Empowering Understanding

A Comprehensive Visual Handbook for Ependymoma

Process Book

Lilly Oldham

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Artist Statement

For many newly diagnosed patients, the idea of learning about a disease that they previously knew nothing about can be a very daunting task. The introduction of a cancer that they had likely never heard of before, coupled with the complexity of its classifications and involved anatomy makes it very hard for patients to understand what is happening inside their own bodies. The focus of this project is to empower the understanding of patients and caretakers impacted by ependymal tumors, giving them a tool to learn about this disease and help them advocate for themselves.

Upon diagnosis, most patients and their families receive little to no resources that help them understand what ependymoma is, leading to a very severe transition into a new medical environment. If resources are provided, they are often very medical in nature, which can lead to additional confusion, potentially turning patients away from seeking more information. This visual guide acts as an introductory resource that will help ease patients into the new and complicated environment that is the world of medicine.

Project Scope

The Objective

The final deliverable of this project is a booklet (5.5" x 8.5" - the size of an average softcover book) that acts as an introductory resource for ependymal tumors.

The Breakdown

It is organized into four sections (the basics, structures and functions, reading scans, and classifications) and additionally broken down by tumor location. The first section includes an introduction to medical terminology as well as descriptions of the medical professionals patients may interact with.

The Technical Side

All illustrations and assets are completed in Adobe Photoshop, and the booklet itself was developed in Adobe InDesign. All of the content within the guide, which is titled *Empowering Understanding: A Comprehensive Visual Handbook for Ependymoma*, was written, illustrated, and designed by Lilly Oldham with the help of committee members.

The reading level of the guide is set to be between 5th grade and early high school in order to appeal to a wide audience with varying levels of literacy and medical literacy. Because of this broad audience in mind, there were limitations to descriptive information in an attempt to keep things as simple and patient-friendly as possible.

Style Guide

The Softwares of Choice

The Colors

The Basics

Structures and Functions

Reading Scans

Classifications

Glossary

Bibliography

The Font

Headings

Section Titles

Pronounciations

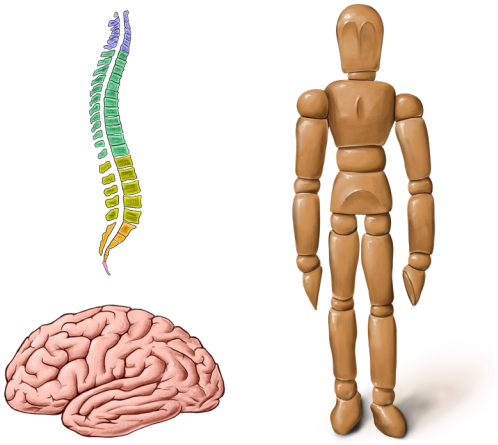
Body Text

Subtext

Labels

Letters for Labels

The Rendering Style



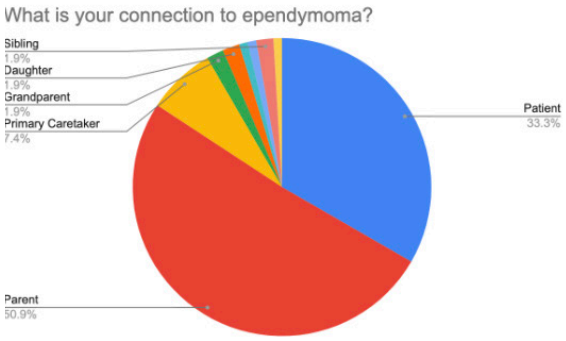
Primary Research

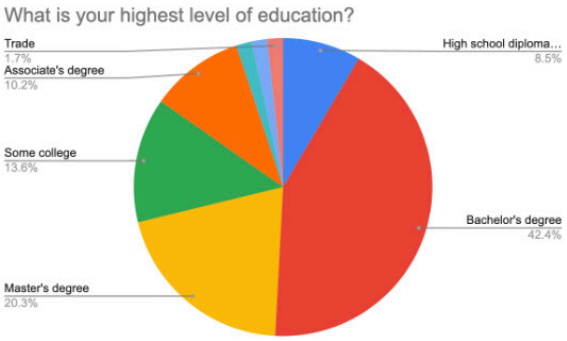
To properly gauge the knowledge and needs of those impacted by ependymal tumors, a 13-question survey was administered. This questionnaire was distributed to a number of private Facebook groups for patients, parents, caretakers, etc. impacted by any of the four classifications of ependymal tumors. Participants were asked what connection they have to the disease, the classification and location of the tumor, and also inquired if they received any resources or educational materials upon diagnosis.

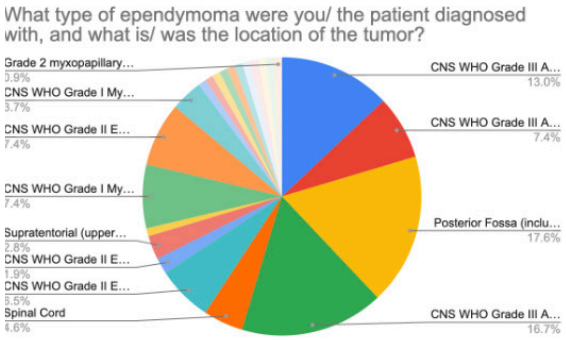
They were then asked if they struggled to understand the research they conducted on a scale from one to five, with one indicating they did not struggle, and five indicating their research was found to be extremely challenging. They were also asked to rate their level of understanding of grading/classifications and biomarker testing on a scale from one to five, with one being the lowest level of understanding and five being the highest. Their familiarity with the medical terminology related to two of the three locations of this tumor type was also questioned in order to gauge their knowledge of anatomical factors, and their highest level of education to determine a potential baseline of medical and general literacy.

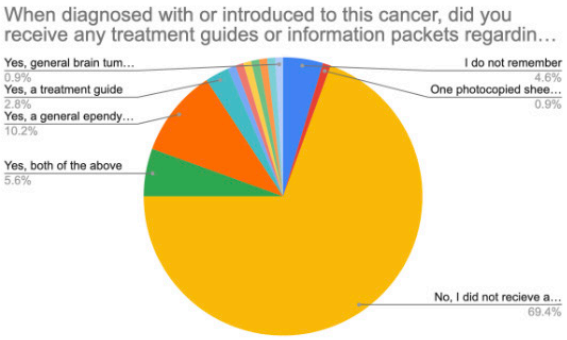
Participants were asked about their preferred learning style, ranging from the preference of all text to the opposing preference of all visuals. Finally, they were asked if they felt more medical illustrations or general visual resources would have been helpful regarding their initial understanding of a diagnosis, with one meaning they found their resources to have an adequate amount of visuals, and a five meaning they wished they had more.

