Color Me Hope

A Resource Guide for People Affected by Brain Tumors

THE BRAIN TUMOR SOCIETY

Committed to a cure through research, education and support

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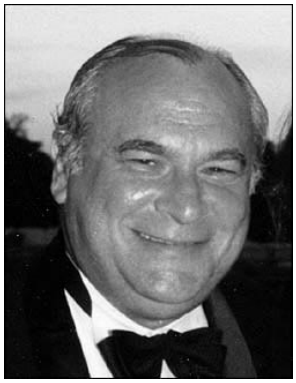


Dedicated to the memory of Richard Ross

Richard Ross was a true visionary. As a founding member of The Brain Tumor Society's Board of Directors, Richard played an instrumental role in creating The Brain Tumor Society's mission. He was the architect of the Society's successful Founding Contributors' fundraising campaign and the catalyst for the Society's Annual Meetings. And it was Richard who saw the need for a comprehensive resource guide for patients and family members dealing with brain tumors.

Sadly, Richard was a victim of the September 11th terrorist attacks as a passenger on American Airlines Flight 11.

Richard conceived the idea and was the driving force behind the very first edition of *Color Me Hope*, in 1994. He and his wife, artist Judi Rotenberg Ross, chaired the Color Me Hope art auction to benefit The Brain Tumor Society, and in conjunction with this benefit, the *Color Me Hope* Resource Guide was born. We find it most fitting to dedicate this 4th edition of the Resource Guide to Richard.

Richard lived life to the fullest. He loved his family, he was as compassionate as he was determined, he was as warm as he was vibrant, and he always remained true to his heart.

Richard served The Brain Tumor Society in many capacities, and all of us at the Society will miss his wisdom and commitment. His passing is a loss to the entire brain tumor community.

We hope that Richard's life will continue to have an impact on brain tumor patients and families through this *Color Me Hope* Resource Guide.

Our Mission:

The Brain Tumor Society exists to find a cure for brain tumors. It strives to improve the quality of life of brain tumor patients and their families. It disseminates educational information and provides access to psychosocial support. It raises funds to advance carefully selected scientific research projects, improve clinical care and find a cure.

Chapter 1:

The Brain Tumor Society's Support Mission: An Introduction

The Brain Tumor Society's Support Mission: An Introduction

People coping with a brain tumor diagnosis express a wide variety of needs, ranging from the most basic information to more technical resource materials. At times, families need crisis intervention. The most common thread that unites everyone in the brain tumor population is the need for validation that their requests, concerns, and feelings are real and legitimate. They need to know that they are not alone.

The Brain Tumor Society provides access to support for brain tumor survivors and their families through personalized assistance, updated resource materials, our *Heads Up* newsletter, national symposia, support group referrals, and a patient/family telephone network. In 1996 the Society created the position of Director of Professional Education and Support, promoting an individualized response to inquiries. We emphasize an appreciation for the diversity of brain tumor survivors. Our population includes people with primary and metastatic cancers, high grade and aggressive tumors, benign and low grade tumors, rare tumors, associated neurological disorders such as acquired brain injury and secondary epilepsy, and a growing number of long-term survivors seeking rehabilitation and support services.

Individualized telephone support may involve *crisis intervention, grief and bereavement support, or appropriate resource referral*. By providing timely access to these services, The Brain Tumor Society hopes to improve the quality of life of brain tumor patients, survivors, and their families.

- *Crisis intervention* is a specialized type of support geared for people whose lives have been disorganized and disrupted by a traumatic event. This type of support involves helping families recognize their unique strengths, upon which they can build adaptive coping strategies.
- *Grief and bereavement support* always has some preventative component. The reassuring message that grief is a normal and healthy human response to illness will avert a multitude of future problems and may help promote emotional healing in the present.
- *Resource referral* does not necessarily consist of reading a yellow-pages list of support services. At times, it involves assessment of need and readiness for support, and some coaching about how best to access that support.

Finally, support can offer an educational component that may include correcting misinformation, simplifying information, limiting information when families are overwhelmed, and facilitating understanding of what the survivor or family member has learned.

Every individual coping with a brain tumor is vulnerable, courageous, absolutely unique, and inspiring. The Brain Tumor Society hopes that our individualized response to families in crisis will serve as a model for other service organizations.

Learning that my 8-year-old daughter had a brain tumor... threw me into a frightening world of high-powered machinery, bizarre chemotherapies, and a seemingly endless variety of clinical studies and experimental treatments. It felt like being dropped into the middle of a runaway nuclear reactor, needing to learn atomic physics fast enough to avoid a meltdown. And the worst part was this – no one else around me seemed to have faced this kind of thing before!

—a Parent

Chapter 2:

Patient and Family Education:
Medical Information about
Brain Tumors and Their Treatment

Patient and Family Education: Medical Information about Brain Tumors and Their Treatment

What is a Brain Tumor?

Brain tumors are abnormal growths found within the skull. Tumors in the brain come from different sources and are categorized by origin:

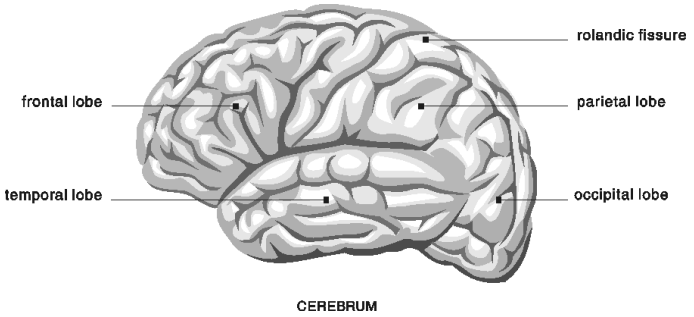
- **Primary** brain tumors come from cells within the brain and its surrounding structures.
- **A metastatic (secondary)** brain tumor occurs when cancer cells from other parts of the body (e.g., the lungs, kidneys, breasts and skin) spread to the brain.

There are many types of primary brain tumors. The cells from which they arise categorize the type of tumor. For example, astrocytomas develop from astrocytes. Astrocytes, most common cell type in the brain, perform a supportive role to the neurons (nerve cells).

Brain tumors are also graded according to their appearance when examined under the microscope. Grading systems were designed to predict how the tumors might behave over time: low-grade tumors grow more slowly and high-grade tumors are more aggressive. The grading system is also useful in choosing treatments.

Sometimes brain tumors are called low-grade or "benign" (slow growing); other tumors are aggressive and "malignant" (fast growing). Although this categorization is often useful, it is not always accurate in predicting long-term outcome. For example, many benign tumors can be treated with surgery and, occasionally, radiation. These patients are often cured. However, because of their location or involvement of blood vessels or nerves, some of these tumors cannot be adequately treated without unacceptable damage to the patient. Therefore, they will grow back and cannot be considered "benign" to these patients.

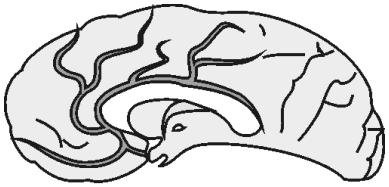
Metastatic tumors from cancers outside the brain (e.g., lung, breast, and melanomas) are systemic and account for over half of all brain tumors. Primary brain tumors rarely spread outside the central nervous system.

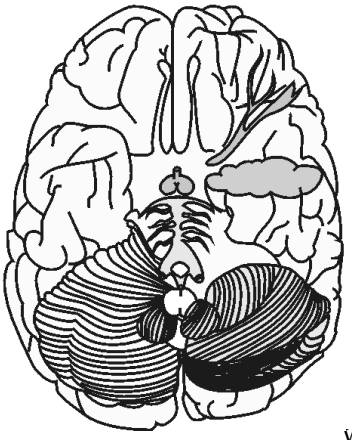


The Brain Tumor Society believes in preserving the dignity of patients confronting the profoundly challenging experience of a brain tumor. The Society supports their right to make informed decisions about treatment and provides educational materials to help them do so.

Anatomy of the Brain

Anatomy is an important consideration when discussing brain tumors. The location of a tumor within the brain will affect the patient's symptoms, as well as many of the treatment options. Frequently, the initial evaluation of a patient involves several imaging studies such as CT scan and MRI in order to determine, as precisely as possible, the location of the tumor in the brain. After this information has been obtained, a decision regarding the most appropriate treatment can be made.





When describing the anatomy of the brain, it is best to begin with a large overview and then proceed to the subdivisions of the brain. When looking at the brain outside of the skull, it appears to be divided into two halves, with a small appendage in the back and a cylindrical object coming out of the base. The two halves are the left and right called *hemispheres*. The structure in the back is the *cerebellum*, and the portion at the bottom is the *brainstem*, where the brain connects to the spinal cord at the top of the neck.

The hemispheres are further divided into *lobes*. The lobe near the forehead is called the *frontal* lobe. Just behind the frontal lobe is the *parietal* lobe. The back of the brain is referred to as the *occipital* lobe. The portion of the hemisphere located above the ear is the *temporal* lobe. Deep within the hemispheres are the *thalamus* and *basal ganglia*. These structures connect to the brainstem. The cerebellum also connects to the brainstem.

Brain Function

The hemispheres are the location of conscious thought and allow us to perform many of the "higher" functions such as reasoning, language, visual perception, and hearing. The basal ganglia and thalamus modulate input to and from the brain. The cerebellum is involved with coordination. The brainstem serves as the final connection of the brain to the rest of the body though the spinal cord.

When examined under a microscope, the brain is seen as highly organized. The *neurons* are the cells in the brain that do the "thinking," or what we think of as the function of the brain. The neurons are supported by cells called *glia*, which provide a type of skeleton for the neurons. There are also blood vessels and other supportive cells present.

The brain is a complex structure with certain portions of the lobes of the brain devoted to particular functions. For example, in most people, including many left-handed people, the left hemisphere of the brain is involved with language function. This language function is further spread out into different lobes of the left hemisphere. The portion of the left frontal lobe just in front of the ear controls the ability to speak, while the left temporal

lobe, slightly behind the left ear, coordinates a person's ability to understand language.

Other portions of the brain that have a known function include the portions of the frontal lobe near the forehead, which control personality. The rear portion of the frontal lobe provides the ability to control movement on the opposite side of the body. The back part of the brain (occipital lobe) allows for the interpretation of vision. The parietal lobes, located between the frontal and occipital lobes, control sensation and spatial orientation (the sense of where your body is positioned), and the temporal lobe is involved with memory function.

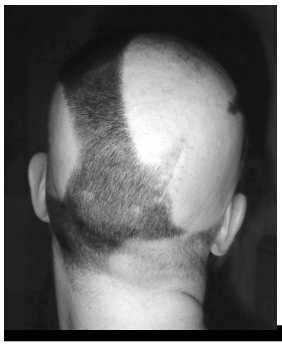
Deeper structures in the brain, such as the thalamus and basal ganglia, are involved with modifying the neural impulses going from the brain to the body or from the body into the brain. There are other portions of the brain that have no readily identifiable function. An example of this is the right frontal lobe or the portion of the temporal lobe behind the eye.

Twelve nerves (*cranial nerves*) leave the brainstem and control functions such as eye movement, facial movement, hearing, vision, smell and swallowing. The nerves are numbered from one to twelve and usually are depicted by Roman numerals. The first cranial nerve is the olfactory nerve and brings smell sensation from the nose to the brainstem. The second cranial nerve is the optic nerve that brings visual input from the eyes to brain. The third, fourth, and sixth nerves control movement of the eyes, and the fifth nerve controls chewing and sensation on the face. The seventh nerve moves the muscles of the face, and the eighth nerve is involved with hearing and balance. The ninth and tenth nerves control swallowing, and the twelfth nerve controls movement of the tongue. Examination of the cranial nerves is important because it often gives a clue to where a tumor might be located. For example, a patient with diminished hearing in the left ear may have a tumor located around the eighth cranial nerve on the left; a patient with double vision may have a lesion located near the third or sixth cranial nerve.

Brain tumors are a complex multiplicity of diseases. Unfortunately, they cannot be prevented because their causes are still unknown.

Tumor Symptoms

A brain tumor's relationship to the anatomy often explains many of the symptoms that affect patients. A small tumor located in the motor cortex of the frontal lobe may affect only the opposite lower leg or foot. On the other hand, a larger tumor that is located in a similar location will affect not only the lower extremity but also the arm as well as the opposite face. The symptoms of the tumor are also related to the rate at which it grows. Tumors that grow at a very slow



Perhaps the most difficult question for a doctor to answer from a patient newly diagnosed with a brain tumor is, "How did I get this disease?"
—Sidney M. Feldman, M.D.

rate can often reach very large size before becoming symptomatic. This is because the brain is capable of compensating for masses such as tumors if the rate of growth is slow. Remarkably, a tumor of very large size in a critical portion of the brain can present with minimal symptoms. Conversely, if a tumor grows quickly or has had recent bleeding causing a rapid expansion in size, a very small tumor can often cause substantial neurological deficits.

Treatment

The anatomic location of the tumor is an important factor when considering treatment. If a tumor is located in an area of the brain that performs a vital function, such as the brainstem or motor area of the frontal lobe, resection or removal of the tumor is not possible without causing great harm to the patient. On the other hand, if a tumor is located in the tip of the frontal lobe or temporal lobe, removal is possible without causing any injury. If a tumor is located deep within the brain, removal is often difficult because the surgeon has to travel through normal areas of the brain to reach the tumor. Thus, even if the tumor itself is in a safe part of the brain for surgery, it may be impossible to reach without causing injury to a different portion of the brain.

There are over 120 types of brain tumors. Some are rare, while others represent subtypes of larger classes.

Brain Tumor Causes: Why Don't We Know More?

As part of the search for a cause, local and state health departments accept requests to evaluate *cancer clusters*, where several similar cancers seem to occur in a local area over a short period of time. Scientists known as epidemiologists must consider many factors when evaluating possible clusters.

- Background risk. Cancer is very common. Over time, it will affect almost three out of four families. It is not unusual for an apparently large number of people in a workplace or community to develop cancer. In fact, requests to evaluate possible clusters are received in the U.S. nearly every day. Epidemiologists ask whether the observed local rate is *greater* than the known high background incidence. If so, further studies may be conducted to explore possible causes.
- Narrow focus. There are over 120 different types of brain tumors, and "cancer" represents over 120 diseases. Researchers believe these different diagnoses have different causes. "True" cancer clusters represent a high incidence of *medically similar diagnoses* in a small area. Benign and malignant tumors are not typically evaluated together. Clusters of rare tumors are also viewed as more likely to represent true clusters, with possible links to local risk factors.
- Size of the population. Many cancer clusters contain such a small number of cases that it is hard to draw meaningful conclusions from statistical analyses. The most productive scientific studies require a large sample size (usually at least a few hundred).
- Community profile. Demographic variables, such as age, must be examined as part of any cancer cluster investigation. Cancer risk increases with age. A community with older residents may thus have a higher incidence of cancer.
- The role of chance. Apparent cancer clusters are surprisingly common. In a random distribution of cancer cases, neighborhood rates of illness will vary naturally, and some clustering will occur by chance. The vast majority of apparent clusters are actually found to occur by chance. Investigators ask whether the incidence seen in one community is high enough to rule out chance occurrence.

True clusters are so rare that fewer than five percent of investigations result in further epidemiological study. A c*ase-control study* is typically the method used to explore possible causes in the area. To date, however, few of these studies have identified the cause of a particular cancer.

Brain Tumor Types

Gliomas

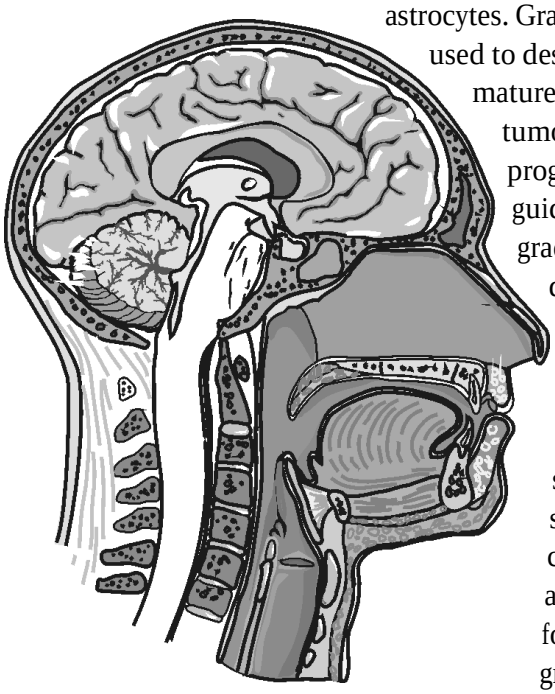
The brain is composed of two types of cells: nerve cells called neurons, and glial cells. The glial cells form the "glue" between nerve cells.

