2nd Edition

Ependymoma

A Guide for Patients, Caregivers and Advocates

cernfoundation™
Collaborative Ependymoma Research Network

Ependymoma

A Guide for Patients, Caregivers and Advocates

The goal of this guide is to give readers the basic facts about ependymoma, its diagnosis and treatment.

We hope this information gives you a better understanding of ependymoma. Keep in mind that your specific case may be different from another person with ependymoma. Please visit the CERN Foundation's website, cern-foundation.org, as we update our site often with new information.

cernfoundation™
Collaborative Ependymoma Research Network

This guide was produced and published by the
Collaborative Ependymoma Research Network (CERN) Foundation.

About the CERN Foundation

The Collaborative Ependymoma Research Network (CERN) Foundation is comprised of a dedicated group of scientists and clinicians. CERN members are committed to improving the care and outcome of people with ependymoma, a type of primary brain or spinal cord tumor, through community support and research efforts. *More information on the CERN Foundation is contained in Chapter 5.*

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MATHILE FAMILY ENTERPRISE™

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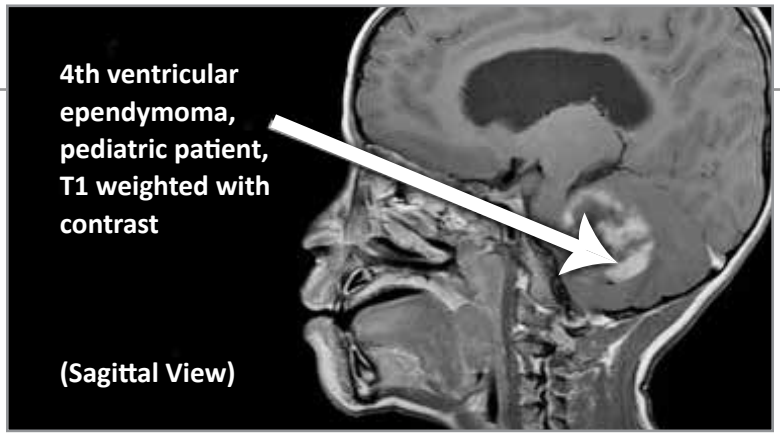
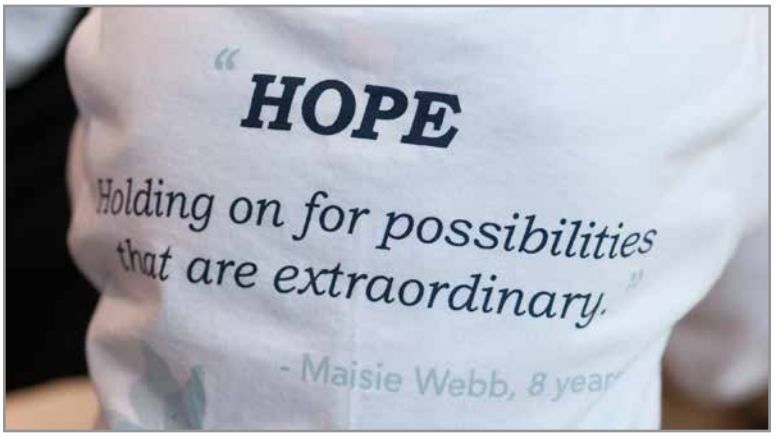
RCD Foundation





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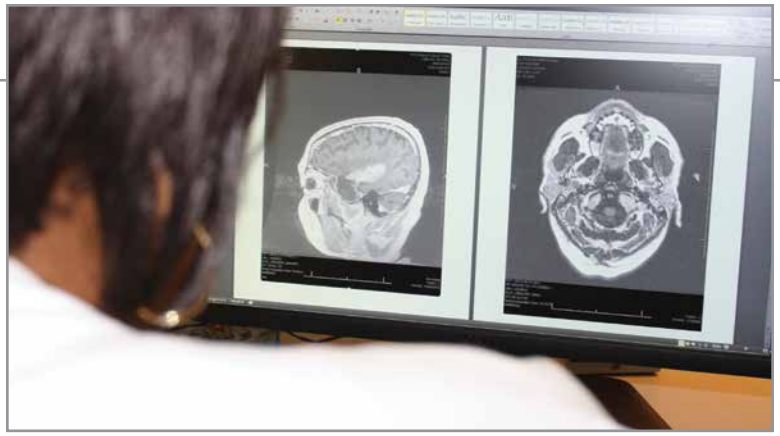


Chapter 1

Ependymoma Basics

A. What is Ependymoma?

B. Brain and Spine Anatomy

C. Ependymoma Statistics

A. What is Ependymoma?

Ependymoma is a rare tumor of the brain or spinal cord. It occurs in both adults and children.

Ependymoma is a primary tumor, which means that it starts in either the brain or spine. The brain and spine are part of the central nervous system (CNS).

Primary brain and spinal cord tumors are typically grouped by where the cells start.

The most common types of cells in the central nervous system are neurons and glial cells. Tumors from neurons are rare. Glial cells are the cells that support the brain. Tumors that occur from these cells are called gliomas.

Glial cell subtypes of the CNS include:

- Astrocytes
- Oligodendrocytes
- Ependymal cells

CNS brain tumors associated with all three types of glial cells are recognized by the World Health Organization as astrocytomas, oligodendrogliomas and ependymomas.

How do ependymomas form?

Scientists believe they develop from precursor cells to the ependymal cells. These cells line the ventricles (fluid-filled spaces in the brain) and the central canal of the spinal cord.

Ependymomas can occur anywhere in the CNS, including the brain and the spinal cord.

The cause of ependymoma is not known.

Do they spread?

Sometimes, ependymoma tumor cells can spread in the cerebrospinal fluid (CSF). They may spread to one or multiple areas in the brain, spine, or both. *See diagram on Page 10*. Although it is rare, ependymoma can spread to other parts of the body.

In general, tumors form where the tumor cells originate, such as the base of the brain and the bottom of the spinal cord.

Who does ependymoma affect?

Ependymomas can occur in both children and adults. Overall, ependymomas occur in males slightly more often than females. It also occurs in white people more often than those of other ethnicities.

Approximately 1,340 people per year are diagnosed with ependymoma in the United States.

How often do ependymomas form in children?

While there are a fewer number of children diagnosed than adults each year, among the children diagnosed with ependymoma each year, it is more common among the pediatric community than the adult community.

Ependymomas are the third most common form of childhood brain and spine tumors.

Most occur in young infants and children. The majority occur in the brain. Often they are seen in the back part of the brain (the posterior fossa). *See diagram on Page 6.*

How often do ependymomas form in adults?

Ependymomas account for 1.9 percent of adult gliomas. The majority occur in the spine. *For more statistics, see Page 11.*

B. **Brain and Spine Anatomy**

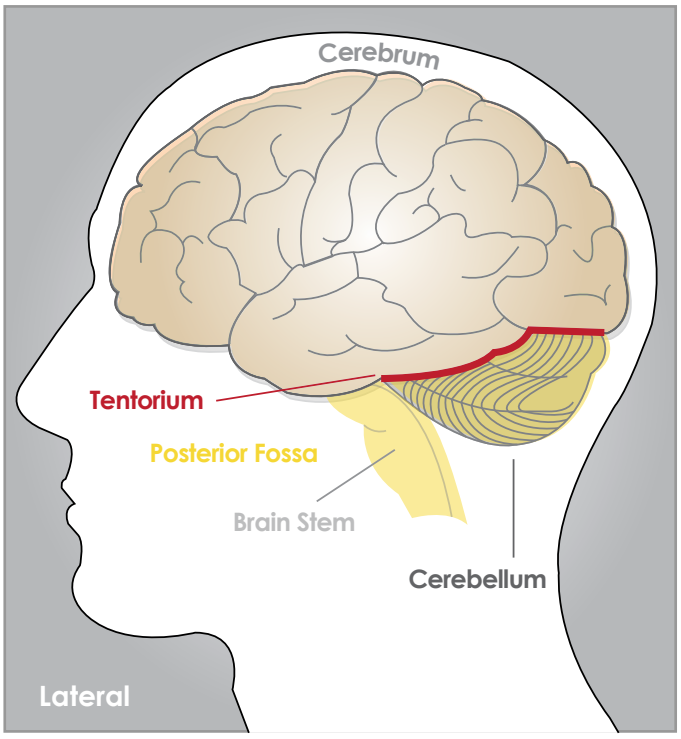
It is important to know where the tumor is located within the brain and the spine so you can understand what symptoms may occur. The biology may also be different based on the location.

During treatment, your health care team will use many terms to refer to locations in the head, neck and spine. The diagrams in this section will help you locate different parts of the brain and spine.

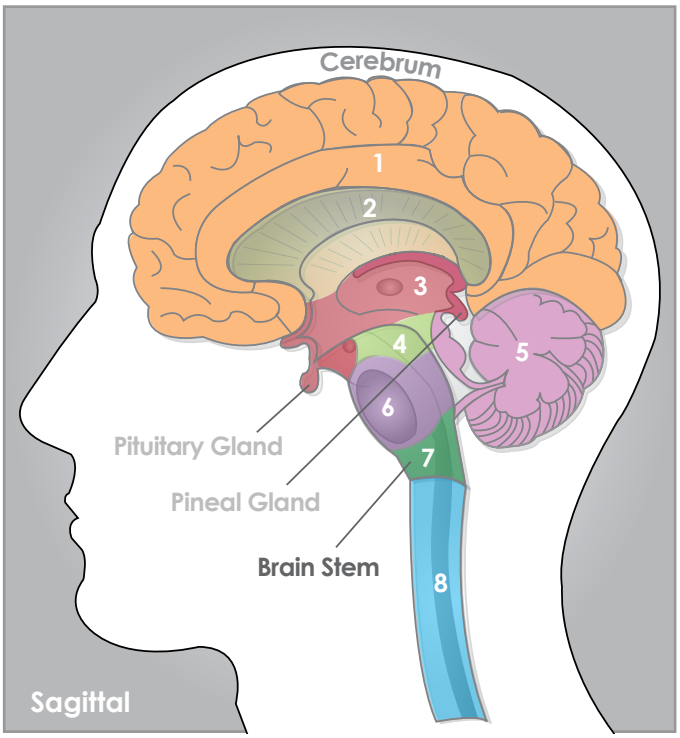
Anatomy

Tentorium Cerebelli

The image below shows a side (lateral) view of the tentorium cerebelli - an extension of the dura matter that separates the cerebellum from the bottom (inferior) portion of the occipital lobes. Tumors below the tentorium are called infratentorial and those above are called supratentorial.



The image below shows a interior (sagittal) view of the brain.



Supratentorial Anatomy

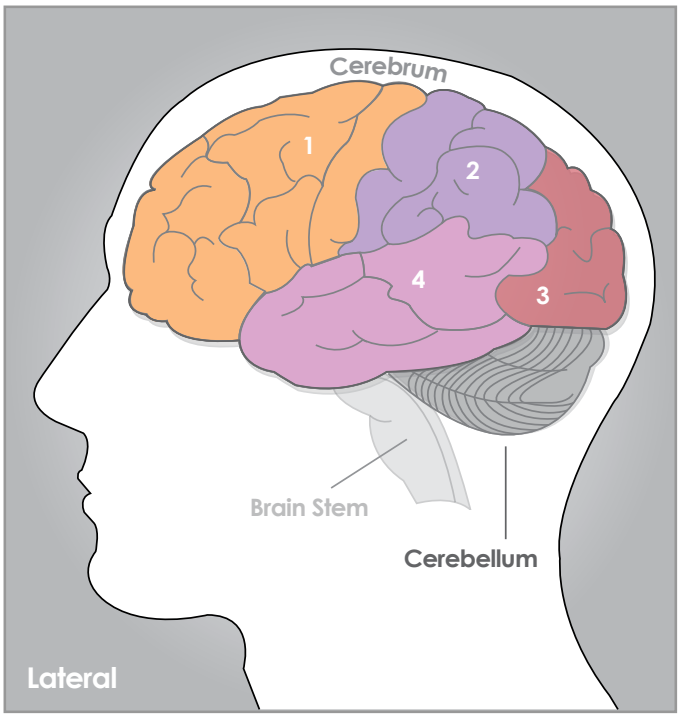
These areas are located in the supratentorial region.

1. Cerebral Hemisphere
2. Corpus Callosum

Infratentorial Anatomy

These areas are located in the infratentorial region.

