

Is Childhood Cancer Included in YOUR State Cancer Plan?

By Ruth Hoffman, MPH

In 1998, the Centers for Disease Control and Prevention (CDC) funded the first comprehensive cancer control programs in five states – specifically Colorado, Massachusetts, Michigan, North Carolina and Texas. Since that time, the CDC through the establishment of the National Comprehensive Cancer Control Program (NCCCP) <http://www.cdc.gov/cancer/ncccp/> has provided grants to assist all 50 states, the District of Columbia, seven tribes and seven U.S. Associated Pacific Islands and Territories with the development and implementation of cancer control plans. These plans guide and coordinate efforts within the state to gather state specific cancer incidence and mortality data (cancer surveillance), as well as support coordinated efforts to increase access to quality care and treatment, promote prevention and early detection programs, develop education programs to promote healthy life-style choices to enhance the quality of life of survivors, and strategies to reduce health disparities.

Each state is charged with identifying and implementing goals and strategies specific to address their cancer burden and needs. The plans are often implemented over a four or five year period and include strategies such as the passing of legislative policies, and investments in early detection such as state sponsored free breast and cervical cancer screenings to low and uninsured women. Plans also include cancer prevention, education, and evidence-based research initiatives to identify and evaluate state cancer priorities and outcomes of the plans as guidance for subsequent plans.

The success of the plans for the past 13 years has been built upon the philosophy that collaborating with the CDC, state's Department of Health, and cancer organizations – i.e. collaboration between public and private organizations will lead to conquering cancer. <http://www.cdc.gov/cancer/ncccp/state.htm>.

Sadly, childhood cancer for the most part has been a 'forgotten child' at this table. In spite of the fact that childhood cancer remains the leading cause of death by disease for our nation's children under the age of 15 years, **twenty-three states have NO mention of childhood cancer in their state's cancer plans.** Children are solely mentioned in context of education and awareness programs aimed at healthy children. These include education programs such as smoking prevention and cessation, healthy lifestyle choices such as exercise and healthy eating with the focus being placed on reducing the cancer burden as adults.

Of the remaining twenty-seven states that do include childhood cancer language, 7 reference this patient population in one sentence; 1 includes two cancer organizations in their resource section; 5 include one paragraph to describe our nation's youngest cancer burden; 6 include one page of text; 7 have dedicated a chapter to childhood cancer with state specific data, objectives and strategies; and ONE state—the state of Idaho has written a full separate 18 page supplementary document entirely dedicated to their state's childhood cancer burden. Idaho's plan includes state specific incidence and mortality rates, text on the impact of the diagnosis on the child and the family's quality of life, school re-entry information, text on clinical trial access, as well as strategies to enhance access to care, patient and family quality of life, long-term care and survivorship, and advocacy, in addition to an education campaign to increase awareness of environmental known carcinogens. Congratulations Idaho for being the first state in the U.S. to dedicate an entire report on the childhood cancer burden in your state!!

http://cancercontrolplanet.cancer.gov/state_plans/Idaho_Childhood_Cancer_Control_Plan.pdf

It is time that our state Departments of Health, our state representatives, governors and 'program partners' heard from us <http://cancercontrolplanet.cancer.gov/partners/list.jsp?r=ALL&cctopic=C>. If childhood cancer is going to be regarded as an issue in our states that is worthy of action, then we need to let them know that childhood cancer needs to be included as a focus within the state cancer plans. To assist with this process, the following two charts summarize those states that have NO childhood cancer language in them, as well as those that do and the extent of that language. The following link provides further links to each state cancer plan in PDF formats for you to read the

existing plans. http://cancercontrolplanet.cancer.gov/state_plans.jsp. Finally, the document below provides suggested language to give to your state's Health Department to assist them with identifying the unique needs of childhood cancer that need to be addressed in their state plans. And for those families who live in Idaho and those states that have dedicated a chapter to childhood cancer, please contact your public health officials representatives and say "Thank you!"

Please email me at: rhoffman@acco.org to update me on your individual advocacy initiatives so that we can keep an active summary of calls and action requests being made to state officials. This will enable ACCO to follow-up by creating parent-led committees and coordinated action plans to move this initiative forward.

As the grassroots voice of our children it is important that we speak on behalf of our children. Working together we can make a difference for our children and those children yet to be diagnosed with this life-threatening disease. We need to be that voice for our children ... because kids can't fight cancer alone!