Neurons rarely give rise to tumors. About half of all primary brain tumors are *gliomas*, arising from the glial cells.

In adults, gliomas usually occur in the cerebral hemispheres but may also arise in other areas, especially the optic nerve and the brainstem. Particularly among children, they arise in the cerebellum. Gliomas are classified into several groups because there are different kinds of glial cells.

Astrocytomas

Astrocytomas represent the most common type of glioma. They develop from star-shaped glial cells called astrocytes. Grading systems are used to describe how mature the cells in the tumor are, to predict prognosis, and to guide therapy. The grading system also describes how aggressive the tumor might be. Unfortunately, there are several grading systems in common use, and the criteria for assigning grades varies somewhat among the systems. The systems are easiest to understand if one begins with names rather than numbers.



Well-differentiated astrocytomas are also known as low-grade astrocytomas. These tumors contain cells that are close to normal cells in appearance, although they are growing as a tumor. Tumors with this appearance grow relatively slowly and may sometimes be completely removed by surgery. However, even well-differentiated astrocytomas can be life threatening if they grow in locations that are surgically inaccessible. These can recur after surgery, sometimes at a higher grade. Either the residual tumor or the tumor bed is sometimes treated with radiation postoperatively.

Anaplastic astrocytomas grow more rapidly than well-differentiated astrocytomas and contain cells with malignant traits. In addition to surgery followed by radiation, chemotherapy or other novel strategies are used to treat anaplastic astrocytomas.

Glioblastoma multiforme are tumors that invade nearby tissue and contain cells that are very malignant and aggressive. A major criterion for their diagnosis is the presence of necrotic (dead) area of tumor. Glioblastoma multiforme is the most common malignant brain tumor that strikes adults. Treatment usually involves surgery followed by radiation therapy. Chemotherapy may be used before, during, or after radiation. At the time of tumor recurrence, treatment may involve reoperation with chemotherapy-impregnated wafers implanted into the surgical cavity for direct delivery of chemotherapy. Other treatment

options include focused forms of radiation, medical therapies, or other experimental strategies (see section on page 38 – clinical trials).

Grading scales are used to describe differences among gliomas. One grading scale is the three-grade scale: Grade I is well differentiated, Grade II is anaplastic, and Grade III is glioblastoma. Four-grade scales divide the well-differentiated tumors into Grades I and II based on how aggressive they look. Anaplastic astrocytoma is Grade III, and glioblastoma is Grade IV.

Ependymomas

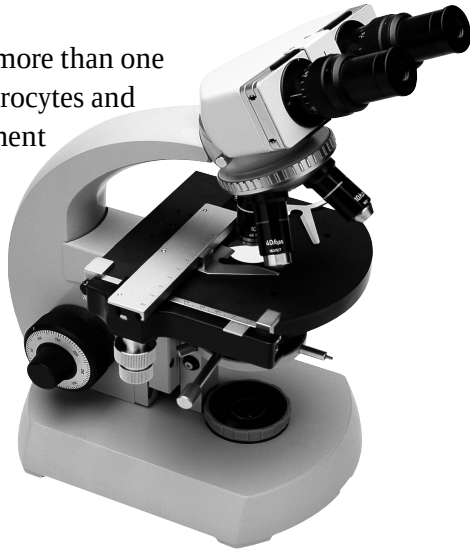
Ependymomas develop from cells that line the hollow cavities of both the brain and the spinal cord. They often affect children, arising in the cavity known as the fourth ventricle. In adults, they occur most commonly in the spinal cord. About 85% of ependymomas are low grade. Treatment usually includes surgery followed by radiation therapy. Chemotherapy is sometimes used, especially for recurrent tumors.

Oligodendrogliomas

Oligodendrogliomas, which develop from glial cells called oligodendroglia, represent about 5% of all gliomas. They occur most often in young adults, within the brain's cerebral hemispheres. Doctors often treat these tumors with surgery followed by chemotherapy and radiation therapy. Many of these tumors are found to be chemo-sensitive and are most often treated with PCV, a combination of the chemotherapeutic drugs procarbazine, CCNU, and vincristine.

Mixed gliomas

Mixed gliomas contain more than one type of glial cell, usually astrocytes and other glial cell types. Treatment focuses on the most malignant cell type found within the tumor. Like oligodendrogliomas, these tumors are regarded as chemo-sensitive and may also be treated with PCV chemotherapy.



Ganglioneuromas and dysembryoplastic neuroepithelial tumors

The rarest forms of glioma, these tumors contain both glial cells and mature neurons. They grow relatively slowly and are usually treated with surgery.

Gliomas arising in special sites

Brainstem gliomas. Named for their location at the base of the brain rather than the cells they contain, brainstem gliomas are most common in children and young adults. Surgery is rarely used to treat brainstem gliomas because their location is so close to vital centers in the brain. Radiation therapy sometimes helps to reduce symptoms and improve survival by slowing tumor growth.

Optic nerve gliomas. These tumors are found on the optic nerve and are particularly common in individuals who have neurofibromatosis (NF). Treatment may include surgery, radiation, or chemotherapy.

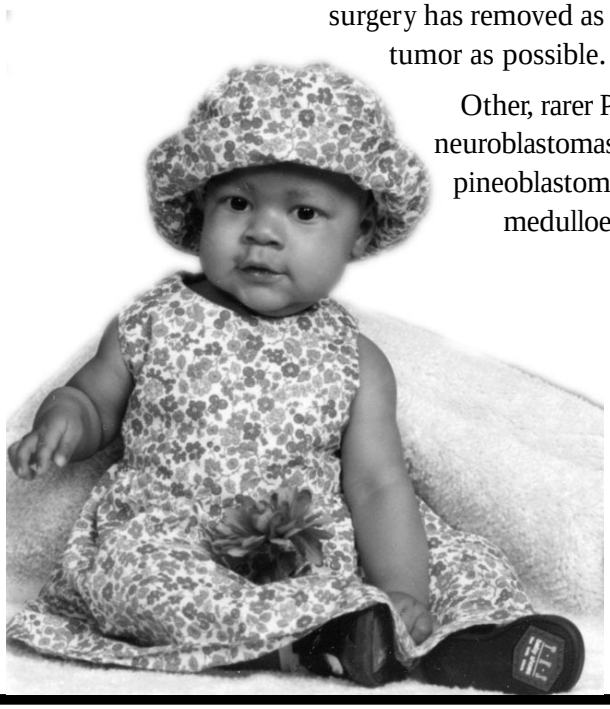
Primitive Neuroectodermal Tumors

Primitive neuroectodermal tumors (PNETs) usually affect children and young adults. Their name reflects the belief among scientists that these tumors spring from primitive cells left over from early development of the nervous system. PNETs are usually very malignant, growing rapidly and spreading easily within the brain and spinal cord. In rare cases, they spread outside the central nervous system.

Medulloblastomas

Medulloblastomas, which are primitive neuroectodermal tumors arising in the cerebellum, represent more than 25% of all childhood brain tumors. They are the most common malignant brain tumor found in children. These primitive tumors respond to radiation and chemotherapy. Because they may spread with the spinal fluid to the spinal cord, the entire brain and spinal cord are usually irradiated after surgery has removed as much of the tumor as possible.

Other, rarer PNETs include neuroblastomas, pineoblastomas, and medulloepitheliomas.



Tumors Arising From Structures Outside the Brain but Inside the Skull

Meningiomas

Meningiomas develop from thin membranes, or meninges, that cover the brain and the spinal cord. They account for about 25% of all brain tumors. Affecting people of all ages, they are most common among those in their 40s and affect more women than men. Meningiomas usually grow slowly, generally do not invade surrounding normal tissue, and rarely spread to other parts of the central nervous system or body. Surgery is the preferred treatment for accessible meningiomas and is more successful for these tumors than for most tumor types. Recurrent meningiomas may require additional treatment including various forms of radiation therapy.

Schwannomas

Schwannomas arise from the cells that form a protective sheath around the body's nerve fibers. They are usually benign and are surgically removed when possible. The more common forms of schwannoma affect the eighth cranial nerve, which contains nerve cells important for balance and hearing. Facial paralysis may occur if the tumor involves the adjacent seventh nerve. Also known as vestibular schwannomas or *acoustic neuromas*, these tumors may grow on one or both sides of the brain and are potentially curable surgically.

Pituitary adenomas

Pituitary adenomas arise from the pituitary gland, a small oval-shaped structure located at the base of the brain. The pituitary gland releases several chemical messengers known as hormones, which help control the body's other glands and influence the body's growth and metabolism.

Tumors that affect the pituitary gland account for about 10% of brain tumors. Pituitary adenomas are classified into two groups: secreting and non-secreting. Secreting tumors release unusually high levels of pituitary hormones, triggering a constellation of symptoms, which can include impotence, cessation of menstruation, milky discharge from the breasts, abnormal body growth, Cushing's syndrome, or an overactive thyroid gland, depending on which hormone is involved. Surgery or the drug bromocriptine is used to treat prolactin-secreting pituitary adenomas. Larger adenomas, those that secrete other hormones, and non-secreting adenomas are treated with surgery and radiation therapy.

Chordomas

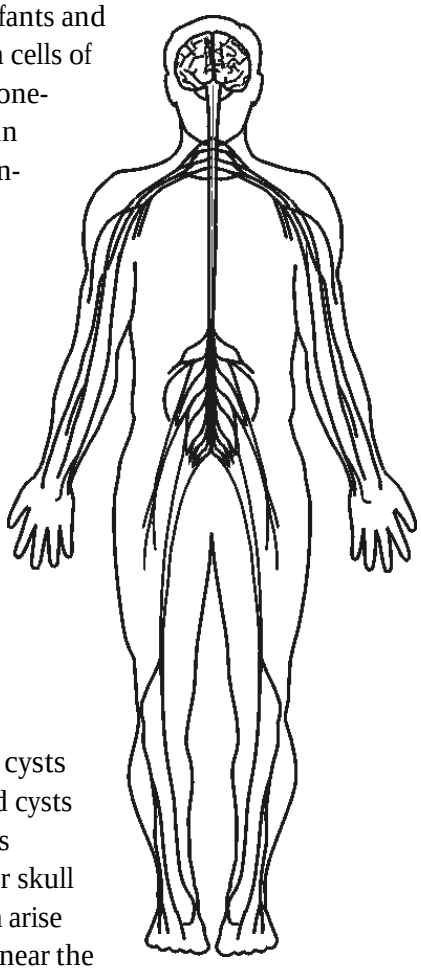
Chordomas, more common in people in their 20s and 30s, develop from remnants of the flexible spinelike structure called the "notochord" that forms and dissolves early in fetal development. Although these tumors are often slow growing, they can metastasize or recur after treatment. Chordomas are usually treated with a combination of surgery and radiation.

Tumors Arising from "Inclusions" Within the Brain and Skull

A number of tumors arise from the developing nervous system and are composed of tissue that normally does not belong there.

Craniopharyngiomas

Craniopharyngiomas are brain tumors that usually affect infants and children. They develop from cells of the oral cavity, which are erroneously included in the skull in early fetal development. Craniopharyngiomas are often located near the pituitary gland, a gland that releases chemicals important for the body's growth and metabolism. Treatment for these tumors usually includes surgery and, in some patients, radiation therapy. Close follow up by an endocrinologist is often needed to manage symptoms related to hormone changes.

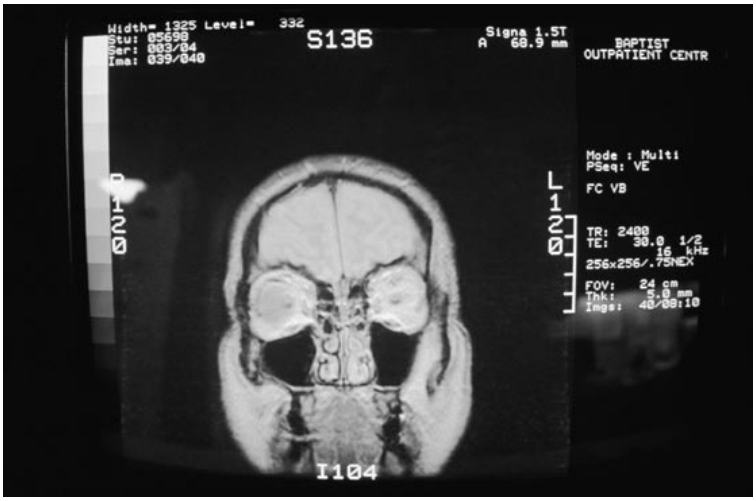


Epidermoid and dermoid cysts

Epidermoid and dermoid cysts are inclusions of skin and its appendages into the brain or skull with development. They can arise anywhere, but epidermoids near the eighth nerve are the most common. The treatment is surgical.

Pineal region tumors

Pineal region tumors arise in the pineal gland, a small structure deep within the brain. They account for about 1% of brain tumors. The three most common types of tumors in this region arise from abnormal inclusions of germ cells. Astrocytomas and PNETs also occur here. When possible, physicians will begin treatment with excision or biopsy to confirm the tumor type. They may also recommend radiation, chemotherapy, or both for malignant pineal tumors.



Skull Base Tumors

Skull base tumors arise from under the brain at the base of the skull and often involve or compress nerves and blood vessels entering and leaving the brain. They include acoustic neuromas, chordomas, glomus jugulare tumors, epidermoids, angiofibromas, pituitary tumors, craniopharyngiomas, esthesioneuroblastomas, some meningiomas, certain forms of cancer, and other tumors. Surgical treatment requires a multidisciplinary approach, which refers to the combined knowledge of several specialties. These include neurosurgery, otolaryngology, plastic surgery, ophthalmologic surgery, neuroradiology, and radiation therapy. The strategy is to eliminate the tumor and the patient's symptoms using the least invasive way possible.

Primary Central Nervous System (CNS) Lymphoma

Primary central nervous system lymphoma usually appears in the form of brain tumors, but it can also involve the eyes and the spinal fluid. It can be disseminated (or spread) throughout the central nervous system in the spinal fluid, but this may not appear on magnetic resonance imaging (MRI).

A type of cancer, primary CNS lymphoma affects a small number of otherwise healthy people and a larger fraction of those who have a weakened immune system, whether from organ transplants, infection with the AIDS virus, or other causes.

Lymphomas are more resistant to treatment when in the central nervous system. Therefore, we must either choose drugs that cross the blood-brain barrier or give standard drugs in high enough doses to force them across that barrier.

For years, CNS lymphoma was treated with radiation therapy. Recently, we have learned that chemotherapy alone can be very effective. There is an emerging consensus that methotrexate is our most important chemotherapeutic agent for this condition.

TBTS is a place where I can get whatever kind of support I am looking for. It feels like you will always be there for me. —Lisa Schweig, ependymoma survivor

Miscellaneous Primary Brain Tumors

Choroid Plexus Papilloma

Choroid plexus papilloma is a rare, benign tumor that represents less than 1% of all primary brain tumors. However, in children under 12, about 4% of primary brain tumors are choroid plexus papillomas. These tumors arise from the tissue in the cavities of the brain that normally makes spinal fluid. They grow slowly but eventually block the flow of cerebral spinal fluid. This causes hydrocephalus (extra fluid within the brain) and increased intracranial pressure. The treatment of choice is surgery. Tumor removal resolves hydrocephalus in half of patients; other patients require a shunt (a method to divert spinal fluid) in addition to resection. *Choroid plexus carcinoma*, the rare inoperable or malignant form of this tumor, may be treated with radiation.