3. Diencephalon
4. Midbrain
5. Cerebellum
6. Pons
7. Medulla Oblongata
8. Spinal Cord



Brain Lobes

1. Frontal Lobe
2. Parietal Lobe
3. Occipital Lobe
4. Temporal Lobe

Supratentorial Anatomy

Lobes

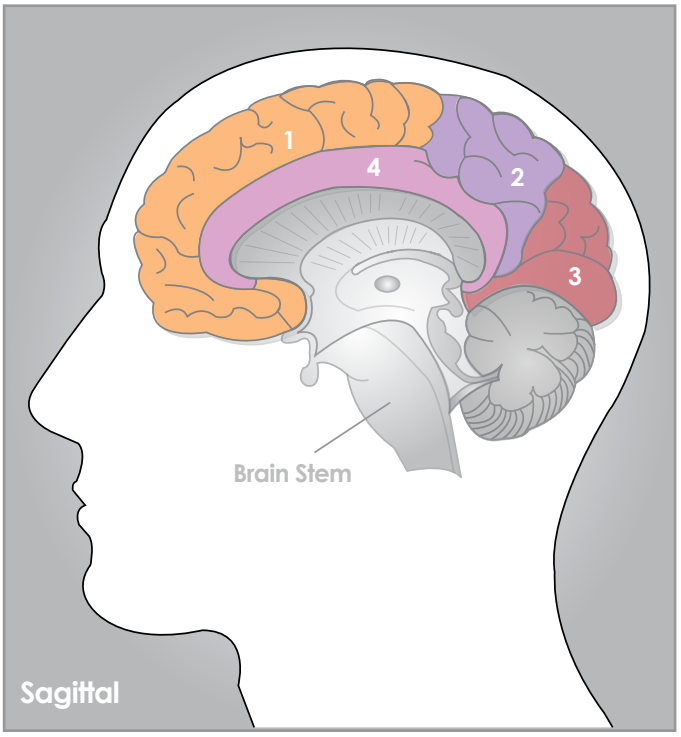
The images show views of the lobes: side (lateral), top (axial) and interior (sagittal). *For more information about the views, see Pages 15-16.*

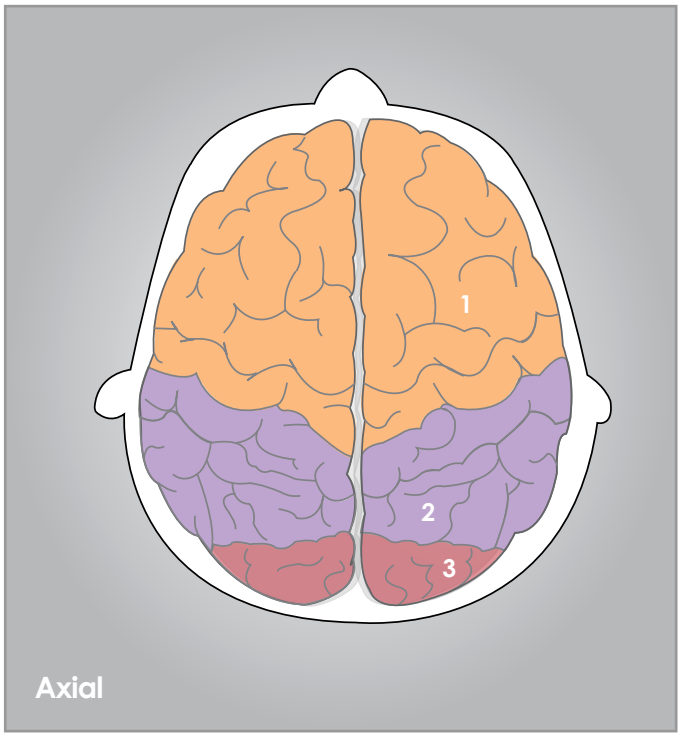
The brain is divided down the middle lengthwise into two halves called the cerebral hemispheres. Each hemisphere is divided into four lobes.

Anatomy

Brain Functions

See the parts of the brain to learn what they do. Knowing the location of your tumor(s) may help you to understand changes in how you act or think. Changes can be due to the impact of the tumor itself or from treatment. For example, if you have a tumor in the temporal lobe, you may have short-term memory loss. Tumors can also be associated with difficulty with multi-tasking, seizures, and headaches. It is important to address these concerns with your health care provider to evaluate if there are options to help alleviate their impact on your quality of life. Use these charts on *the next page* to learn more.





Anatomy

Brain Function Areas

1. Motor Association Area
Coordination of muscle strength and movement

2. Expressive Speech
Written and spoken language

3. Higher Mental Functions
Executive function including concentration, coordination of thought and activity, judgement, emotional expression, inhibition

4. Motor Area
Strength on opposite side of body

5. Sensory Area
Sensation on opposite side of body

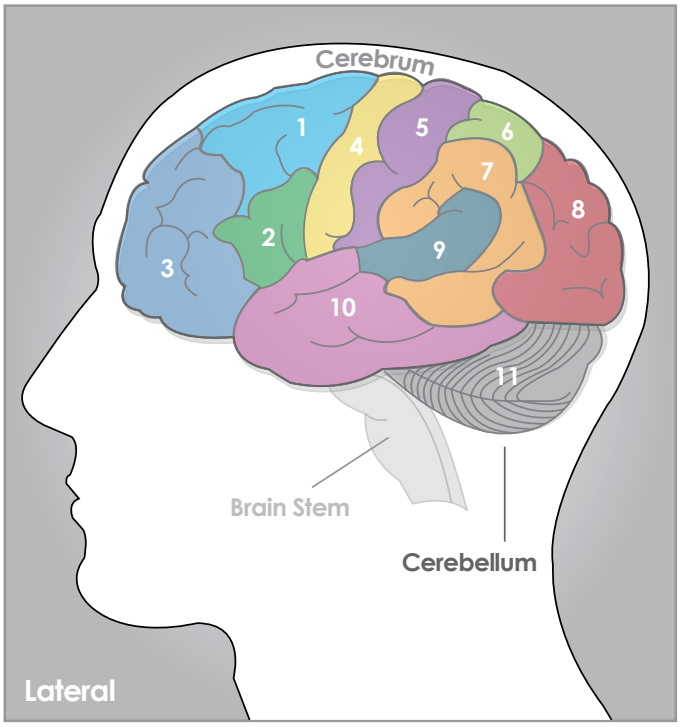
6. Somatosensory Association Area
Understanding objects characteristics (for example, texture and temperature and position in space)

7. Global Language
Expressive and receptive language comprehension

8. Vision
Sight on opposite side, image recognition

9. Receptive Speech
Understanding words and directions

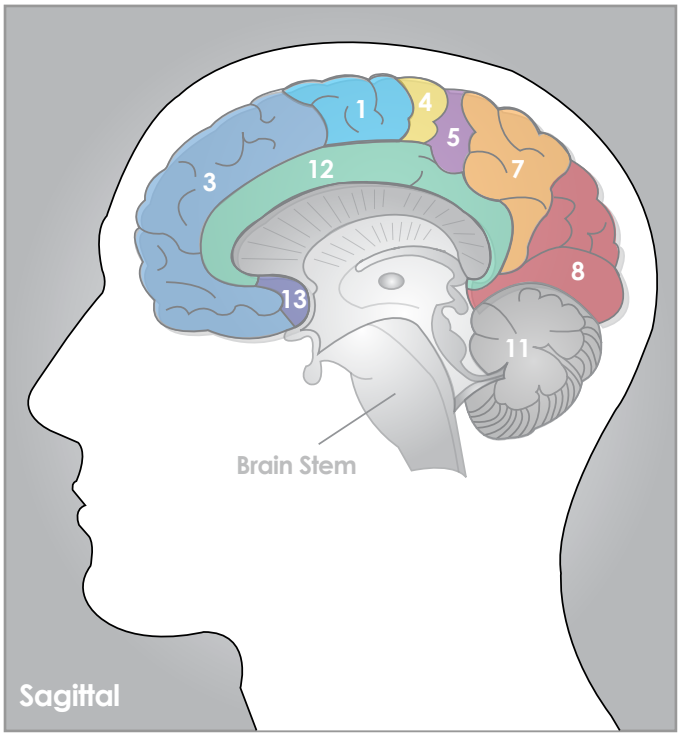
10. Association Area
Short-term memory, emotion

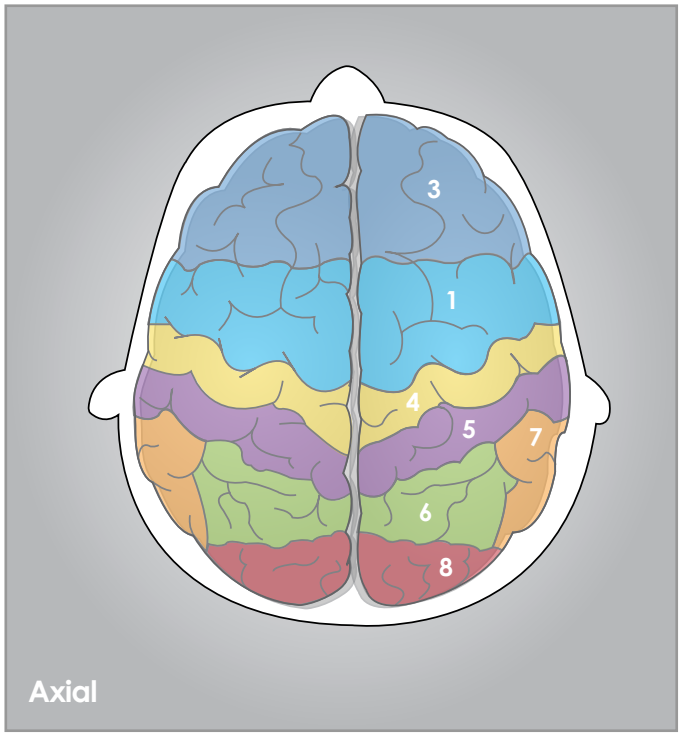


11. Cerebellum
Balance and coordination of movement of body, arms and legs

12. Emotional Area
Pain, hunger, "fight or flight" response

13. Olfactory Area
Understanding scent

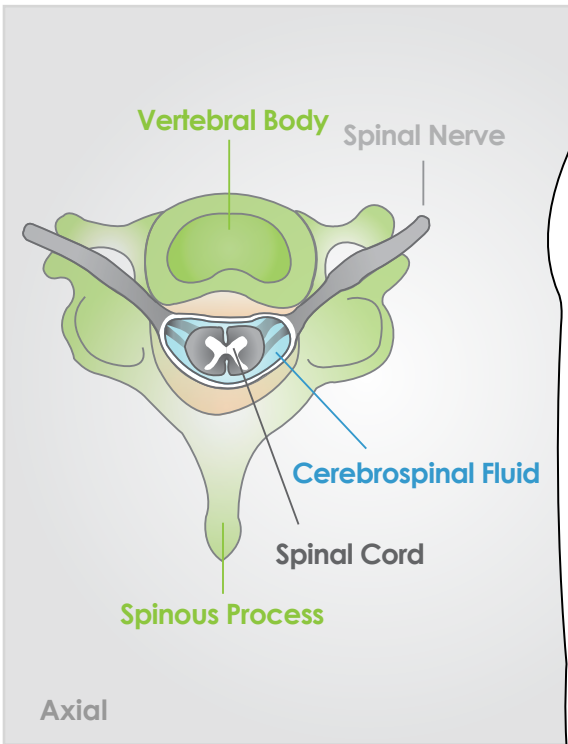


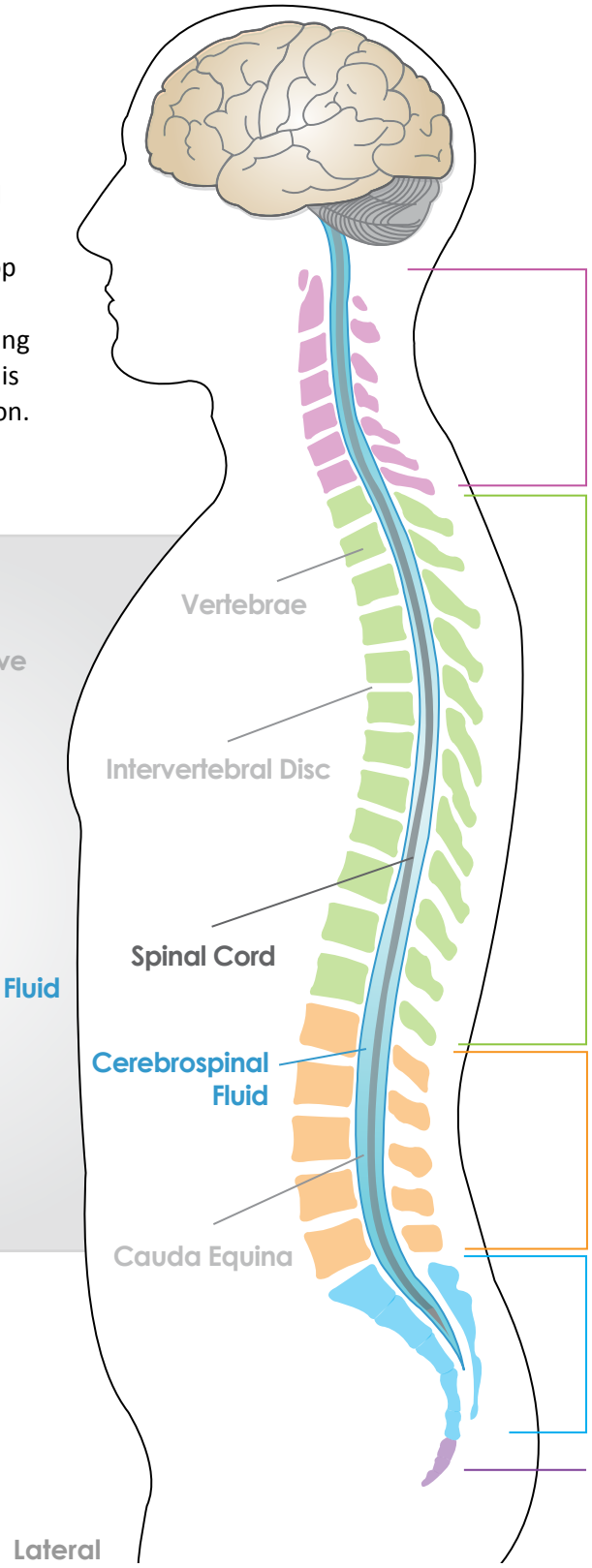


Anatomy

Spinal Functions

See the parts of the spinal cord to learn what they do. The image on the right shows the side (lateral) view of where the different spinal functions exist. The spine is separated into four parts called the cervical, thoracic, lumbar, and sacral region. Each spinal region is made up of vertebra. The image below shows the top (axial) view of the vertebrae and spinal cord. The vertebrae are numbered starting with one and continue. For example, T2 is the second vertebra in the thoracic region. Use these charts to learn more.





