medical centers because of reimbursement changes in the health care industry.

• Support is required for appropriate resource and reference laboratories, as well as cell and tumor tissue repositories, to promote correlative research and expanding translational research opportunities, which will eventually have an impact on development of new therapies.

• Support is required to establish and implement an on-site monitoring and audit program to address important issues in data verification, protocol compliance, compliance with regulatory requirements for the protection of human subjects, and accountability of investigational agents.

• Support will be required for specific scientific disciplines in addition to pediatric oncology:
  * Pathology to provide central verification of histopathologic diagnosis, because known variabilities in accuracy can pose potential problems, and such data may provide prognostic information
  * Radiation oncology for central review, either concurrently or retrospectively, of port films and compliance with protocol-specified doses
  * Surgery for assessment of the adequacy of protocol-specified surgical procedures (where relevant) and in the development of new surgical approaches to the management of childhood cancer
  * Diagnostic imaging for central review of claimed responses and adequacy of imaging as well as prospective assessment of new imaging modalities and potential problems associated with current imaging modalities
  * Pharmacy to provide assistance with uniformity of drug distribution, handling, and management across all studies
* Pediatric cancer nursing to support education and development of nursing research programs and to expand responsibilities for interfacing with patient and parent advocacy groups

Potential Organizations to Involve

- American Cancer Society
- Centers for Disease Control and Prevention
- Food and Drug Administration
- Leukemia and Lymphoma Society
- National Childhood Cancer Foundation
- National Cancer Institute
- National Institutes of Health
- Private organizations and corporations with a mission of research support

Recommendation 2

Apply and develop efficient mechanisms for timely application of effective new treatments.

Currently, an unacceptable lag period exists between the time of relevant scientific discovery and clinical application. This is due in part to a very long time between the development of an innovative clinical study concept based on new scientific discovery and implementation of such a study. Further complicating this lag period is the fact that such innovative studies must often be completed in adults with cancer prior to testing in pediatric patients. A mechanism needs to be developed that will foster a more efficient infrastructure to conduct innovative clinical studies in pediatric patients with cancer. Developing such a mechanism could reduce by 50 percent the time required for clinical trial development, implementation, and reporting (to within three years).

Accomplishing this goal will require allocation of specific resources to fast-track novel ideas in key areas of clinical research. An infrastructure of shared core clinical research centers should be developed among the NCI and other centers, which will include shared tissue resources for research. Use of new and emerging technologies will foster use of shared clinical research centers. A focused, rapid-response consortium of research centers of excellence linked to national clinical trial efforts also will be an important component.

Implementing these goals will require a significant increase in resources to specifically support research into the basic mechanisms of human disease, health care delivery, and psychosocial science. Public and private support of basic research, which will provide new approaches to disease prevention and control, must increase. Most important, any projected increases in funding must be translated into increased support for basic and translational research efforts relevant to childhood cancer.

Sources of funding for these efforts should be sought from the National Institutes of Health, industry, private agencies, nonprofit foundations, and other committed organizations and individuals. A professional staff should be developed to coordinate a coalition of grassroots advocacy efforts.

Potential Organizations to Involve

- Centers for Disease Control and Prevention
- Food and Drug Administration
- National Childhood Cancer Foundation
- National Cancer Institute
- National Institutes of Health
- Pediatric Brain Tumor Foundation of the United States
- Private organizations and corporations with a mission of research support

Recommendation 3

Recruit, train, mentor, and retain skilled research professionals.

The current shortage of skilled investigators impedes rapid development, execution, and reporting of clinical trials and laboratory investigation. Recruiting, training, and retaining skilled research professionals are therefore essential to
the success of research efforts in pediatric oncology. Increasing the number of investigators dedicated to curing cancer in children and adolescents will require developing and marketing initiatives to identify, support, and educate individuals interested in pursuing cancer research at various levels of training. A reference guide that outlines currently available resources for clinical investigator support should be compiled and regularly updated. Additional financial support should be dedicated to investigator-driven development, implementation, and reporting of clinical trials in pediatric cancer, and new monetary awards should be created to support young investigators and clinical research faculty mentors in pediatric oncology.

**Potential Organizations to Involve**

- American Society of Pediatric Hematology/Oncology
- Children’s Oncology Group
- National Childhood Cancer Foundation
- National Institutes of Health
- Pediatric Brain Tumor Foundation of the United States
- Private organizations and corporations with a mission of research support

**Recommendation 4**

**Prioritize emerging research initiatives.**

National focus on and prioritization of research areas will strengthen the ability to support and implement cutting-edge discoveries. Future improvements in the diagnosis and treatment of children and adolescents with cancer will likely be based on translating discoveries in molecular biology, immunology, and informatics to clinical application, and the linkage of the biophysical sciences with novel imaging technologies. Utilization of genomic, proteomic, and microarray methodologies will be fundamental to determining cancer predisposition probabilities and to precision prognostic typing of tumors, as well as the determination of optimal treatments. In addition, such technologies may be able to help monitor patients for premalignant conditions and allow application of interventions to prevent the development of aggressive malignancies.