Hemangioblastoma

Hemangioblastoma may occur sporadically but is also linked in a small number of people to a genetic disorder called von Hippel-Lindau disease. Hemangioblastomas do not usually spread, and surgery is curative. A screening evaluation is recommended to rule out renal cancer, adrenal tumors, and retinal abnormalities, especially in patients with von Hippel-Lindau disease. These patients can find additional information by contacting the VHL Family Alliance at (800) 767-4845.

Metastatic Brain Tumors

Although primary brain tumors account for less than 5% of malignancies, brain metastases are the most common complication of cancer, occurring in 20-40 % of oncology patients.

Brain metastases are brain tumors arising from cancer cells outside the brain. While lung, breast, colon, and kidney cancers as well as melanomas pose the greatest risk, brain metastases have been associated with many other cancers. Continued development of improved treatments means that patients with systemic cancer are living longer with advanced disease and its associated complications, including secondary brain tumors.

Contrast-enhanced magnetic resonance imaging (MRI) is the best study to date for evaluating patients for brain metastases. Contrast MRI is not only a very sensitive test for detecting small metastatic tumors, it also provides precise anatomic location, which is extremely useful in the surgical planning for tumor resection.

Up to two-thirds of brain metastases will produce symptoms at some time during the life of the patient. Brain metastases produce symptoms like any expanding mass in the brain. Symptoms can be placed in two broad categories: increased intracranial pressure and focal irritation or disruption of brain function.

Increased intracranial pressure can be caused by expansion of the tumor, swelling or edema associated with the metastatic tumors, obstruction of cerebral

spinal fluid pathways causing hydrocephalus, or a combination of these effects. Patients often present with non-specific symptoms such as headache, nausea, vomiting, confusion, and lethargy.

Focal brain irritation or disruption of brain function will often lead to seizures, weakness, speech or language deficits, visual problems, and gait disturbances. Unlike symptoms of increased intracranial pressure, symptoms from focal brain irritation or disruption often have localizing value, meaning they can suggest the location of the metastatic lesion.

The management of patients with brain metastases depends on many different factors, some of which may be difficult to precisely assess. Therefore, there may be more than one single "best" treatment. Treatment decisions cannot be generalized and should be tailored to each patient.

The use of corticosteroids (dexamethasone or Decadron) can help temporarily by reducing the swelling caused by the tumor and often can relieve neurologic symptoms very rapidly. Surgery is generally limited to tumors that are causing symptoms, especially to single metastasis in patients with limited or controlled disease elsewhere in the body. Whole brain radiation is useful in improving neurologic symptoms and in lengthening survival. This treatment is usually recommended for most patients with brain metastases.

More recently, the use of focused radiation or stereotactic radiosurgery has been used to treat small (less than 3 cm in diameter) metastases in deeper or sensitive regions of the brain where surgical removal would carry higher risks of neurologic damage. This method can be used to treat multiple lesions.

With improvement in the treatment of systemic cancer, the need to treat brain metastases has become increasingly important as patients are now living longer. Newer and more effective treatments will need to be developed.

Spinal Cord Tumors

Spinal cord tumors can be the same cell types as tumors found in the brain, such as meningiomas and various gliomas. Chordomas, lymphomas, several forms of sarcoma, multiple myelomas, and other cancers can also affect the spine. Most spinal cord cancers are metastatic, meaning that they arise from a wide variety of primary cancers. These include lung, breast, prostate, head and neck, gynecologic, gastrointestinal, thyroid, and unknown primary cancers, as well as melanoma, renal cell carcinoma, and others.

Surgery is increasingly recommended for benign and malignant primary spinal cord tumors. Radiation is regarded as a primary treatment for spinal cord compression due to metastatic cancer. Chemotherapy similar to that used for brain tumors may be recommended in adults for spinal gliomas that progress after surgery and radiation. It may also be used in a few chemo-sensitive cancers such as CNS lymphoma and small cell lung cancer, as well as for some breast cancers or when surgery and additional radiation are not recommended.

Related Conditions

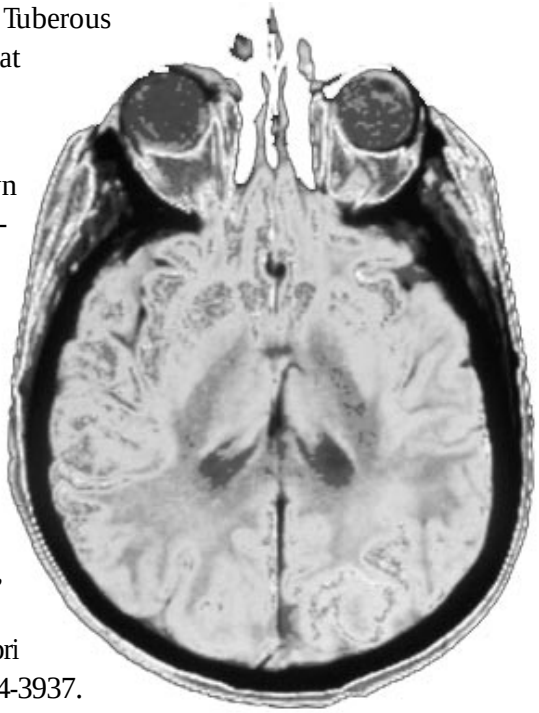
Neurofibromatosis (NF). The neurofibromatoses are a set of three genetic disorders that can cause tumors in several parts of the nervous system. The most common form of this disorder, neurofibromatosis type 1, often causes gliomas of the optic nerves, cerebral hemisphere, and brainstem.

Neurofibromatosis type 2 causes multiple central nervous system tumors including bilateral vestibular schwannomas (acoustic neuromas), neurofibromas, and optic nerve gliomas. Treatment usually consists of surgery, when possible, to remove these tumors that cause symptoms.

A new form of NF, schwannomatosis, has only recently been recognized. People with this rare variant of the condition develop multiple tumors called schwannomas on cranial, spinal, and peripheral nerves. A primary focus of treatment is pain management.

For additional information, contact Neurofibromatosis, Inc. at (800) 942-6825 and the National Neurofibromatosis Foundation at (800) 323-7938.

Tuberous Sclerosis. This genetic disorder causes numerous neurological and physical symptoms including tumors of the kidneys, eyes, and central nervous system. About 15% of persons with tuberous sclerosis (TS) develop benign brain tumors known as subependymal giant cell astrocytomas (SEGAs). Some of these astrocytomas grow large enough to cause hydrocephalus. For additional information, Please contact the Tuberous Sclerosis Alliance at (800) 225-6872.



Pseudotumor Cerebri, also known as benign intracranial hypertension, refers to an abnormal increase of pressure within the brain in the absence of a brain tumor. For more information, contact the Pseudotumor Cerebri Society at (315) 464-3937.

Hypothalamic Hamartoma. Physicians describe this childhood condition known as “a collection of cells” or “brain material in the wrong place” rather than as a classic tumor. Due to its location in the brain, symptoms often include unusual, even aggressive behaviors. These may take the form of gelastic seizures (giggling episodes), age-inappropriate tantrums, early puberty, obesity, or delayed cognitive development. Because it is so rare, most neurologists and neurosurgeons can go a lifetime without seeing a case.

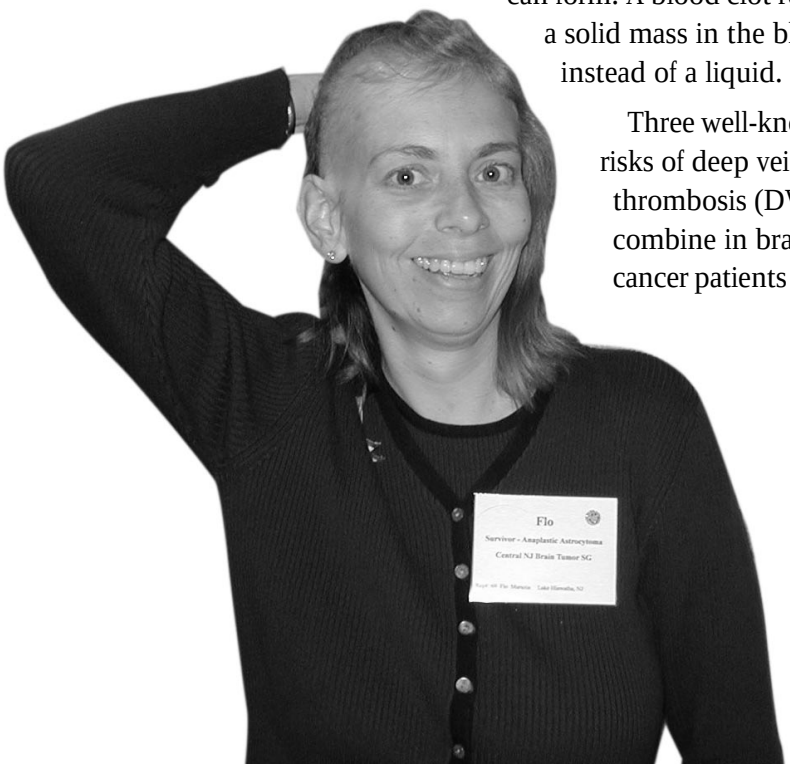
Effects of Brain Tumors

Meningeal Carcinomatosis

This condition develops when individual cells from cancer outside the central nervous system enter into the cerebrospinal fluid and grow like seeds. These cells travel with the fluid and can form colonies or small tumors in many places, including the roots of nerves, the surface of the brain, the brainstem, and the spinal cord. Treatment usually involves the delivery of chemotherapy directly into the cerebral spinal fluid. Radiation is also provided when indicated.

Deep Vein Thrombosis

In the deep veins of the leg, blood is normally pushed out toward the heart as muscles contract. If this fails to occur and the blood pools in the vein, a clot can form. A blood clot refers to a solid mass in the blood instead of a liquid.



Three well-known risks of deep vein thrombosis (DVT) combine in brain cancer patients to make them more prone to this complication. They include having any form of cancer, loss of mobility, and "hemiparesis" (one-sided weakness), particularly in the leg.

Symptoms may include tenderness or pain in the calf, behind the knee, or the thigh. Other symptoms are swelling in one leg, pain in the leg when it is squeezed, and pain in the leg when you try to flex the foot up towards the face.

As soon as possible after surgery, brain cancer patients are encouraged to get out of bed. They are given venodyne compression stockings. These devices mimic muscular action on the legs, keeping the blood flowing. Nurses or physical therapists in the hospital teach patients leg exercises such as ankle pumps after checking with the physician.

Some cancer patients are given heparin to prevent DVT. However, in persons with brain cancer, anticoagulants such as heparin and coumadin increase the risk of bleeding in the brain and are rarely used for prevention.

While most other cancer patients are started on intravenous heparin (a blood thinner) at diagnosis, treatment of DVT in brain cancer is a controversial decision. Most of the time physicians opt not to treat with anticoagulants unless a pulmonary embolus is found. Instead, many doctors recommend the placement of a spider-shaped Greenfield filter in the large vein of the abdomen to catch any clots and stop them from moving toward the lungs and brain.

It helped me to keep track of seizure patterns. My seizures have an emotional component. Panic and fear and tears are an actual part of the seizure. Now I am able to just let this be, rather than attaching additional meaning to the feelings.

—Rachel Henderson Falls, long-term survivor of malignant astrocytoma

Seizures and Epilepsy

Epileptic seizures are a common symptom of brain tumors and may become significantly disabling. They can vary tremendously in features: slight numbness of a finger, unexplainable physical or emotional feelings, or more severe attacks with convulsive movements and loss of consciousness. Symptoms and signs depend on the parts of the brain involved.

A seizure is the behavioral manifestation of sudden, uncontrolled electrical activity in the brain. It usually lasts from seconds to minutes. Epilepsy is a tendency toward recurrent seizures. No more than 5% of epilepsy cases are attributable to brain tumors, but 30-50% of brain tumor patients develop epilepsy. Return of seizures after a period of substantial control does not necessarily mean the tumor has recurred.

In most cases, seizures can be controlled. However, when tumors grow in sensitive areas of the brain or other factors are present, seizures can be difficult to manage. Nearly all patients who have brain tumors and seizures are treated with one or more anti-epileptic drugs. Several new epilepsy medications have been introduced in recent years. These medications have a variety of dosing regimens and side effects.

Identifying precipitating factors such as missed medications, sleep deprivation, and excessive alcohol consumption can lead to improved control. New medications also improve seizure control. Surgical treatment of the tumor (and adjacent areas of the brain, if necessary) can greatly help some patients. Ultimately, balancing seizure control, side effects of medications, and quality of life is the goal.

Helpful information about seizure recognition, first aid, and seizure management is available from the Epilepsy Foundation of America at (800) 332-1000.

Brain Tumor Symptoms

Brain tumors produce symptoms by mass effect (pressure on the brain and surrounding structures), by blockage of cerebral spinal fluid pathways, or by causing irritation of the brain. Because of the many ways in which tumors can cause symptoms, they may imitate other neurologic problems. The tumor's location in the brain often determines the nature of symptoms.

Brain tumor symptoms usually progress over a period of weeks to years. However, there are exceptions. Tumors that cause brain irritation can cause seizures, which occur as sudden events.

The following symptoms may indicate a brain tumor:

- A new seizure in an adult
- Gradual loss of movement or sensation in an arm or leg
- Unsteadiness or imbalance, especially if it is associated with headache
- Loss of vision in one or both eyes, especially if it is more peripheral vision loss
- Double vision, especially if it is associated with headache
- Hearing loss with or without dizziness
- Gradual onset of speech difficulty
- Flu-like symptoms

The following symptoms, although usually not the result of a brain tumor, may sometimes indicate brain tumors:

- Headache is probably the most common symptom of a brain tumor. Most people with headache, even persistent or severe headaches, do not have a tumor. However, some kinds of headache are particularly worrisome. A steady headache that is worse in the morning than the afternoon, a persistent headache that is associated with nausea or vomiting, or a headache accompanied by double vision, weakness, or numbness all suggest a possible tumor.
- A change in behavior may also be caused by a brain tumor. The development of an "I don't care" attitude, short-term memory loss, loss of concentration, and general confusion may all be subtle signs. An evaluation by a neurologist may be an important step, but a CT or MRI will also help.

- Infertility and/or amenorrhea (abnormal cessation of menstruation) are usually associated with pituitary tumors.
- Some symptoms that seem to suggest other diseases may in fact be a tumor. For example, a stroke, even when it looks like one on a CT, may turn out to be the result of a tumor. Sometimes a fall can come from a seizure caused by a tumor. A pituitary tumor can present like a subarachnoid hemorrhage, a type of stroke.

As you can see from this list, the possible ways a brain tumor can present are quite varied. If you are concerned, you should call a doctor who is familiar with these tumors. Early detection and treatment may increase survival. If symptoms persist, gentle urging for an MRI is important to ensure patient health.

The Diagnosis of Brain Tumors

Research has made major strides in the ability to detect and diagnose brain tumors. When a doctor suspects a brain tumor because of a patient's medical history and symptoms, he or she can turn to a number of specialized tests and techniques to confirm the diagnosis. However, the first test is often a traditional neurological exam.

Neurological Exam

A neurological exam checks eye movement, eye reflexes and pupil reactions, reflexes, hearing, sensation, movement, balance, and coordination.

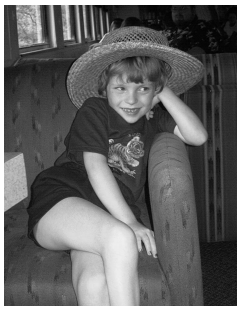
The next step in diagnosing brain tumors often involves special imaging techniques and laboratory tests that can detect the presence of a tumor and provide clues about its location and type. Special imaging techniques developed through research have dramatically improved the diagnosis of brain tumors in recent years.

The most commonly used techniques for diagnosing a brain tumor include Computed Tomography (CT), Magnetic Resonance Imaging (MRI), Positron Emission Tomography (PET) and biopsy.

Computed Tomography (CT)

CT uses a sophisticated X-ray machine and a computer to create a detailed picture of the body's tissues and structures. Often, doctors will inject an iodine dye into the patient before performing a CT scan. The dye, also called contrast material, makes it easier to see abnormal tissue.

A CT scan often gives doctors a good idea of where the tumor is located and can sometimes help them determine the tumor's type. It can also help doctors detect swelling, bleeding, and other associated conditions. In addition, CT scans can help doctors check the results of treatment and watch for tumor recurrence.