Cervical Region (C1-C7)
Arm and hand functions

Thoracic Region (T1-T12)
Chest and abdominal functions

Lumbar Region (L1-L5)
Leg, knee and foot functions

Sacral Region (S1-S5)
Leg, buttocks, foot, bowel, bladder and sexual functions

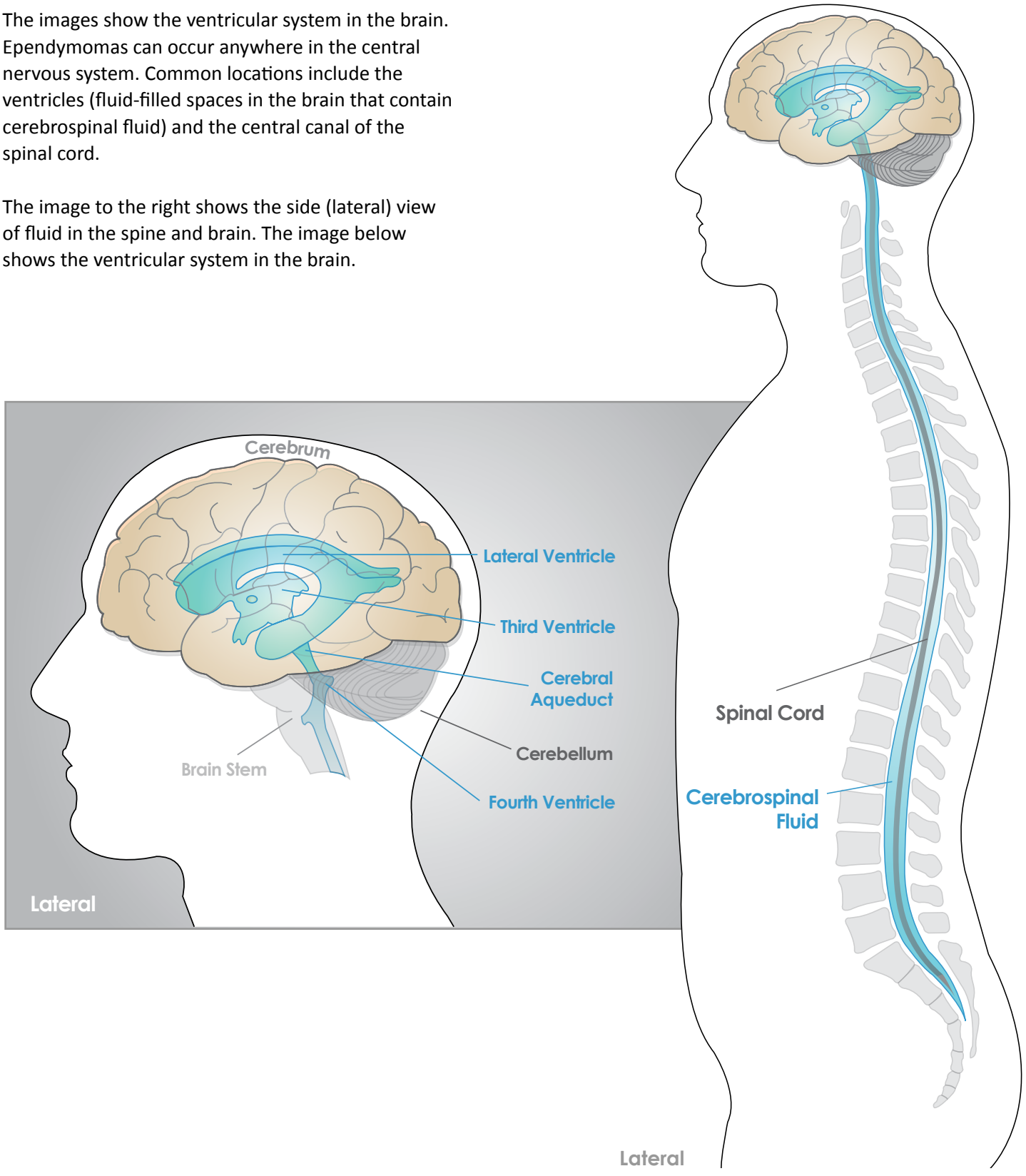
Coccyx

Anatomy

Ventricles

The images show the ventricular system in the brain. Ependymomas can occur anywhere in the central nervous system. Common locations include the ventricles (fluid-filled spaces in the brain that contain cerebrospinal fluid) and the central canal of the spinal cord.

The image to the right shows the side (lateral) view of fluid in the spine and brain. The image below shows the ventricular system in the brain.



C. Ependymoma Statistics

This section shares information about how often ependymoma occurs. Numbers result from the collaborative work of two groups: The Collaborative Ependymoma Research Network (CERN) Foundation and Central Brain Tumor Registry of the United States (CBTRUS). The data is pulled from the 2015 published report called *CBTRUS Statistical Report on Primary Brain and Central Nervous System Tumors Diagnosed in the United States in 2008-2012*.

What is CBTRUS?

CBTRUS is a not-for profit research corporation. Its mission is to gather and spread current epidemiologic data on all primary brain and central nervous system (CNS) tumors. This lets people see incidence and survival patterns, evaluate diagnosis and treatment, facilitate etiologic studies, establish awareness of the disease, and ultimately, prevent brain tumors.

Statistical Definitions

- *Incidence:* The occurrence of newly diagnosed disease that appears in a particular population during a specified period of time (typically yearly). In this report, the crude incidence rates are calculated by counting the number of people with newly diagnosed primary brain and CNS tumors and dividing by the total population at risk (e.g. the total population in a state or collection of states) and are usually expressed per 100,000 persons. Incidence rates can also be calculated specifically for those diagnosed with ependymoma.

- *Age-adjustment:* Age-adjustment is a procedure designed to minimize the effects of differences in age composition when comparing incidence and mortality rates among different populations. Age-adjustment of rates in this report is calculated by the direct method adjusting to the 2000 U.S. standard million population.

- *Prevalence:* The number or proportion of people with a particular disease or attribute (in this case, both those with a newly diagnosed brain or CNS tumor and those who may have been diagnosed in the past and are living with the disease) in a given population at a specific time.

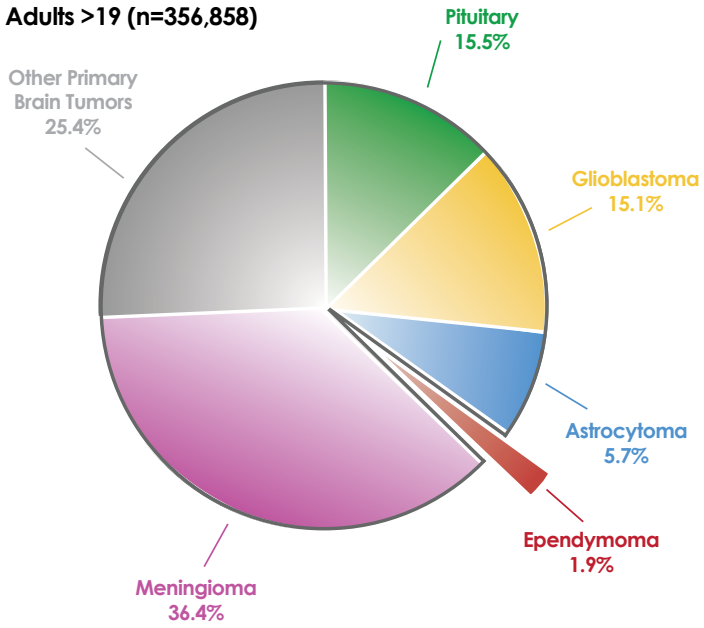
- *5-year survival rate:* The probability that a patient will survive for 5 years from the date of diagnosis of a disease (in this case, diagnosis of a brain or CNS tumor).

Incidence of Primary Brain or CNS Tumors

For all primary brain and CNS tumors, CBTRUS estimates that the average annual age-adjusted incidence rate is 28.57 cases per 100,000 persons for the years 2008-2012.

An estimated 77,670 new cases of primary brain and other CNS tumors are expected to be diagnosed in the U.S. in 2016.

Distribution of Adult Primary Brain / CNS Tumors



CBTRUS Statistical Report: NPCR and SEER Data from 2008-2012

For all primary brain and central nervous system tumors, the incidence rate is 21.97 cases per 100,000 person-years. An estimated 4,630 new cases of childhood primary brain and other CNS tumors are expected to be diagnosed in the U.S. in 2016.

Ependymomas (ependymoma, NOS (not otherwise specified), epithelial ependymoma, cellular ependymoma, clear cell ependymoma, tanycytic ependymoma, anaplastic ependymoma, ependymoblastoma) and ependymoma variants (myxopapillary ependymoma) are rare, and represent 1.9% of all primary brain and CNS tumors.

Approximately 1,340 ependymomas and ependymoma variants are diagnosed per year.

Adults (> 19 years):

In adults 20+ years, ependymomas accounted for 1.9% of all tumors diagnosed.

Approximately 1,100 adults are diagnosed with ependymoma per year.

Ependymomas/anaplastic ependymomas occur with similar incidence in males and females. The incidence of ependymoma variants is higher in males than females. The incidence of both ependymomas/anaplastic ependymomas and ependymoma variants was higher in whites than blacks.

Children (aged 0-19 years):

In children aged 0-14 years, ependymomas accounted for 5.7% of all tumors diagnosed.

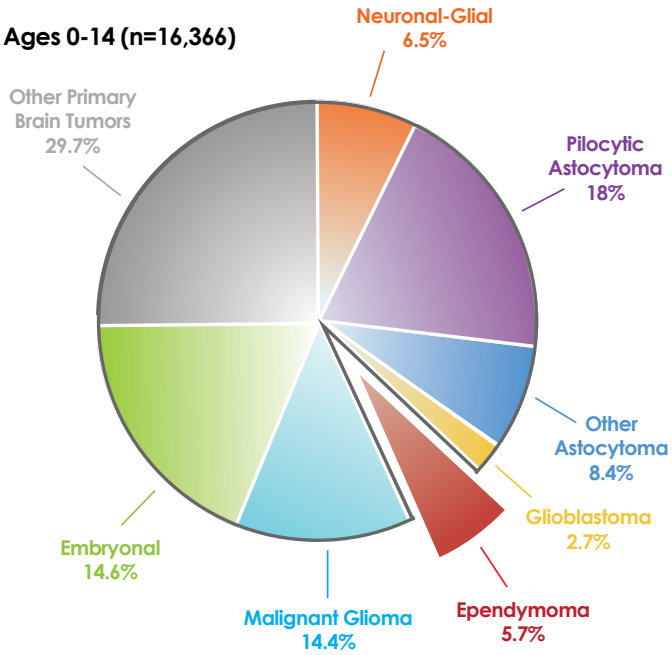
Approximately 185 children are diagnosed with ependymoma per year.

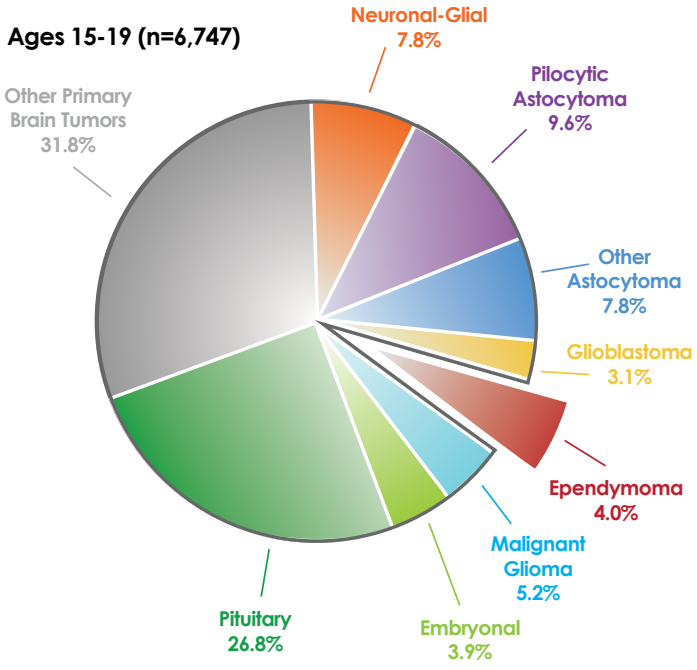
In children aged 15-19 years, ependymoma accounted for 4% of all tumors diagnosed.

Approximately 50 teenagers are diagnosed with ependymoma per year.

The incidence of ependymomas/anaplastic ependymomas in children (aged 0-19 years) was similar in males and females. The incidence of ependymoma variants is higher in males than females.

Distribution of Childhood Primary Brain / CNS Tumors





CBTRUS Statistical Report: NPCR and SEER Data from 2008-2012

Spinal Cord Tumors:

For tumors involving the spinal cord, spinal meninges and cauda equina, ependymomas accounted for 20.5% of all tumors diagnosed in adults aged 20+ years and 21.6% of all tumors diagnosed in children aged 0-19 years.

Approximately 690 people are diagnosed with spinal cord ependymoma per year.

Prevalence of Primary Brain or CNS Tumors

The prevalence rate of primary brain and central nervous system tumors was estimated that 688,000 persons in the U. S. were living with a diagnosis of primary brain and CNS tumors in 2010.

For children (aged 0-19 years), the prevalence rate for all pediatric primary brain and central nervous system tumors was estimated that 28,000 children were living with one of these diagnoses in the U.S. in 2010.