There is also a need for development of better research methods to assess short- and long-term quality of life issues. The ability to more accurately assess a wide range of outcome measures in children with cancer will help determine the success of new therapies.

A third major area of research, which will play an increasingly important role in the future, is health services, particularly with respect to the impact of managed care, quality of care, and resource utilization. The ability to develop more efficient and accurate approaches to acquiring such data will play an important role in the acceptance of both new treatments and prevention strategies.

**Potential Organizations to Involve**

- American Society of Pediatric Hematology/Oncology
- Centers for Disease Control and Prevention
- Children’s Oncology Group
- Food and Drug Administration
- National Childhood Cancer Foundation
- National Cancer Institute
- National Institutes of Health
- Private organizations with a mission of research support
The American Cancer Society launched an initiative in June 1999 to bring together organizations and individuals involved in the fight against pediatric cancer. The rationale for the initiative was to create a collaborative effort among these groups to identify the key issues in the area of childhood cancer and to jointly develop a plan of action to address these issues. The goal of the initiative was to improve the outcome of childhood cancer in terms of treatment, reduced morbidity and mortality, and improved quality of life by developing a collaborative National Action Plan for Childhood Cancer.

Although many local and national organizations address the needs of children with cancer, there had not previously been a coordinated national plan to address those needs. Proceeding on the premise that such a collaborative plan would eliminate duplication and maximize effectiveness of effort, the Society took the lead in convening organizations working in the area of pediatric cancer.

The American Cancer Society had in the past brought together groups of experts to confer on childhood cancer, most notably, two national workshops in 1993 and 1996. The new initiative would differ since it would, instead, bring together experts to look at the larger picture: what needed to be done overall to reduce morbidity and mortality from pediatric cancer and, more importantly, how all organizations in the childhood cancer community could work together to achieve results.

**Process**

As a first step in this undertaking, the American Cancer Society convened a multidisciplinary group of experts in the various fields of pediatric cancer to serve as a volunteer Summit Steering committee to spearhead the new childhood cancer initiative. The committee was charged with developing a plan for bringing together organizations to identify issues and to develop specific plans for addressing them. These individuals were selected because of their demonstrated knowledge and interest in specific areas of childhood cancer and their willingness to participate in this volunteer effort. The Society committed to sponsoring the effort, including funding all expenses associated with meetings and other work of the steering committee and the National Summit Meetings. It was also agreed that the American Cancer Society would facilitate rather than direct the effort to ensure that the results would reflect a consensus of all organizations participating in the summit meetings.

The first meeting of the steering committee was held in February 1999 in New York. At this meeting, steering committee members recommended that to be most effective, the Society should convene two summit meetings of all appropriate national organizations to identify key issues, needs, and strategies for improving treatment and outcomes in childhood cancer. The committee recommended the following goals and strategy for the two meetings:

- Develop a collaborative national action plan for addressing the issues key to childhood cancer
- Provide opportunities for synergy among organizations working in the area of childhood cancer
- Identify and support specific action steps for implementation by all participating organizations

**Appendix A**

**Background: The Origins of the Summit Meetings**

The American Cancer Society launched an initiative in June 1999 to bring together organizations and individuals involved in the fight against pediatric cancer. The rationale for the initiative was to create a collaborative effort among these groups to identify the key issues in the area of childhood cancer and to jointly develop a plan of action to address these issues. The goal of the initiative was to improve the outcome of childhood cancer in terms of treatment, reduced morbidity and mortality, and improved quality of life by developing a collaborative National Action Plan for Childhood Cancer.

Although many local and national organizations address the needs of children with cancer, there had not previously been a coordinated national plan to address those needs. Proceeding on the premise that such a collaborative plan would eliminate duplication and maximize effectiveness of effort, the Society took the lead in convening organizations working in the area of pediatric cancer.

The American Cancer Society had in the past brought together groups of experts to confer on childhood cancer, most notably, two national workshops in 1993 and 1996. The new initiative would differ since it would, instead, bring together experts to look at the larger picture: what needed to be done overall to reduce morbidity and mortality from pediatric cancer and, more importantly, how all organizations in the childhood cancer community could work together to achieve results.
Originally, it was envisioned that the first summit meeting would include two representatives from each of approximately 30 national organizations involved in pediatric cancer. Its focus would be on creating a collaborative three-year plan that would be owned by and provide a guide for all organizations. The three-year plan would detail specific actions to be taken by participating organizations that would have the greatest possible impact on improving treatment and outcomes in pediatric cancer.