I had an MRI. It makes noise like a washing machine and galloping horses.
—Ellen Rose O'Brien, age 5

Magnetic Resonance Imaging (MRI)

MRI uses a magnetic field rather than X-rays and can often distinguish more accurately between healthy and diseased tissue. MRIs give better pictures of tumors located near bone than CT scans, do not use radiation as CT does, and provide pictures from various angles that can enable doctors to construct a three-dimensional image of the tumor. Contrast material is often injected as in CT.

Positron Emission Tomography (PET)

PET provides a picture of brain activity rather than structure by measuring levels of injected glucose (sugar) or methionine (amino acid) that has been labeled with a radioactive tracer.

Based on recent research, some scientists believe that PET scans offer important clues for diagnosis of brain tumors. For example, physicians sometimes have trouble detecting recurrent tumors with CT or MRI scans, especially after the patient has undergone radiation. Recent studies have shown that PET scans may make it easier to detect recurrent brain tumors.

Scientists are also examining whether PET scans can help physicians tell the difference between benign and malignant tumors before performing a biopsy or surgery. Similar results may be obtained with functional MRI (a specialized type of MRI).

Biopsy

The final step in confirming the diagnosis of a brain tumor is a biopsy. A biopsy is a surgical procedure in which a small sample of tissue is taken from the suspected tumor to determine an exact diagnosis. By examining the sample under a microscope, the pathologist, a physician who specializes in understanding how disease affects the body's tissues, can determine what kinds of cells are in the tumor.

Available Treatments

Surgery

Treatment often begins with surgery to remove as much of the tumor as possible. Once the remaining tumor is as small as possible, physicians believe that further treatments (if necessary) may be more effective.

Surgeons define an accessible tumor as one that can be removed without causing severe neurological damage. If removal is not possible, a biopsy could establish a diagnosis that would provide the foundation for further treatment. Sometimes surgery is also used to relieve fluid buildup (called hydrocephalus) behind a tumor. Treatment of hydrocephalus involves placement of a bypass called a shunt. This procedure sometimes saves lives.

New technologies allow a level of precision that could not be imagined a decade ago. Many parts of the brain can now safely be biopsied, and tumors can be removed safely from almost every area. Some techniques are listed below.

- Techniques that permit more aggressive removal of tumors previously regarded as inoperable. These include new ***skull base techniques*** that require close teamwork among neurosurgeons, plastic surgeons, and ear, nose, and throat (ENT) specialists to remove benign or malignant tumors at the base of the brain. They also include the ability to do surgery in such areas as the pineal region, the ventricles of the brain, and the brainstem.
- Better visualization of the tumor and its relation to surrounding structures. Techniques for visualization include the ***operating microscope*** and magnetic resonance (MR) or CT imaging, either intraoperatively (during surgery) or preoperatively.
- Greater use of image-guided surgery including ***stereotaxis*** and three-dimensional reconstructive techniques. (In stereotaxis, a computer uses information from CT or MRI to create a three-dimensional map of the operative site.) These tools allow minimally invasive surgery to identify the tumor and to leave normal brain tissue unharmed. Other image-guided systems create a three-dimensional map followed by its registration to the scalp and skull. Images from SPECT, PET, functional MRI (fMRI), or MR spectroscopy (MRS) can be incorporated into these systems and add to the understanding of the biology of the tumor.
- New surgical tools for the actual destruction of tumor tissue. These include the ***ultrasonic aspirator***, which uses high frequency sound waves to destroy tissue and then remove it; the ***laser***, which uses a

I turned to various medical journals, which directed me to scientists and clinicians conducting research on my son's diagnosis. I called them all from Toronto to Tokyo, trying to track down someone who might provide answers.
—a parent

concentrated energy beam to destroy tissue; and focused radiation techniques including ***radiosurgery*** to concentrate radiation to make it a surgical tool.

- Improved ***monitoring of neurological function*** during surgery to ensure that critical structures and pathways are not harmed. This includes monitoring of cranial nerves such as the seventh (facial) and eighth (hearing) nerves during acoustic neuroma surgery, the monitoring of evoked potentials during surgery around the brainstem or motor and speech areas, and monitoring of visual function during surgery in and around the optic nerve and optic chiasm.
- ***Surgery under local anesthesia*** (while the patient remains awake) to be sure that speech, movement, sensation, and vision are not harmed during the surgical procedure. This technique is a very powerful one to ensure that surgery of tumors in the cerebral cortex is safe.
- New developments, such as the *intraoperative MRI*, that allow almost real-time imaging of the surgical field while the surgeon operates from within the scanner. Surgeons can quickly assess complications. The degree of surgical resection can be measured, and the relation of the tumor to surrounding structures can be evaluated. The CT or MRI aids the surgeon's vision.

All these techniques allow for safer and more effective surgery for brain tumors. For most tumors, the complication rate should be less than five percent and the mortality rate less than two percent.

It is likely that the future will bring continued developments in surgery, especially as it becomes more molecular in focus. For example, neurosurgeons may collaborate closely with radiation oncologists using some local radiation techniques. They may give chemotherapy through chemotherapy-soaked wafers or other technology and they may place new viral delivery systems for gene therapy into the brain. As neurosurgery adopts and uses new insights from imaging and molecular biology, it will remain a major part of brain tumor management.

New technologies allow a level of precision that could not be imagined a decade ago

Radiation Therapy

Radiation therapy plays a central role in the treatment of most brain tumors, whether benign or malignant. After surgery, radiation therapy targets the residual tumor with the goal of reducing its size or stabilizing it. For malignant lesions, even when it appears that all tumor has been removed, microscopic cells remain in the surrounding brain tissue. To prevent or delay recurrence, radiation therapy to these areas is recommended.

Some benign brain tumors may become life threatening if their growth is not controlled. When the entire tumor cannot be removed safely, radiation therapy is often recommended postoperatively to prevent remaining tumor cells from growing. Other low grade and benign brain tumors are treated with radiation at time of recurrence.

Traditional Radiation Therapy. Conventional radiation therapy uses external beams of either x or gamma rays to destroy brain tumor cells. This therapy delivers radiation from outside the patient's body and usually begins a week or two after surgery, after the surgical incision heals, continuing with uniform dosages throughout the treated areas for approximately six weeks. Until recently, conventional therapy for brain metastases involved whole brain radiation for a period of two weeks. However, effective new technologies are quickly replacing this method (see stereotactic procedures below).

Radiosensitizers. Many scientists are testing the usefulness of several chemotherapeutic drugs known as radiosensitizers that make tumor tissue more vulnerable to radiation. They are also using the knowledge that hypoxic cells (low in oxygen) are particularly resistant to radiation and that oxygen is a powerful radiosensitizer.

Stereotaxis, Stereotactic Procedures. "Stereo" in this context means three-dimensional in space; "tactic" refers to touch. During stereotactic radiosurgery, a head frame is attached to the patient's skull. Then, with the assistance of a CT or MRI scanner providing a three-dimensional image, and a computer, the frame pinpoints the tumor location without opening the skull.

Recently, technology has been developed that replaces the head frame with navigational wands, robotic devices, or other frameless systems, some of which locate the tumor by using skin-based markers to fix points in space.

Numerous technologies exist…all share the goal of delivering high dose radiation while minimizing damage to surrounding tissue

Despite its name, stereotactic radiosurgery does not require a surgical incision and, in fact, offers a promising treatment option for patients who are not surgical candidates. During stereotactic radiosurgery, a single high dose of focal external beam radiation is delivered. Most of the time spent during the procedure is in precisely planning the delivery of radiation beams to focus on the tumor and minimize damage to surrounding, normal brain tissue. This is known as conformal treatment planning.

Sometimes stereotaxis is used in conjunction with biopsy or surgery and helps the neurosurgeon in devising an

I have found that the worst thing I can do is hide my feelings and put on my brave face, when I am not feeling at all brave. People may want to see courage, but when I feel fear and dread, I have to express them.
—survivor of recurrent astrocytoma

approach to the tumor. In stereotactic radiotherapy, fractionated external beam radiation is delivered over a period of time with multiple small doses.

While numerous technologies exist that vary in how they provide radiation (e.g., Gamma Knife, LINAC, and cyclotron), all share the goal of delivering high dose radiation while minimizing damage to surrounding tissue. The Gamma Knife uses multiple point sources of gamma radiation converging on one source. With the linear accelerator (LINAC), non-coplanar arcs are used. The cyclotron delivers high-energy proton beams (positively charged atomic particles).

Investigators using stereotactic radiosurgery have found that it can help them reach and treat some small (less than 4 cm) tumors located deep in the brain that were previously considered inoperable. In certain circumstances, the procedure can be repeated. It is increasingly considered to be the treatment of choice for multiple small metastatic brain tumors in people whose cancer is otherwise stable. Occasionally, the procedure is used for children and adults with small areas of residual tumor after surgery or as a boost after conventional radiotherapy.

Interstitial Brachytherapy. In a small number of recent clinical trials using stereotactic techniques, radioactive "seeds" were implanted directly into brain tumors where they remained over a period of time. This approach is believed to allow the seeds to target tumor cells, which are in various stages of growth.

Boron Neutron Capture Therapy. During this procedure, a boron compound, which tumor cells pick up more selectively than does normal brain tissue, is given intravenously and is absorbed by the tumor. A single dose of radiation with thermal or low energy neutrons (produced by a cyclotron) that targets the boron in tumor cells, is then administered. High-energy alpha particles released from the boron travel a very short distance and are toxic to the tumor cells. While a few U.S. clinical trials were conducted in recent years, this treatment has not been widely adopted in this country.

Chemotherapy

Chemotherapy interferes with the normal function of the tumor, preventing it from receiving all the genetic information it needs to grow. The tumor either becomes sterile or cannot tolerate its environment.

Because chemotherapies target cells that are dividing, they are especially toxic to malignant tissues. Some chemotherapeutic drugs can be taken orally at home, while some are injected into the bloodstream. Because not all tumors respond to the same anticancer drugs, doctors often use a combination of drugs for chemotherapy,

[My husband] and I both have degrees in science...However, emotionally, I could only go so far. I would tell [him] when to stop reading to me as I paced myself through the information... and the reality of our situation.
—a woman with brain metastases

and much chemotherapy research is seeking to determine the best combination of drugs that will effectively combat brain tumor growth.

Scientists continue to work to overcome a unique obstacle to effective chemotherapy for brain tumors: the blood-brain barrier. This barrier is a network of blood vessels and cells that protect the brain and prevent certain molecules from passing through. A major challenge in brain tumor chemotherapy is to get the drugs where they need to be in the brain to do their job. Investigators are testing drugs that may open the barrier without worsening neurological deficits.

Another experimental path aimed at improving drug delivery into the central nervous system is called interstitial chemotherapy. In this technique, doctors place disc-shaped wafers soaked with a biodegradable chemotherapeutic drug directly into the surgical cavity after a tumor is removed. This technique may help physicians increase the dose of life-prolonging drugs while limiting side effects, as less of the drug spreads elsewhere in the body. Finally, intrathecal infusion, delivering drugs directly into the spinal fluid, is employed to treat some brain, spinal cord, and metastatic tumors.

In adults, oligodendrogliomas, mixed gliomas, and primary CNS lymphomas often respond to chemotherapy. For persons who have brain metastases, the chemotherapy used in most treatment centers is that which has been found most effective with the primary cancer.

Chemotherapy has played a major role in the treatment of childhood brain tumors that spread outside the brain (e.g., to the bone and bone marrow). The most common example of this is childhood medulloblastoma. For children with this disease, chemotherapy is routinely used; in recent years, it has remarkably decreased the incidence of spread outside the nervous system.

Chemotherapy has also found a place in the treatment of infants with brain tumors. These individuals are particularly susceptible to the harmful side effects of radiation therapy on the developing brain. Thus, chemotherapy has been used to delay the time to start radiation and in a few rare instances, has even been able to replace radiation therapy. Some treatment centers are combining high dose chemotherapy with autologous bone marrow transplantation.

Chemotherapy is rarely used with benign brain tumors.

Other Medical Therapies

The following treatments target the biological processes that cause a normal cell to become a cancer cell and then to multiply. They are most often used following standard treatments with tumors that have not responded to such treatments.

- *Angiogenesis inhibitors* are a class of drugs that interfere with the growth of tumor-associated blood vessels, effectively starving tumors of vital nutrients and oxygen. The strategy, which targets the tumor's blood supply, is known in some treatment centers as angiostatic therapy. Anti-angiogenesis agents currently under investigation include thalidomide, TNP-470, platelet factor 4 (PF4), interferon, and endostatin.
- *Differentiating agents* are a class of drugs that can convert immature dividing tumor cells into mature cells, stopping tumor growth. Examples include retinoic acid, phenylacetate, and bryostatin.
- *Immunotherapy* aims to make the immune system more effective in seeking out and destroying cancerous cells. Currently under investigation are several tools considered useful for boosting the immune system.

  Interferons are families of natural proteins created by the immune system that are toxic to many tumor cells.

  Lymphocytes have a particular ability to fight cancer. These can be harvested, grown, and activated in the laboratory using cellular transfer techniques and injected directly back into the tumor to boost an immune response. The cells most commonly used for this purpose are called lymphokine-activated killer (LAK) cells.

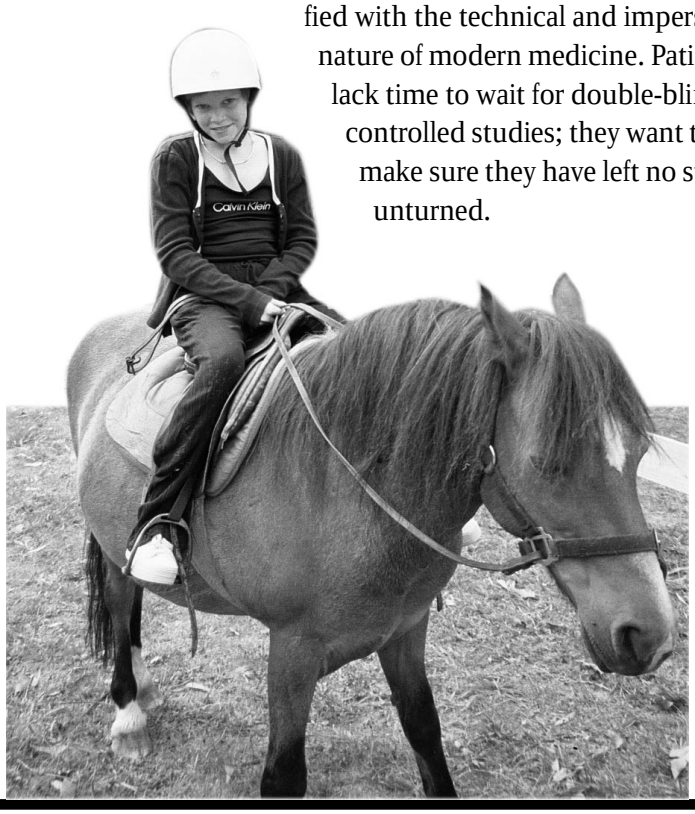
  "Tumor vaccines" are created when tumor cells are removed from the patient and modified so that they can no longer grow when transferred back to the patient. These vaccines can elicit a powerful immunologic response against the tumor.
- *Gene therapy* involves the transfer of genetic material into a tumor cell to destroy the cell or to stop cell growth. Numerous types of genes are under investigation, including those that signal tumor cells to self-destruct, genes that make cells more mature (halting cell growth), genes that can strengthen the immune system's attack on the tumor, and those that increase the cell's responsiveness to certain drugs. Viruses are nature's own method for getting foreign genetic material into cells. By modifying a particular virus both to prevent a viral infection (by altering the virus so it will not divide) and to deliver a therapeutic gene to the tumor, tumor cells are selectively damaged. Gene therapy viruses or "vectors" can be administered by way of a stereotactic injection directly into the tumor. This experimental treatment is currently available only to those patients who have malignant brain tumors that have not responded to standard chemotherapy.

Complementary Medicine

A 1993 study by Eisenberg found that 33% of patients had sought an alternative practitioner for a medical symptom or illness in the preceding year. Of that group, 70% did not share that information with their doctor.