5-year Survival Rates for All Primary Brain or CNS Tumors

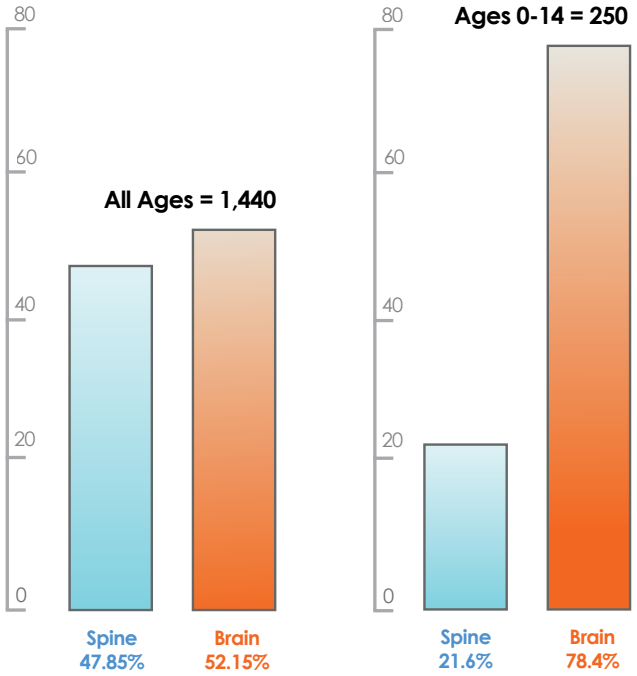
The 5-year relative survival rate for all primary brain and central nervous system tumors is 34.4%. For children aged 0-19 years, the 5-year relative survival rate is 73.6%.

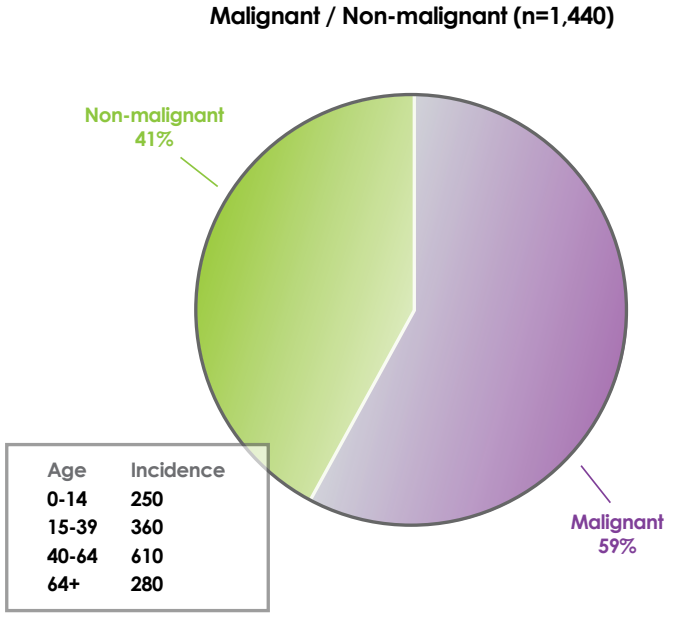
5-year Survival Rates for Ependymomas

For those with ependymoma, the overall 5-year relative survival rate is 83.4%. 5-year relative survival rates are highest for those aged 20-44 years (91%), and decrease with increasing age at diagnosis with a 5-year relative survival rate of 57.8% for those aged 75+ years. For children aged 0-19 years, the 5-year relative survival rate is 75.2%.

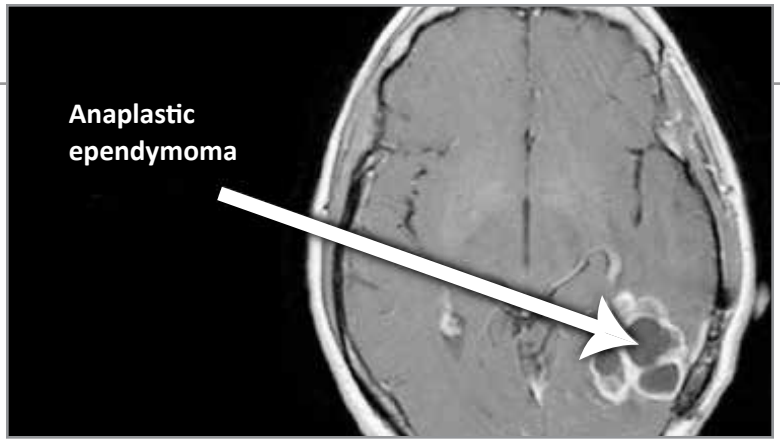
Please recognize that these numbers are helpful for general information related to ependymoma, but may not be meaningful for any one individual. Please discuss any questions or concerns that you have about your own diagnosis with your treating physician.

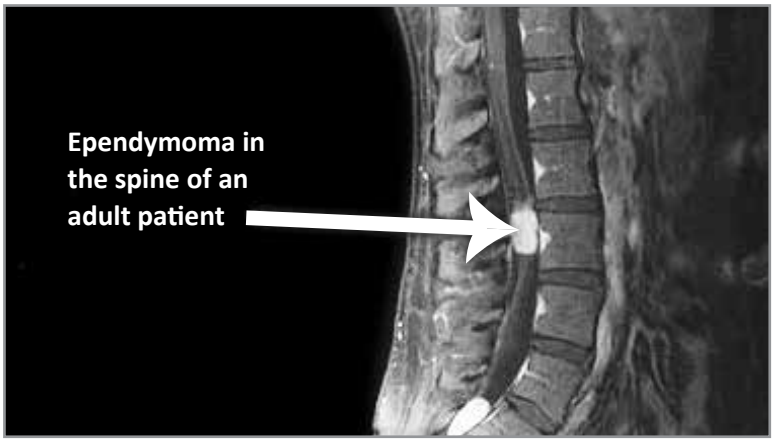
Estimated New Cases in 2016

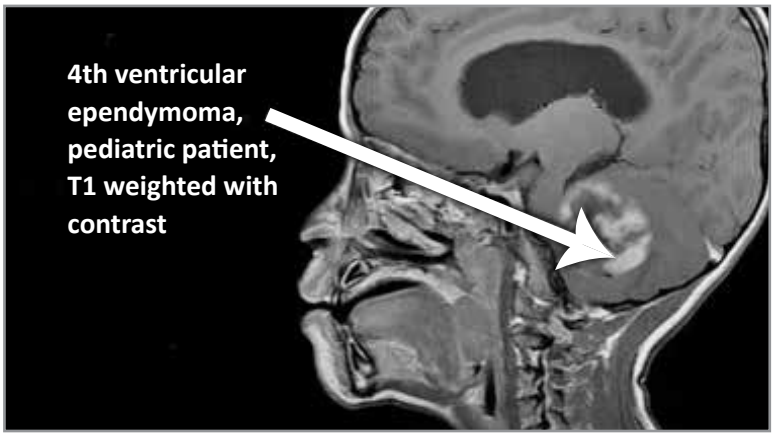


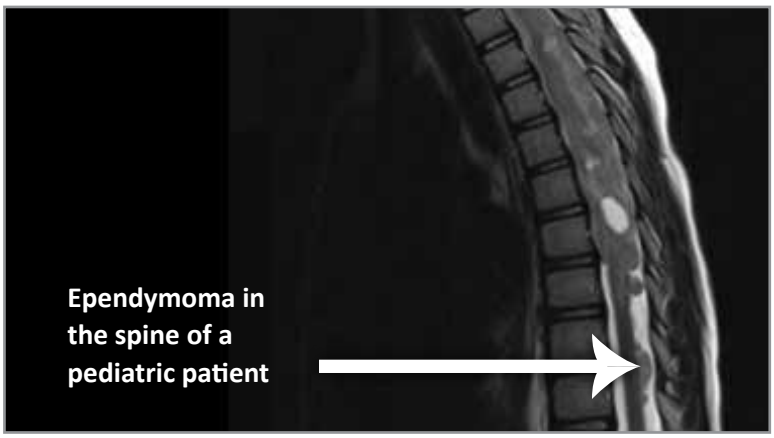


*DATA EXTRACTED FROM Ostrom, Q.T., Gittleman, H., Fulop, J., et al (2015). CBTRUS Statistical Report: Primary Brain Central Nervous System Tumors Diagnosed in the U.S. in 2008-2012. Neuro-Oncology, Vol 17.









Chapter 2

Diagnosis

A. How is Ependymoma Diagnosed?

B. Pathology

C. What To Ask Your Doctor

D. Coping With The Diagnosis

A. How is Ependymoma Diagnosed?

Usually, people with ependymoma are diagnosed after showing symptoms. Symptoms may start slowly and may not be diagnosed until they worsen.

Other times, problems occur suddenly and result in an urgent trip to an emergency room or clinic. An exam by a health care provider often shows neurologic problems. A common diagnostic test that identifies potential neurologic problems is a magnetic resonance image or MRI.

What is an MRI test?

An MRI is typically the preferred test for people who may have a brain or spinal cord tumor. It shows a better picture of the brain, spine and tumor than computed tomography (CT) scans, although a CT scan may be the first test that is done.

After the initial testing, more diagnostic tests may be needed. If the MRI shows a possible primary brain or spinal cord tumor, patients normally do not need other imaging tests of the body. This is mainly because ependymoma tumors do not tend to spread outside of the central nervous system (CNS). MRI of the brain or spine is not only used as a baseline test, but may also be used to evaluate the whole central nervous system.

What does an MRI test involve?

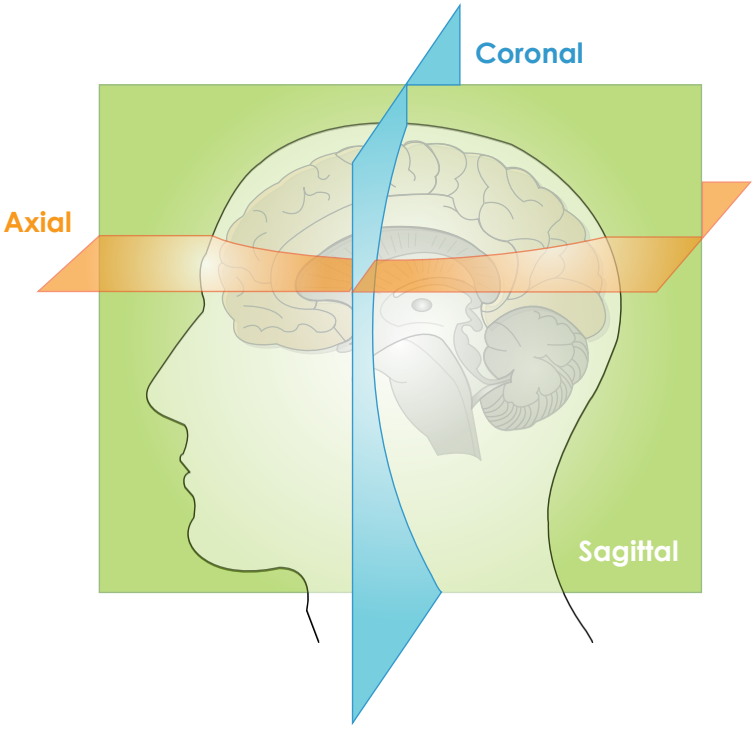
Three different views are typically taken of the head, neck or spine for a tumor diagnosis. Contrast material is used to show abnormal tissue more clearly. The patient must lie still inside the MRI machine for about an hour.

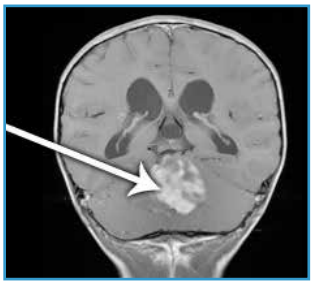
Some pediatric patients, mainly children, may require sedation. After the images are taken, the medical provider or radiologist will read the digital images and create a report.

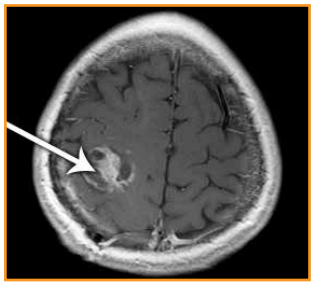
What types of images does an MRI take?

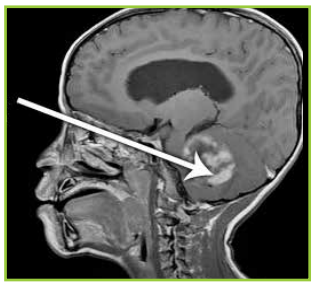
MRIs use three different views (see below) to show a tumor's location and position. This helps your doctor compare the tumor with normal brain (or spinal cord) structures. Using these views, different scans can be done to produce exact images that best show the tumor and the area around the brain or spine. New techniques are being developed and tested on a regular basis.

MRI - *Brain*




Coronal


Axial


Sagittal

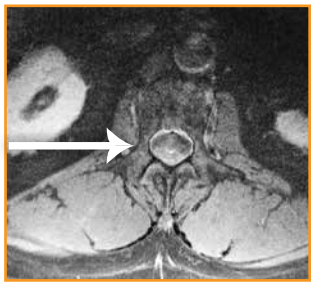
The three types of MRI 'views' or images include:

- **Sagittal:**
  This is a vertical plane passing through the standing body from front to back
- **Coronal:**
  This is a vertical plane from head to foot that is parallel to the shoulders
- **Axial:**
  This is a straight line passing through a spherical body between two poles that the body may revolve around

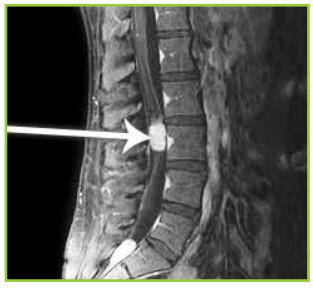
Other Tests

Sometimes a lumbar puncture (spinal tap) is necessary if there is concern that the tumor has spread into the cerebrospinal fluid.