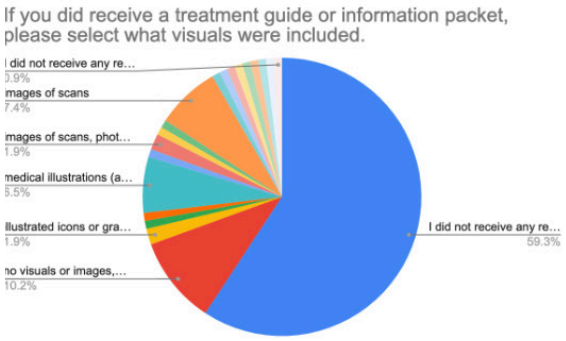
Primary Research

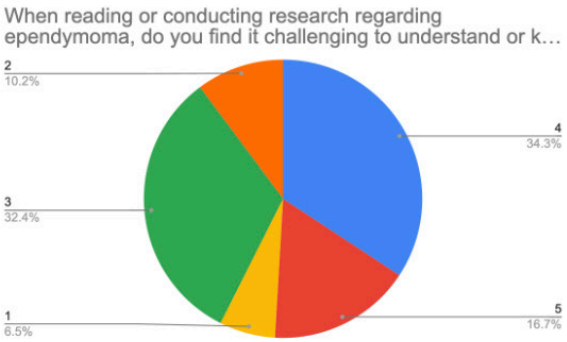




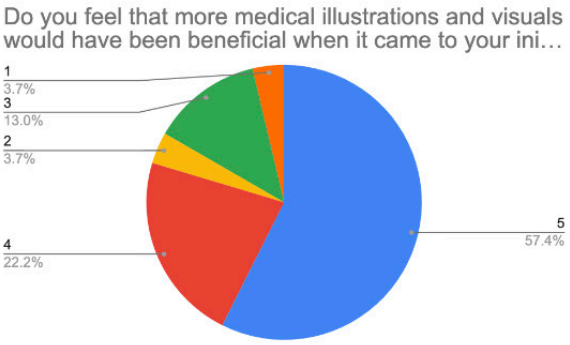


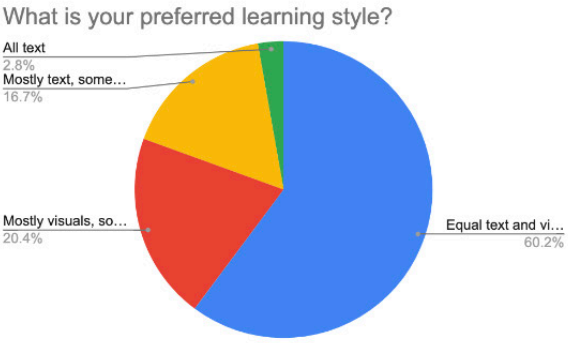


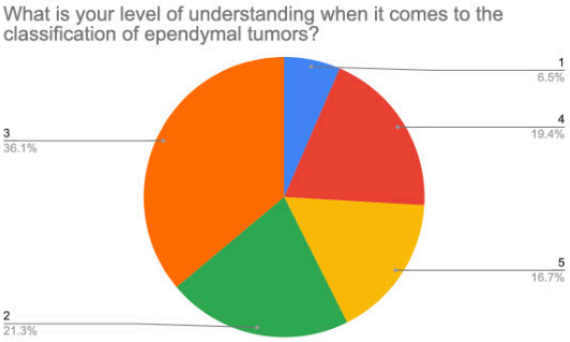


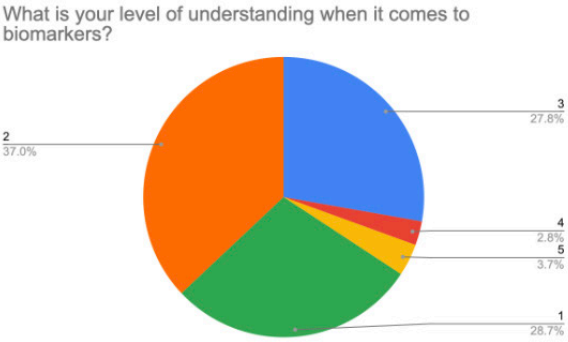


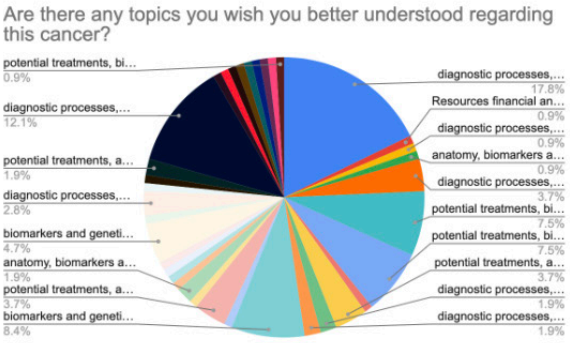
Primary Research

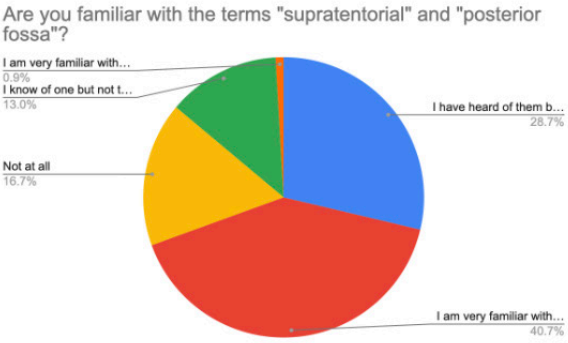












Primary Research

The Results

In total, 108 responses were collected from patients (33.3%), caretakers and parents (58.3%), and others impacted by ependymal tumors. Of all participants, 80 reported that they received no information packets regarding the disease upon diagnosis, with only 11 reporting that they received a general ependymoma information guide. Despite these results, 100 of the 108 participants felt that more visual resources would have been helpful regarding their initial understanding of the disease, ranking a three or above out of five on a scale.

On a similar scale, 78 participants noted that they struggled to keep up with language used in resources they were given or sought out, with 15 of the 78 reporting it to be "extremely challenging". In terms of grading and classification, participants were more knowledgeable with only 18 being unfamiliar with the respective topic. Contrarily, when it came to biomarkers and genetic testing, an overwhelming majority of 98.1% (101 participants) knew little about the topic, with 31.3% reporting that they had never heard of the terms.

Thesis Prospectus

Introduction / Abstract

The focus of this project is to provide both patients and caretakers impacted by ependymal tumors with the proper resources necessary to better understand the disease and the ways it can impact the human body. Ependymal tumors represent 1.8% of all tumors found in the primary central nervous system (CNS), and are the third most common brain tumor in children, accounting for 5.2% of all primary CNS tumors in children 19 years and younger (Rudá et al., 2017).

Despite their clinical importance, there is a severe lack of accessible and coherent materials for patient education which perpetuates persistent gaps of knowledge between patients, caregivers, and their families and the complex nature of the disease they are impacted by. Because of this scarcity of comprehensive visual and written educational material, an illustrated guide for those newly diagnosed or seeking more in-depth information would be highly beneficial.

Thesis Prospectus

Literature Review

Focus Question: What is the importance of grading and classification of ependymal tumors?

For many newly diagnosed patients, the idea of learning about a disease that they previously knew nothing about can be a very daunting task. The introduction of a tumor type that they had likely never heard of before, coupled with the complexity of its classifications makes it very hard for patients to understand what is happening inside of their own bodies, and a lack of patient education material only perpetuates this gap of patient and caretaker knowledge. From a scientific and medical standpoint, grading and classification of ependymal tumors helps those diagnosing these individuals create a specialized treatment plan, and aid in determining the speed of growth, location, and more of each tumor. This knowledge is also highly valuable to patients when it comes to their own understanding.

Classification by location

Ependymal tumors are classified by their location in three separate categories. These categories include supratentorial, posterior fossa, and spinal cord, and are further classified by their histopathological features as well as molecular features that can only be determined by a surgical resection followed by studies performed on the extracted tissue (Fowler, 2016). The location of this tumor helps medical professionals as well as patients and caretakers determine what side effects may be experienced as a result of what structures the tumor may

be impeding. These classifications allow patients to have a more narrow framework regarding researching the disease, as it allows a breakdown of only specific structures rather than the entire central nervous system if one chooses to look into further research, and gives medical professionals more structure when it comes to treating their patients.

The difference in location is also utilized when it comes to the initial diagnosis of ependymal tumors. Due to the anatomical structures associated with each region/ location, there are specific symptoms that may be present due to location that are not at all present when at a different location. While it is not probable to diagnose an ependymal tumor without surgical resection and studying tumor tissue due to the need for molecular and histopathological information, inferences can be made when tumors are found in the fourth ventricle, for example, it may be an ependymal tumor due to rarity of other tumors found in that location (Zamora, 2023). However, further research is highly necessary to properly determine this diagnosis, and further testing is necessary to determine specifics beyond the general overarching tumor type.