States that do NOT include childhood cancer language in their cancer plans

Alabama	Arizona	Connecticut	Georgia
Hawaii	Indiana	Iowa	Kansas
Kentucky	Louisiana	Michigan	Minnesota
Missouri	Nebraska	New Hampshire	North Dakota
Ohio	Pennsylvania	South Carolina	South Dakota
Vermont	West Virginia	Wisconsin	

States that include childhood cancer language and the quantity devoted to it.

Alaska (1 paragraph)	Arkansas (1 sentence)	California (1 page)	Colorado (1 sentence)
District of Columbia (dedicated chapter)	Florida (dedicated chapter with state specific info and objectives)	Idaho (18 page separate childhood cancer strategic plan)	Illinois (1 sentence)
Maine (dedicated chapter)	Maryland (1 paragraph on hospice, palliative care and several other brief references)	Massachusetts (2 brief references)	Mississippi (1 paragraph)
Montana (dedicated chapter)	Nevada (two organizations' contact information only)	New Jersey (dedicated chapter)	New Mexico (dedicated language)
New York (1 sentence)	North Carolina (dedicated chapter)	Oklahoma (1 sentence)	Oregon (1 sentence)
Rhode Island (3 references)	Tennessee (dedicated section with objectives and strategies)	Texas (dedicated language on childhood cancer survivorship)	Utah (dedicated page)
Virginia (dedicated page)	Washington (1 sentence)	Wyoming (dedicated chapter with state specific data, goals and strategies.)	

State Cancer Plan Recommended Childhood Cancer Language

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Overview/Introduction:

Childhood cancer is the leading cause of death by disease in children. Each year 12,400 children, ages birth to 19 years are diagnosed with cancer¹. For every four children diagnosed with cancer, one will survive and lead a normal healthy life, one will die and two will survive with life long complications of their treatment.

Childhood cancer differs from adult cancers by type and duration of treatment. Whereas the average adult with cancer is treated for six months to a year, children are treated for six months to three years depending on the diagnosis and type of treatment. The cancers most prevalent in children under 14 years of age include Acute Lymphoblastic Leukemia, central nervous system tumors, neuroblastoma, Wilms' Tumor and non Hodgkins Lymphoma in children. Teens and young adults experience higher rates of Hodgkins disease, germ cell tumors, non-Hodgkins Lymphoma, osteosarcoma, Ewings' sarcoma and soft tissue sarcomas. Although significant advances have been made in the diagnosis and treatment of pediatric cancer over the past five decades little is known about the causes and prevention of childhood cancer.

The primary focus of cancer control in childhood cancer is survivorship and the long term effects of treatment. Childhood cancer represents approximately 1% of the US cancer burden. Classified as an orphan disease steps must be taken to reduce existing barriers to new drug development and targeted therapies. Current drug therapy for the most common form of childhood cancer – i.e. acute lymphocytic leukemia includes 11 chemotherapy agents. Half of these were discovered in the 1950's, and all but one of the remaining were discovered in the 1960s. There has been one new drug approved by the FDA for childhood cancer in the last 20 years. As such, there has been no change in the overall survival of childhood cancer in more than a decade. Current traditional therapies for childhood cancer have reached a plateau with maximum dosage being given, and maximum curative outcomes reached. It is imperative that research priorities be established for childhood cancer that includes a substantial increase in funding for basic and translational discoveries.

It is important that state cancer control plans recognize that childhood cancers are distinct from adult cancers and should be given necessary attention and resources in each plan. The plans and resources should also focus on the unique needs of children and adolescents with cancer (and their families) from diagnosis through the entire continuum of care, including survivorship, long-term effects of treatment and end-of-life care. Whereas most adults have completed their education, have been employed and have completed their families when diagnosed with this life-threatening disease, children are just beginning their life. Cancer treatment can effect their physical and psychosocial development and impact their ability to complete their education, get and sustain employment and have a family.

To ensure that these issues are appropriately addressed, work groups responsible for drafting state cancer plans should include grassroots organizations representing the childhood cancer population and their families.

¹ Ries LAG, Smith MA, Gurney JG, Linet M, Tamra T, Young JL, Bunin GR (eds). Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975-1995, National Cancer Institute, SEER Program. NIH Pub. No. 99-4649. Bethesda, MD, 1999.

Critical background information should be included in pediatric cancer chapter in each state cancer plan that addresses the following information/demographics:

- State childhood cancer prevalence and mortality rate by cancer diagnosis and age
- Participation rates in clinical trials, including comparisons for gender, age, and ethnicity
- Age variability for survival
- Disease risk factors
- Average distance to comprehensive children's treatment center
- Referral patterns of children and adolescents to specialized care

At a minimum, state cancer plans should address the following information related to childhood cancer:

Content

The primary focus should be on cure and prevention/reduction of late effects from treatment, as well as stressing the need to address psychosocial/emotional needs as these impact the long-term effects for the child and family. The content should also specify the unique life-long problems associated with childhood cancer survivors (employability, insurability, educational and physical complications associated with treatment, etc.).