The second summit meeting was envisioned to include a broader range of childhood cancer and youth-serving organizations to fine tune the action plan developed at Summit I, to determine the steps needed for implementation, and to identify organizations that might wish to participate in implementation.

In advance of the first summit meeting, the steering committee met several times and identified numerous organizations that should be invited to the meetings. Thirty organizations were invited to send representatives to participate in the first summit meeting.

The 30 participating organizations were asked to propose the pediatric cancer issues which they considered important to address at the summit meetings. Five key areas were identified for focusing the National Action Plan:

- Access to Care and Patterns of Care
- Advocacy and Professional Issues
- Long-term Care and Survivorship
- Patient and Family Quality of Life
- Research Priorities

It was emphasized that the collaborative action plan proposed would require that participating organizations commit to providing appropriate resources for implementing the plan and to cooperation with other committed organizations. Participating organizations were expected to determine the best steps for implementation of the plan once it was developed.

The Summit Steering committee recommended that participants at the summit meetings be organized into workgroups, each of which would focus on one of the five key areas identified. The workgroup and summit meeting agendas would be structured to ensure communication across and among the workgroups and to permit all participants to provide input to all other workgroups. Participants were given a list of the five workgroups and a description of the area each would encompass. They were asked to indicate their first and second choices of the workgroup they wished to join.

The First Summit Meeting

The meeting was convened November 1-3, 1999. Attendees included one volunteer and one staff member from each of the 30 organizations invited. The meeting was held at the Evergreen Conference Center near Atlanta. The American Cancer Society paid all travel and meeting expenses.

This was the first time that a broad group of organizations, all dedicated to childhood cancer, came together in a single meeting for the purpose of overall planning. No participants knew all other participants. In this sense, the meeting was a landmark event that signified a strong first step toward addressing in a collaborative way the compelling problems and challenges involved in the childhood cancer experience.

The meeting began with a plenary session with introductory remarks and a discussion of critical subject areas and goals for the meeting. Attendees then convened the five predetermined workgroups. Attendees had been assigned to their first or second choice, and the groups were not equal in number. The two representatives from each organization were encouraged to participate in separate workgroups. A recorder and a facilitator was assigned to each group and reported for the workgroup to all attendees at two plenary sessions during the summit meeting. Following the report of each workgroup, all attendees had an opportunity to provide comments and suggestions, to raise questions, and to provide input into the action plan to further the work of each group. At the end of the Summit
meeting a final plenary session was devoted to presentation and discussion of the refined plans of each workgroup.

**Recommendations From The First Summit Meeting**

As part of the general session discussion, many participants endorsed the concept of developing a national childhood cancer coalition. This concept provided a basis for considering the implementation of the recommendations from all workgroups.

**Evaluation**

At the first summit meeting, an evaluation form was circulated to all participants in order to measure the success of the meeting and to use this information to better plan for the next summit meeting. The survey included questions to rate the effectiveness of the workgroup sessions, the effect of the summit meeting on facilitating organizational collaboration, and the ability of the summit meeting to facilitate the creation of a national action plan, reenergize participants professionally, and encourage networking.

The most frequent comment was endorsement of the need for a national coalition of childhood cancer organizations. Another frequent comment was that the next summit meeting should focus on how to implement the recommendations and strategies from all workgroups and who would do so. The survey was very positive and the evaluations were very helpful in planning for the second summit meeting.

**The Second Summit Meeting**

Using the workgroup reports from Summit I, the steering committee conducted a series of conference call meetings to assess the progress of the participants as a group and to determine how to proceed with the second summit meeting. The second summit meeting was scheduled for June 4-6, 2000, at the Evergreen Conference Center.

The following were determined to be the goals of the second meeting:

- To review the results of Summit I, revise this work as necessary, and establish implementation priorities for all five workgroups
- To establish clear roles and responsibilities for participating organizations in the implementation of recommendations and strategies from all five workgroups
- To clarify and reach agreement on which parts of the overall National Action Plan for Childhood Cancer may best be implemented by working within or more appropriately addressed by working outside of a national coalition
- To discuss and reach agreement on the purpose, goals, and structure of a national coalition; consider related organizational issues; and formally approve the creation of a national coalition on childhood and adolescent cancer
- To establish responsibility and accountability for all decisions and actions agreed to at the summit meetings to ensure that their implementation will be timely, effective, and responsive to the needs identified by participants

Participants in the second summit meeting were asked to bring to the meeting their organization’s mission statement, comments on and suggested revisions to the plan that emerged from Summit I, and a list of specific ways their organization would be able to implement the recommendations from the summit meetings.

