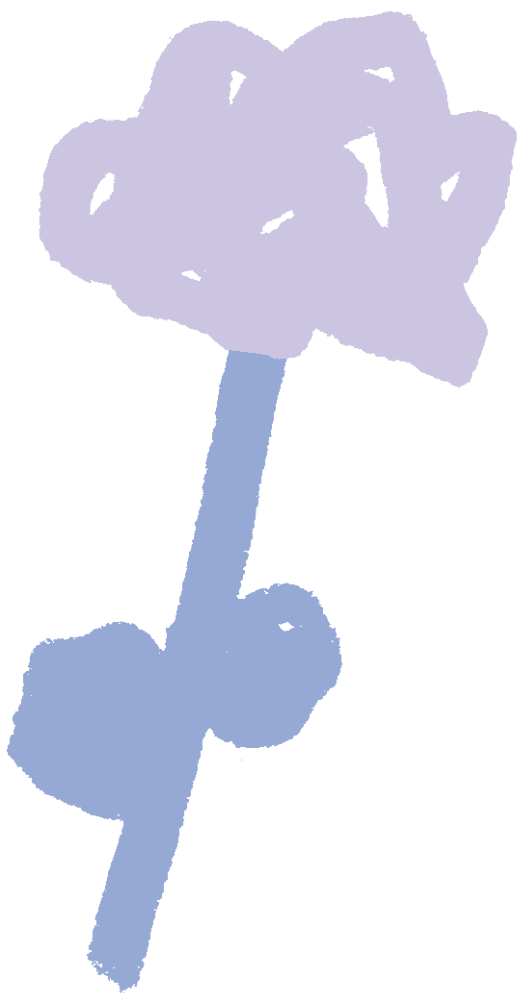


BASIC FACTS ABOUT PEDIATRIC BRAIN and SPINAL CORD TUMORS

*“Where hope
springs eternal”*



Pediatric Brain Tumor Foundation
A Resource for Families

ACKNOWLEDGEMENTS

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SOURCES

Statistical data in this publication obtained from the Central Brain Tumor Registry of the United States (CBTRUS).

DISCLAIMER

The Pediatric Brain Tumor Foundation does not engage in rendering medical advice or professional medical services. Information contained in this publication is NOT intended to be a substitute for medical care and should not be used for the diagnosing or the treatment of a brain tumor or any other health problem. If you have or even suspect you have a problem concerning your health or that of someone else, you should consult with your healthcare provider.

The materials provided by the Pediatric Brain Tumor Foundation are compiled based on current information at the time that they were written. Medical research concerning disease and treatments is an ongoing process. We endeavor to keep our materials current. However, you should review with your doctors and medical institutions to attempt to seek the most current information available.

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Mission Statement

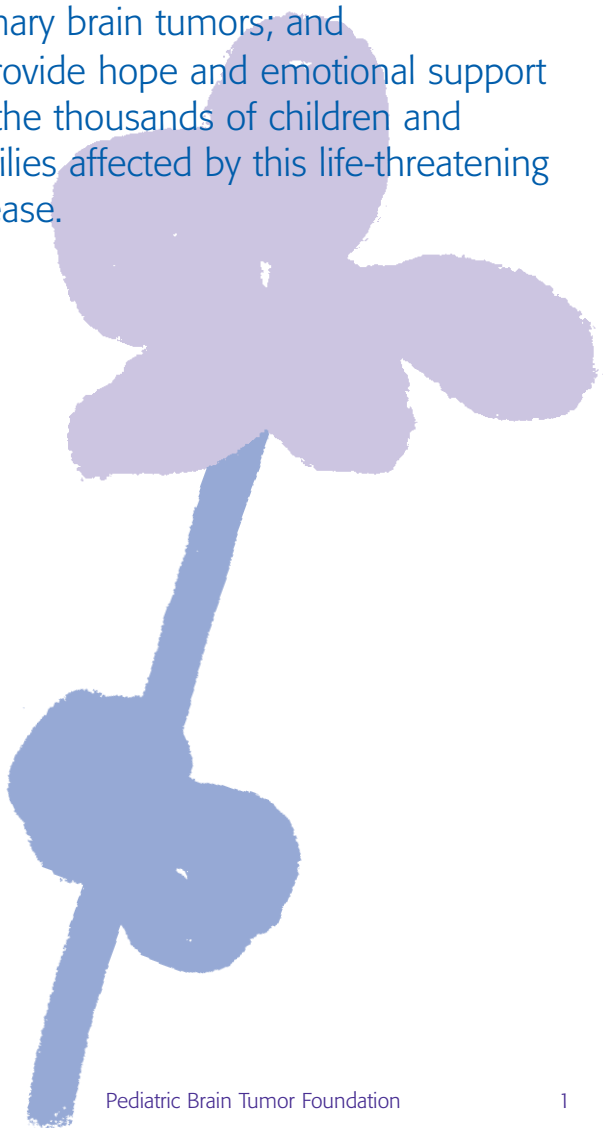
Find the cause and cure of childhood brain tumors through the support of medical research;

Increase public awareness about the severity and prevalence of childhood brain tumors;

Aid in early detection and treatment of childhood brain tumors;

Support a national database on all primary brain tumors; and

Provide hope and emotional support for the thousands of children and families affected by this life-threatening disease.