Direct testing of the cerebrospinal fluid is done to look for the presence of tumor cells. In addition, an MRI of either the brain or spine may be ordered in addition to the baseline test to evaluate the entire CNS.

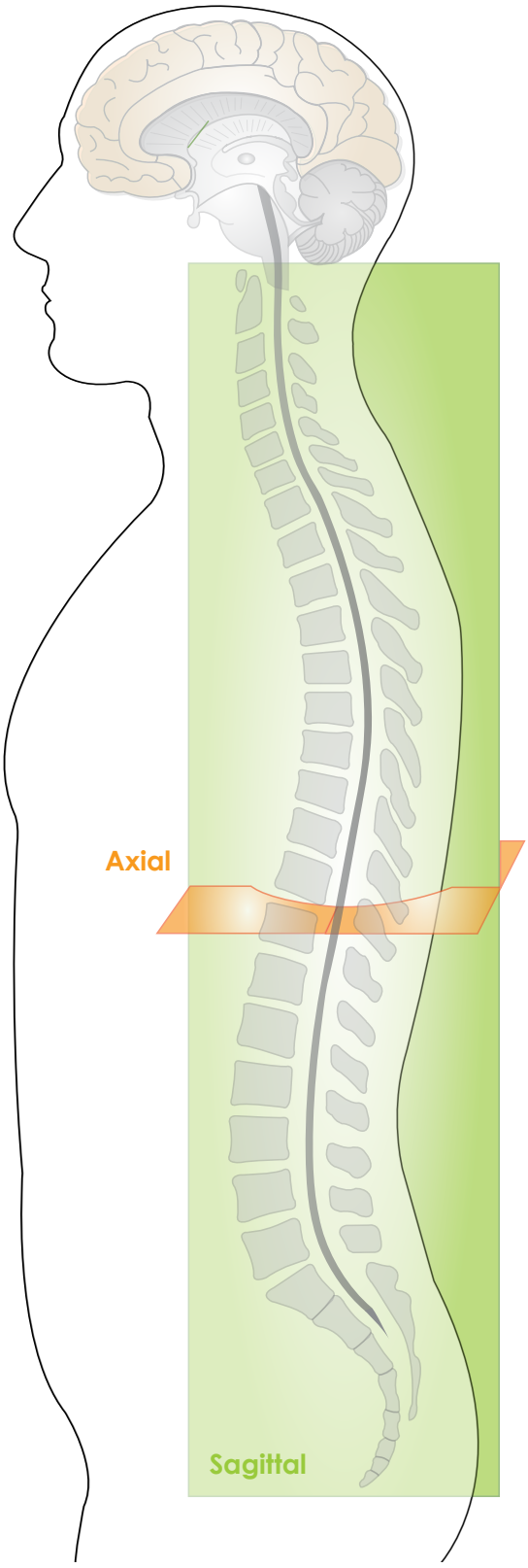


Axial



Sagittal

MRI - *Spine*



B. Pathology

Pathology is the examination of tissues and body fluids in order to make a diagnosis. This involves taking a tissue sample of the tumor when a biopsy or surgery is done to remove the tumor. The sample is then sent to a pathologist for review. Once the diagnostic lab report is completed, it is sent to your doctor who shares it with you.

Ependymoma is less common than other brain or spinal cord tumors. In addition, it is sometimes difficult to distinguish it from other tumor types. This can make it difficult to diagnose or a delay may occur. Seeking a second opinion is always a good option when dealing with rare diseases. Contact the CERN Foundation if you would like a second opinion by e-mailing administrator@cern-foundation.org.

What is the classification system for ependymomas?

The most widely used system to classify primary brain tumors is the World Health Organization (WHO) system. The WHO uses morphological features to classify these tumors into various 'types' and 'grades'. This involves examining tissue under a microscope.

Tissue samples are reviewed under a microscope by a pathologist.

The WHO was updated in 2016. In addition to what the tumor looks like under the microscope, molecular changes in the tumor are used to further refine the diagnosis in terms of tumor type and grade.

Unlike other cancers, primary brain and spine tumors generally do not spread (metastasize) outside of the central nervous system (CNS). For this reason, the Tumor-Node-Metastasis (TNM) staging system widely used for most "solid tumor" cancers is not useful for primary brain tumors.

What is classification based on?

The WHO assigns a grade to ependymomas based on the following:

- Variability in size and shape of the tumor cells (pleomorphism)
- How fast the tumor cells are growing (mitotic count)
- Crowding of tumor cells (cellularity)
- Growth of tumor blood vessels (vascular proliferation)
- Tendency for tumor cells to outgrow their blood supply (tumor necrosis)
- How much the tumor has spread into the surrounding normal tissue (invasion)
- Molecular and genetic features

These criteria apply to both pediatric and adult ependymomas. While a tumor may show characteristics from one or more tumor types and grades, doctors treat patients based on the highest-level tumor grade or what the features are for the majority of the tumor. *See Chapter 3 for more details on treatment.*

What are the types of ependymoma classification?

The WHO classification defines ependymoma and divides them into subtypes:

Subtypes that have been previously recognized by the WHO classification include subependymoma, myxopapillary ependymoma, as well as morphologic variants (for example: cellular ependymoma, papillary ependymoma and tancytic ependymoma).

It is recognized that myxopapillary tumors tend to occur in the spine and subependymomas tend to occur along the ventricles.

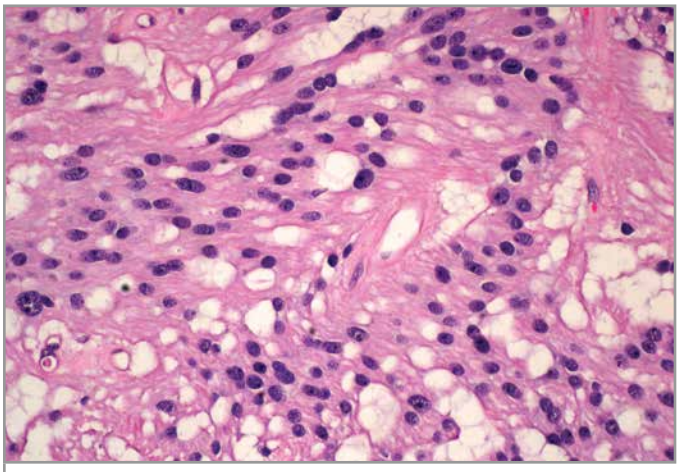
Recently, underlying genetic changes have revealed that ependymoma tumor subtypes may be different based on location.

There are three locations thought to be important: those that are supratentorial, infratentorial in the posterior fossa, and those located in the spine. *See Chapter 1 for more details on these locations.* Recently, it was discovered that in approximately two-thirds of ependymomas in the supratentorial region, there is a molecular abnormality which is a gene fusion called RELA that results in a unique protein.

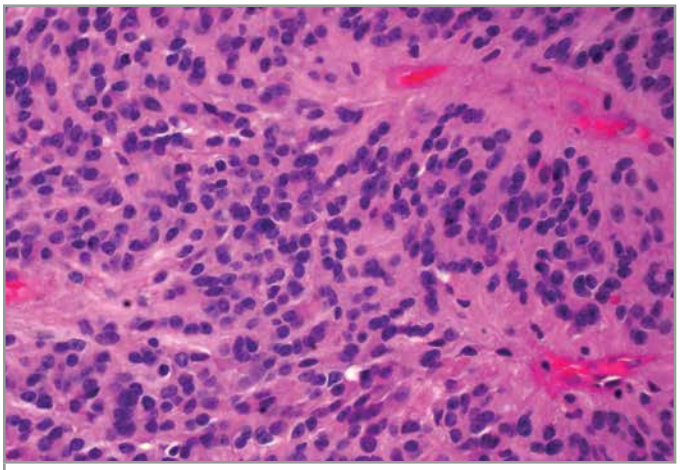
This fusion, RELA, results in the uncontrolled activation of a specific tumor cell molecular pathway called the NF-kB pathway. NF-kB contributes to the formation of the tumor and its uncontrolled growth. The 2016 WHO classification recognizes that tumors that are RELA-fusion positive occur in the supratentorial region. If tumors are in the supratentorial region, it is recommend that the tumor is tested for the RELA-fusion protein.

Scientists are beginning to identify characteristic changes in posterior fossa tumors, and specific epigenetic and gene expression profiles have been identified as potential markers to separate posterior fossa ependymomas into clinically distinct groups.

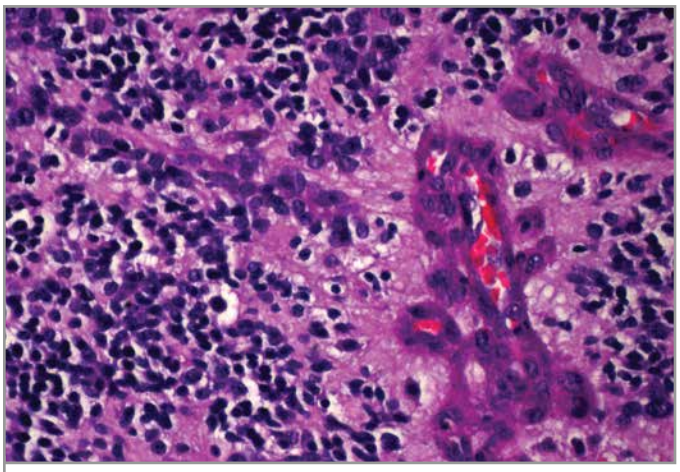
Finally, myxopapillary and subependymoma continue to be classified based on characteristics seen under the microscope.



WHO Grade I Ependymoma (Myxopapillary)



WHO Grade II Ependymoma



WHO Grade III Ependymoma (Anaplastic)

The WHO classifies ependymomas into three grades:

- **Grade I:**
  Myxopapillary Ependymoma and Subependymoma
- **Grade II:**
  Ependymoma (conventional)
- **Grade III:**
  Anaplastic Ependymoma
  (*which is more cancerous*)

What are the characteristics of each type?

WHO Grade I
Myxopapillary Ependymoma

- Slow growing
- Commonly occurs in young adults in the spinal cord, sometimes in the bottom of the spinal cord, an area referred to as "cauda equina".
  See diagram on Page 9.
- Tend to have good long-term survival after surgical resection

WHO Grade I
Subependymoma

- Slow growing noninvasive tumor
- Are less cellular masses usually attached to the ventricle wall (cerebrospinal fluid filled cavity in the brain). *See diagram on Page 10.*
- More common in adults and older men
- Associated with long-term survival
- Surgery can be potentially curative

WHO Grade II
Ependymoma (conventional)

- Most common brain tumor in young children
- Most common type of spinal glioma in adults
- Often develop in the ventricles when intracranial
- Several variants exist making diagnosis challenging:
  - Cellular ependymoma
  - Papillary ependymoma
  - Tanycytic ependymoma
  - Supratentorial ependymomas can be further subclassified as RELA-positive or RELA-negative
- Can potentially recur as a higher grade tumor even after treatment

WHO Grade III
Anaplastic Ependymoma

- Show evidence of increased tumor cell growth compared to conventional ependymoma
- Show evidence of new blood vessel formation to support active growth
- Exhibit more aggressive behavior than low grade ependymomas
- Often require additional treatment after surgery and can recur

CERN has the largest ependymoma tissue database collected in the world.

The relevance of conventional grading (grade II versus grade III ependymomas) and the prognostic relevance of this approach is currently a matter of discussion and debate. Researchers are currently looking at how to better define the features that set apart a grade II from a grade III tumor.

C. What to Ask Your Doctor

Here are some helpful questions to ask your doctor about ependymoma.

Several types of doctors care for patients with ependymoma. Each type of doctor has expertise in different parts of your care, so it's important to learn about your tumor so you know what kinds of questions to ask. *See our recommended list of resources in Chapter 6* and cern-foundation.org.

What is the exact type and grade of my ependymoma?

Ependymoma is a class of tumor that can occur in the brain or spinal cord. It includes different subtypes and grades. For example, ependymoma may be defined by grade (I, II, or III) or may have an added name such as myxopapillary ependymoma (a grade I tumor) or anaplastic ependymoma (a grade III tumor). The grading system describes microscopic features that may predict how aggressive a tumor may be. It is not clear how well grade predicts the outcome of ependymoma.

What is the size of my tumor?

In addition to your tumor's size, you should also ask about the amount of tumor spread into nearby tissues and whether the tumor has spread to other areas of the central nervous system. Doctors use the tumor subtype, grade and stage to plan treatment.

How complete is the diagnosis?

Ependymoma is a rare cancer. If there is a question about the diagnosis, ask if your tumor tissue can be sent to a specialized center for review and to confirm the diagnosis.

What is my prognosis?

Your prognosis is what the doctor thinks will happen with your cancer – your chance of recovery, the expected course of the cancer, or the length of time you will be sick. All this depends on the type and grade of ependymoma, treatment you can have, your age and general health.

How many patients have you treated with ependymoma?

It is important that you make sure that your doctor or surgeon is qualified. If they have not seen a patient with an ependymoma, we would recommend seeking out a second opinion at a CERN center.

Should you obtain a copy of your pathology and MRI report?