Supratentorial Tumor Classifications

In addition to specifics of location, ependymal tumors are further classified by molecular and histopathological features that can be studied following a surgical resection of tumor tissue. For supratentorial ependymal tumors, further categorization is defined by the presence or lack of ZFTA fusion, which was classified as RELA fusion prior to the World Health Organization's 2021 classifications, and YAP1 fusion

(Mu and Dahmoush, 2023). The presence of ZFTA fusion, which stands for “zinc finger translocation associated” fusion, can lead to “a 10-year overall survivor rate of approximately 50%”, which is lower than that of the YAP1 fusion counterpart (Mu and Dahmoush, 2023). Regarding the general physical characteristics of ZFTA fusion-positive supratentorial ependymal tumors, the majority are found to be large, heterogeneous masses with a mix of solid as well as cystic elements (Zamora, 2023). Additionally, the presence of necrotic tissue, calcification, and hemorrhaging are commonly associated with these types of tumors (Zamora, 2023).

YAP1 fusion-positive supratentorial ependymal tumors, while less common and accounting for only 7% of supratentorial tumors, have a generally better prognosis than those with ZFTA fusion and are also found to be slightly more prevalent in female patients (Mu and Dahmoush, 2023). In terms of the physical appearance of these tumor types, similar to ZFTA fusion-positive tumors, they present as a mix of solid and cystic elements although are generally less heterogeneous, which is apparent through imaging (Zamora, 2023).

Supratentorial ependymomas, which present with neither ZFTA nor YAP1 fusion, can be categorized as either CNS WHO Grade 2 or 3 tumors, while those with molecular markers are not given a grade (Mu and Dahmoush, 2023). The lack of grade is due to a gap in research regarding these molecular markers and gene fusions, therefore the specification of the presence of these molecular markers accomplishes the same task as a grade associated with tumors not found to have notable gene fusions (Louis et al., 2021).

Thesis Prospectus

Posterior Fossa Tumor Classifications

Ependymal tumors of the posterior fossa, or the lower back part of the brain consisting of structures such as the brain stem and cerebellum, are divided into three subgroups. These groups are determined by the presence of methylation, breaking posterior fossa ependymal tumors into PFA and PFB subgroups, as well as a general posterior fossa classification for lack of molecular markers (Louis et al., 2021).

When comparing the prognosis of PFA and PFB ependymomas, it is found that group A tumors have a lower survival rate as well as a higher recurrence and metastasis rate, therefore a significantly worse prognosis (Mu and Dahmoush, 2023). In addition to these differences, molecular markers have also shown a distinction when it comes to prevalence in age as well as gender, with PFA tumors being more apparent in "infants and young children, with a median age of three years and a slight prevalence in male patients" while PFB tumors are generally more common in "adolescents and young adults, with a median age of 30 years, and are slightly more common in females" (Mu and Dahmoush, 2023).

From a physical standpoint, there are not any significant differences, although PFA tumors are more likely to calcify than their PFB counterparts (Mu and Dahmoush, 2023). These changes, while they may be minor to some patients, signify the importance of molecular data concerning cancer diagnoses and their resulting prognoses.

Thesis Prospectus

Spinal Tumor Classifications

Ependymal tumors found in the spinal cord are separated into two classifications, MYCN amplified and spinal ependymoma, which can be graded at CNS WHO 2 or 3 (Louis et al., 2021). These tumors can be found in any section of the spinal cord, but tend to be most common in the cervical area (Louis et al., 2021). Symptoms associated most with spinal ependymal tumors are weakness, pain, and sensory changes, and incontinence is also occasionally observed; the commonality of sensory symptoms is likely due to the location of these tumors (the center of the spinal column) (Mu and Dahmoush, 2023).

MYCN amplification accounts for a relatively small amount of spinal ependymal tumors, with "fewer than 30 cases reported" in the WHO's 2021 classifications, and they are observed to be more frequent in adolescent young adult female patients (Mu and Dahmoush, 2023). Prior to the 2021 WHO report, the MYCN-amplified spinal ependymal tumors would have been classified as grade 3 anaplastic ependymomas, and now have no associated grade due to the research gap in these molecular findings (Rudá et al., 2017). MYCN-amplified tumors physically present as large, often involve more than a single vertebral layer, and can be found intramedullary or extramedullary (Louis et al., 2021).

Spinal ependymal tumors that lack MYCN amplification tend to be less aggressive and much smaller, while still generally being heterogenous (Mu and Dahmoush, 2023). These tumors may not be removed, and may also be referred to as benign.

Thesis Prospectus

Subependymomas and Myxopapillary Ependymomas

Following the WHO 2021 classifications, myxopapillary and subepedymomas remained unchanged, with no additional molecular markers adding to their specificity (Mu and Dahmoush, 2023).

Media Rationale

The chosen medium of a printed booklet with availability in PDF format online is the most beneficial as it gives the audience something tangible to flip through as well as a more easily accessible version to browse through virtually. Because many patients viewing this material may have visual or cognitive limitations, a printed booklet with large text and clear illustrations is vital to their understanding of the information being provided. This medium allows all of the information to stay together cleanly in one place without the risk of losing specific pages or things getting out of order and thus becoming confusing. The digital format also allows the audience to zoom in and out as needed for purposes of clarity and also provides more access to those not able or wanting to get a physical copy. For native English speakers, either version is ideal and may be up to personal preference regarding what medium they prefer, and printed material is generally more easily understandable for non-native English speakers. Studies have shown that printed material is more accessible to patients and a generally preferred medium when it comes to patient education material.

Thesis Prospectus

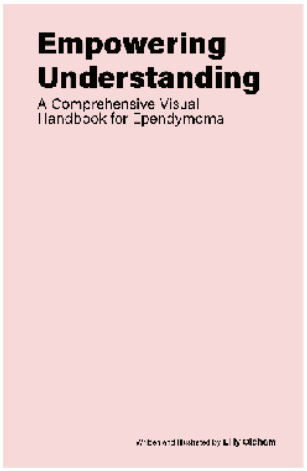
Audience Analysis

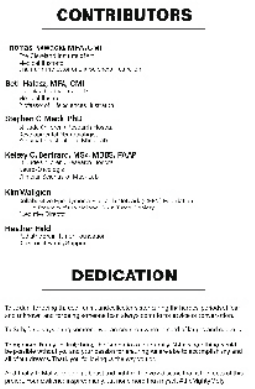
The intended audience of this project is patients and caretakers impacted by ependymal tumors. The goal is to provide a succinct and comprehensive guide to the relevant anatomy, terminology, and general information regarding the tumor type, with portions geared specifically toward patients and other sections meant for caretakers or those seeking more in-depth information. Because some patients are not interested in learning anything beyond basic anatomy, distinctions will be made for sections that this audience may be hoping to avoid. Having all of the information in a single resource allows accessibility for both children and adults, as well as the different demographics that may seek different levels of understanding.

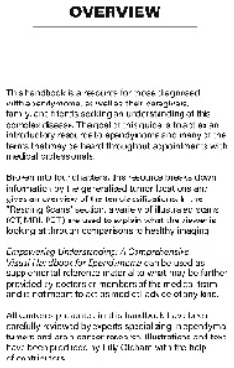
Audience Effectiveness

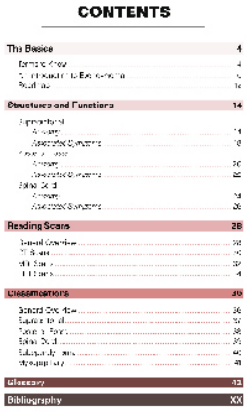
Primary research was conducted via an online survey through Google Forms, and 112 responses were collected from a variety of patients, caretakers, and others impacted by ependymal tumors. Based on the collected responses, it is clear that the majority of patients only care about learning about grading and classification along with relevant anatomy, and tend to avoid additional information in fear of finding statistics that are stressful or damaging to their mental health, while many caretakers wish to learn as much as possible about this disease.