About 40% of the current population in the U.S. will develop some form of cancer during their lives. Currently, about 64% of cancer patients turn to alternative medicine; half of them do not inform their doctors.

Patients seek alternative treatments for many reasons. Conventional therapies have failed, and many have unpleasant side effects. Patients want to be cared about as well as cared for when ill. Many perceive that "natural is better" and are dissatisfied with the technical and impersonal nature of modern medicine. Patients lack time to wait for double-blinded controlled studies; they want to make sure they have left no stone unturned.

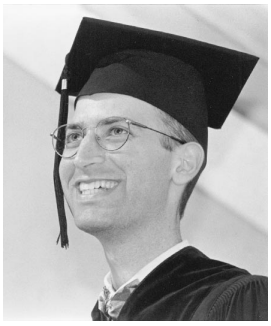


Cancer patients seek information regarding diet, antioxidants, nutrients and vitamins, exercise, acupuncture, and the role of prayer. Unfortunately, most Western physicians are unfamiliar with data in these areas. The available data are often based on small sample size, are often considered anecdotal, and are not always double-blinded. Funding for such studies has historically been limited. Nevertheless, cancer patients fighting for their lives continue to push scientists to collect this valuable information to use along with conventional chemotherapy and radiation.

To date, there are no documented cures for cancer among complementary therapies. Their effectiveness has almost never been studied in brain tumor patients as a group. However, there is some information that we do know. Acupuncture has been effective in reducing postoperative and chemotherapy-induced nausea and vomiting. Exercise (20-30 minutes a day) during cancer treatment has been shown to improve physical functioning and patient quality of life. Guided imagery, prayer, and support groups all promote the healing of the patient during their journey.

Psychoneuroimmunology, the newly founded field of mind-body connections between psychological state and neurological, endocrine, and immune systems, is now being developed and studied. Also under investigation are the role of antioxidants, vitamins A and E, coenzyme Q10, selenium, glutamine, and flavanoids.

Forays into alternative medicine, despite my skeptical nature and rigorous scientific training, are not difficult to understand. When conventional medicine gives you zero per cent odds of surviving five years, it becomes a simple matter of wanting to live, rather than wanting to have proof.
—Jordan Fieldman, M.D., physician and survivor



Due to the chance of drug/herb interactions and herb/herb interactions causing surgical complications or weakening standard drugs, it is imperative that there be an open dialogue between physicians and patients.

Unfortunately, many more questions exist than answers. An open and trusting relationship between patients and physicians represents our most vital strategy. Research is accelerating and appears promising. Above all is the need for hope.

Rehabilitation

Brain tumors arise in regions of the brain that control movement, speech and language, vision, and other vital nervous system functions. Rehabilitation may be necessary to promote recovery. Usually, rehabilitation can begin any time during brain tumor therapy, and it often can be adapted to fit into radiation or chemotherapy treatment schedules. It is accomplished by the coordinated efforts of a variety of specialists.

Neurology. Neurologists work closely with neurosurgeons to provide for the medical care of patients with brain tumors. One of their responsibilities is to organize the overall rehabilitation plan.

Neuropsychology. Neuropsychologists test for learning disorders and other deficiencies of higher brain function. They work closely with vocational training programs and schools to ensure that educational programs are matched to the skills of the patient.

Occupational therapy. Occupational therapists focus on functional rehabilitation, particularly of the upper extremities and hands. They work with patients to restore compromised tasks of daily living or skills that are needed for education or employment. They often administer driving evaluation programs for both teenagers and adults.

Physical therapy. Physical therapists concentrate on rehabilitation of strength, endurance, balance, and independent mobility. Their emphasis is on gross and fine motor aspects of walking, running, and stair climbing, and they assess for the need of functional aids such as braces, canes, walkers, or wheelchairs.

Speech, language, and cognitive therapy. Speech therapists work with patients to restore the ability to speak clearly. They work with communication specialists to devise aids of communication when speech is not clear. They may also help with cognitive skills (problem solving, attention, and organization) and teach strategies to compensate for short-term memory loss.

Vision. Ophthalmologists provide assessment and correction of visual deficits. In some cases where vision loss is particularly significant, they work with low vision specialists to provide visual aids.

Vocational rehabilitation specialists provide guidance for work re-entry. They can be located through your state's rehabilitation commission and, if applicable, through your state epilepsy organization.

Specialized rehabilitation for patients with cranial base tumors (which may produce facial paralysis, weakness, or numbness) can include facial reanimation surgery or facial neuromuscular retraining. These services are usually only available at large medical centers.

Vestibular rehabilitation for persons coping with balance disorders is occasionally available at established rehabilitation hospitals and clinics.

Together these specialists work to restore functions or provide adaptations for deficits that arise from injury to the nervous system. Their overall aim is to return brain tumor patients to a full life as their therapy is completed.

Clinical Trials: Part of the Drug Approval Process

New drug therapies in clinical trials offer hope to patients who have not had success with standard medical treatments. In choosing to enroll in a clinical trial, patients accept a certain level of risk associated with the experimental drug with the hope that the benefits will outweigh the risks.

Clinical Testing Stage	Primary Research	How Many Brain Tumor Patients?
Phase I	Safety	e.g., 10-50
Phase II	Dosage	e.g., up to 100
Phase III	Efficacy	e.g., up to 150

Under current law, the US Food and Drug Administration (FDA) approves new treatments after the drug's sponsor has shown it to be safe and effective. The process begins when the sponsor gives the FDA an "investigational new drug application" (IND). The IND details the tests to be performed in humans to prove the new treatment safe and effective. The drug sponsor begins the IND after studies in animals have defined the early limits for safe use of the drug in humans.

Phase I is the first time the experimental drug will be used in people. Phase I studies determine the safety of the drug along with the metabolism, absorption, elimination, and other drug activities. Phase I studies involve dose escalation. They also show the preferred mode of drug administration (e.g., oral or IV) and safe dose range. Physicians generally conduct these studies in healthy volunteers except for cases where the disease has no cure and all first-line treatments have failed.

I have a friend with a "benign" brain tumor who has had two brain surgeries and over a dozen shunt revisions. That is not a small matter!
—Jeff Wallace, survivor of recurrent ependymoma

Before enrollment in any clinical trial, physicians evaluate patients for their medical suitability. They discuss the known risks and side effects of the experimental drug. Physicians carefully monitor patients for acute adverse effects.

There are certain risks involved in Phase I testing. In general, more risks are encountered than in Phase II. The number of patients enrolled in a Phase I trial is 10-50. After careful review of the data, the drug sponsor will determine whether the drug should advance to Phase II trials.

Phase II studies involve greater numbers of patients (e.g., 50-100 for brain tumor studies). A clinical trial involving a new chemotherapeutic agent will be looking at how well the drug performs to treat a specific type of brain tumor (e.g., the trial is conducted on adult patients with gliomas).

The Phase II trials narrow the viable therapeutic applications (i.e., specific types of brain tumors) and dosage regimes. They also further evaluate the activities of the drug. These data are insufficient, except in extremely rare cases, to determine the efficacy of the drug. The patients are always carefully monitored and are immediately removed from the treatment if their condition worsens due to the treatment. Physicians inform the FDA about any adverse effects from the treatment.

The next stage of clinical development of the drug is called Phase III, involving even more patients with the disease. This critical phase provides the test of the drug's safety, effectiveness, and best dosage schedule for the treatment of a specific disease in a specific group of patients (e.g., chemotherapeutic agent for pediatric patients with medulloblastoma). These studies are highly controlled. The trial may be run "blinded and placebo controlled." This means a certain group of patients with the disease are given the drug and others are given a "placebo" (inactive substance resembling a medication) for a defined time period. "Blinded" means not even the physicians know which drug has been given. This is done to prevent bias on the part of the physician. After this time period, the results are "unblinded" to reveal how the treatment worked for the patients treated with drugs compared to those given placebos.

In the case of a life-threatening medical situation, provisions are generally made to switch the placebo-controlled patient to the drug if the drug has been shown to work. Additionally, in this case, a drug sponsor may ask the FDA for a "treatment IND," which is a mechanism for providing eligible patients the investigational drug, providing there is no satisfactory alternative treatment available.

The data gathered from the various clinical trial stages allow the FDA to make a judgment on the drug's relative effectiveness as well as less common side effects and adverse reactions. This process clarifies the drug's risk versus benefit relationship in the patient.

For further reading on this topic of clinical trials consult "What are Clinical Trials all about?" NIH Publication 95-2706. Or contact the Natinal Cancer Institute at 1-800-4-CANCER for the NCI Clinical Trial Information Series.

The Decision to Participate in Clinical Trials

The decision to enroll in a clinical trial can be an agonizing process. Remember that the decision to participate in a clinical trial is entirely up to the patient. It is also the patient's responsibility to learn as much as possible about the known risks and potential benefits of the clinical trial before making a decision. Consult your doctors as well as people close to you for their opinions. Support is an essential part of the decision-making process.

Some key questions to consider

- What is the nature of the experimental brain tumor drug or therapy and what will this mean for me?
- What phase of the clinical trial will I be in?
- How long has the study been ongoing and how many patients have been enrolled and exposed to the experimental treatment?
- What has been the outcome thus far of the patients in the trial?

Remember that all prior testing has been carried out in animals in a Phase I study, thus, little to no human data may be available. Phase III trials usually have access to results of earlier trials in humans. In general, the information available about outcomes, even in late studies, is too preliminary to draw firm conclusions about efficacy of the experimental treatment.

- What risks might be associated with the experimental treatment, especially:
  - side effects (the number and frequency).
  - harm caused by receiving a placebo (inactive substance) instead of the drug.
  - expense to the patient, if any, as a result of participation in the study.
  - legal risks from questions asked of you or tests performed on you as a result of the study.
- What potential benefits might the unproven treatment have for you, such as:
  - the possibility your brain tumor would improve.
  - frequency of monitoring your tumor and general health condition as a result of participation in the study.
  - having treatment expenses paid by the study.
- What standard treatment options can you choose if you decide not to participate?

Patients review and sign a consent form, which explains the trial, rules for patient enrollment, and risks. For consent forms written in complex terms, ask the staff to explain them to you. By signing the form, you give up no rights. You may change your mind or withdraw from the study for any reason. Carefully weigh your treatment options, make an informed choice, and be positive about your decision whether to participate in a particular clinical trial.

Coping with Your Diagnosis

Aggressive Tumors

One common way families begin to approach a new diagnosis is to search for reasons why it occurred. The scarcity of known risk factors for brain cancer, especially factors under individual control such as diet or smoking, adds to the mystery. In frustration, many families describe a sense of unfairness about the disease, saying, for example, "He was so healthy! He ate right and exercised. This should not have happened."

At the start of the twenty-first century, brain tumors are still frequently mistaken for other illnesses such as strokes, especially in the elderly. Families express frustration and anger over the delay of diagnosis as well as the treatment options lost to misdiagnosis.

Brain cancer differs from other malignancies in many ways:

- The blood-brain barrier renders many proven chemotherapies ineffective.
- The anticonvulsants taken by many patients may make some chemotherapies less effective.
- Brain tumors rarely metastasize outside the central nervous system and are staged differently from other cancers.
- It is less clear how to distinguish a benign brain tumor from a malignant one.
- Patients often do not appear "medically" ill and may be ineligible for home nursing services.
- The prevailing wisdom in the cancer community about how the illness affects energy level, sexuality, and quality of life has only limited applicability to brain tumors.
- Brain cancer is the only cancer that may affect personality. The brain injury literature suggests that personality and behavior changes are harder for families to manage than physical changes, even those as severe as paralysis.

The loss of control experienced with a life-threatening, unexplained neurological illness makes it especially important for families to find ways to regain control. Here are a few suggestions that might help.

- Decide how much information gathering is right for *you*. If another family member or friend wants to know more, tell them you will signal when you are ready to hear more about what they have learned.
- Communicate to family members how much involvement you want in the decision-making process and how much involvement you wish for others to have.
- Delegate the tasks you find overwhelming.
- Choose the times when you will and will not accept phone calls and visitors.
- Select a family liaison to communicate updates to extended family and friends.

Webster defines "benign" as showing kindness and gentleness. What happened [to me] was certainly not benign.
—John Pistel, a survivor

Low-grade and "Benign" Brain Tumors

Physicians describe low-grade tumors as well defined and slow growing. These tumors tend to respond to surgical approaches to their treatment. The most common low-grade tumors include meningiomas, acoustic neuromas, pituitary adenomas, and low-grade gliomas.

The word "benign" is a double-edged sword, providing real hope while failing to convey the potential gravity of the condition. Most patients do achieve long-term remissions or cures with excellent quality of life. However, some meningiomas cause seizures. An atypical meningioma can grow aggressively. Some acoustic neuromas cause permanent disability and disfigurement or may be associated with prolonged recovery and rehabilitation. Some pituitary adenomas create the need for long-term hormone replacement therapy. Low-grade gliomas, particularly if located near the brainstem or other sensitive structures, can be life threatening. Some low-grade gliomas grow back as malignant tumors. While many patients stress that they feel fortunate to have a lower-grade tumor, they tend to experience a lack of validation from the community that they, too, face serious concerns.

Low-grade and "benign" brain tumors have several characteristics:

- Subtle onset
- Diagnosis is often unexpected
- Slow growth
- Noninvasive
- Well circumscribed
- Potential for surgical cure or long-term remission
- May respond to radiation

The treatment goal for low-grade tumors is either to cure the tumor through surgical removal or to prevent progression to a higher grade. While surgical expertise is found at cancer centers, few supportive services (such as support groups) are geared to this population. Furthermore, because a substantial number of people with benign tumors receive treatments associated with cancer such as radiation and even chemotherapy, they may seek information through cancer-related organizations. However, at present, such information is difficult to obtain. Their collective insight about living as long-term survivors who cope with long-term effects of treatment has rarely been noted.

In an effort to recognize and meet the needs of people with these tumors, The Brain Tumor Society offered the first special interest track on low-grade and benign tumors at a national patient conference in 1997. Drawing well over 100 participants, this track is now a permanent feature of all our national symposia.

Rare Tumors of the Central Nervous System

Fewer than 200,000 people in the United States have any type of tumor of the brain or central nervous system, including even the most common forms. Because so few persons develop these tumors, brain tumors are regarded as an "orphan" disease. The periodic media updates that describe emerging treatments for the most frequently occurring cancers do not include information on tumors of the central nervous system.

Moreover, as there are more than 120 different types of brain and spinal cord tumors, quite a few of these diagnoses are extremely rare, affecting only a handful of persons worldwide. Families affected by the rarest types of tumors find few resources and may have difficulty locating members of the healthcare community who have experience with their diagnosis.

Even among the more common tumor types, a rare manifestation, presentation, or complication of the illness can isolate a patient and family dramatically. For example, parents of a child with glioma may struggle to find information about posterior fossa syndrome. An adult with medulloblastoma may seek other adults coping with this "pediatric" tumor.

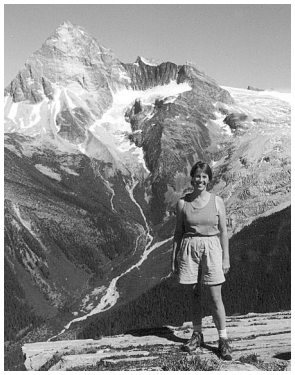
Despite the diversity of our population, patients and families facing uncommon conditions tend to express common concerns. As a group, they encounter little or no expertise in the medical community about their diagnosis. Rare tumors are omitted from patient education sources or dismissed under the heading of "other."

Lacking patient-oriented materials, many tackle professional journals to find tidbits of information. Technical literature may dwell on worst cases or complications, rarely providing the hope sought by families.

Occasionally, the family and the physician learn about a rare diagnosis together, as data supporting a treatment plan may be based on a mere five or ten cases. This affords a "backstage view" of how medical teams handle novel and unfamiliar situations and can provide an important basis for developing trust and confidence. When no expert can be found, families try to engage the team most willing to stand by them during what may be an extended search for answers.

In an ever-expanding age of information, patients and families increasingly seek medical data in order to participate meaningfully in treatment decisions. Yet the lack of readily available educational materials for rare tumors can greatly compound the anxiety that a new diagnosis brings.