Diagnosis and treatment of brain or spine tumors is based on the results of your pathology and MRI report. Therefore, understanding your pathology and MRI reports is key in making treatment decisions.

Information in a pathology report includes:

- The tumor type and organ from which the tumor developed
- Whether cancer cells are present at the edges of the surgical resection
- The results may include special tests, such as the presence of special markers on the tumor cells
- The tumor size, how aggressive it is and if it has spread
- The tumor grade

You have a right to obtain copies of your medical records.

What happens to my tumor tissue, and will I have access to it in the future?

Often and with a patient's permission, tissue is stored in a tissue bank for future testing. For example, results from certain tissue tests may tell your doctor if there are abnormal findings. Also, results could tell your doctor if you would benefit from a targeted drug or if you are eligible to participate in any clinical trials.

Are there other questions that I should ask?

Here are a few more questions you should ask:

1. Are there more tests I need to have?
2. Are there other brain or spinal cord tumor specialists I need to see?
3. Am I eligible to participate in any clinical trials?

If you have questions about what you should ask your doctor or need more help, please contact CERN. You can never ask too many questions.

D. Coping With The Diagnosis

Coping with an ependymoma diagnosis can feel overwhelming. We can't always control everything that happens to us but we can decide how we let unexpected news affect our life moving forward.

The following coping mechanisms can help you cope with your diagnosis in a healthy way, at your own pace.

Communicate

Communication is key and can't be expressed enough. This is a very difficult time for everyone involved. Learn how to communicate with your healthcare team to ensure your needs are met. Communicate your concerns to your healthcare team.

The more honest and open you are, the more your physical, psychological and physiological needs can be managed. Sometimes, there is an expectation that physicians should know what you're experiencing but that is not always the case. Everyone is unique, so communicate your needs so your treatment and care can be tailored to you.

Keep a record of care, writing down symptoms and side effects you are experiencing between appointments and share this with your healthcare team.

Communicating with family and friends about a spinal or brain tumor is painful and difficult. Sharing with supportive people will help you move forward.

You decide how much information they should know, but be honest and decide who you feel comfortable being honest with. Those close to you should be familiar with your course of treatment, so they can understand what you will be going through, both physically and emotionally.

Keep a Journal

Journaling can be helpful to express your thoughts and feelings when they present themselves. The positive thing about this is, it's your own personal record of your journey.

Journaling is cathartic and helps you release any thoughts you may be having instead of letting them build up.

The last thing you want is everything to build up inside and not have a way to deal with your emotions. Sometimes when this happens, you explode in unexpected situations or towards innocent bystanders (spouse, children, healthcare team, friends, etc). Another good thing about having a journal is it gives you time to think about steps you can take to resolve a concern that has been plaguing you.

Be Present

During this time, you can be overwhelmed with everything going on and it can be difficult to focus on one issue at a time.

Learn to be mindful and present in your current state.

Take each day in and focus on your senses (sight, hearing, touch, smell, taste) in each moment. This reduces negative thoughts and things you can't control and keeps you present in your current situation so you are able to enjoy the moment you are in.

Find Balance in Your Life

Balance is a key component in maintaining stability. Prior to being diagnosed, you possibly had a routine. Continue to have a routine while coping with your diagnosis. Don't over exert yourself and do things within your physical abilities.

Have a life that you can be happy with outside of appointments and treatment visits.

One of the things that occurs when dealing with any type of life changing news is sometimes we tend to shut down or isolate, not knowing how to deal with the news and having concerns over our future. Having a schedule or routine gives you a purpose. It motivates you to do what you can, when you can and a sense of hope.

Learn Coping Strategies

Learn ways to deal with unexpected news throughout this process, from when you initially get diagnosed to receiving treatment, to being in follow-up appointments after completing treatment.

Incorporate stress-relieving techniques to use to ease your anxiety about upcoming appointments or treatment.

Learn to practice these techniques that you're able to incorporate in your daily routine. Try guided imagery, progressive muscle relaxation or diaphragmatic breathing. Seek out the guidance of a counselor or therapist who can help you implement more techniques into your daily routine.

Have Your Faith

If this was an important part of your life prior to diagnosis, continue to restore or maintain your faith in a higher power and look to him/her for the guidance that you are seeking.

Set Goals

Set realistic goals for yourself. Learn to breakdown a big goal into smaller compartments to achieve it.

Use the SMART technique to set your goals:

- Make your goal **S**pecific
- How is it going to be **M**easured?
- Is it **A**ttainable?
- Be **R**ealistic about being able to accomplish this goal
- **T**imely - How long will you give yourself to complete your goal?

One of the most important lessons from goal setting is rewarding yourself throughout this process. If you were able to get out of bed, walk to the mailbox, or wiggle some of your fingers today, be proud of that. We tend to wait until we have attained a big goal before fully celebrating our accomplishments.

Additional resources are available in Chapter 6.

Chapter 3

Treatment

A. Treatment for Adults

B. Treatment for Children

C. What to Expect During Treatment

D. Recurrence

Many factors impact decisions about the treatment of ependymoma including the tumor location and grade, and the age of the person.

Children and adults tolerate treatments differently. As a result, the treatment for each age group may be very different.

Your treating doctor will determine your treatment plan. If you get a second opinion, the two doctors may have different plans. Therefore, it is important for you to understand all options and possible side effects so you can make the best decision for yourself.

To make the best treatment decisions, you need to understand all of your options.

One option may include a clinical trial. Learn about the basics of participating in a clinical trial by visiting cern-foundation.org. Talk to your doctor to see if a clinical trial is an option for you.

Partnering with your medical team is an important part of beginning your treatment path and determining your personal plan.

Knowing what to ask your doctor and what questions to ask about treatment are the first steps in your journey through treatment.

A. Treatment for Adults

Your Medical Team
There are several members of your medical team that may be involved in your care.

Neuro-oncology team members typically include:

- *Neuro-oncologist* – a doctor who treats brain or spine cancer
- *Neurologist* – a doctor who deals with disorders of the nervous system
- *Neurosurgeon* – a doctor who operates on the brain or spine
- *Radiation oncologist* – a doctor who administers radiation therapy
- *Neuropathologist* - a doctor who studies diseases of the nervous system
- *Neuro-ophthalmologist* - a doctor who deals with diseases that manifest in the visual system
- *Psychologists and social workers* - offer emotional support and assists in managing the practical and financial impact of a tumor
- *Nurses and nurse practitioners* - oversee the management of patient care as recommended by doctor

Cancer treatment for adults may include one or a combination of the following:

Surgery

When possible, removing the brain or spinal cord tumor is the first step in treatment. Surgery serves two important purposes: (1) removes as much of the tumor as possible and (2) gives a biopsy (sample) of the type of the cells for diagnosis.

Radiation Treatment

External beam radiation treatment is often used to treat ependymoma.

This treatment uses beams of X-rays, gamma rays or protons aimed from outside the head or spine at the tumor. The beam kills cancer cells and shrinks tumors. The treatments are given daily as an outpatient over several weeks. There are several methods of delivering radiation treatment. Conformal radiotherapy and intensity-modulated radiotherapy (IMRT) are computer assisted techniques that are more precise. Proton beam radiotherapy is another technique used. It may provide additional protection of the normal structures compared to other X-ray techniques.

Stereotactic radiosurgery (SRS) is another technique for delivering radiation therapy. SRS allows precisely focused, high-dose X-ray beams to be delivered to a small, localized area of the brain. It is administered over 1-3 days. It requires very precise planning and treatment delivery. It can be delivered with a variety of different machines including: linear accelerator, Gamma Knife® or Cyberknife®.

Chemotherapy

Chemotherapy is drug treatment for cancers or tumors. There are many types of drugs used to treat cancer. Traditional chemotherapy are called cytotoxic agents designed to kill growing tumor cells. These agents often have side effects such as hair loss, nausea and vomiting and can cause a decrease in blood counts. However, now there are more types of drugs available. These include drugs called signal pathway modulators. These drugs target molecular pathways in cancer cells that cause the cell or pathway to survive. These drugs can either be chemical agents or antibodies targeting proteins in the pathways. Examples are drugs that impact formation of blood vessels in the tumor or that allow invasion of the tumor into surrounding normal tissue. These drugs typically have different side effects. For example, some cause skin rash, others cause diarrhea. Usually these drugs do not cause low blood counts or hair loss.

The Current Standard of Care for Ependymomas

One of the great challenges in knowing what treatment is best is the rarity of the disease. Most doctors see fewer than a handful of patients with ependymoma each year.

A primary goal of the CERN Foundation is to establish a network of centers for patients with ependymoma.

The CERN Foundation is designed to be a referral source so that patients can find the best treatments available.

Grade I or II

The standard therapy for low-grade ependymoma is complete surgical removal. If this cannot be safely done or if there are other concerns, radiation therapy is usually given after recovery from surgery.

Complete surgical removal is often not possible because of the location of the tumor and the concern for damage to surrounding brain or spine tissue during the operation. Radiation treatment is often recommended for patients where the ependymoma could not be completely removed. Additionally, there are conflicting opinions whether all patients with low-grade ependymoma should receive radiation to the area of tumor regardless of the extent of tumor removal.

Grade III

For patients with the more aggressive anaplastic ependymoma, the standard of care is to attempt a complete removal of tumor by surgery. After surgery, radiation is usually given to the area of tumor. If there is tumor spread into other parts of the central nervous system or spinal fluid, the brain and spinal cord may need radiation treatment. Chemotherapy may be given in addition to radiation. Since this is rare, there are only a limited number of studies evaluating chemotherapy treatment on anaplastic ependymoma tumors. And none have specifically tested whether adding chemotherapy improves outcomes. Talk to your doctor.

Alternative and Complementary Therapies

The CERN Foundation is not currently investigating the effects of alternative and complementary therapies on ependymoma. However, some patients research these options with the guidance of their doctors. Some options include massage and diet.

B. Treatment for Children

Your Child's Medical Team
There are several members of your medical team that may be involved in your care.

Neuro-oncology team members typically include:

- *Pediatric neuro-oncologist* – a doctor who treats brain or spine cancer
- *Pediatric neurologist* – a doctor who deals with disorders of the nervous system
- *Pediatric neurosurgeon* – a doctor who operates on the brain or spine
- *Radiation oncologist* – a doctor who administers radiation therapy
- *Neuropathologist* - a doctor who studies diseases of the nervous system
- *Neuro-ophthalmologist* - a doctor who deals with diseases that manifest in the visual system
- *Psychologists and social workers* - offer emotional support and assists in managing the practical and financial impact of a tumor
- *Nurses and nurse practitioners* - oversee the management of patient care as recommended by doctor
- *Child life specialist* - help families cope with the challenges of hospitalization, illness, and disability

Cancer treatment for children may include one or a combination of the following:

Surgery

Removing the tumor is usually the first step in cancer treatment if possible. If all visible tumor is removed there is a better chance for long-term survival. In children, staged surgeries are frequently used.

In staged surgeries, instead of trying to remove the tumor all at once, neurosurgeons will take a small part out first. Then they shrink the tumor with chemotherapy or radiation therapy. After several months of treatment, the surgeon may go back in to remove the rest of the tumor.

Radiation Treatment

Radiation treatment is used frequently to treat ependymoma. This process uses external beams of X-rays, gamma rays or protons aimed at the tumor to kill cancer cells and shrink tumors. The treatment is usually given over a period of several weeks. Delivery techniques target the tumor while protecting nearby healthy tissue.

Radiation treatment in children can have serious long-term effects on the brain and other organs. It is important to have treatment performed at a center that specializes in ependymoma. It is also important to discuss the potential side effects and complications with your child's doctor.

Chemotherapy

Chemotherapy is often administered through a special, long-lasting IV catheter called a central line. Chemotherapy may require frequent hospital stays. Although chemotherapy has many short-term side effects, it has fewer long-term side effects than radiation therapy. Unlike tumors in adults, many children with brain or spine tumors are highly sensitive to the effects of chemotherapy and respond well to high doses of it. However, giving a child high-dose or intensive chemotherapy can cause serious damage to bone marrow. Special precautions are taken to minimize damage.

Alternative and Complementary Therapies

CERN is not currently investigating the effects of alternative and complementary therapies on ependymoma. However, some patients research these options with the guidance of their physicians. Some options include massage and diet.

C. What to Expect During Treatment

Patients have unique experiences with brain and spinal cord tumor treatment. Some patients tolerate chemotherapy and take the prescribed treatment schedule while some patients do not.

Side effects from brain or spine cancer treatment can have a large impact on your life and family interactions. Do not underestimate the importance of partnering with your medical team.

It is important for both the patient and caregivers to discuss any changes they see during treatment with their health care providers. Have an open dialogue throughout treatment.

Each type of treatment comes with its own set of side effects.

In some cases, the side effects are extreme.

Surgery Side Effects

- Neurologic problems
- Bleeding
- Blood clots
- Infection
- Stroke
- Seizure
- Swelling of the brain or spine
- CSF (cerebrospinal fluid) leak
- Nerve damage
- Paralysis of muscles
- Wound (surgical incision) healing problems

These side effects can be minimized when procedures are performed in specialized centers. Where an experienced neuro-oncology team, working in the most technologically advanced settings, can provide the most extensive resections while preserving normal tissue.