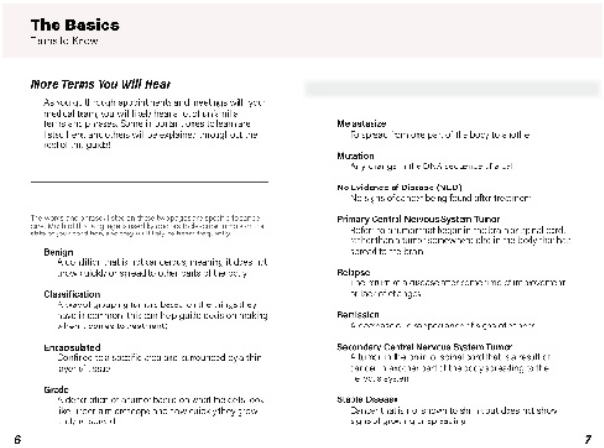
Mid-Year Sketches

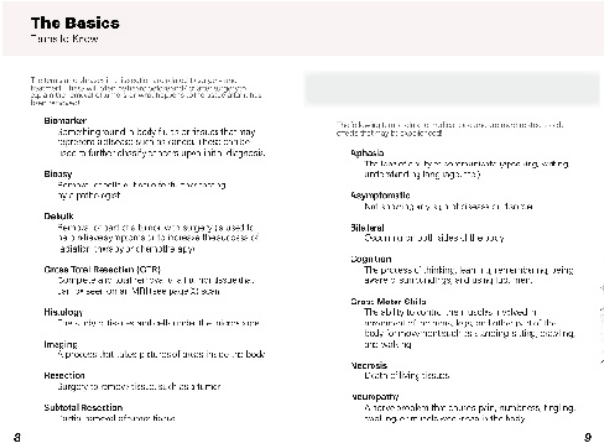


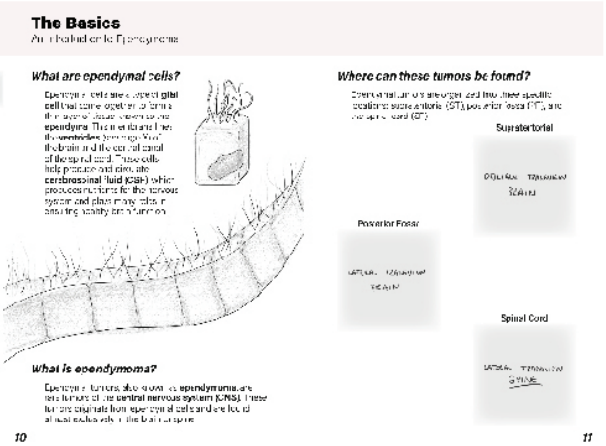




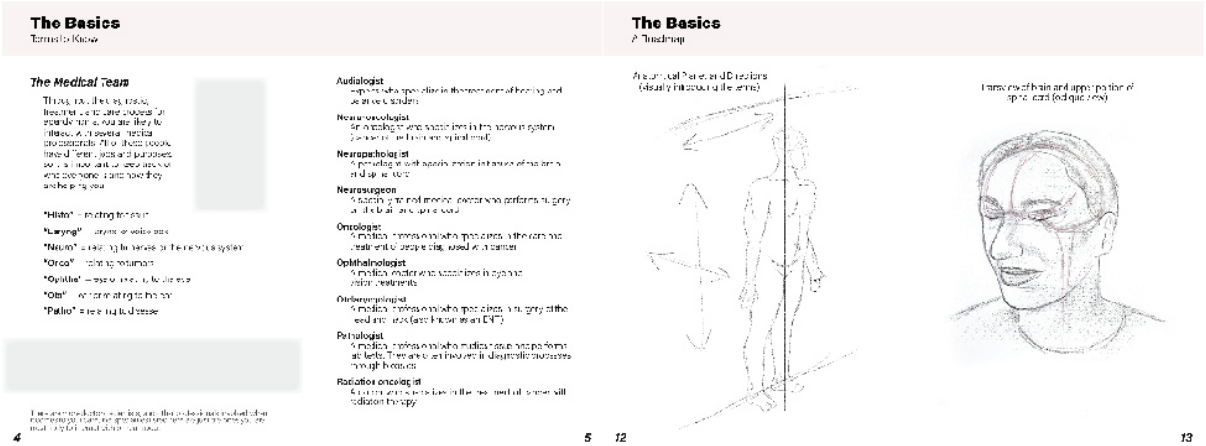








Mid-Year Sketches



The Basics
Terms to Know

The Medical Team

"Histo" – relating to tissue
"Laryng" – relating to voice box
"Neuro" – relating to nerves or the nervous system
"Oreo" – relating to mountain
"Ophtho" – relating to the eye
"Oto" – relating to the ear
"Patho" – relating to disease

Audiologist
A specialist who specializes in the assessment of hearing and balance disorders.

Neuro-oncologist
An oncologist who specializes in the treatment of tumors in the nervous system (brain, spinal cord, and peripheral nerves).

Neuropsychologist
A psychologist who specializes in the assessment and treatment of cognitive, behavioral, and emotional disorders related to brain function.

Neurosurgeon
A medically trained physician who performs surgery on the brain, spinal cord, and peripheral nerves.

Oncologist
A medical professional who specializes in the diagnosis and treatment of cancer, using chemotherapy, immunotherapy, and other targeted therapies.

Ophthalmologist
A medical doctor who specializes in eye and vision treatments.

Otolaryngologist
A medical professional who specializes in surgery of the head and neck (also known as an ENT).

Pathologist
A medical professional who studies tissue samples to identify diseases. They play a crucial role in diagnosing cancer through biopsies.

Radiation oncologist
A medical oncologist who uses high-energy radiation, such as X-rays, to kill cancer cells or shrink tumors.

4 5

The Basics
A Timeline

Anatomical Terms of Directions
(usually in reference to the arms)

Transverse of brain and upper portion of spinal cord (oblique view)

12 13

Structures and Functions
Supratentorial Anatomy

Cerebrum

Left Hemisphere

Anterior (front) — Posterior (back)

frontal

temporal

parietal

occipital

14 15

Structures and Functions
Supratentorial Anatomy

Diencephalon

diencephalon

Cerebral Ventricular System

Lateral and Third Ventricles

ventricles

ventricles

16 17

Reading Scans
PET

Healthy Scan

Scan Showing Tumor

Color Chart

What you see...

Transview

Solid and Cystic

34 35

Reading Scans
Scans: Overview

Types of Scans

CT Scan

MRI Scan

PET Scan

28 29

Final Product

The Basics
Terms to Know

Audiologist
Experts who specialize in the treatment of hearing and balance disorders

Neuro-oncologist
An oncologist who specializes in the nervous system (cancer of the brain and spinal cord)

Neuropathologist
A pathologist with specialization in tissues of the brain and spinal cord

Neurosurgeon
A specially trained medical doctor who performs surgery on the brain and spinal cord

Oncologist
A medical professional who specializes in the care and treatment of people diagnosed with cancer

Ophthalmologist
A medical doctor who specializes in eye and vision treatments

Otolaryngologist
A medical professional who specializes in surgery of the head and neck (also known as an ENT)

Pathologist
A medical professional who studies tissue and performs lab tests. They are often involved in diagnostic processes through biopsies

Radiation oncologist
A doctor who specializes in the treatment of cancer with radiation therapy

The Basics
Terms to Know

The Medical Team

Throughout the diagnostic, treatment, and care process for ependymoma, you are likely to interact with several medical professionals. All of these people have different jobs and purposes, so it is important to keep track of who everyone is and how they are helping you!