As a service to persons coping with rare tumors, The Brain Tumor Society has created information files about every rare diagnosis for which inquiries have been received. If you do not find your tumor type listed here, you are invited to contact us at (800) 770-8287 for individualized assistance with your search.



Additionally, you may find the following guidelines helpful.

- Most people do not realize their community hospital has a library that serves patients and families. About 75% of such libraries are open to the public and accept questions via phone or email; many offer access to the Internet. As a strategy to reduce isolation, try to involve medical librarians or hospital resource room staff/volunteers as search partners. Ask them to assist you in handling the technical nature of medical writings. They can also help you verify information found on the Internet.
- If you find nothing, look for misspellings, which are surprisingly common. Look also for word reversals (e.g., pseudotumor cerebri rather than cerebral pseudotumor). Also check for embedded names. For example, if the diagnosis esthesioneuroblastoma yields no information, try simply neuroblastoma. Be alert to name changes for your diagnosis over time as more information becomes available. Recently, for example, acoustic neuromas have been more often referred to as vestibular schwannomas.
- Case reports may be accompanied by literature reviews. Look for names that appear frequently in references. Reference lists may identify physicians who have experience with the condition.
- If the diagnosis represents a relatively new classification, such as dysembryoplastic neuroepithelial tumor, little information will be available about long-term outcomes.

Evaluating Information

How to Evaluate Press Releases

Some friends and relatives wishing to help will contact you to share information they just heard on the radio or TV news about a promising new treatment that they hope will be right for you.

The following questions can help you determine whether the information truly applies to your situation.

- Did the press release specifically mention brain tumors? Most new treatments announced by the media have been tested for lung, breast, or prostate cancer.
- Has the emerging treatment yet been tested on humans? Many news reports actually refer to developments in the laboratory that may (or may not) eventually be used in the clinic.
- Is the treatment covered in the news really new? Often an existing or even longstanding method will be profiled because an area hospital has recently purchased equipment or built a new treatment center.
- If these questions cannot be addressed, contact the news source (the TV station or media outlet). Often, a transcript can be made available.

When the Experts Disagree About Treatment

Families are almost universally unprepared for the possibility that they will receive conflicting recommendations or lack of consensus about treatment options. However, this situation occurs surprisingly often. Medicine is partly an art as well as a science.

Patients approach the information-gathering process with the quite reasonable hope that an additional opinion from an independent source will clarify a course of action. There are times, however, when they grapple with almost as many opinions as practitioners. Patients say this development is one of the most frustrating stressors they encounter during workup and treatment planning.

If you find yourself in this situation, keep the following pointers in mind.

- When the experts disagree, request additional information from them to help you evaluate your options.
- Know that, at present, few treatments are compared directly to one another in research studies.
- Know that institutions and medical specialties may heavily promote their own protocols. Ask your medical team why they have faith in their approach.
- It is okay to ask your physicians to respond to the opinions of their colleagues.

With the help of a loving family and supportive friends, I garnered the strength to seek additional opinions, and to hopefully find the latest and best treatment modality. I quickly realized that such a search was very idealistic: there was no collective opinion or single new treatment. Rather, I encountered vast disagreement about my disease and the proper course of action to defeat it. This was, at first, very unnerving!
— Neal Levitan, astrocytoma survivor

- Inquire about rates of response and about toxicity.
- Consider the risk/benefit ratio of each option presented to you.
- Ask about the uncertainties associated with each possible course of action.
- "Try on" different treatments to see which ones feel right to you.
- Once you have gathered the necessary information, pay attention to your instincts about what to do. Follow up on any regrets about options you did not pursue. Similarly, listen to that small voice that may be holding you back from a certain recommendation. Your own values matter a great deal when it comes to selecting a treatment plan.

Taking the Lead in Healing Yourself

Getting diagnosed with a brain tumor is a very frightening experience. Most people cannot even comprehend the possibility of this diagnosis. A myriad of questions goes through your mind. What do I do? Who do I talk with about my situation? Where do I go for information?

Where do you start...? Most importantly, you must choose how to manage your own illness. You, your family, and your friends can actively involve yourselves in managing your plan of action. Relying exclusively on doctors, nurses, and other caregivers for information can actually hinder you from finding your best path to healing. Alternatives include seeking out additional resources in medical libraries and the Internet. Patient resource organizations can also provide helpful information in an easy-to-understand format.

Your first step in managing your illness might be determining exactly who serves on your healthcare team. As a healthcare consumer, you deserve to have a medical team that treats you with respect and takes the time to ensure that you are receiving proper care. When possible, you may want to seek treatment at a large medical center known for its work on brain tumors. If you know someone who has been treated for a brain tumor, you may want to ask about their experiences with particular doctors. Once you have found a team that meets your needs and makes you feel comfortable, you can direct your energies toward understanding your entire course of treatment. It may help to take an active role, asking questions and gathering information to help you understand your diagnosis.

In addition to asking questions of your healthcare team and seeking information on your own, you may want to try visiting a support group to share information and network with other patients. The Brain Tumor Society can provide you with referrals to appropriate resources and educational materials about brain tumors, and you can find a list of organizations with brain tumor-related services in this booklet.

Your medical team will certainly do everything to treat your body, but you will need to take the lead in treating your mind. You may feel anxiety, depression, anger, or fear, and these feelings are natural. During this time, you may want to review various aspects of your life to improve your physical and emotional condition. For example, you may want to take some time to look at your nutritional habits. Are you eating healthy foods instead of just grabbing "fast food"? Perhaps a nutritionist could help you develop a positive eating plan.

Regular exercise also promotes healing. Try going out for a daily walk or resume activities you enjoy on a level that feels comfortable to you. Each person maintains a different activity level, so you may want to examine your own habits of exercise to determine how to customize a plan to work for you. Most fitness centers have physical trainers available to help people work out a healthy activity level. If you have disabilities, physical therapy may help. Your doctor can refer you to a qualified therapist if he or she feels physical therapy would be appropriate.

Create a healing environment on three levels: socially, emotionally, and spiritually. Do not be afraid to ask for help or direction if you need it, but you may find that exercising your own power brings its own form of healing. Many people find that trying new things helps: telling jokes, meditation, seeking alternative/complementary therapies, practicing relaxation techniques, learning to cook, reading a good book, or seeing favorite movies. Treat yourself!

HEAL YOURSELF!

Chapter 3:

Employment and Financial Issues

Employment and Financial Issues

Job Accommodation and the Americans with Disabilities Act (ADA)

Does the ADA apply to brain tumors? Actually, the first employment lawsuit filed under the Americans with Disabilities Act of 1990 (ADA) was on behalf of a brain tumor survivor. In July 1992, Charles L. Wessel, Executive Director of AIC Security Investigations, was fired with one day's notice after telling his company he had inoperable brain metastases from lung cancer. The Chicago-based company's owner told Mr. Wessel that his position had been eliminated.

The EEOC (Equal Employment Opportunity Council) is responsible for enforcing Title I of the ADA. On November 5, 1992, the EEOC filed this first federal ADA "test case" with their Chicago district office. The EEOC claimed Mr. Wessel was able to perform the essential functions of his role of executive director and that his firing violated Title I of the ADA. EEOC lawyers described the case as "a classic example of the type of discrimination" the ADA was intended to prevent.

On March 18, 1993, the Chicago jury awarded Mr. Wessel $22,000 in back pay, $50,000 in compensatory damages, $250,000 in punitive damages against AIC, and $250,000 in punitive damages against the company owner. The court later reduced the punitive damage awards the jury had made because they exceeded the amount allowed by law.

Reference: U.S. EEOC v. AIC Security Investigations, Civil Action No. 92C-7330 (U.S.D.C., N.D. Ill.). The six-page complaint is available from the Pike Institute, Boston University School of Law, 765 Commonwealth Ave., Boston MA 02215. Ask for Item #3919, and ask about current rates charged for copying and postage.

Several organizations help brain tumor survivors counteract employment discrimination.

- The **Job Accommodation Network** provides free information about what employers can do to accommodate persons with disabilities.
  Call (800) 526-7234.
- The **National Coalition for Cancer Survivorship (NCCS)** provides national advocacy to combat employment and insurance discrimination. Contact NCCS at (877) 622-7937.
- The **Disability Rights Education and Defense Fund** explains the ADA, offers dispute resolution, and describes how to file complaints.
  Call (510) 644-2555.

Financial Resources

While your clinic or hospital social worker can best direct you in finding appropriate financial services, this short resource list can get you started on your search for assistance right away.

Governmental

Social Security Income (SSDI)

Money you have accumulated through payroll deductions over time is used to restore an income stream lost due to disability.

- (800) 772-1213
- www.ssa.gov

Medicaid

Public assistance is available for those ineligible for other programs.

- Call your local Department of Social Services or Dept. of Public Welfare.
- www.hcfa.gov/medicaid

Hill-Burton Program

Funding for free or low cost care from certain hospitals and medical facilities.

- 800-638-0742
- www.hrsa.gov/osp/dfcr

Food stamps

Vouchers used as cash to buy food.

- Call your local food stamp office. It may be listed under "Food Stamps," "Social Services," "Human Services," "Public Assistance," or a similar title.
- www.fns.usda.gov/fsp

State pharmaceutical assistance programs

- Call your council on aging or elder service agency.

State services for elders

- Call your council on aging or elder service agency.

Community programs

- Call your city/town hall.

OTHER

American Cancer Society

Limited funding for a variety of resources.

- 800-227-2345 for your local office
- www.cancer.org

Easter Seals

Funding for rehabilitation, job training and home health care.

- 312-726-6200 for your local office
- www.easter-seals.org

Disability insurance

- Call your employer.

Reverse Mortgages

A special type of loan used to convert the equity in your home in to cash to meet your expenses.

- Call the bank that holds your mortgage
- www.reversemortgage.org

Viatical Settlements

The sale of your life (term or permanent) insurance policy for immediate funds

- Call your accountant.

Pharmaceutical company indigence programs

Provision of free medications to those unable to afford them.

- Call the Department of Social Services at your hospital

Special Hospital programs

- Call the Department of Social Services at your hospital.

Local churches and synagogues

Chapter 4:

A Pediatric Perspective on Survivorship

A Pediatric Perspective on Survivorship

What is it Like to be a Kid with a Brain Tumor?

Colleen Sheehy and Ellen Rose O'Brien, long-term survivors of pediatric brain cancer who are also close friends, volunteered to share information they hoped would help other kids who are facing diagnosis and treatment. They decided that Color me Hope would be incomplete without their experiences, and chose to discuss feelings and ideas they wish had been written down for them back in the early 1990s. The following is a summary of an interview that took place years after their treatment.

What do you remember about what it was like when you were first diagnosed?

"It can be scary. You wonder what will it be like, what will happen next. So it helps to have hope. When you have hope you say to yourself, things are okay today, and they will probably be okay tomorrow."

How do other kids deal with your cancer?

"Kids don't ask about our cancer unless we touch on it at school. Like in science class, we studied the human body. The teacher kept referring back to me, asking me questions. I wanted to help; it is okay to help, but I am only thirteen. The class can be a good time to let people ask questions, but I don't want them to think I am the teacher's pet!"

"When I talk about my cancer in front of kids, I have to keep the tears back. They wouldn't understand if I cried. They already make a big deal over my height, weight, and hair. They could say these things in a nicer way!"

"Sometimes kids used to be scared of me, and so they acted mean. When you are a kid with a brain tumor, you do know a lot about medical things and cancer, way more than other kids."

Do you feel you are treated differently than other kids?

"Even when the treatment is over you still have other things to remind you. You still have to get shots, blood tests, MRIs. The kids say we are 'so lucky' to be taken out of school, to skip a day for an MRI. No, we're not! It is not fun for us!"

"Sometimes we have to act older than other kids, but people think we look younger. We both like things that younger kids like. We still find stuffed animals comforting at the hospital, and we like cartoons and Disney. That really bugs our younger sisters and brothers! They don't listen to us the way they listen to other kids our age. Other kids are allowed to do more mature things."

"When you have a brain tumor it is hard to do things fast. The kids think I am 'lucky' because I use an AlphaSmart computer. I think they don't understand that it helps me."

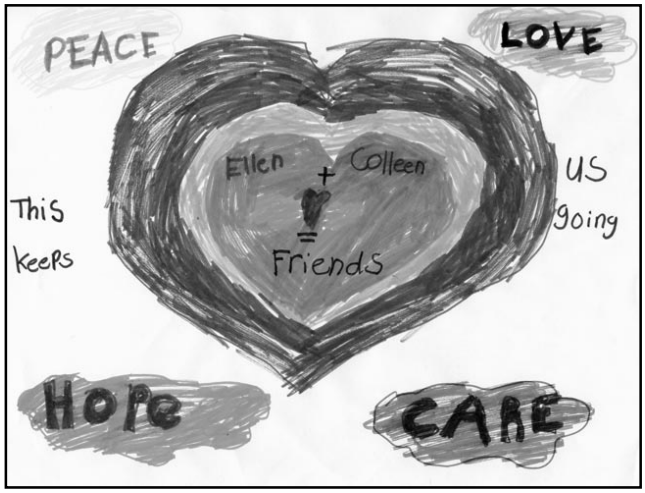
What has helped you get through your illness and treatment?

"It really helps to have 'traditions' after an MRI or a visit to the hospital, like going out to dinner or going to the store. Or getting extra prizes, like being allowed to stay up late, after getting a shot. It also helps to get to decide some things when you have treatment. I sit up for all my shots, and I have another rule: No ear-plugs during an MRI! I bring a stuffed animal with me during all my scans."

"What makes it easier? It helps to talk to my counselor. I have an aide in class who gives me enlarged papers that I can see, who reads to me, and helps me go up and down the stairs safely."

"We also have each other. We are partners."

Ellen Rose said, "I hope this doesn't happen, and I don't think it will, but if my cancer ever comes back, Colleen is the first person I will call."



Chapter 5:

Support Services Offered by The Brain Tumor Society

Support Services Offered by The Brain Tumor Society

Telephone Support Line

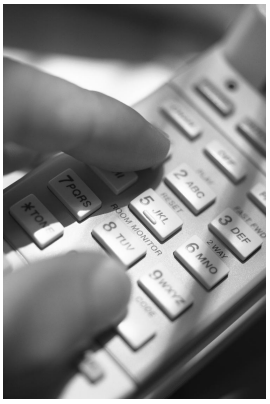
One of the most beneficial programs of The Brain Tumor Society has been the one-to-one support we have provided to thousands of patients and their families. Services offered by professional staff often begin with the provision of up-to-date brain tumor information. Through our toll-free telephone line we support callers in their effort to make informed decisions about treatment and help them regain a sense of control, which is so often lost under the circumstances. Bereavement support, including information about the late stages of the illness, is available to families facing the loss of a loved one.

Because long-term survivors represent an ever-growing number of our callers, we have developed resources where none existed before, including long-term survivorship stories in our newsletter, survivorship panels at our conferences, and articles addressing some of the ongoing and unresolved concerns of this group.

It is our belief that support enhances and improves the quality of life of brain tumor patients and their families. We also believe that support may serve as an integral part of the recovery process. Thus, the Society provides access to a growing number of support groups located throughout the United States and Canada.

Referrals to Brain Tumor Support Groups: A Vital Service

The brain has long been accepted as the center of thought, intelligence, emotion, and movement. A brain tumor is often perceived as an attack on the whole person, an assault on his or her very identity, making it unique among cancers and nonmalignant tumors. No other tumor has the potential to affect the patient to such an extent. Brain tumor support groups address all the associated features of this life-threatening illness—problems it may cause with memory, speech, sensation, perception, behavior, personality, and overall health.



Telephone support is available by calling 800-770-8287

While general cancer support groups, head injury groups and epilepsy support services help many people, such groups may miss the big picture of the overall impact of brain tumor diagnosis, treatment, recurrence, and/or survivorship.

Often, affected persons have played a pivotal family role. They may find themselves suddenly unable to manage family decisions, operate a motor vehicle, or maintain prior income. Sometimes the illness necessitates an immediate shift in family roles without allowing time for negotiation. Single adults must scramble to find support services. Parents try to balance the needs of their diagnosed child with those of their other children. Normally, a brain tumor diagnosis or recurrence precipitates the type of crisis often associated with a temporary breakdown in adequate coping. A sense of loss of control and fear of the unknown may complicate adjustment.