INTRODUCTION

At a fairly young age, most of us realize that life can be a challenge, even when everything goes according to plan. By the time we become parents, we've learned to expect a few bumps in the road. But no mother or father is ever prepared for the words: "Your child has a brain tumor" or "Your child has a spinal cord tumor."

Before anything else is said, you know life will never be the same. An unexpected, unwanted entity has invaded the very center of your family's world. All at once the triumphs and trials of everyday existence hold little importance.

You may be angry and determined to fight, or you may feel helpless and afraid. You may find it impossible to believe this is happening. You may wonder if something you did or didn't do caused the tumor. You may be struggling with a hundred different emotions, or you may feel empty and numb.

As you deal with this enormous challenge, it is important to remember that a childhood brain or spinal cord tumor affects the whole family. Parents must pay attention to the needs and concerns of their other children, as well as those of the ailing child. Equally important, they must take care of themselves and seek support to avoid becoming overwhelmed.

Pediatric brain tumors require specialized, up-to-date treatment methods. There are medical centers that specialize in the treatment of pediatric brain tumors.

We at the Pediatric Brain Tumor Foundation want you to know that you are not alone. Our primary purpose is to offer hope. We can help you get the information, emotional support, and advice you need.

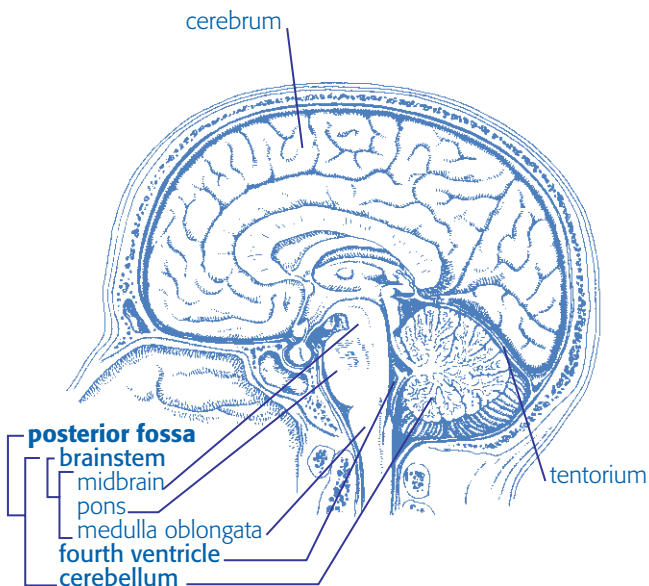
This booklet contains basic facts about brain and spinal cord tumors. If you are interested in receiving more information, several other publications are available. Please contact the Pediatric Brain Tumor Foundation at 1-800-253-6530 or e-mail: familysupport@pbtfus.org for details.

A FEW BASIC FACTS ABOUT BRAIN AND SPINAL CORD TUMORS

Like the bodies of all living creatures, the human body is made up of cells. Certain types of cells perform specific functions. Cells that perform the same function group together to form tissue. Skin, bone, and fat are examples of different kinds of tissue. During childhood, our bodies are growing, producing new cells continually. In adults, the body normally produces new cells only as needed to replace damaged cells.

Sometimes, for reasons we do not completely understand, cells are produced and multiply even when they are not needed. They don't belong in any of the body's existing groups of cells, so they clump together, forming a mass called a tumor. A mass that starts in the brain is called a primary brain tumor. Tumors can also spread (metastasize) to the brain and spinal cord. These are called secondary brain tumors or secondary spinal cord tumors.

The brain and spinal cord make up the central nervous system, or CNS. The CNS controls our behavior, personality, senses, basic body functions, and coordination. When you consider the important role the CNS plays in our ability to function, it is easy to see why a tumor in the brain or spinal cord would cause serious problems. Additional challenges arise when a tumor occurs in a child, because a child's body and brain are still developing.



What causes a tumor to develop in the CNS?

The short answer is: We don't know. Researchers believe that inherited and genetic factors may be involved. Environment may play a part. While studies have yielded valuable information, they have not provided a concrete answer about the cause. The key may even lie in areas not yet investigated by science.

Do CNS tumors strike certain groups of people more often than others?