Chemotherapy Side Effects

Tumor cells are fast-growing. Chemotherapy is designed to attack fast-growing cells, rapidly dividing cells. However, some normal cells, are also fast-growing (such as hair follicles, bone marrow and stomach cells) and so are often affected by chemotherapy. Patients may experience:

- Hair loss
- Nausea/Vomiting
- Diarrhea
- Low blood counts
- Low red blood cells (anemia): fatigue
- Low white blood cells (leucopenia or neutropenia): risk of infection
- Low platelet count (thrombocytopenia): risk of bleeding

Chemotherapy can cause fatigue due to anemia. It can increase risk of infection. These side effects can be effectively managed under most circumstances with standard medical approaches.

Radiation Treatment Side Effects

Radiation treatment often produces inflammation. This can temporarily intensify symptoms and dysfunction. Steroids are sometimes used to control inflammation. Patients who receive radiation treatment to the head may experience these side effects:

- Redness and irritation in the mouth
- Dry mouth
- Difficulty swallowing
- Changes in or loss of taste
- Nausea
- Fatigue
- Hair loss
- Short and long term cognitive and neurologic problems

Other side effects may include:

- Skin changes such as redness, flaking and swelling

These side effects can be effectively managed under most circumstances with standard medical approaches.

Radiation Treatment Side Effects in Children

Children experience additional side effects because of their developing bodies.

Radiation may cause these side effects in young patients:

- Damage to normal brain and spinal cord structures, causing learning problems or slow growth and development
- Increased risk of developing brain or spinal cord tumors later in life

Finding the delicate balance between giving enough therapy to eliminate the cancer, but not so much as to damage healthy cells and cause unnecessary side effects is one of the most difficult challenges in treating tumors in children. It is important to understand the potential side effects and all treatment alternatives.

Additional resources are available in Chapter 6.

D. Tumor Recurrence or Regrowth

Even after the best treatment, ependymomas can regrow or recur. There is no way to predict which patients are more likely to have tumor recurrence.

For this reason, routine check-ups and MRIs are highly recommended. Most commonly, the regrowth occurs in the same spot as the first tumor. But it is possible for the tumor to grow somewhere else within the central nervous system. The time from treatment to tumor regrowth can be varied. Often patients are tumor-free for years before testing shows new tumor growth.

Clinical Trials

If you have learned of a recurrence of ependymoma the same treatment options may be available. Talk with your doctor about all options. This is a common time when clinical trials are considered. Clinical trials evaluate the safety and effectiveness of investigational cancer therapies. All standard treatments are a result of past clinical trials.

NIH Clinical Trials
www.cancer.gov/about-cancer/treatment/clinical-trials/search
Includes a current list of NCI-supported clinical trials. These studies are sponsored or otherwise financially supported by NCI. This database allows you to search by location, cancer type, treatment type, keyword or by trial phase.

CERN Foundation
cern-foundation.org
Includes a current list of CERN supported clinical trials available for ependymoma.

The IBTA
theibta.org/clinical-trials-registry/
Includes a current list of the major international or national clinical trials available online.

Chapter 4

Symptoms

A. Common Symptoms

B. Fatigue

C. Pain

D. Sleep Disturbance

The symptoms that patients develop from brain and spinal cord tumors depend on the location of the tumor(s) within the central nervous system (CNS). Most of these tumors are slow growing. So symptoms may develop slowly and worsen over weeks or months.

In general, symptoms from brain and spinal cord tumors can be divided into two groups. The first group, called generalized symptoms, is more common with brain tumors. They usually are related to increased pressure within the brain. The second group of symptoms, called focal symptoms, depend on the location of the tumor within the brain or spinal cord. The location will affect the brain or spinal cord function in that area.

Increased pressure occurs when the tumor presses within the skull (for a brain tumor) or along the spinal axis (for a spinal tumor).

Brain cancer symptoms associated with increased pressure may include pain, vomiting, changes in sight, confusion and sleepiness.

For spinal tumors, the pressure may also result in pain. The pain may be over site of the tumor, or along the nerve paths. Focal symptoms are dependent on the tumor's location in the CNS.

A. Common Symptoms

People living with ependymoma commonly report on fatigue, pain and sleep disturbances during the course of illness.

This has been shown through research conducted by the CERN Foundation as part of the Ependymoma Outcomes Project.

It is important to talk with your doctor about any symptoms that are bothering you.

Symptoms that are common based on location can be seen on the diagram on Page 8.

Common brain tumor symptoms

- Headache or pressure in the head
- Nausea or vomiting
- Vision changes
- Weakness or numbness and tingling on one side of the body
- Problems with thinking, remembering or speaking

Common spinal cord tumor symptoms

- Back pain
- Weakness in the arms or legs
- Numbness or tingling in the arms, legs or trunk
- Problems going to the bathroom or problems controlling bowel or bladder function

B. Fatigue

Fatigue is common in people with all types of tumors and those who are undergoing treatment such as radiation and chemotherapy.

Ways to Manage Fatigue

Stay active

Regular exercise has been shown to improve fatigue in people with other cancers. Exercise should be done in moderation. Do not exercise to the point of feeling winded or exhausted.

Walking is an exercise that has been shown to be helpful in other cancers. Talk to your health care professional about specific exercise recommendations for you.

Rest

Short naps or breaks in activity may help you manage daily tasks.

If you nap, don't overdo it. In general, 30 minutes of napping or less are recommended so you don't disrupt your sleep during the night.

If you have difficulty sleeping at night or require more rest than 30 minutes during the day, talk to your health care professional.

Plan ahead and accept help

It may be helpful to spread your activities during the day. Or you may want to plan a rest period before strenuous activity. Prioritize what you want to do and what you need to get done during the day.

If there are certain tasks that are difficult for you to do or drain your energy, accept help from family or friends. Don't push yourself to do more than you can manage.

Eat well and drink fluids

Food and fluids are the fuel to help you complete the tasks that you need to do. If you have lack of appetite or have had a change in weight, talk to your health care professional.

Get support: you are not alone

Fatigue is a problem for many people with tumors and who are getting treatment. Consider joining a support group. *See Page 38 for recommended support organizations.*

Talk to your doctor about medications that can help with managing symptoms.

C. Pain

Pain is a common symptom of ependymoma. People with tumors in the brain may experience headache pain, whereas those with spine tumors may experience pain along the spine or radiating into the arms, legs or buttocks.

Ways To Manage Pain

Communication

Only you know what your pain feels like. Good communication with your treating doctor is key.

Be sure to share with your health care team the following information: what the pain feels like; what makes it worse; what makes it better; if your current pain medication provides relief and for how long; and how the pain affects your life.

Pain recurs

Consider keeping a pain record that you can bring to the doctor to share the pattern of your pain.

Treatment options

Ask what medicine is available to help with the pain; when to take the medicine and for how long; and what to do if it doesn't help.

Other treatment options

Other treatments are also available and may provide relief. Some examples are relaxation, biofeedback, acupuncture, physical therapy, and counseling.

Talk to your health care provider about the use of these techniques and how to access them in your area.

D. Sleep Disturbance

Sleep disturbance is a common symptom that occurs in people with brain and spine tumors.

The most common type of sleep disturbance is insomnia. Insomnia occurs if someone has trouble falling or staying asleep.

According to the guidelines published by the American Academy of Sleep Medicine, the following information may be helpful in addressing sleep disturbance.

Ways To Manage Insomnia

Recognize it

- Complaints of difficulty initiating sleep, maintaining sleep, or waking up too early
- Sleep difficulty occurs despite adequate opportunities for sleep
- Fatigue
- Difficulty concentrating or remembering
- Difficulty interacting with others or completing work
- Irritability
- Decreased motivation
- Daytime sleepiness
- Headache or problems with stomach or bowels
- Worries about sleep

Identify causes

Often, there are other things that impact the person's ability to sleep.

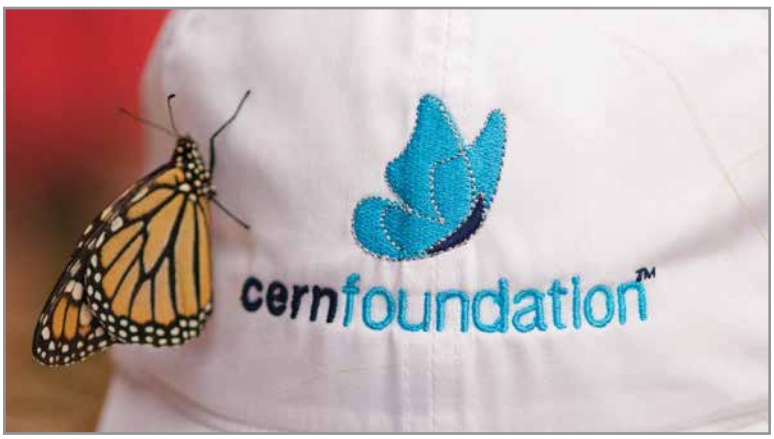
Work with your physician to identify and treat underlying causes.

Examples include excessive caffeine, stress, sleep apnea, pain, or side effects of medications like steroids.

Additional resources are available in Chapter 6.

Ways to help you sleep

- Use fixed bed and wake times
- Relax before going to bed
- Avoid clock-watching
- 20 minute 'toss and turn' rule (If you aren't asleep in 20 minutes, get out of bed and do another relaxing activity for 20 minutes then try to go to sleep again)
- Avoid daytime naps
- Avoid caffeine, alcohol and nicotine within six hours of going to bed
- Exercise regularly but not within 20 minutes of going to sleep



Chapter 5

The CERN Foundation

A. About the CERN Foundation

B. CERN Projects

A. About the CERN Foundation

The CERN Foundation has made tangible progress towards a better understanding of this difficult disease. By bringing together a broad range of experts to study this particular type of tumor, we have expanded our knowledge of ependymoma, both scientifically and clinically.

The CERN Foundation is committed to improving the care and outcome of people with ependymoma through community support and research efforts.

Established in 2006, the CERN Foundation is a 501c3 nonprofit organization dedicated to improving the lives of those affected with ependymoma.

Thanks to the efforts of an international network of collaborators, the CERN Foundation has been responsible for the publication of over 50 peer-reviewed papers in leading medical journals. This body of research has greatly advanced our understanding of ependymoma and has left a lasting legacy for future investigators to build upon.

Today, the CERN Foundation continues to advance ependymoma research by supporting scientific fellowships, clinical trials, sponsoring professional conferences and symposia, and investigating risk factors for the disease.

The CERN Foundation is currently engaged in a range of community outreach programs and support efforts designed to have a positive impact on the lives of children and adults living with ependymoma, as well as their families and caregivers.

History

For over a decade, the CERN Foundation has been at the forefront of the fight against ependymoma, a type of brain and spinal cord tumor. Taking a broad investigative approach involving scientists from some of the world's most respected cancer centers, the work of the CERN Foundation has contributed to a vastly improved understanding of the genetic make-up and biology of ependymoma. Today, this knowledge is helping scientists around the world develop new therapies and improve the quality of life for those living with the disease.

The concept for the Collaborative Ependymoma Research Network (CERN) Foundation was sparked in 2006, when during the course of treating a patient facing a recurrence of ependymoma, Dr. Mark Gilbert recognized that there was relatively little in the medical literature on this type of tumor. Responding to the need for more information, Dr. Gilbert proposed the creation of an international group of researchers who would for the first time join together to take a collaborative approach to investigating the disease.

To help him in this effort, Dr. Gilbert reached out to a core group of colleagues, including Dr. Richard Gilbertson, a renowned expert in the research of childhood brain tumors, Dr. Kenneth Aldape, a leader in the pathology of adult brain tumors, Dr. Terri Armstrong, an expert in clinical care and patient outcomes, and Dr. Amar Gajjar, one of the United States most respected pediatric neuro-oncologists. Together, they assembled a team of laboratory-based and clinical researchers who were not only top in their field, but were also known for their collaborative mind set.

Over the years, the work of the CERN Foundation has greatly expanded our understanding of ependymoma. CERN funded research has been published in some of the most respected medical journals in the world. CERN supported investigators have led an effort to develop a biologically-based molecular classification system of ependymoma, which in turn is contributing to the development of individualized therapies based on tumor specific targets. This research found differences in outcome in patients with similar tumors: if patients with aggressive tumors can be identified at the time of diagnosis, those patients could be targeted for intensive therapy.

2015 CERN Leadership Meeting

Ependymoma Tissue Samples

2013 Butterfly Release at
St. Jude Children's Research Hospital

Patients with less aggressive tumors could be spared the potential harmful side effects of intensive therapy, if found to be unnecessary to achieve a good outcome.

These advances would not have been possible without data collected through the CERN tissue study, which today contains close to 1000 ependymoma tumor samples - the largest repository of its kind in the world. This tremendous resource will allow ependymoma researchers around the world to more accurately classify ependymoma tumor types and predict outcome. Now, and in the future, the CERN tissue bank will help scientists to predict with increasing accuracy which drugs, and combination of drugs, will have a therapeutic effect.

As the only organization devoted solely to ependymoma, the CERN Foundation's awareness and patient education efforts are a key part of our organizational mission. CERN has developed a comprehensive Ependymoma Guide and thousands of copies have been distributed for free worldwide. Our website, cern-foundation.org, is constantly updated with coping strategies, inspirational stories and news from the field, and our social media efforts allow for patients and caregivers to connect with CERN and each other.

Last, but certainly not least, our annual Ependymoma Awareness Day has become the flagship event in the ependymoma community. This outreach effort has had a heartwarming and positive impact on the lives of children and adults living with ependymoma, their families and caregivers. CERN's advocacy efforts have also brought a much needed spotlight to this disease as we seek to educate the public about ependymoma.

Despite tremendous advances made over the last ten years in our understanding of the basic biology of ependymoma, new treatments and therapies are still needed. Future advances will only be possible though donations and the collaborative relationships between researchers, clinicians, patients, caregivers and industry.

