



Children's Brain Tumor Foundation

Embracing the challenge today gives hope for tomorrow

Pediatric Brain and Spinal Cord Tumors Fact Sheet

Brain and spinal cord tumors remain the deadliest childhood cancer, despite decreases in overall cancer death rates since the early 1990s.

- While there are “only” 3400 cases annually in the United States, roughly one-third of kids diagnosed with brain tumors don’t survive beyond five years.
- Brain tumors are often difficult to diagnose because their signs and symptoms may mimic those of other disorders. Symptoms will also vary according to the exact location of the tumor. Many early signs are due to the effects of raised intracranial pressure (ICP), brought on by the tumor’s size or location, blocking the normal flow of cerebrospinal fluid (CSF) from the brain.
- Treatment includes surgery, radiation, and chemotherapy, depending on the type, rate of growth and location of tumors. Treatment of brain or spinal cord tumors usually begins with surgical resection to remove all or part of the tumor. Although complete removal of the tumor (gross total resection) is often the treatment of choice, partial removal of the tumor will occasionally relieve a child’s symptoms. Removal of the tumor often relieves some of the uncomfortable, dangerous pressure that an unwelcome mass in the brain or spinal cord causes. Surgery also establishes the diagnosis by obtaining portions of the tumor for a pathologist’s analysis.
- Even benign tumors (slow-growing and not spreading) can be dangerous in the brain because they destroy healthy cells that may be vital to the quality of life or life itself.
- Kids with brain tumors often spend long periods of time in the hospital, oftentimes with their parents staying full-time, too. They are isolated from their peers and lose the experience of normal childhood.

There are 20,000 brain tumor survivors alive today in the U.S. Survivorship is a relatively new phenomenon, and many survivors are just reaching adulthood now.

- Surviving a brain tumor doesn’t mean the child is “home free”. In fact, brain tumor survivors aren’t always like other pediatric cancer survivors.
- The tumor and treatment (surgery, chemotherapy and radiation) can cause damage that has permanent effects. These include thinking and learning, movement and communications.
- Parents are survivors too, grateful for their child’s life and oftentimes also facing a permanent change in their child’s and their own quality of life.

Research progress has been challenging for several reasons:

- There are many different kinds of children’s brain and spinal cord tumors.
- Because the disease is rare and tissue samples of tumors are small, it takes time to test and validate new treatment options.
- Doctors and researchers are dealing with a growing child’s brain and body, so they must first ensure they avoid harming the child.

For more information, contact Joe Fay, Executive Director, Children’s Brain Tumor Foundation at jfay@cbtnf.org or 212-448-9494. Please visit our website at <http://www.cbtf.org>.

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Children's Brain Tumor Foundation Backgrounder

The Children's Brain Tumor Foundation (CBTF) was founded in 1988 by a group of parents, physicians and friends to improve the treatment, quality of life, and the long term outlook for children with brain and spinal cord tumors through research support, education, and advocacy to families and survivors. CBTF's goal is to ensure that parents and children know they are not alone in their struggle.

The Foundation is dedicated to improving the treatment, quality-of-life and long-term outcomes for children with brain and spinal cord tumors, through several initiatives.

The Children's Brain Tumor Foundation:

- Serves 1500 children and their families nationwide annually through a toll-free hotline staffed by professionals, web site, parent-to-parent ("P2P") network and direct counseling by staff social workers.
- Funds research and collaborates with other similar organizations to fund research.
- Funds quality-of-life programs for kids and families including Camp Sunshine in Maine, our Kids' Cruise, our Big Apple Circus, etc.
- Promotes parents as their children's best advocates.
- Launched the only national pediatric brain tumor survivorship program.

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