Tumors of the CNS seem to occur most frequently in older adults and in children under the age of fifteen. Approximately 9% (1,831) of the total number of primary brain tumors occurred in children under age 20 with an incidence rate of 3.8 per 100,000 person years (CBTRUS).

What is the difference between a benign tumor and a malignant tumor?

CNS tumors are classified as "benign" or "malignant" based on the appearance of their cells under a microscope. In general, benign tumors are slow-growing and do not spread to areas of the CNS distant from their initial site of origin. In some cases, they also have well-defined borders that help in their removal. However, when located in a vital area of the brain or spinal cord, a benign tumor can be life-threatening.

A malignant tumor, also called "cancer," is always a threat to life. Malignant tumors invade and destroy healthy tissue. They usually grow rapidly, and can send "roots" into normal tissue. Individual cells from malignant CNS tumors sometimes break free from the mass and travel or metastasize to other parts of the CNS or to other parts of the body.

Are there other ways of categorizing CNS tumors?

Yes. One of the first steps doctors take when a brain or spinal cord tumor is discovered is to classify the tumor, or give it a name. Names of tumors can be confusing. There are many pediatric tumor types, and classification is an ongoing process. Classification is based on the tumor's cell structure, composition, and the function of the tissues involved. You may encounter different classification systems but, in general, most physicians use the system approved by the World Health Organization (WHO).

The name or classification of a tumor may change after the initial diagnosis. For example, if only a small sample of the tumor is examined at first, that sample may not truly reflect the nature of the whole tumor, and the original classification may not be totally accurate. Tumor cells not examined initially may reveal a different diagnosis. In addition, the tumor itself can change with time.

Tumors are also “graded.” Grade I tumors are considered benign (non-cancerous). Grade II is a significant step higher with cells that more easily become malignant. Grade III and IV tumors are malignant with increased severity. The more aggressive and dangerous the tumor, the higher the grade. Assigning a grade helps doctors communicate clearly about the tumor.

Staging is another way to categorize a CNS tumor. The “stage” of a cancerous tumor is based on its size and the extent to which it has metastasized, or spread, beyond the site of its origin. Staging is very useful for some childhood brain tumors, especially medulloblastoma and primitive neuroectodermal tumors (PNET). For others, including benign tumors, its usefulness is limited.

How do doctors discover that a tumor exists?

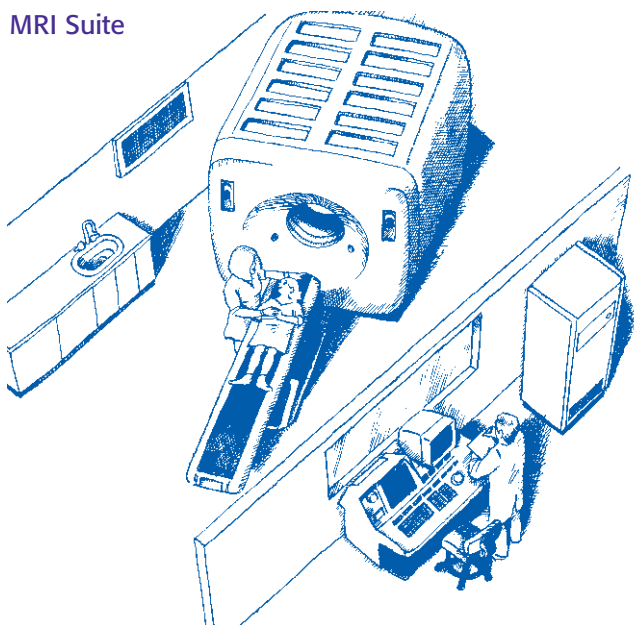
Your child’s symptoms – which may have included headaches, nausea, vomiting, coordination problems, seizures, or extreme sleepiness – led you to consult a doctor for a diagnosis. Diagnosis is the process of determining the cause of a disease, or finding out which disease is causing a person’s symptoms. The most reliable tools for CNS tumor detection and classification are:

MRI (Magnetic Resonance Imaging)

An MRI scan combines high-frequency radio waves and a strong magnetic field to produce a picture of the inside of the body. No x-ray radiation is involved. Before the test begins, the doctor may inject a special dye called contrast material into the patient’s vein. The dye makes it easier to see abnormal tissue. The procedure usually takes from thirty minutes to an hour. To have an MRI, the patient lies on a mechanical table. The table is then moved into a large structure with a doughnut-shaped opening. If a “closed MRI” is used, it’s a little like going into a tunnel. An “open MRI” is open on top and on the sides.

Children are never left alone during an MRI. Your

MRI Suite



child is continually monitored during the procedure. Some MRI centers will allow parents to remain with their children as well. Although the scan should not cause any pain, the thumping noise that occurs from time to time during the procedure may startle young children. An accurate scan can only be obtained if the patient is still. For this reason, a mild sedative may be used to calm a child who seems very upset. At times they may play music during the scan to assist with relaxation.