Experience has shown that providing information and education, as well as psychological support and advocacy, helps patients and families cope with the ongoing situation. Parents feel best able to support a child when they have access to information and support themselves. A group setting offers a ready-made support network and furthers the chances that others will have shared one's particular experience.

People who have not attended such meetings frequently express a number of concerns about support group participation. We have addressed several here.

"Support groups are only meant for those brain tumor patients and family members who are not coping. We are doing pretty well so far."

Our experience suggests that because your particular illness is a new and unexpected occurrence in your life, you may feel as though you are making it up as you go along in order to cope. A growing body of knowledge is being passed along in support groups to prevent you from having to reinvent the wheel. When others in your situation provide validation that your reactions are not unusual, a sense of relief often follows. Networking among group members to exchange practical information and support can be reassuring and energizing. Others may also benefit from hearing how well you are doing.

"It is not time to think about joining a support group. We haven't given up yet."

Group members emphasize that the hope sustained within the group is one of the things that keeps them going.

"I don't know if I can talk among strangers."

Many people feel that way. Some visit a group just to listen at first. They are surprised to find themselves more comfortable speaking with a person who is not emotionally involved in their situation, someone who provides a new perspective or may even unlock an old problem.

"I think I would find the group too depressing."

Support groups differ in emotional tone and intensity at each meeting. On some days, sadness and frustrations are expressed. At other times, participants experience the lighter side of coping with chronic illness. Because groups vary from time to time, you are encouraged to attend several meetings before deciding whether the group works for you.

It is especially difficult to face the possibility that you will meet someone whose illness has progressed. Many find they receive enormous encouragement as well as valuable insight from longer-term group members after hearing how other members keep hope alive.

"I don't want to burden anyone."

Some brain tumor patients find that offering you and others their support helps to heal some of the damage done to their self-esteem from the illness. As a new member, you may also find that your presence and experiences have enriched the group or helped veteran members.

This is one of the very few places where you can be angry at the tumor or feel frustrated and not have someone say, "Don't feel that way!"
—a support group participant

"I don't need support as much as I need some reliable information."

Many groups invite speakers to give educational presentations especially geared to the needs of participants. Topics may focus on the latest technology in brain tumor treatments, nutrition, coping with treatment effects, or other themes and issues chosen by interested group members.

"I cannot leave my loved one even for an evening without feeling guilty."

Nearly everyone feels this way. Participants find that feelings of guilt that accompany the caregiver role are more manageable with group support.

For those who are currently homebound, alternatives to group meetings include patient/ family telephone networks and computer-based support groups such as BRAINTMR or a chat room on the Internet. With these resources you can connect with others at the very moment you are feeling most in need of support.

"I may just want to listen. Is that okay?"

Sure. There is no requirement that anyone attending has to speak during the group. Meetings are structured to provide a safe, nonjudgmental, and confidential forum for exploring ways of coping with a brain tumor.

Adapted from "Support groups for cancer patients, their families and friends" by Roberta D. Calhoun and Karen K. Fielder; a poster on display at The University of Texas M.D. Anderson Cancer Center.

I drew a great deal of strength from the networking available at your Boston and Providence conferences.
—Jackie Girard, long-term survivor of glioblastoma

Training and Resources for Support Group Leaders

New support group facilitators and persons thinking of starting a group will benefit from a series of resources offered by The Brain Tumor Society. The following articles have been combined into a packet of materials made available to all potential and current group leaders.

- How Two Mothers Launched a Group. The step-by-step origins of a California pediatric brain tumor support group.
- Step One in Planning: Investigating the Need. Why the most important step in planning a new group is conducting a needs assessment.
- Learning by Observing. A new group leader discusses what she learned from observing oncology, brain injury, and epilepsy support groups.
- Publicizing Your Group. Marketing ideas that will boost attendance.
- The Value of Brain Tumor Support Groups. Challenges the many myths about support group attendance.
- Profile of a Longstanding Group. Members of the Lahey Clinic brain tumor support group discuss what makes their group thrive.
- Email Group Profile. Parents from the hypothalamic hamartoma email list talk about how this online group meets their needs.
- Group Sponsors Conference. A ten-year representative of a group that has achieved non-profit status talks about how members planned a regional brain tumor conference.

The Brain Tumor Society offers individual support to new and veteran group leaders through our telephone support line. We have offered formal training for support group facilitators in conjunction with the National Brain Tumor Foundation, the Acoustic Neuroma Association, and Duke University Medical Center.

The newest resource for group leaders is our *Joey's Song* videotape. This 30-minute tape depicts one family's early recovery from the loss of their 3-year-old child to a brain tumor as a process, and illustrates many details of life after the loss of a child. It is our hope that families will receive validation for their feelings as they view the tape and that group leaders, chaplains, social workers, and nurses will share this story to show that healing is possible after loss. Bereavement groups in particular may use the tape to spark discussion, since families may be more willing to share their own stories once they have heard others speak.

Patient/Family Symposia, Regional Conferences, and Teleconferences

Because the illness is so rare, many brain tumor patients lack access to area support groups and, therefore, have never had the opportunity to meet others who share similar experiences. Participants in the patient/family conferences offered by The Brain Tumor Society find that the contact with other survivors is just as vital as obtaining the latest information about emerging treatments.

For the homebound, telephone conferences offer an ideal opportunity to obtain information and support in a convenient format.

For people who are unable to attend our conferences, The Brain Tumor Society offers conference-related resources including handouts, audiotapes, and videotapes.

Patient/Family Telephone Network

As a longstanding part of our support program, The Brain Tumor Society offers a Patient/Family Network. Volunteers offer support through a sharing of mutual experiences via telephone and email conversations. Our volunteers include people who have or have had a brain tumor themselves, families of adult patients, and parents of pediatric patients.

Informal patient networks such as ours often serve as a powerful, healing resource to reduce isolation. They can help you make sense of your experiences, provide an opportunity to feel understood at a deeper level, validate feelings, and offer emotional release as well as perspective.

To arrange a phone or email contact with one of our volunteers, or to volunteer for this network, please call The Brain Tumor Society at (800) 770-8287 or e-mail us at info@tbts.org. In the event that we cannot match you with someone, we will offer to print a paragraph about your situation in our newsletter column, *Making Connections,* or we will suggest a network offered by one of our sister organizations.

Do you remember the last time I stood in front of you? I was bald. I was thin. Although I'd had my first clear scan already, I was still recovering from the most difficult year I had as yet endured. I was sick and I was scared and I was tremulous and tentative. I came to you then to say thank you for the efforts you were making on my behalf, on the behalf of my family and my friends. I came to thank you for your help. And now maybe I can help you. Maybe I can renew your faith.
—Rachel Henderson Falls, survivor of inoperable astrocytoma

Chapter 6:

Hope

Hope

Hope is an important ingredient in life, more so when life is threatened. We all live on the basis of hope, which guides our futures and helps us maintain our spirits. How can we maintain hope in the face of serious illness?

There is no contradiction between facing illness directly and maintaining hope. We need realistic hope, hope that we can effectively use the best that medical care can offer, hope to slow the progression of disease if not cure it. But there are other kinds of hope as well. There is hope that we can spend the precious time we have as fully as possible. Hope can lead us to tell loved ones how much they mean to us. Hope can direct us toward changing life priorities, completing important tasks, and helping others with similar problems. We have evidence that such a tough-minded 'fighting spirit' may help the body as well as the mind cope with serious illness.

Hope can be a guide to what is important in the future, but it must not blind us to the realities of the present. Use it as a means of finding the best in your life, not hiding from the worst.

David Spiegel, M.D., author of the above section, is Professor of Psychiatry & Behavioral Sciences at Stanford University School of Medicine and author of Living Beyond Limits: New Hope and Help for Facing Life-Threatening Illness, published by Times Books.

There will be a Cure!

Progress in the battle against brain tumors depends on a broad-based research effort. Several agencies of the Federal Government, along with non profit organizations such as The Brain Tumor Society are sponsoring research that is leading to new understanding of the causes and innovative treatments. The Brain Tumor Society funds basic scientific research projects for up to a two-year period at a maximum of $200,000 for each approved project.

North American Brain Tumor Coalition

The *North American Brain Tumor Coalition* (NABTC) is a network of charitable organizations dedicated to eradicating brain tumors. Member organizations of the Coalition have awarded over $20 million in private funds for research related to brain tumors. The Coalition represents the interests of its constituency by raising public awareness of brain tumors and by advocating for increased research funding, access to specialized care, and other issues affecting brain tumor patients.

Since its inception in 1991, the Coalition has established a strong public policy voice on behalf of adults and children with brain tumors. NABTC representatives have testified before Congress in favor of increased biomedical research and ready access to new drugs and therapies. The Coalition also participates in meetings on biomedical research and health care delivery at the Food and Drug Administration (FDA), the national Institutes of Health (NIH), and other federal agencies, and collaborates with other organizations representing patients with serious life-threatening illnesses.

Visit the Coalition's web site at http://nabraintumor.org.

Central Brain Tumor Registry of the United States

The Central Brain Tumor Registry of the United States (CBTRUS) is a not-for-profit corporation committed to collecting and disseminating statistical data on all primary brain tumors irrespective of their behavior.

CBTRUS aggregates incidence data from collaborating state cancer registries and generates summary statistics. These statistics are published in the form of a Biannual Report that is mailed free of charge to over 2000 members of the neuroscience community and to others upon request. CBTRUS statistics may also be found on the worldwide web at www.cbtrus.org.

For the time period 1992 to 1997, a total of 41,906 malignant and benign brain and central nervous system tumors were reported to the participating registries. The average annual incidence rate of all primary malignant and benign tumors was 11.3 per 100,000 person-years. The incidence of tumors in males (11.8 per 100,000 person-years) was significantly higher than in females (11.0 per 100,000 person-years). The most frequently reported histologies were meningioma (25.7% of all tumors) and glioblastoma (23.1%).

A total of 3,243 tumors (7.7%) were reported in children under 20 years old. The incidence rate for pediatric tumors was 3.7 per 100,000 person-years, and the most common pediatric histologies were medulloblastoma and pilocytic astrocytoma.

The CBTRUS database attempts to fill a gap in the available information about brain tumors by providing accurate, population-based incidence rates by histology, race, age and gender that were previously unavailable in a systematic context. These data may serve as a baseline for comparison with regional incidence rates, assist in the allocation of specialized health care services and aid in development of etiologic hypotheses.

At [our] hospital, information on brain tumors in general and medulloblastoma specifically was in very short supply, especially on Labor Day weekend. Then a nurse gave me The Brain Tumor Society's phone number. I called the day before my daughter's surgery and reached Bonnie Feldman. She provided me with a beginning, and with hope! —Jack Sheehy, parent

CBTRUS also conducts special studies aimed at broadening the scope of descriptive epidemiology. CBTRUS has estimated survival rates for different types of brain tumors using data from other surveillance sources and can do specialized data runs upon request. CBTRUS has just concluded a study with the Massachusetts Cancer Registry to address data completeness and another study with the Connecticut Cancer Registry to assess diagnostic accuracy of brain tumor data.

CBTRUS firmly believes that data on brain tumors are incomplete without the inclusion of those tumors coded as benign. CBTRUS therefore encourages registries on all levels to collect data on all primary brain tumors irrespective of behavior.

More information on CBTRUS can be obtained by contacting the CBTRUS office by telephone (773- 579-0021), fax (630-655-1756), or e-mail (cbtrus@aol.com).

Hope Heals

Physician and brain tumor survivor Jordan Fieldman, M.D, wrote the following in his closing keynote speech at The Brain Tumor Society's 1997 symposium:

One of the most ludicrous ideas I'd encountered during medical school was the nonsensical notion of "false hope." People *need* hope. Hope heals. While often invoked under the pretext of not misleading a patient, the notion of false hope implies that what I am feeling in the moment is somehow not valid, not real.

Yet hope is a feeling. You either have it or you don't. It cannot be false any more than we can experience false joy, false sorrow, or false frustration. Most of us are probably feeling happy right now at the culmination of such a fabulous symposium. Can we be sure this is not false happiness?

Hope is but one of the many colors on the palate of life's experiences. It arises spontaneously, yet can be actively cultivated as a beneficial adjunct to the healing process.

Chapter 7:

Resource Organizations

Resource Organizations

We, at The Brain Tumor Society, respect patients' rights to make knowledgeable decisions about care and treatment. Thus, the Society provides patients, family members, and other concerned individuals with up-to-date educational information about brain tumors. As part of our effort to address all aspects of this multi-faceted disease, we have compiled a comprehensive list of related organizations. Updates to this much-requested list are offered online at http://www.tbts.org/resorgwl.htm.

Organizations for brain tumor patients and their families

The Brain Tumor Society
124 Watertown Street, Suite 3-H
Watertown, MA 02472
(800) 770-8287 • (617) 924-9997
e-mail: info@tbts.org
http://www.tbts.org

Raises and allocates funds for basic scientific research. Conferences for patients and professionals, resource guide and educational materials, public education, access to psychosocial support including telephone networks, and bimonthly newsletter, Heads Up.

Acoustic Neuroma Association
600 Peachtree Parkway, Suite 108
Cumming, GA 30041
(770) 205-8211 • FAX: (770) 205-0239
e-mail: ANAUSA@aol.com
http://anausa.org

A patient-organized mutual aid group offering national meetings, local support networks, information booklets, public education, research, and a quarterly newsletter, Notes. For patients who have experienced acoustic neuroma or other tumors affecting the cranial nerves.

American Brain Tumor Association
2720 River Road, Suite 146
Des Plains, IL 60018-4110
(800) 886-2282 • (847) 827-9918
e-mail: info@abta.org
http://www.abta.org

Written information about specific brain tumors, treatments and clinical trials; patient conferences, phone line, newsletter, The Message Line; funds research.

Brain Tumor Foundation for Children, Inc.
1835 Savoy Drive
Suite 316
Atlanta, GA 30341
(770) 458-5554 • (770) 458-5467
e-mail: btfc@bellsouth.net
http://www.btfcgainc.org

Promotes public awareness and information activities, family support and educational programs, funds research; also provides periodic newsletter.

Brain Tumor Foundation of Canada
650 Waterloo Street, Suite 100
London, ON Canada N6B 2R4
(519) 642-7755 • FAX: (519) 642-7192
e-mail: btfc@btfc.org
http://www.btfc.org

Funds brain tumor research, provides patient and family support services and educates the public. Pediatric and adult patient resource guides and quarterly newsletter, BrainStorm.

Central Brain Tumor Registry of the United States (CBTRUS)
3333 West 47th Street
Chicago, IL 60632
(773) 579-0021 • FAX: (630) 655-1756
e-mail: cbtrus@aol.com
http://www.cbtrus.org

A not-for-profit corporation that collects data on primary benign and malignant brain tumors into a central database.

Childhood Brain Tumor Foundation
20312 Watkins Meadow Drive
Germantown, MD 20876
(301) 515-2900
e-mail: cbtf@mnsinc.com
http://www.childhoodbraintumor.org

Heightens public awareness of childhood brain tumors, funds clinical as well as basic scientific research, enhances efforts to develop safer and more effective therapies, and serves as an advocate for children disabled by this disease.

Children's Brain Tumor Foundation
274 Madison Avenue, Suite 1301
New York, NY 10016
(212) 448-9494 • (866) 228-4673
FAX: (212) 448-1022
e-mail: cbtfny@aol.com
http://www.cbtf.org

CBTF raises funds for research programs and medical personnel training, hosts monthly parent support meetings in New York City; provides free resource guide for parents of children with brain and spinal cord tumors.

Clinical Trials and Noteworthy Treatments for Brain Tumors
Musella Foundation For Brain Tumor Research & Information
1100 Peninsula Blvd.
Hewlett, NY 11557
(516) 295-4740
e-mail: musella@virtualtrials.com
http://www.virtualtrials.com

A web site that supplies information on the treatments available for brain tumors, with a focus on new and/or experimental treatments.

