

# The Healthy Living After Treatment For Childhood Cancer Act of 2008

## Concerning Developmental Needs of Children And Youth With Cancer

### Minnesota Childhood Cancer Survivors Coalition Advocating For Change:

As a childhood cancer survivor or a parent of a childhood cancer survivor, you are faced with many serious life challenges. You are eager to help other cancer patients and determined to make life better, safer, and easier for childhood cancer survivors. Childhood cancer survivors will most likely never return to normalcy or their pre-cancer life. Instead, childhood cancer survivors and their families have courageously won the fight against cancer but continue to be challenged with other medical conditions because of treatment. Survivorship of childhood cancers has gone up from 30% in the late 70's to over 85% now.

Recent scientific reports indicate that treatment for cancer during childhood or adolescence may affect educational progress due to neurotoxic agents (such as chemotherapy or radiation) to control or prevent spread of the disease to the brain/and or spinal cord. This therapy can sometimes affect memory, attention, and learning abilities. In addition, prolonged absences or reduced energy levels that frequently occur during treatment may also contribute to children's difficulties. Some factors that may place children and teens at increased risk for difficulties in school include: diagnosis of cancer at a very young age, multiple types of treatment (e.g., surgery, radiation, chemotherapy), numerous or prolonged school absences, cancer treatment affecting the central nervous system, reduced energy levels, reduced hearing or vision (as a result of treatments), or cancer treatment that results in physical disabilities. Radiation and chemotherapy are very effective at killing cancer cells but they also cause slow damage to the brain and its growth and development later on. Children who are treated before the age of five are most susceptible to cognitive deficits.

Children with brain tumors, tumors involving the eye or ear, acute lymphoblastic leukemia (ALL) or non-Hodgkin's lymphoma face a higher risk of developing educational difficulties. Brain tumors are the most common form of childhood cancer in the United States and often have the most significant impact on a child's development because the tumor itself, as well as the treatments and their consequences, may affect the brain's development. Neuropsychological testing early in the treatment process provides baseline information whether there are "late effects" when the child is a survivor. Reevaluation every 18 months to years are usually recommended to assess changes due to treatment and revise recommendations for interventions.

Minnesota's childhood cancer survivors need neuropsychological testing to help them, their parents, and teachers identify their cognitive strengths and weaknesses as well as interventions so that they can go on to have productive, hopeful futures. The impact on the child's ability to learn, to do well in school and ultimately move to succeed in work and social relationship magnifies the need for this important piece of legislation.

## What Are Developmental Needs of Children Living After Surviving Cancer and How Can Neuropsychological Testing Help?

The brain is a very complex structure that continues to grow and develop throughout childhood adolescence, and early adulthood. Common learning problems for childhood cancer survivors include difficulties: concentrating or attending, doing two tasks simultaneously (such as taking down notes while they're looking at a blackboard or listening to the teacher), remembering, learning new handwriting, learning new information, completing work quickly, comprehending what they've read, doing math problems, and problem solving. Some survivors experience social difficulties with peers or may have ongoing issues with anxiety, depression, or other emotional concerns. Given the complexity of the medical, developmental, and neurological issues involved, public schools are not in the position to be able to complete these kinds of specialized evaluations. They also do not have access to much of the medical information needed to understand the individual's treatment history.

Extraordinary progress has been made in improving the cure rates for childhood cancers but not without varying degrees of risks for both acute and chronic toxicities. Half of all childhood cancer survivors have diseases and/or treatment that result in long term learning problems that emerge after treatment or even many years after treatment ("late effects"). Few educators are aware of the educational late effects related to cancer treatment. The late effects often appear years after treatment is completed and may be misdiagnosed or ignored all together.

A specialized evaluation by a pediatric neuropsychologist or psychologist is recommended for any young person who has had any cancer treatments at the time of diagnosis or entry into long-term follow-up. This type of testing will measure IQ (cognitive) and school based skills (e.g., reading, writing, mathematics), along with more detailed information about how the child processes and organizes information (e.g., language processing, problem-solving, attention, memory, motor skills, visual-perceptual skills, executive functions, behavior, emotional and social development).

Once the cognitive and learning challenges are recognized they can be typically be overcome or adapted to through classroom modifications or other interventions such as cognitive remediation, pharmacotherapy, or tutoring. Studies have shown that neuropsychological testing will provide the necessary documentation for children to receive special education services and enable the parents and school to develop a plan to maximize the child's learning potential.

Neuropsychological testing in Minnesota costs between \$2,000 and \$3,500 and generally involves 4-10 hours of direct testing, interviews with parents and/or child, scoring, interpretation of test results, report write-up, review of the medical and educational records, and contact with the child's teachers and doctors.

## The Healthy Living After Treatment of Childhood Cancer Act of 2008:

The Healthy Living After Treatment For Childhood Cancer Act of 2008 concerns the developmental needs of children and youth surviving childhood cancer and ensures these survivors are granted access to neuropsychological testing. Recent studies support the importance of testing to assess the extent of any cognitive or developmental delays in such child due to chemotherapy or radiation. This important legislation ensures that the needs of childhood cancer survivors are being met by including cognitive and developmental testing as a part of childhood cancer treatment covered under insurance. Additionally, it provides that prior authorization from state or private plans will not be required, and, beginning after enactment, both private and state insurers in Minnesota will have to cover neuropsychological testing for children diagnosed with cancer on or after January 1, 2000.

Due to the small number of potential children in the Medicaid program who would likely be subject to this testing; only minimal cost is anticipated.

This bill does not define “child.” The law requires individual or group health insurance policies that cover dependents to do so through age 18 and up to age 23 if they are full-time students at an accredited school.

Similar legislation is being passed throughout the country on a bipartisan and no opposition basis.

### A bill for an act

Relating to insurance; requiring specified individual and group insurers to provide coverage for neuropsychological testing for children diagnosed with cancer on or after January 1, 2000; requiring a licensed physician to order the testing to assess the extent of any cognitive or developmental delays in such child due to chemotherapy or radiation; requiring the Minnesota Department of Human Services to amend the state Medicaid plan and children’s health insurance plan to provide such coverage; proposing coding for new law in Minnesota Statutes, chapter 62A.

### BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA

Section 1. Minnesota Statutes 2006, section 62A is amended to read:

Subd. 2. **Required coverage:** Every policy, plan, certificate, or contract referred to in subdivision 1 that provides coverage to a Minnesota resident must provide coverage without prior authorization for each child diagnosed with cancer on or after January 1, 2000, for neuropsychological testing ordered by a licensed physician, to assess the extent of any cognitive or developmental delays in such child due to chemotherapy or radiation treatment.

The Commissioner of Human Services, to the extent permitted by federal law, shall take such action as necessary to amend the Medicaid state plan to provide coverage without such prior authorization for each child diagnosed with cancer on or after January 1, 2000, who is covered under Minnesota Care, Part A or Part B, for neuropsychological testing ordered by a licensed physician, to assess the extent of any cognitive or developmental delays in such child due to chemotherapy or radiation treatment.

Sec. 2. EFFECTIVE DATE:

Section 1 is effective the day following the enactment.