The CERN Foundation will continue to serve as a platform for these collaborations and as a catalyst for progress as we work closer towards a cure everyday.

B. CERN Projects

The CERN Foundation is engaged in a range of activities to support patients, caregivers, advocates and medical professionals.

Ependymoma Referrals

CERN routinely connects patients and families with institutions and physicians that specialize in treating ependymoma. We are also happy to make connections between treating physicians and CERN representatives.

Ependymoma Guide

Now in its second edition, the Ependymoma Guide provides the basic facts surrounding ependymoma, its diagnosis and treatment. The Ependymoma Guide is distributed at no charge to patients, caregivers and advocates in print and online.

CERN Postdoctoral Basic Science Research Fellowship

This fellowship provides support for two years of funding to promising postdoctoral researchers whose focus is on ependymoma research.

Professional Development

The CERN Foundation supports the development of dedicated ependymoma content during the two largest international neuro-oncology conferences: the annual meeting of the Society for Neuro-Oncology and the Biennial International Symposium on Pediatric Neuro-Oncology.

Clinical Trials

CERN offers information about ongoing clinical trials and we provide education and direction to the ependmoma community. Our hope in with these trials is to collect critical data that will advance the treatment of ependymoma.

Ependymoma Outcomes Surveys

Quality of life is a critically important issue for children and adults diagnosed with an ependymoma. The Ependymoma Outcomes surveys allow us to continue to improve our understanding of the experience and current health status of those living with ependymoma.

The goal of the EOP surveys is to ensure a high standard of care for ependymoma patients.

Risk Assessment Project

CERN is expanding the work of our successful Ependymoma Outcomes Surveys to include the evaluation of potential risk factors for the occurrence of ependymoma as well as the evaluation of potential genomic changes that may lead to the development and progression of ependymoma.

Ependymoma Awareness Day

Recognized and celebrated around the world, the annual Ependymoma Awareness Day has become the flagship event in the ependymoma community. The event culminates in a mass butterfly release that is videotaped and streamed to viewers around the globe. The CERN awareness and outreach team also partners with other groups to support awareness efforts in their local area.

Learn more about these projects at cern-foundation.org.

Chapter 6
Resources

A. Organizations Specific to Ependymoma

B. Patient Support Organizations and Information Resources

C. Cancer Resources

D. Books

A. Organizations Specific to Ependymoma

Adult Ependymoma Online Support Group
braintrust.org/groups/adultependy/

The Adult Ependymoma Online Support Group is comprised of survivors, caregivers, family members, friends or anyone else with an interest in ependymoma.

Collaborative Ependymoma Research Network (CERN) Foundation
cern-foundation.org

The CERN Foundation is committed to improving the care and outcome of people with ependymoma through community support and research efforts. The CERN website is dedicated to informing patients and caregivers about treatment, diagnosis, clinical trials, symptom management and recurrence. It is a valuable resource for those affected by ependymoma, including patient stories. You can also follow us on Twitter and Facebook.

EpendyKids
ependykids.org

EpendyKids is a directory of children who are fighting a rare pediatric brain tumor called ependymoma.

Ependyparents
ependyparents.org

Ependyparents is a list of parents of ependymoma patients, survivors and angels of brain tumors. Facebook group page: EpendyParents.

B. Patient Support Organizations and Information Resources

Adult Patients

American Brain Tumor Association
abta.org

The mission of the American Brain Tumor Association is to advance the understanding and treatment of brain tumors. With the goals of improving, extending and, ultimately, saving the lives of those impacted by a brain tumor diagnosis. They do this through interactions and engagements with brain tumor patients and their families, collaborations with allied groups and organizations, and the funding of brain tumor research.

ASCO - Living with Cancer
cancer.net

Cancer.Net provides timely, comprehensive information to help patients and families make informed health care decisions. The American Society of Clinical Oncology's (ASCO) patient information website brings the expertise and resources of ASCO to people living with cancer and those who care for and care about them. Well-informed patients are their own best advocates and invaluable partners for physicians.

brainstrust
brainstrust.org.uk

Brainstrust is a UK based brain cancer charity, dedicated to improving clinical care for brain tumour sufferers and providing coordinated support in their search for treatment. They provide support and advice at the point of diagnosis and beyond, by updating treatment, improving care and, ultimately, saving lives.

Cancer Support Community
cancersupportcommunity.org

The Cancer Support Community is an international non-profit dedicated to providing support, education and hope to people affected by cancer. CSC offers a menu of personalized services and education for all people affected by cancer. Its global network brings the highest quality cancer support to the millions of people touched by cancer. These support services are available through a network of professionally-led community-based centers, hospitals, community oncology practices and online, so that no one has to face cancer alone.

Clinical Trials and Noteworthy Treatment
virtualtrials.org

Created by The Musella Foundation for Brain Tumor Research, virtualtrials.org is a non-profit organization that uses computer technology to organize brain tumor data and to provide a means of communication between brain tumor communities.

International Brain Tumor Alliance
theibta.org

Alliance of the support, advocacy and information groups for brain tumor patients and carers in different countries and also includes researchers, scientists, clinicians and allied health professionals who work in the area of brain tumors.

National Brain Tumor Society
braintumor.org

National Brain Tumor Society brings together the best in brain tumor research and supportive patient services. They offer hope to patients, families, and caregivers during every stage of the treatment journey. NBTS invests wisely and strategically in innovative research that will lead to advances and ultimately to a cure.

National Cancer Institute Physicians Data Query
cancer.gov/cancertopics/pdq

The Physicians Data Query (PDQ) is the comprehensive cancer database of the National Cancer Institute, one of the most highly regarded sources of cancer information in the world. The database offers peer-reviewed summaries, prevention and screening, supportive care and alternative medicine options. It also houses over 23,000 clinical trials for cancer and a list of professionals that perform genetic services.

PubMed
pubmed.gov

PubMed comprises more than 23 million citations for biomedical literature from MEDLINE, life science journals, and online books.

Spinal Cord Tumor Association
spinalcordtumor.org

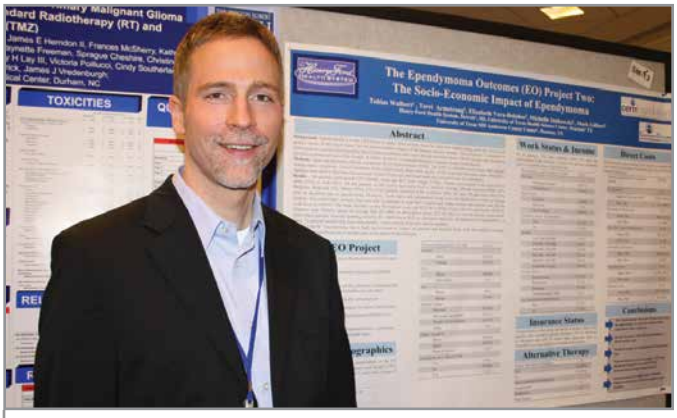
The Spinal Cord Tumor Association, Inc. is a not-for-profit organization formed by spinal cord tumor survivors for the purpose of supporting survivors and their families.

Spinal Cord Tumour Forum
spinalcordtumour.org.uk

The Spinal Cord Tumour Forum is a support group based in the UK for people who have had, or whose lives have been affected by, benign spinal cord tumours.

Even though they are benign these tumours can cause significant damage. The group was created and is run by spinal cord tumour sufferers.

The website contains a forum plus information on spinal cord tumours, personal stories and news updates. They also hold meetings twice a year in London.



Dr. Tobias Walbert at the Annual SNO Meeting

Pediatric Patients

Children's Brain Tumor Foundation
cbtf.org

A non-profit organization founded in 1988 by friends and families of children with brain tumors and the physicians who dedicated their lives to a cure. The Children's Brain Tumor Foundation provides dedicated information to families and has awarded over $5 million in grants to clinical research and quality of life funds around the world.

Pediatric Brain Tumor Foundation
curethekids.org

The Pediatric Brain Tumor Foundation (PBTF) is a non-profit charitable organization that seeks to find the cause of and cure for childhood brain tumors by supporting medical research. PBTF also looks to aid in detecting the early symptoms of brain cancer and treatment of childhood brain tumors and provide educational and emotional support for children and families affected by this life-threatening disease.

C. Cancer Resources

Accelerate Brain Cancer Cure
abc2.org

Accelerate Brain Cancer Cure (ABC2) applies entrepreneurial approaches to medical research and bridges the gap which often exists between academic researchers who often make significant scientific discoveries and companies which bring those treatments to patients.

Since 2001, ABC2 has provided more than $20 million in research funding to highly qualified research investigators and physician-scientists from 42 institutions.

American Cancer Society
cancer.org

For 100 years, the American Cancer Society (ACS) has worked relentlessly to save lives and create a world with less cancer and more birthdays. Together with millions of supporters worldwide, the ACS is helping people stay well, helping people get well, finding cures, and fighting back against cancer.

American Association of Cancer Research
aacr.org

The mission of the American Association for Cancer Research (AACR) is to prevent and cure cancer through research, education, communication, and collaboration.

Through its programs and services, the AACR fosters research in cancer and related biomedical science; accelerates the dissemination of new research findings among scientists and others dedicated to the conquest of cancer; promotes science education and training; and advances the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world.

Cancer*Care*
cancercare.org

CancerCare is the leading national organization committed to improving lives by providing professional services to help people manage the emotional and financial challenges of cancer.

Dr. Stefan Pfister with Dr. Riccardo Soffietti at the Annual SNO Meeting

Livestrong
livestrong.org

LIVESTRONG provides support to guide people through the cancer experience, bring them together to fight cancer—and work for a world in which our fight is no longer necessary.

National Cancer Institute
cancer.gov

The National Cancer Institute coordinates the National Cancer Program.

They conduct and support research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients.

National Institutes of Health
nih.gov

The National Institutes of Health's (NIH) mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

National Institute of Neurological Disorders and Stroke
ninds.nih.gov

The mission of National Institute of Neurological Disorders and Stroke (NINDS) is to reduce the burden of neurological disease – a burden borne by every age group, by every segment of society, by people all over the world.

Oncology Nursing Society
ons.org

The Oncology Nursing Society (ONS) is a professional organization of over 35,000 registered nurses and other healthcare providers dedicated to excellence in patient care, education, research, and administration in oncology nursing.

Society of Neuro-Oncology
soc-neuro-onc.org

The Society for Neuro-Oncology (SNO) is a multidisciplinary organization dedicated to promoting advances in neuro-oncology through research and education. The premier North American organization for clinicians, basic scientists, nurses and other health care professionals whose focus is central nervous system tumors in children and adults.

Dr. Sonia Partap, Dr. Eugene Hwang and Dr. Stewart Goldman at the Annual SNO Meeting

Please note that the resources listed is provided solely as an informational resource for patients with ependymoma, their family members and caregivers. These organizations are not associated with the CERN Foundation and we are not responsible for the content on these sites.

D. **Books**

If You Love Me, Take Me Now
by Steve Cox

Damn the Statistics, I Have a Life To Live: Coping with a Brain Tumor My Personal Story
by H. Charles Wolf

No Such Thing as A Bad Day – *A Memoir*
by Hamilton Jordan

Damaged But Not Broken; A Personal Testimony of How to Deal with the Impact of Cancer
by Larry Burkett, Michael E. Taylor

Living with a Brain Tumor: Dr. Peter Black's Guide to Taking Control of Your Treatment
by Peter Black

Brain Tumors: Leaving the Garden of Eden–A Survival Guide to Diagnosis, Learning the Basics, Getting Organized, and Finding Your Medical Team
by Paul M. Zeltzer

Navigating Through a Strange Land; a Book for Brain Tumor Patients and Their Families
by Trish Roloff

Love, Medicine and Miracles
by Bernie Siegal, M.D.

The Official Parent's Sourcebook on Childhood Ependymoma: A Revised and Updated Directory for the Internet Age
by Icon Health Publications

Childhood Brain & Spinal Cord Tumors: A Guide for Families, Friends & Caregivers
by Tania Shiminski-Maher, Patsy McGuire Cullen and Maria Sansalone

My Brain Tumour Adventures: The Story of a Little Boy Coping With a Brain Tumour
by Sharon Dempsey, Daria Halprin

Physician, Heal Thyself A Brain Cancer Surgeon's Journey Through Brain Cancer
by Samuel J. Hassenbusch M.D. Ph.D., Ken McFarland

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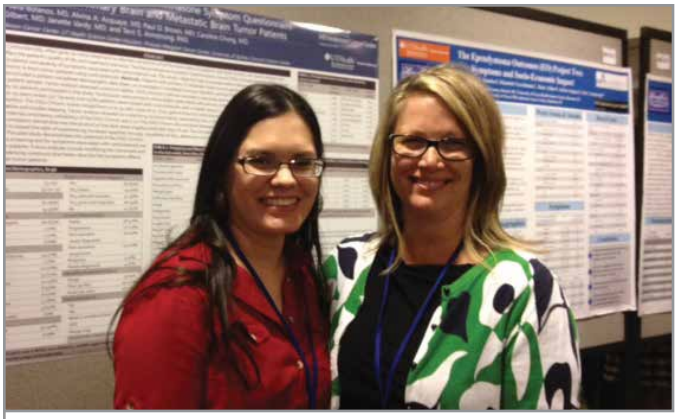

Terri Armstrong, PhD and Elizabeth Vera at the Annual SNO Meeting

Chas Haynes and Dr. Mark Gilbert at the Annual SNO Meeting

2013 Annual CERN Foundation Investigators Meeting

cernfoundation™
Collaborative Ependymoma Research Network

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MATHILE
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