"Histo" = relating to tissue
"Laryng" = larynx, or voice box
"Neuro" = relating to nerves or the nervous system
"Onco" = relating to tumors
"Ophtha" = eye or relating to the eye
"Oto" = ear or relating to the ear
"Patho" = relating to disease

There are more doctors, scientists, and other professionals involved when it comes to your care, the specialties listed here are just the ones you are most likely to interact with or hear about!

The Basics
Terms to Know

More Terms You May Hear

As you go through appointments and meetings with your medical team, you will likely hear a lot of unfamiliar terms and phrases. Some important ones to learn are listed here, and others will be explained throughout the rest of this guide!

The words and phrases listed on these two pages are specific to cancer care. Much of this language is used by doctors to describe tumors or the state of your condition, and they will likely be heard frequently.

Benign
A condition that is not cancerous, meaning it does not grow quickly or spread to other parts of the body

Classification
A way of grouping tumors based on the things they have in common (this can help guide decision-making when it comes to treatment)

Encapsulated
Confined to a specific area and surrounded by a thin layer of tissue

Grade
A description of a tumor based on what the cells look like under a microscope and how quickly they grow and/or spread

Metastasize
To spread from one part of the body to another

Mutation
Any change in the DNA sequence of a cell

No Evidence of Disease (NED)
No signs of cancer being found after treatment

Primary Central Nervous System Tumor
Refers to a tumor that began in the brain or spinal cord, rather than a tumor somewhere else in the body that has spread to the brain

Relapse
The return of a disease after some time of improvement or lack of changes

Remission
A decrease or disappearance of signs of cancer

Secondary Central Nervous System Tumor
A tumor in the brain or spinal cord that is a result of cancer in another part of the body spreading to the nervous system

Stable Disease
Cancer that is not shown to shrink but does not show signs of growing or spreading

The Basics
Terms to Know

The terms and phrases in this section are related to surgery and treatment. These will often be heard before and/ or after surgery to explain the removal of tumors, or what happens to the tissue after it has been removed!

Biomarker
Something found in body fluids or tissues that may represent or help classify a disease such as cancer (also called molecular markers)

Biopsy
Removal of cells or tissue for further testing

Debulk
Partial removal of a tumor with surgery

Gross Total Resection (GTR)
Complete and total removal of all tumor tissue that can be seen on an MRI scan

Histology
The study of tissues and cells under the microscope

Imaging
A process that takes pictures of inside the body

Resection
Surgery to remove tissue, such as a tumor

Subtotal Resection
Partial removal of tumor tissue

The following terms relate to medical care and are more related to side effects that may be experienced!

Aphasia
The loss of ability to communicate (speaking, writing, understanding language, etc.)

Asymptomatic
Not showing any sign of disease or disorder

Bilateral
Occurring on both sides of the body

Cognition
The process of thinking, learning, remembering, being aware of surroundings, and using judgment

Gross Motor Skills
The ability to control the muscles involved in movement of the arms, legs, and other part of the body for movement such as standing, sitting, crawling, and walking

Necrosis
Death of living tissues

Neuropathy
A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in the body

The Basics
Terms to Know

Pediatric-Specific Terms

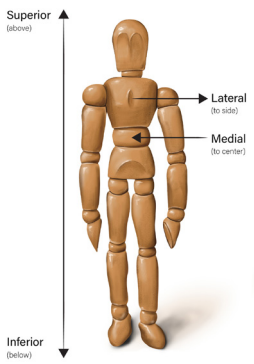
The following few terms are related to the treatment and care of pediatric patients. While many of the specialists working with adult patients are also able to assist in the treatment of children and young adults, there are additional specialists and concepts involved in their care to ensure all needs are met!

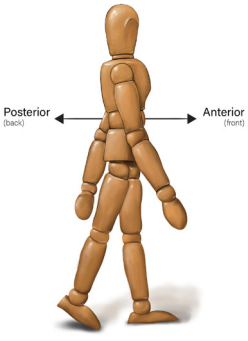
Certified Child Life Specialist (CCLS)
A professional who provides insight to children and their families when it comes to preparing for and understanding their diagnosis, treatment, coping tools, and much more! These specialists work with the rest of the medical team and focus on the comfort of pediatric patients and their families

Medical Social Worker
A professional who works alongside a medical team to assist patients and their families with the transition into a medical environment

Pediatric Palliative Care
A medical specialty that focuses on the comfort and quality of life of young patients with severe diseases

The Basics
Anatomical Directions





The Basics
An Introduction to Ependymoma

What is ependymoma?

"uh-pen-duh-mow-mah"

Ependymal tumors, also known as **ependymoma**, are rare tumors of the **central nervous system (CNS)**. These tumors originate from ependymal cells and are found almost exclusively in the brain or spine.

Brain cancer and tumors are represented through grey ribbons, and the symbol for ependymoma is the monarch butterfly!

What are ependymal cells?

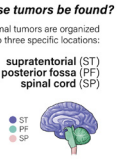
"uh-pen-duh-mahl"

Ependymal cells are a type of **glial cell** that come together to form a thin layer of tissue known as the **ependyma**. This membrane lines the **ventricles** (see pages 19 and 21) of the brain and the central canal of the spinal cord. These cells help produce and circulate **cerebrospinal fluid (CSF)**, which produces nutrients for the nervous system and plays many roles in ensuring healthy brain function.

Where can these tumors be found?

Ependymal tumors are organized into three specific locations:

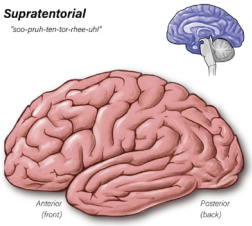
supratentorial (ST)
posterior fossa (PF)
spinal cord (SP)



Final Product

Structures and Functions
Supratentorial Anatomy

Supratentorial
"soo-pruh-ten-tor-rhee-uhl"



Cerebrum
"suhr-ee-brum"

The upper part of the brain, which is known as the **cerebrum** (or telencephalon), is split into two sections called **hemispheres** (the left is seen above). These hemispheres, right and left, are further broken down into four sections called **lobes**. Each of these lobes has specific jobs that work together to make your body do its thing!

Lobes of the Brain

Frontal

The largest of the four, the frontal lobe has many jobs. Some of these functions include problem-solving, impulse control, and voluntary movement.

Temporal

Known best for helping us hear, the temporal lobe also plays a role in understanding language, as well as when it comes to long-term memory and reading!

Parietal

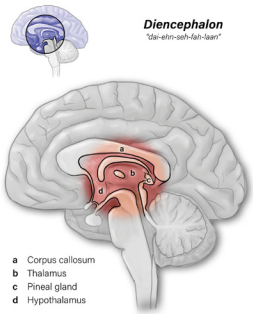
Located in the back upper part of the brain, the parietal lobe takes information from nerves and translates it into the things we feel and see.

Occipital

The occipital lobe, with the word "occipital" referring to the location in the back of the head, is tasked with helping us understand what we see!

Structures and Functions
Supratentorial Anatomy

Diencephalon
"dai-ehn-seh-fah-laan"



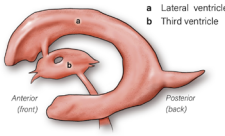
a Corpus callosum
b Thalamus
c Pineal gland
d Hypothalamus

The **diencephalon** (also called the interbrain) is a section of the brain that lies between the cerebrum and the hindbrain (see page 20). It contains structures that help release hormones and regulate sleep cycles!

Cerebral Ventricular System
"suhr-ee-brahl ven-tri-kuh-lahr"

The **ventricles** of the brain are part of a system called the **cerebral ventricular system**, which includes four ventricles, or cavities, that work together to produce cerebrospinal fluid. These ventricles are found in both the supratentorial and posterior fossa areas of the brain, with the **lateral ventricles** (there are two, one in each hemisphere) and the **third ventricle** being supratentorial. The fourth ventricle is found in the posterior fossa (see page 20). These structures are lined by ependymal cells which form the ependyma.