Florida Brain Tumor Association, Inc.
P.O. Box 770182
Coral Springs, FL 33077-0182
(954) 755-4307 • FAX 954-755-3206
Email: Bt1Diva@aol.com
http:// www.sbtf.org

Three support groups that meet monthly. Every 18 months, FBTA presents a 2½ day brain tumor conference attracting over 600 participants.

National Brain Tumor Foundation
414 - 13th Street, Suite 700
Oakland, CA 94612
(800) 934-CURE • FAX: (510) 839-9779
e-mail: nbtf@braintumor.org
http://www.braintumor.org

Telephone support line, information about treatment, clinical trials and local support groups nationwide, national and regional conferences, fundraising for research, and publications including The Resource Guide & quarterly newsletter, Search.

Pediatric Brain Tumor Foundation of the United States
315 Ridgefield Court
Asheville, NC 28806
(800) 253-6530 • (828) 665-6891
e-mail: Ride4Kd@IBM.NET
http://www.ride4kids.org

The initial funder of the brain tumor registry, PBTF promotes awareness of brain tumors so increased funding for laboratory research will be available.

Pituitary Network Association
223 Thousand Oaks Blvd
Suite 320
Thousand Oaks, CA 91360
(805) 496-4932 • FAX: (805) 557-1161
http://www.pituitary.com

Disseminates information regarding early detection, symptoms, treatments and resources for pituitary tumor patients.

Southeastern Brain Tumor Foundation
P.O. Box 422471
Atlanta, GA 30342
(404) 843-3700 • FAX: (404) 255-7554
e-mail: sbtfatlanta@aol.com
website: www.sbtf.org

Dedicated to improving the lives of brain tumor patients and their families by providing information, education, and emotional support. A major objective as well is to raise funds for research projects that improve treatment options and search for a cure.

Organizations serving persons diagnosed with cancer

American Cancer Society
National Headquarters
1599 Clifton Rd, N.E.
Atlanta, GA 30329
(800) ACS-2345 • (404) 320-3333
http://www.cancer.org

Alliance for Lung Cancer
P.O. Box 849
Vancouver, WA 98666
(800) 298-2436 • (360) 696-2436
e-mail: info@alcase.org
http://www.alcase.org

BMT Infonet
(Blood and Marrow Transplant)
2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
(888) 597-5674 • (847) 433-3313
e-mail: help@bmtinfonet.org
http://www.bmtinfonet.org

Cancer Care, Inc.
275 Seventh Avenue
New York, NY 10001
(800) 813-HOPE
(212) 712-8080 • FAX: (212) 712-8495
e-mail: info@cancercare.org
http://www.cancercare.org

Candelighters Childhood Cancer Foundation
P.O. Box 498
Kensington, MD 20895
(800) 366-2223 • (301) 657-8401
e-mail: info@candlelighters.org
http://www.candlelighters.org

Children's Hospice International
901 North Pitt St.
Suite 230
Alexandria, VA 22301
(800) 242-4453 • (703) 684-0226
e-mail: chiorg@aol.com
http://www.chionline.org

Coping Magazine
P.O. Box 682268
Franklin, TN 37068-2268
(615) 790-2400
e-mail: copingmag@aol.com

Cure for Lymphoma Foundation
215 Lexington Avenue
New York, NY 10016-6023
(212) 213-9595
Toll free: (800) CFL-6848
FAX: (212) 213-1987
e-mail: infocfl@cfl.org
http://www.cfl.org

Lymphoma Research Foundation of America
1311 Marmaroneck Ave.
Los Angeles, CA 90034
(310) 204-7040 • FAX: (310) 204-7043
e-mail: lrfa@aol.com
http://www.lymphoma.org

Leukemia and Lymphoma Society
1311 Mamaroneck Ave.
White Plains, NY 10605
(914) 949-5213
FAX: (914) 949-6691
e-mail: infocenter@leukemia.org
http://www.leukemia-lymphoma.org

National Bone Marrow Transplant Link
20411 W. 12 Mile Rd.
Suite 108
Southfield, MI 48076
(800) 546-5268 • (800) LINK-BMT
(810) 932-8483

National Cancer Institute
Building 31, Room 10A24
Bethesda, MD 20892
Cancer Information Service and
Physician Data Query
1-800-4CANCER • (800) 332-8615
http://cis.nci.nih.gov

National Coalition for Cancer Survivorship
1010 Wayne Avenue, Suite 770
Silver Spring, MD 20910
(301) 650-8868 • (877) 622-7937
FAX: (301) 565-9670
info@cansearch.org
http://www.cansearch.org

National Hospice Organization
1700 Diagonal Rd., Suite 300
Alexandria, VA 22314
(800) 658-8898 • (703) 837-1500
e-mail: info@nhpco.org
http://www.nhpco.org

Neuroblastoma Children's Cancer Society
P.O. Box 957672
Hoffman Estates, IL 60195
(800) 532-5162
(847) 490-4240 • FAX: (847) 490-0705
http://www.granitewebworks.com/nccs.htm

Post-Treatment Resource Program
Memorial Sloan-Kettering Cancer Center
215 East 68th Street, Ground Floor
New York, NY 10021
(212) 717-3527 • FAX: (212) 717-3534

Support for People with Oral and Head and Neck Cancer
P.O. BOX 53
Locust Valley, New York 11560-0053
(516) 759-5333 • (800) 377-0928
e-mail: spohnc@ix.netcom.com
http://www.spohnc.org

The Wellness Community National Office
35 East Seventh St.
Suite 412
Cincinnati, OH 45202
(888) 393-WELL • FAX: (513) 794-1822
e-mail: help@wellness-community.org
http://www.wellness-community.org

Related Organizations

American Society for Deaf Children
P.O. Box 33355
Gettysburg, PA 17325
(800) 942-2732 (ASDC)
e-mail: ASDC1@aol.com
http://www.deafchildren.org

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(800) 638-8255 • FAX: (301) 897-7348
e-mail: actioncenter@asha.org
http://www.asha.org

American Tinnitus Association
P.O. Box 5
Portland, OR 97207-0005
(503) 248-9985 • (800) 634-8978
FAX: (503) 248-0024
e-mail: tinnitis@ata.org
http://www.ata.org

Aneurysm and AVM Support Group
State University of West Georgia
Carrollton, GA 30118
e-mail: wmaples@westga.edu
http://www.westga.edu/~wmaples/aneurysm.html

Brain Injury Association, Inc.
105 North Alfred Street
Alexandria, VA 22314
(703) 236-6000 • (800) 444-6443
FAX: (703) 236-6001
e-mail: FamilyHelpline@biausa.org
http://www.biausa.org

Cushing's Support and Research Foundation
65 East India Row, #22B
Boston, MA 02110-3389
(617) 723-3674
e-mail: csrf@world.std.com
http://world.std.com/~CSRF

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785-7223
(800) 332-1000 • FAX: (301) 577-4941
e-mail: postmaster@efa.org
http://www.epilepsyfoundation.org

Hydrocephalus Association
870 Market Street, Suite 955
San Francisco, CA 94102
(415) 732-7040 • (888) 598-3789
Operates listserv HYCEPH-L
http://www.hydroassoc.org

Hydrocephalus Foundation, Inc.
910 Rear Broadway, Rt. 1
Saugus, MA 01906
(781) 942-1161
e-mail: hyfil@netscape.net
http://www.hydrocephalus.org

Hydrocephalus Research Foundation (Cushing's Syndrome)
1670 Green Oak Circle
Lawrenceville, GA 30243
(770) 995-9570
FAX: (770) 995-8982

International Radiosurgery Support Association
P.O. Box 60950
Harrisburg, PA 17106-0950
(717) 671-1701 • FAX: (717) 671-1703
e-mail: intouch@irsa.org
http://www.irsa.org

Let's Face It (Facial difference)
Box 29972
Bellingham, WA 98228-1972
(360) 676-7325
http://www.faceit.org
50 page resource list published annually; available for cost of postage.

National Aphasia Association
156 Fifth Avenue, Suite 707
New York, NY 10010
(800) 922-4622 • FAX: (212) 989-7777
e-mail: naa@aphasia.org
http://www.aphasia.org

National Association for Parents of the Visually Impaired
P.O. Box 317
Watertown, MA 02272-0317
(800) 562-6265 • FAX: (617) 972-7444
http://www.spedex.com/NAPVI

National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447
(612) 553-0020 • FAX: (612) 553-0167
e-mail: naf@ataxia.org
http://www.ataxia.org

National Center for Learning Disabilities, Inc.
381 Park Avenue South, Suite 1401
New York, NY 10016
(888) 575-7373 • (212) 545-7510
FAX: (212) 545-9665
http://www.ld.org

National Chronic Pain Outreach Association, Inc. (NCPOA)
7929 Old Georgetown Rd., Suite 100
Bethesda, MD 20814-2429
(301) 652-4948 • FAX: (301) 907-0745
e-mail: NCPOA1@aol.com
http://neurosurgery.mgh.harvard.edu/ncpainoa.htm

National Family Caregivers Association
10400 Connecticut Ave. #500
Kensington, MD 20895-3944
(800) 896-3650 • FAX: (301) 942-2302
e-mail: info@nfcacares.org
http://www.nfcacares.com

National Institute on Deafness and Other Communication Disorders
National Institutes of Health
31 Center Drive, MSC 2320
Bethesda, MD 20892-2320
(800) 241-1044 • FAX: (301) 907-8830
e-mail: nidcd@aerie.com
http://www.nih.gov/nidcd

National Library Service for the Blind and Physically Handicapped
Library of Congress
Washington, DC 20542
(202) 707-5100 • FAX: (202) 707-0712
e-mail: NLS@loc.gov
http://www.loc.gov/nls

National Neurofibromatosis Foundation
95 Pine Street, 16th Floor
New York, NY 10005
(800) 323-7938 • (212) 344-6633
FAX: (212) 747-0004
e-mail: NNFF@nf.org
http://www.nf.org

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673 • (203) 746-6518
e-mail: orphan@rarediseases.org
http://www.rarediseases.org

National Rehabilitation Information Center
1010 Wayne Avenue, Suite 800
Silver Spring, MD 20910-3319
(800) 346-2742 • FAX: (301) 562-2401
e-mail: naricinfo@kra.com
http://www.naric.com

Neurofibromatosis, Inc.
8855 Annapolis Rd. Suite 110
Lamham, MD 20706-2924
(800) 942-6825 • (301) 918-4600
FAX: (301) 918-0009
e-mail: NFINC@gnn.com

Neuropathy Association (Peripheral Neuropathy)
60 E 42nd St. Suite 942
New York, NY 10165
(800) 247-6968 • FAX: (212) 692-0662
e-mail: info@neuropathy.org
http://www.neuropathy.org

NIH National Center for Complimentary & Alternative Medicine
P. O. Box 7923
Gaithersburg, MD 20898
(888) 644-6226 • FAX: (866) 464-3616
e-mail: info@nccam@nih.gov
http://nccam-nih.gov

NIH Neurological Institute (NINDS)
P.O. Box 5801
Bethesda, MD 20824
(800) 352-9424
(301) 496-5751
http://www.ninds.nih.gov

NIH Office of Rare Diseases
National Institutes of Health
31 Center Drive, MSC 2084
Building 31, Room 1B-19
Bethesda, MD 20892-2084
FAX: (301) 480-9655
e-mail: hh70f@nih.gov
http://rarediseases.info.nih.gov

Patient Advocate Foundation
753 Thimble Shoals Blvd.
Suite B
Newport News, VA 23606
(800) 532-5274 • (757) 873-8999
e-mail: help@patientadvocate.org
http://www.patientadvocate.org

Pseudotumor Cerebri Society
750 East Adams Street
Syracuse, NY 13210
(315) 464-3937
Pamingram@aol.com

Pseudotumor Cerebri Support Network
6632 Kennington Square South
Pickerington, OH 43147
(614) 759-7760
e-mail: redbird@iwk.net
http://www.angelfire.com/ok/PTCSupportNetwork

Self-Help for Hard of Hearing People, Inc. (SHHH)
7910 Woodmont Ave. Suite 1200
Bethesda, MD 20814
(301) 657-2248 • FAX: (301) 913-9413
TTY: (301) 657-2249
email: National@shhh.org
http://www.shhh.org

Tuberous Sclerosis Alliance
801 Roeder Rd. Suite 750
Silver Spring, MD 20910
(800) 225-6872 • FAX: (301) 562-9870
e-mail: info@tsalliance.org
http://tsalliance.org

The Healing Exchange Brain Trust
(All brain disorders)
P.O. Box 4467
186 Hampshire St.
Cambridge, MA 02139-1320
(617) 876-2002 • FAX: (617) 876-2332
e-mail: info@braintrust.org
http://www.braintrust.org

Vestibular Disorders Association
Portland, OR 97208-4467
(800) 837-8428 • (503) 229-7705
TTY: (503) 228-8665
e-mail: veda@vestibular.org
http://www.vestibular.org

VHL Family Alliance (von Hippel-Lindau)
171 Clinton Road
Brookline, MA 02445
(800) 767-4845 • (617) 277-5667
FAX: (617) 734-8233
e-mail: info@vhl.org
http://www.vhl.org

Well Spouse Foundation
610 Lexington Avenue, Suite 208
New York, NY 10022-6005
(800) 838-0879 • FAX: (212) 644-1241
e-mail: wellspouse@aol.com
http://www.wellspouse.org

Online Resources

An excellent beginner's guide to cancer resources on the Internet is *CANSEARCH: A GUIDE TO CANCER RESOURCES*, courtesy of the National Coalition for Cancer Survivorship. The guide's web address is:
http://www.cansearch.org/resources/cansearch.html.
A cancer survivor walks you through the steps involved in accessing each online resource write it. By clicking on underlined or color-highlighted keywords, you can find out more about the resources you want.

Types of online resources are more briefly described here:

1. Listservs (e-mail lists):

People sharing a common interest in an illness or another subject can communicate with one another using a listserv, a simple way to use the Internet. Participants send e-mail to a special address which forwards the message to *all* group members. The "discussion" does not occur live but develops from a series of topic-oriented messages sent and received over a period of time. You will receive several e-mail messages daily as long as you subscribe to the list. Three such groups are described below:

BRAINTMR is a forum to discuss topics related to all types of brain tumors, whether benign or malignant. To subscribe, send a message from your e-mail account to:

listserv@mitvma.mit.edu

The text of your message should read: subscribe BRAINTMR <your name>

Example: subscribe BRAINTMR Jane Doe

EPILEPSY-L is an e-mail based support group for people with seizure disorders. Complete information is available at the Epilepsy List web page:
http://home.ease.lsoft.com/Archives/Epilepsy-L.html.

HYCEPH-L is an information and support forum for hydrocephalus. To subscribe, send e-mail to: listserv@vm.utcc.utoronto.ca

Text: subscribe HYCEPH-L <your name>

Other Listserv mailing lists include DISABILITIES, CANCER-L, the Hem-Onc listserv (includes CNS Lymphoma), HOSPIC-L and bmt-talk; some of these are described in detail in the NCCS CANSEARCH guide mentioned above; many can be accessed through ONCOLINK's Automated E-mail Discussion Group Subscriber.

2. Online discussion groups

Usenet is the part of the Internet specifically designed for newsgroups, of which there are more than 10,000. View the list paying particular attention to “alt” and “misc” groups, such as alt.support.cancer, alt.support.epilepsy, alt.support.tinnitis, sci.med.diseases.cancer, or misc.health.alternative.

The Brain Tumor Society Publications Order Form

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The Brain Tumor Society, 124 Watertown St. Suite 3H, Watertown, MA 02472.

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____ Brain Tumor Book List
An annotated bibliography of books relevant to brain tumor survivors and their families.

____ Color Me Hope Resource Guide
A resource guide for survivors and supporters, including up-to-date information on medical topics and coping with a brain tumor diagnosis.

____ Heads Up Newsletter
A bimonthly newsletter with articles on the latest news in TBTS-funded research, personal narratives from brain tumor survivors, and features on upcoming events.

____ Fact Sheet on Fatigue
Quick facts on causes and treatments for fatigue in brain tumor survivors at your fingertips.

____ Support Group Leadership Packet
A collection of articles designed to help local support group facilitators in starting, publicizing, and maintaining their groups.

____ TBTS Agency Brochure

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