It became apparent that additional planning was needed to complete and refine the interim reports produced at Summit I. It was decided to devote a substantial amount of time to implementation strategies for the workgroup recommendations and to provide time for discussion of the proposed national childhood cancer coalition.
Recommendations From The Second Summit Meeting

The second summit meeting produced a high level of synergy and a sense of ownership among organizations in each workgroup. Participants discussed the need for an implementation strategy for the National Action Plan for Childhood Cancer and the value of a national coalition of childhood cancer organizations in some of its strategies.

The meeting illustrated that there were many ways for organizations to be involved in and contribute to implementing the summit recommendations, including those with limited resources. Each workgroup elected two of its members as their representatives on a Summit Implementation Task Force that would begin to define and then propose the purposes, the structure, the membership, and the operational logistics of a coalition. There was informal consensus that the Implementation Task Force would replace the Summit Steering committee. Dr. Denman Hammond, co-chair of the National Summit meetings, was elected chair of the Implementation Task Force. (See Appendix F.) Representatives from the American Society of Clinical Oncology (ASCO) offered administrative and legal assistance in drafting a proposed charter for a national coalition and in assisting the Implementation Task Force in developing the proposed coalition.

Next Steps

Taken together, the two National Summit Meetings on Childhood Cancer represent the coming together of a large number of organizations involved in childhood cancer in a new way. The product of these meetings can best be summed up as:

- A succinct National Action Plan for Childhood Cancer that identifies the greatest current needs in childhood cancer
- The understanding that it is critical for participants to creatively address these needs through partnership, collaboration, and a national coalition in order to achieve implementation of the summit recommendations

As the Summit Implementation Task Force carries on the work begun at the summit meetings, the next tasks involve finalization and dissemination of the National Action Plan for Childhood Cancer and the Report of the National Summit Meetings, establishment of a national coalition, and continued strong and frequent communication with all participants.
Appendix B
Summit Steering Committee

Robert Arceci, MD, PhD
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Johns Hopkins University
Pediatric Oncologist

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St. Jude Children’s Research Hospital
Pediatric Oncology Nurse

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University of Colorado School of Medicine
Pediatric Surgeon

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Associate Vice President, Health Affairs
University of Southern California
Pediatric Oncologist

John Laszlo, MD
National Vice President for Research (retired)
American Cancer Society

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Stanford University School of Medicine
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Past President, American Cancer Society

Aimee Merszei
Former Trustee
National Childhood Cancer Foundation
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Director, Hematology/Oncology
Children’s National Medical Center
Professor of Pediatrics
George Washington University
Pediatric Oncologist

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Ronald McDonald Children’s Hospital
Pediatric Oncology Social Worker

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University of Minnesota School of Medicine
Epidemiologist

Beth Stevenson, MPH
Director, Children and Youth Initiatives
American Cancer Society
## Appendix C

