



SUMMARY OF CHILDHOOD CANCER POLICY IN STATE CANCER ACTION PLANS

Ruth Hoffman, MPH
Jamie Ennis Bloyd, MPA

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 and the District of Columbia, (as well as 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 20 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. https://www.cdc.gov/cancer/ncccp/ccc_plans.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-nine states have NO mention of childhood cancer in their state's cancer plans. This represents an increase on the number of states without any mention of childhood cancer in their state cancer plans from 23 states in 2011!** 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, HPV vaccination, healthy lifestyle choices such as exercise and healthy eating,

sun screen prevention, reduction in obesity etc. with the focus being placed on reducing the cancer burden as adults.

Of the remaining twenty-one states that do include childhood cancer language, 10 reference this patient population that represents the number one disease killer of children in America in one or two sentences; 1 state plus the District of Columbia included one to two paragraphs to describe our nation's youngest patients' cancer burden and sadly only 9 states have dedicated childhood cancer language with state specific data, objectives and strategies.

States that do NOT include childhood cancer language in their cancer plans (Nov. 2018)

Alabama	Arizona	Arkansas	Delaware
Georgia	Hawaii	Idaho	Illinois
Indiana	Louisiana	Maine	Massachusetts
Minnesota	Missouri	Nebraska	New Hampshire
New Mexico	North Dakota	Ohio	Oklahoma (2 childhood cancer stories but NO data, objectives, goals, strategy)
Pennsylvania	Rhode Island	South Carolina	South Dakota
Utah	Vermont	Washington	West Virginia
Wisconsin			

States that include childhood cancer language and the quantity devoted to it. (Nov. 2018)

Alaska (1 line – down from one paragraph in 2011)	California (1 line on leukemia incidence down from 1 page in 2011)	Colorado (1 sentence)	Connecticut (2 line about palliative care access)
District of Columbia (paragraph reference to palliative care, down from dedicated section on childhood cancer from 2011)	Florida (3-page comprehensive section including strategies)	Iowa (2 sentence reference to survivors)	Kansas (2 paragraphs focused on survivorship; 1 story)

Kentucky (comprehensive report including strategies/goals)	Maryland (1 page including MD incidence, survivorship but no plan/objectives)	Michigan (1 sentence survivorship included with adult context)	Mississippi (5 sentences incidence)
Montana (dedicated chapter with objectives and strategies)	Nevada (Specific objectives and strategies)	New Jersey (dedicated comprehensive chapter with specific goals, objectives and strategies along the continuum of care)	New York (1 sentence, palliative care)
North Carolina (2 short paragraphs no objectives. Was dedicated chapter in 2011)	Oregon (2 sentences)	Tennessee (dedicated chapter with objectives and strategies)	Texas (dedicated language on childhood cancer with strategies across the continuum including survivorship)
Virginia (comprehensive plan including goals and objectives; previously one page in 2011)	Wyoming (dedicated chapter with state specific data, goals and strategies.)		

If childhood cancer is going to be regarded as a top priority in our states, it is imperative childhood cancer is included as a focus within the state cancer plans.

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 affect their physical and psychosocial development and impact their ability to complete their education, get and sustain employment and have a family.

Furthermore, 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. Heavy emphasis on screening, prevention, and early detection as metrics of success in current state cancer action plans, unintentionally discriminate against childhood cancer inclusion because there are no universally accepted standards for screening or prevention for most childhood cancer diagnoses.

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. Critical background information should be included in a 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; and referral patterns of children and adolescents to specialized care.

We suggest 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.

- 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

For more information on our organization and our advocacy initiatives including our state focused advocacy called Why Not Kids, signature programs, services, and free resources to children diagnosed with cancer and their families, please visit www.acco.org.