Overall Goals:

- Increase survivorship for all child and adolescent cancers, as well as the long-term quality of life of survivors.
- Ensure access to pediatric comprehensive treatment center. A key strategy for this is to educate referring physicians.
- Access to support programs/resources to assist the whole family (i.e., patient, parents and siblings) throughout the childhood cancer journey, including psychosocial and emotional support services.
- Ensure that those diagnosed as teenagers and young adults are treated at pediatric cancer centers (in the 15-19 age range).
- Ensure access to pediatric palliative/hospice care programs.
- Recognize the need for enhanced research support for pediatric cancers, including improved mechanisms for pediatric drug development

Treatment and Late-Effects of Treatment Information:

Each state should clearly articulate information and the latest data on the following:

- National data on late effects (cognitive, organ, fertility, secondary cancers, etc.)
- Specific psychosocial care services that should be provided to children and families
- Recommendations/standards for follow-up care (e.g., COG Guidelines) that should be followed, including baselines for neuro-cognitive status and follow-up screening
- State-specific data collected on secondary cancers (childhood survivors who develop secondary cancers).
- Develop guidelines for access to survivorship care, such as the COG Passport to Care

Research:

All plans should advocate for enhanced research funding to address the needs of childhood cancer patients and survivors across the continuum of care.

- Support for research leading to new therapies targeted specifically for children with cancer that are effective and less toxic.
- Promotion of basic/molecular research leading to understanding the causes of pediatric cancers
- Make all phases of clinical trials more available to patients
- Promote research to improve the quality of life for survivors that address the physical, cognitive and psychosocial consequences of treatment from diagnosis through late effects.
- Support funding for pediatric cancer research

Palliative and Hospice Care:

Each state cancer plan should address the unique needs of children with cancer and their families. These include alleviating symptoms and improving the quality of life for patients and their families throughout the continuum of care. Effective palliative care begins at diagnosis and utilizes a wide range of resources to assure pain and symptom management while addressing the physical and psychosocial needs of the patient and family to maintain the best quality of life possible. Pediatric hospice care is imperative at the end of life to support families who want to bring their child home to die. Resources need to be in place to support these family decisions.

- Adequate reimbursement for home and hospice care
- Families should not have to terminate treatment to be able to care for their child at home
- Provide community support for patients to live as actively as they desire until their death
- Provide programs to manage the stress of childhood cancer including financial, education and employment for the family
- Provide bereavement support that continues to support the family even after the death of their child

Education/Awareness/Advocacy:

Each state cancer control plan should address the need to provide resources and educational information to include the following:

- Consumer friendly explanations of clinical trials, informed consent, and referral patterns
- Family educational needs (diagnosis, treatment, late-effects, psychosocial support programs, sibling support, respite care)
- Support that should be available through the school (IEP, educational consultants, etc.)
- Adopt a standardized neuro-cognitive baseline and follow up assessments in all 50 states as established by COG
- Strategies to *provide continuing* education and awareness of pediatricians regarding diagnosis of childhood cancer and referrals to pediatric cancer centers
- Ready access to standards/guidelines for follow-up assessments/surveillance for survivors
- Highlight strategies to increase general awareness of incidence and impact of disease on America's children
- Improve awareness of clinical trials in the pediatric/adolescent population
- Increase awareness of need for novel therapies.
- Increase awareness of impact on survivors and families.
- Establishment of funding mechanisms to support non-profits providing quality educational materials to children with cancer and their families.

Financial Impact:

Each state cancer plan should include information about the financial impact of childhood cancer, addressing the following:

- Loss of income by parents
- Out of pocket costs for care
- Data on financial hardship/medical bankruptcy
- Long-term financial impact on the survivors (employability, insurability)

States should ensure that information is available on state-based resources that may help families understand and access these resources.

Insurance:

Each state plan should clearly articulate the health insurance coverage requirements for childhood cancer patients, including:

- Coverage at comprehensive pediatric treatment center as opposed to community hospital for all children and adolescents.
- Access to affordable and comprehensive coverage including experimental therapies recommended by the treating oncologist.
- Access to insurance in spite of pre-existing diagnosis for long term follow-up care.
- Coverage for all services (include pain/palliative/psychosocial); coverage should include appropriate services for family and siblings.