### Participating Organizations and Their Representatives

<table>
<thead>
<tr>
<th>Organization</th>
<th>Representative</th>
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<tbody>
<tr>
<td>AirLifeLine</td>
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<td>John Wurtzberger</td>
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<td>American Academy of Pediatrics</td>
<td>Jerry Z. Finklestein, MD</td>
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<td>Edwin Forman, MD, PhD</td>
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<td>John Hipchen</td>
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<td>Mary Ellen Keith, MSN, RN</td>
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<td>Gerald Haase, MD</td>
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<td>Marie Lauria, MSW</td>
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<td>American Pediatric Surgical Association</td>
<td>Michael LaQuaglia, MD</td>
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<td>Robert Shamberger, MD</td>
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<td>American Society of Clinical Oncology</td>
<td>Deborah Kamin, PhD</td>
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<td>Michael P. Link, MD</td>
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<tr>
<td>American Society of Pediatric Hematology/Oncology</td>
<td>George Buchanan, MD</td>
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<td>Susan Shurin, MD</td>
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<td>American Society for Therapeutic Radiology and Oncology</td>
<td>Larry Kun, MD</td>
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<td>Association of Pediatric Oncology Nurses</td>
<td>Alice Ettinger, MSN, RN, CPNP</td>
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<td>Kathleen Klaeser, CAE</td>
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<td>Association of Pediatric Oncology Social Workers</td>
<td>Marilyn Lees Reinish, MSW, LCSW</td>
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<td>Karen Tilley, MSW, LCSW</td>
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<td>Bear Necessities Pediatric Cancer Foundation</td>
<td>Kathleen Casey</td>
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<td>Michael O’Brien</td>
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<td>Centers for Disease Control and Prevention</td>
<td>Brooke Steele, DO</td>
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<td>Children’s Cancer Group</td>
<td>W. Archie Bleyer, MD</td>
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<td>Gregory H. Reaman, MD</td>
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<tr>
<td>Organization</td>
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<tr>
<td>Children’s Brain Tumor Foundation</td>
<td>Craig P. Lustig, MPA</td>
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</table>
| The Children's Cause                                            | Craig P. Lustig, MPA
Susan L. Weiner, PhD                                             |
| Children’s Oncology Camping Association International            | Brian Crater
Jean Lockrow, BSN, MA                                               |
| Intergroup Rhabdomyosarcoma Study Group                          | William M. Crist, MD                                                   |
| Leukemia and Lymphoma Society                                   | Cheryl Bradley, MSW
Robin Kornhaber, MSW                                                |
| National Cancer Institute                                        | Barry Anderson, MD, PhD
Lee J. Helman, MD
Julia Rowland, PhD
Malcolm Smith, MD, PhD
Alan Wayne, MD                                                      |
| National Childhood Cancer Foundation                             | G. Denman Hammond, MD
Aimee Merszei
Lisa Parks                                                           |
| National Children’s Cancer Society, Inc.                        | Mark Stolze
Michael Tucker                                                       |
| National Coalition for Cancer Research                           | Marguerite Donoghue Baxter, RN, MSN                                    |
| National Coalition for Cancer Survivorship                       | Susan L. Weiner, PhD                                                   |
| National Wilms Tumor Study Group                                 | Daniel M. Green, MD
Nita Seibel, MD                                                      |
| Pediatric Brain Tumor Foundation of the United States           | Dianne S. Traynor
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| Pediatric Oncology Group                                         | Sharon Murphy, MD
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| Society of Pediatric Psychology                                 | F. Daniel Armstrong, PhD
Mary Jo Kupst, PhD                                                     |
| STARBRIGHT Foundation                                            | Jordana Huchital                                                       |
Appendix D
Participants in the Summit Meetings

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Alice Ettinger, MSN, RN, CPNP
Robin Kornhaber, MSW
Marie M. Lauria, MSW
Michael P. Link, MD
Mark D. Moncino, MD
Sharon Murphy, MD
Mark Stolze

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Jerry Z. Finklestein, MD
G. Denman Hammond, MD
Ruth Hoffman
Deborah Kamin, PhD
Mary Ellen Keith, MSN, RN
Michael LaQuaglia, MD
Lisa Parks
Robert Shamberger, MD
Susan L. Weiner, PhD

Long-term Care and Survivorship
F. Daniel Armstrong, PhD
Daniel M. Green, MD
Gerald M. Haase, MD
Craig P. Lustig, MPA
Aimee Merszei
Donna Mitchell, RN, PON
Leslie L. Robison, PhD
Julia Rowland, PhD
Michael Traynor

Patient and Family Quality of Life
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Brian Crater
Edwin Forman, MD
Jordana Huchital
Kathleen Klaeser, CAE
Mary Jo Kupst, PhD
Jean Lockrow, BSN, MA
Richard Love
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Karen Tilley, MSW, LCSW
Michael Tucker
Alex Wattles
Jon Wurtzburger

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Robert J. Arceci, MD
W. Archie Bleyer, MD
George Buchanan, MD
William M. Crist, MD
Marguerite Donoghue Baxter, RN, MSN
Lee Helman, MD
John Hipchen
Larry Kun, MD
John Laszlo, MD
Gregory H. Reaman, MD
Nita Seibel, MD
Malcolm Smith, MD, PhD
Brooke Steele, DO
Susan Shurin, MD
Dianne S. Traynor
Alan Wayne, MD
Appendix F
Summit Implementation
Task Force

(Elected by Each Workgroup)

Access to Care and Patterns of Care Workgroup
Alice Ettinger, MSN, RN, CPNP
Michael P. Link, MD

Advocacy and Professional Issues Workgroup
G. Denman Hammond, MD (Chair of Task Force)
Ruth Hoffman

Long-term Care and Survivorship Workgroup
Gerald M. Haase, MD
Craig P. Lustig, MPA

Patient and Family Quality of Life Workgroup
Edwin Forman, MD, MPH
Mary Jo Kupst, PhD

Research Priorities Workgroup
Robert Arceci, MD, PhD
Dianne S. Traynor