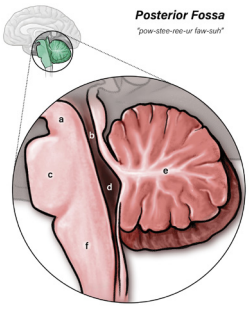
Lateral and Third Ventricles



a Lateral ventricle
b Third ventricle

Structures and Functions
Posterior Fossa Anatomy

Posterior Fossa
"pow-stee-ree-ur faw-suh"



a Cerebral pundicle
b Cerebral aquaduct
c Pons
d Fourth ventricle
e Cerebrum
f Medulla oblongata

Hindbrain

The hindbrain is the lower part of the brain that is made of two important structures: the brainstem and the cerebellum.

The **brainstem** is one of the most important parts of the central nervous system and consists of three parts, each of which has specific roles to play when it comes to general bodily functions.

The **cerebellum**, which is often presented as a wrinkly, coral-like texture, helps control voluntary movements and things such as posture and balance!

Cerebral Ventricular System

The **fourth ventricle** of the brain, the last part of the cerebral ventricular system (see page 19), is located between the pons and cerebellum. This ventricle is slightly different from the others, as it extends down into a very thin canal that enters the spinal cord.

The cerebrospinal fluid that fills the space within this cavity also drains into the space surrounding the spinal cord, which is called the **subarachnoid space**.

Structures and Functions
Spinal Cord Anatomy

Vertebral Column
"vur-tuh-bruhl kaah-luhm"

The vertebral column is divided into five sections based on the location and structure of the vertebrae, which are the bones that make up the spine. These sections are known as the **cervical**, **thoracic**, **lumbar**, **sacral**, and **coccygeal** regions.

- **Cervical** ("sur-vuh-kl")
- **Thoracic** ("thr-a-suhk")
- **Lumbar** ("luhm-baar")
- **Sacral** ("seih-kruhl")
- **Coccygeal** ("kaak-si-gee-uhl")

Each spinal region is made of a different number of vertebrae, and are represented with a corresponding letter and number. The bones are numbered starting superiorly, or from the top of the spine, and moving down.

The cervical region, which is the neck, has seven bones which are referred to as **"C1" through "C7"**.

There are twelve thoracic vertebrae, **"T1" through "T12"**, which make up the upper portion of the back.

Lastly, there are only five lumbar vertebrae, which are noted as **"L1" through "L5"**, and make up the lower part of the spine.

The sacrum is made of five vertebrae, which fuse together as we grow to form one structure.

Similarly, the coccyx is made of several fused vertebrae, although this number can vary from three to five, with four being most commonly seen!

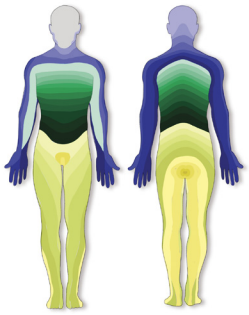
Structures and Functions
Spinal Cord Anatomy

Spinal Nerves
"spai-nuhl nurves"

The spinal cord is contained within the vertebral column and has many **spinal nerves** that branch out between the vertebrae. These branches from the spinal cord are responsible for sensation throughout the body, so knowing the connection between the location of a tumor and where sensations may be impacted is important.

Dermatomes, which can be seen on the next page, help visualize these connections, as each color on the body corresponds to a spinal nerve seen on the vertebral column! While there are only seven cervical vertebrae, there are eight corresponding nerves!

Dermatomes



Reading Scans
General Overview

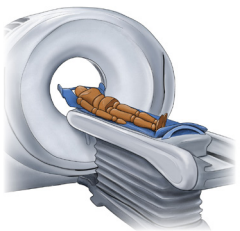
Types of Scans

There are several types of scans, or imaging, that can be run in order to look for changes within the body. The most common types that an ependymoma patient may experience are CT, MRI, and PET scans, which are described on the following pages.

Computed Tomography (CT)
"kuhm-pyoo-tuhd tuh-maa-gruh-fee"

Magnetic Resonance Imaging (MRI)
"mag-neh-tuhk reh-zuh-nuhns i-muh-jung"

Positron Emmissions Tomography (PET)
"paa-suh-traan ee-mi-shnz tuh-maa-gruh-fee"



These machines can look big and scary, but they are only here to help. For some types of scans, patients may hear some loud noises that can be intimidating; these sounds are normal and necessary for the machines to do their jobs.

It may take time to get used to the sounds and everything involved in getting scans, but your medical team is there to help and provide tips and tricks to get more comfortable!

Final Product

Reading Scans
CT

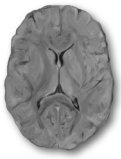
Computed Tomography Scan

CT scans are very fast and are generally performed in emergency rooms to get an early understanding of what is happening within the body. These give more information than X-rays (which are mainly used to look at bones) but are the least detailed of the three examples shown in this guide.

CT scans use a very small dose of radiation to create the imagery doctors use to diagnose tumors or other changes to the body, and this amount is specifically calculated and tailored to each patient.

Important to note:

While this type of imaging does use doses of radiation, these amounts are very small and will not stay in the body after the scans are complete.



Understanding the Colors

- **Gases and liquids** tend to appear black on CT scans, as they are not absorbing as much light from the X-rays when compared to bone or other more solid structures!
- **Bone** and harder parts of the body appear white on these scans.
- **Softer structures** of the body (like parts of the brain) will be represented in different shades of gray. These shades depend on the density of the tissue and how they interact with the X-rays.

CTs can be taken with something called a contrast agent, which may be given as a drink or through an injection depending on what is being looked at. This material blocks the X-rays that are used to take the images and will help emphasize blood vessels or other structures that may be important for a doctor to look at.

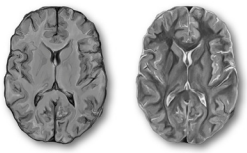
After scans with contrast are taken, patients may be asked to drink a lot of water or fluids to help speed up the process of flushing the contrast agent!

Reading Scans
MRI

Magnetic Resonance Imaging Scan

These scans can capture intricate details through the use of magnets and radio waves. MRI scans are slightly different than X-rays and CTs, as they do not use radiation, and can also require patients to be still for a long time as the machine works.

Because MRIs use a strong magnetic field, the patient must have no metal on or in their body, which includes jewelry, hearing aids, pacemakers, etc.



T1
(used to see anatomy and tissues within the body)

T2
(used to show anatomy with a focus on fluids such as CSF)

Understanding the Colors

T1	T2
Bones and fluids (such as CSF or vertebrae)	**Bones and liquids** (such as CSF or vertebrae)
Fat content such as white matter as well as new areas of inflammation	**Fluids** such as CSF
Dark gray represents **grey matter** while lighter gray represents **white matter** in the brain (**muscles** also appear gray)	Light gray represents **grey matter** while darker gray represents **white matter** in the brain (**muscles** also appear gray)

This is the most common type of imaging for patients needing consistent scans for check-ins because there is no radiation involved. There are also a lot of different types of MRIs, each with different purposes for what a doctor may want to look at (T1 and T2 seen on the left are standard and will likely be seen).

These scans can be run with or without contrast, which for MRIs is an injection that adds clarity to the images by changing the way fluids interact with the magnets of the machines taking the images.

Reading Scans
PET

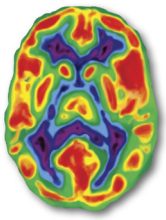
Positron Emission Tomography Scan

PET scans are used to show the rate of chemical reactions (the metabolism) of cells within tissue and organs. In order to make this happen, something called a tracer must be introduced into the blood, which allows these metabolic rates to show up on the imagery (like contrast agents for CTs and MRIs).