CT (Computerized Tomography)

A CT scan uses a sophisticated X-ray machine combined with a computer to create a picture of the inside of the body. Before the test begins, the doctor may inject a special dye called contrast material into the patient's vein. The dye makes it easier to see abnormal tissue. When it is time for the scan, a technologist positions the patient on a movable padded table. The table inches slowly through a doughnut-shaped scanner ring, stopping about every half-inch for a picture to be taken. During the scan, the technologist watches through a glass window and talks to the patient on an intercom. The sound of motors and gears can be heard as the scanner takes the pictures. A CT scan normally takes less than an hour.

PET (Positron Emission Tomography)

A PET scan provides a picture of brain activity. It may be used when trying to tell whether a CT or MRI scan is

showing the return of a tumor or tissue damage caused by radiation. PET may be used in addition to CT or MRI.

SPECT (Single Photon Emission Tomography)

SPECT provides information similar to the PET scan, but is more widely available.

Biopsy

A biopsy is a procedure in which a sample of tumor tissue is removed so that doctors can study its characteristics. The sample can be obtained through an open or surgical biopsy, or a needle biopsy. The surgeon uses CT or MRI to guide the placement of the needle into the tumor to obtain a sample of the tissue. Needle biopsy is most often used on deep-seated tumors.

Is treatment the same for all childhood CNS tumors?

No. The treatment approach varies, depending on the type, location and stage of the tumor. The age and general health of the child are also considered. Treatment may include surgery, radiation therapy, and/or chemotherapy. Sometimes steroids are given to reduce swelling. In the future, scientists hope to begin using treatments that stimulate the body's own immune system to destroy tumor cells. Gene therapy is another treatment option being studied.

What are the chances of surviving a childhood CNS tumor?

The prognosis, or chance of recovery, depends on the type of tumor, grade, location, and the extent to which it has spread. The child's age is also a factor. In order to estimate the future course of a tumor, doctors need to know how long the child had symptoms before the tumor was found, how much the tumor has already affected the child's ability to function, and the extent of any surgery or other treatment that has been performed.

CONCLUSION: HOPE FOR TODAY AND TOMORROW

By now, you have probably discovered that when you are dealing with a brain tumor or spinal cord tumor, you do not travel in a straight line from beginning to end. Instead, one step forward can be followed by two steps backward, followed by three steps forward, and so on. An attempt to treat one complication may create other

problems, which then must be solved. Yet you also experience small triumphs along the way, and you are always aware that a major victory may be just around the corner.

As you continue on this difficult journey, we encourage you to ask questions and express your concerns. At the same time, seek out people and places that give you energy and hope. Only when you are nourished can you give of yourself to those who need you.

We are making progress. Every study and clinical trial increases our understanding of a tumor's origin and behavior, improving our ability to destroy it. One day, we will learn how to prevent it. And with each advance, more and more children will be able to enjoy a long and productive life.

(See back cover for listing of booklets on various types of tumors and audio CDs available to families.)

Pediatric Brain Tumor Foundation Reference Library

The following resource literature and archived Internet Conference audio compact discs are available to patient families, medical professionals and social services specialists at no charge by calling (800) 253-6530 or by e-mailing familysupport@pbtfus.org.

1. Questions For Your Medical Care Team When Your Child Has a Brain Tumor
2. Basic Facts About Pediatric Brain and Spinal Cord Tumors
3. Basic Facts About Medulloblastoma/PNET
4. Basic Facts About Juvenile Pilocytic Astrocytoma
5. Basic Facts About Astrocytoma
6. Basic Facts About Glioma
7. Basic Facts About Ependymoma
8. *Helping Hand* National Newsletter
9. *Caring Hand* National Newsletter
10. **Informed Parent Internet Series** - The Importance of a Multi-Disciplinary Approach to Treating Children with Brain Tumors
11. **Informed Parent Internet Series** - The Clinical Trials Process
12. **Informed Parent Internet Series** - School Re-entry Following the Diagnoses and Treatment of Your Child's Brain Tumor
13. **Informed Parent Internet Series** - Healing the Family
14. **Informed Parent Internet Series** - Growth and Development: Endocrine Issues Facing Pediatric Brain Tumor Survivors
15. **Informed Parent Internet Series** - Post Traumatic Stress: Helping Families Survive Childhood Cancer
16. **Informed Parent Internet Series** - Siblings Issues: The Impact of Cancer on Healthy Siblings
17. **Informed Parent Internet Series** - Brothers & Sisters & Brain Tumors: A Child's Point of View of Coping with Cancer in the Family
18. **Informed Parent Internet Series** - Combining Curative and Palliative Care for Children with Brain Tumors



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