These scans can be used alongside CTs and MRIs to help detect things such as recurrence, the spreading of cells, and to see how effective a treatment is!

What you see...

When looking at a PET scan, you may notice that there are several colors shown throughout the image. These colors represent different metabolic rates, which determine how active certain cells may be in specific areas!



Color Chart

Low Activity — High Activity

Classifications
Subtypes of Ependymoma

How does it work?

Ependymomas are classified based on several factors, including location and biomarkers (see page 8). As seen throughout this guide, the supratentorial, posterior fossa, and spinal cord regions are important not only because of the differences in anatomy and resulting impacts on the body but also because they play a role in the classifications themselves.

Important to note:

As more research is done to aid in the understanding of ependymoma, more accurate classifications and, as a result, more accurate diagnoses can be made. This means it is important to keep up with new research and stay up-to-date on these tricky categories!

What are grades and stages?

When thinking of cancer and tumors, it is common to associate a grade or stage along with the type ("stage 2 breast cancer" or "grade 1 breast cancer"). Grades refer to the cancer cells themselves and what they look like under a microscope. Stages, on the other hand, relate more to the size of an initial or primary tumor and how it is spreading in the body.

Does that apply to ependymoma?

Instead of categorizing them by the severity or how they spread, ependymomas are assigned a specific name based on what is found genetically and where it is located. This allows a more specific diagnosis to be made, which is why it is important to know the specific type of ependymoma a patient has!

For some tumors, however, there are no significant biomarkers found. For these, a grade can be assigned in addition to their location. Additionally, there are cases where biomarkers are not assessed; in these cases, they may be classified as "not otherwise specified" (NOS).

Classifications
Subtypes of Ependymoma

Supratentorial Subtypes

These are broken down based on molecular markers, specifically looking at fusions of two specific genes: ZFTA and YAP1. If either of these gene fusions is present, the classification is based on the biomarker.

If there are no gene fusions found, the tumor would be classified as a supratentorial tumor and can be assigned a grade of 2 or 3.

Supratentorial Ependymoma (ST-EPN)

ZFTA Fusion-Positive Ependymoma (ST-EPN-ZFTA)

YAP1 Fusion-Positive Ependymoma (ST-EPN-YAP1)

Posterior Fossa Subtypes

Posterior fossa tumors found to have no biomarkers can also be assigned a grade of 2 or 3, much like their supratentorial counterparts.

These tumors, however, are grouped into PFA and PFB categories based on methylation rather than specific gene fusions, which is another type of biomarker!

Posterior Fossa Ependymoma (PF-EPN)

Posterior Fossa A Ependymoma (PFA-EPN)

Posterior Fossa B Ependymoma (PFB-EPN)

Spinal Cord Subtypes

Spinal cord ependymomas are classified based on the presence (or lack) of an amplification of a specific gene, meaning there are extra copies of the MYCN gene. When this occurs, these tumors are put into their own classification and are not assigned a grade.

Just like the ependymomas found in the brain, spinal tumors with no additional biomarkers can be given a grade of 2 or 3.

Spinal Cord Ependymoma (SC-EPN)

MYCN Amplified Spinal Cord Ependymoma (SC-MYCN-EPN)

Additional Subtypes

Subependymoma (SE)

These are grade 1 tumors that can be found in either the brain or the spine, and unlike the other subtypes, they are not classified by location.

Subependymomas tend to be very slow-growing, so patients may be treated more for their pain rather than undergoing an aggressive treatment plan.

Myxopapillary Ependymoma (MPE)

Myxopapillary ependymomas are categorized as grade 2 and are found in the spine. Much like subependymoma, this classification is often very slow-growing and they are often considered to be benign.

Glossary
Ad - Bi

Ce - Co

Adolescent young adult (AYA)
Refers to those between the stages of childhood and adulthood, and can range anywhere from age 10 to 29 depending on the institution

Anterior
Referring to the front of the body (opposite of posterior), also called "ventral"

Aphasia
The loss of ability to communicate (speaking, writing, understanding language, etc.)

Asymptomatic
Not showing any sign of disease or disorder

Audiologist
Experts who specialize in the treatment of hearing and balance disorders

Benign
A condition that is not cancerous, meaning it does not grow quickly or spread to other parts of the body

Biomarker
Something found in body fluids or tissues that may represent a disease such as cancer (these can be used to further classify cancers upon initial diagnosis)

Biopsy
Removal of cells or tissue for the purposes of further testing by a pathologist

Central nervous system (CNS)
Consists of the brain and spinal cord

Cerebral ventricular system
Includes four ventricles that work together to produce cerebrospinal fluid (see "ventricle")

Cerebrospinal fluid
Produces nutrients for the nervous system and plays many roles in ensuring healthy brain function

Cerebrum
The upper part of the brain which is split into two hemispheres

Certified child life specialist (CCLS)
A professional who provides insight to children and their families when it comes to preparing for and understanding their diagnosis, treatment, coping tools, and much more

Cervical
Relating to the neck

Classification
A way of grouping tumors based on the things they have in common (this can help guide decision-making when it comes to treatment)

Coccygeal
Relating to the coccyx and the surrounding area

Final Product

Cognition
The process of thinking, learning, remembering, being aware of surroundings, and using judgment

Computed tomography scan (CT)
A type of scan that can be performed very quickly, generally performed in emergency rooms to get an early understanding of what is happening within the body

Dermatome
A visual guide that uses color to show what region of the body correspond to a spinal nerve seen on the vertebral column

Diencephalon
Also called the interbrain, a section of the brain found between the cerebrum and the midbrain which contains structures that release hormones and regulate sleep cycles

Encapsulated
Confined to a specific area and surrounded by a thin layer of tissue

Ependyma
A specialized tissue that is made of ependymal cells and is found lining the spaces of the central nervous system filled with cerebrospinal fluid

Ependymal cell
A type of glial cell that come together to form a thin layer of tissue known as the ependyma

Frontal lobe
Located in the front of the brain, functions include problem-solving, impulse control, and voluntary movement

Glial cell
A specialized cell that holds nerve cells in place ("glial" meaning glue)

Grade
A description of a tumor based on what the cells look like under a microscope and how quickly they grow and spread

Gross motor skills
The ability to control the muscles involved in movement of the arms, legs, and other part of the body for movement such as standing, sitting, crawling, and walking

Hemisphere
Sections of the cerebrum (there are two, left and right) which are further broken down into lobes

Hindbrain
The lower part of the brain which is made up of the brainstem and cerebellum

Histology
The study of tissues and cells under the microscope

Imaging
A process that takes pictures of areas inside the body

Inferior
Referring to the bottom of the body toward the feet (opposite of superior)

Lateral
Referring to the sides of the body and away from the center (opposite of medial)

Lobe
Sections of the brain (each hemisphere has four) with specific functions

Lumbar
Relating to the lower part of of the vertebral column and surrounding area

Magnetic resonance imaging scan (MRI)
A type of scan that uses strong magnets and radio waves to capture intricate details and images of the body

Medial
Referring to the middle of the body (opposite of lateral)

Medical social worker
A professional who works alongside a medical team to assist patients and their families with the transition into a medical environment

Metastasize
To spread from one part of the body to another

Mutation
Any change in the DNA sequence of a cell

Necrosis
Death of living tissues

Neuro surgeon
A specially trained medical doctor who performs surgery on the brain and spinal cord

Neuro-oncologist
An oncologist who specializes in the nervous system (cancer of the brain and spinal cord)

Neuropathologist
A pathologist with specialization in tissues of the brain and spinal cord

Neuropathy
A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in the body

No Evidence of Disease (NED)
No signs of cancer being found after treatment

Occipital lobe
Located in the back of the head and is tasked with helping understand what is seen (see "lobe")

Oncologist
A medical professional who specializes in the care and treatment of people diagnosed with cancer

Ophthalmologist
A medical doctor who specializes in eye and vision treatments

Otolaryngologist
Better known as an ear, nose, and throat doctor, or an ENT; A medical professional who specializes in surgery of the head and neck

Palliative care
A medical specialty that focuses on the comfort and quality of life of patients with severe diseases

Parietal lobe
Located in the back upper part of the brain and takes information from nerves and translates it into the things we feel and see (see "lobe")

Pathologist
A medical professional who studies tissue and performs lab tests (they are often involved in diagnostic processes through biopsies)

Pediatric palliative care
A medical specialty that focuses on the comfort and quality of life of young patients with severe diseases.

Positron emission tomography scan (PET)
A type of scan used to show the rate of chemical reactions (the metabolism) of cells within tissue and organs

Posterior
Referring to the back of the body (opposite of anterior), also called "dorsal"

Posterior fossa
Referring to the lower part of the brain and its structures

Primary brain tumor
Refers to a brain tumor that began in the brain, rather than a tumor somewhere else in the body that has spread to the brain

Radiation oncologist
A doctor who specializes in the treatment of cancer with radiation therapy

Relapse
The return of a disease after a time period of improvement or lack of changes

Remission
A decrease or disappearance of signs of cancer

Resection
Surgery to remove tissue, such as a tumor

Sacral
Relating to the sacrum and the surrounding area

Secondary brain tumor
Refers to a brain tumor that began somewhere in the body and has spread to the brain

Stable disease
Cancer that is not shown to shrink, but does not show signs of growing or spreading

Superior
Referring to the top of the body (toward the head)

Supratentorial
Referring to the upper part of the brain and its structures

Temporal lobe
Located on the sides of the brain, plays a role in understanding language, long-term memory, and reading (see "lobe")

Thoracic
Relating to the chest and the surrounding area

Tumor
An abnormal growth of tissue within the body

Ventricle
Connected cavities (empty structures) of the brain that protect the brain and are filled with cerebrospinal fluid

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Artist Statement

For many newly diagnosed patients, the idea of learning about a disease that they previously knew nothing about can be a very daunting task. The introduction of a cancer that they had likely never heard of before, coupled with the complexity of its classifications and involved anatomy makes it very hard for patients to understand what is happening inside their own bodies. The focus of this project is to empower the understanding of patients and caretakers impacted by ependymal tumors, giving them a tool to learn about this disease and help them advocate for themselves.

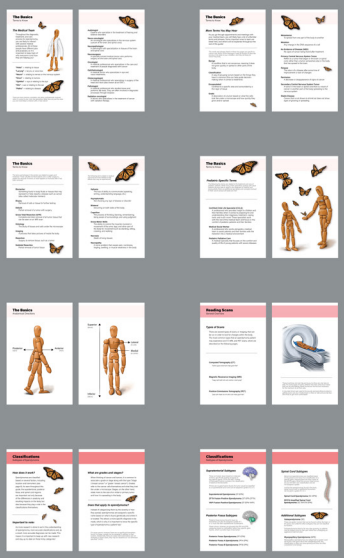
Upon diagnosis, most patients and their families receive little to no resources that help them understand what ependymoma is, leading to a very severe transition into a new medical environment. If resources are provided, they are often very medical in nature, which can lead to additional confusion, potentially turning patients away from seeking more information. This visual guide acts as an introductory resource that will help ease patients into the new and complicated environment that is the world of medicine.

Dedication

To the siblings of cancer warriors: your voice is heard and you are not alone. This is an incredibly difficult position to be in, but it is important to allow yourself to feel your emotions and understand that while you are not the face of this fight, you are still an important piece of the puzzle and your grief and emotions are valid. Cancer is something that happens to a family, not just an individual, so give yourself grace, take care of yourself, and know that people are thinking of you and rooting for you. I know I am.

Empowering Understanding

A Comprehensive Visual Handbook for Ependymoma



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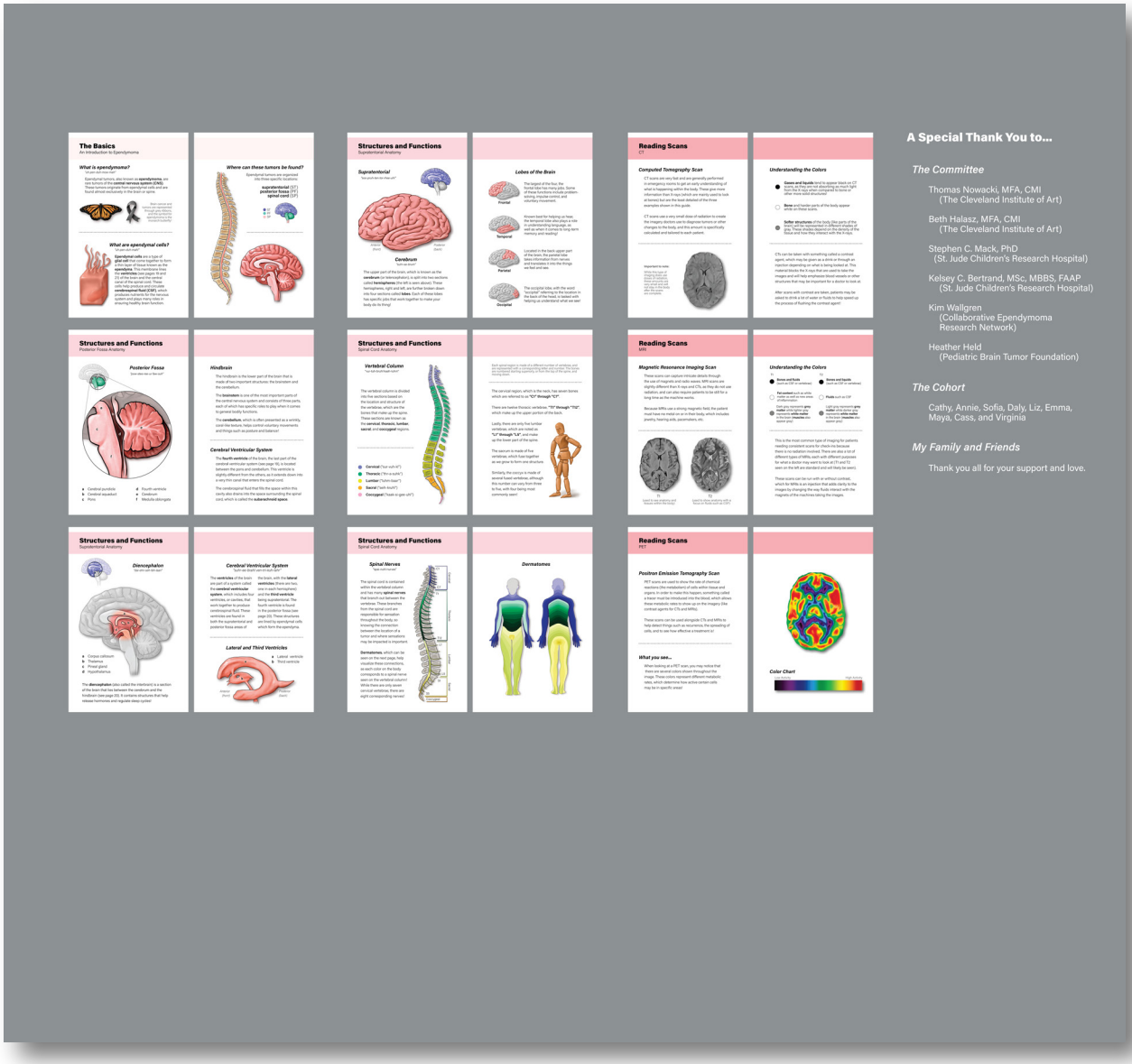

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