

# Brain Tumors 101



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Get Through it Together

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**PART 1**

**CHAPTER 1**

**ABOUT**

## GET THROUGH IT TOGETHER

At four months old, Misha was diagnosed with a brain tumor. It snaked in and out of her brainstem and exploded into the rest of her brain. It took out most her



cranial nerves on the right side of her face so she lost her ability to hear out of her right ear, move her face, and her right eye floated around like the die on the inside of a magic eight ball.

A day before she turned five months she had her first brain surgery. When she was done fighting her cancer Misha had over 13 surgeries, a

ventriculoperitoneal shunting (surgery to relieve pressure in the skull due to hydrocephalus [water in the brain]), a bone marrow and stem cell transplant, and enough radiation to light up your house for a year.

She survived three tumor resections, tons of chemotherapy, a bone marrow and stem cell transplant, and 5200 centigrays of stereotactic radiotherapy. This does not include all the trips to the hospital for infections, high-grade fevers, or the dozen or so supportive surgeries she had to go through to put in a broviac or to fix the paralysis on the right side of her face.

The moment the neuro-radiologist at Hoag Hospital told my parents “your daughter has a brain tumor”, the direction of my life stopped being my own. And I was not even alive when it was spoken.

I put this blog together to share my family's story and the decision making process my parents used to help my sister survive a horrible disease. My parents learned more about brain tumors and all the possible treatments of brain tumors than any person should.

From the time I was born, I have been given a front seat education to cancer and

the toll the treatments had on Misha's body and brain.

Whether I knew it or not, from a young age I was being prepped to take care of Misha in case her cancer came back.

The good news is that Misha is in remission. Despite her outcome, there were mistakes made by my parents and Misha's many doctors. A good example is after Misha's first surgery several doctors said that Misha's tumor was a juvenile pilocytic astrocytoma and basically a benign (non-cancerous) tumor. She was safe.

One month after her surgery, the tumor had quintupled in size, blocked the fourth ventricle in her brain (consider a ventricle like one of the canals in Venice, if blocked the water would have no place to go and Venice would flood). And that is the first lesson my father learned—understanding the true biology and behavior (pathology) of the brain tumor is the most critical aspect to determining treatment.

That lesson is having the right team to advise you. Just as every hospital has a brain tumor board to discuss each case, you must have one as well. My father had 32 doctors and specialists on his team. Not all of them knew they were on his board, but all of them gave the advice he needed to make a decision.

There were many mistakes, but there was more good done than bad. And none of it was by accident. And all of it was dictated by my mother and father's tenacity and understanding the brain tumor, the symptoms, and the talent they recruited to be on Misha's team.

First and foremost you must have a complete understanding of the language of cancer. Click on types of brain tumors. Review the symptoms and possible treatments. You cannot make a proper decision unless you have basic understanding of what cancer is and how it works in the body.

The next step is to know the types of doctors that will directly or indirectly determine treatment for your child. After that you need to recruit your brain tumor board. I use that term loosely. Rather you are gathering a group doctors that will advise you when it is time to make a critical decision. For example: whether or not to do surgery or radiation. Your brain tumor board is not for the everyday decisions, like blood draws or how to treat an infection.

I have done much of the leg work for you. In terms of getting an understanding of brain tumors, it will never replace your child's neurosurgeon, neuro-oncologist, or neurologist. You may have read it on the internet, but the odds are you have not brought up anything new. Regardless there is a chance that what you find combined with your doctor's prescribed treatment and the love you have for your baby might move him or her closer to surviving their disease.

Never stop researching the disease that is threatening your kid and put together your own brain tumor board. Please understand one thing: you cannot expect the doctors to do all the work. You must research and research and research, and question and question until you get the result you want. And you cannot take forever. My dad read thousands of pages, hundreds of articles in the first week of Misha's diagnosis just so he could make the right and best decisions for Misha. When he did that he was able to ask the right questions and understand the answers.

Where do you start? If your child has just been diagnosed start with understanding what cancer is, types of brain tumors, treatment for brain tumors, and then the brain tumor board. If you are in the middle and have been going at this awhile, start with the brain tumor board. Maybe you need a new perspective from a new set of ears.

For those of you who have survived the cancer and are now having to deal with the debilitating effects of the disease and treatments, you may want to start with education or life after treatment.

In this website I try to show where I found my research and put a link to the source at the end of each article. In the blog I will be interviewing doctors, writing on conferences, and discussing new research. In the News section, I will be placing links to news worthy articles and events. Please go through both to help in your research.

Lastly I am only an email away: amritoch@gmail.com. As you can tell I am not new to this and I am great researcher, and will use what I do know and skills to help you. Whatever I do not know I will find out and point you in the right direction. If there is something I forgot to add or you feel is important, email me and I will put it in.

I am not a doctor. I am just a girl whose life was predetermined the moment a doctor discovered a tumor the size of golf ball that threatened my sister's life. In

this blog I will share with you Misha's life and the way she overcame all her obstacles and how my family helped her survive a brainstem glioma.

Hopefully it will give you some insight and inspiration in your fight to help your baby overcome their brain tumor as well.

## **BRAIN TUMORS AND CANCER**

### **WHAT IS CANCER?**

It's scary to hear the words "Your child has cancer" coming from a doctor. You know it's a dangerous thing, but what exactly is it? Let's talk, and I'll tell you.

Cancer is a group of abnormal, sometimes damaged, cells that form and grow at an incredibly fast rate. When enough of them group together, they form a tumor. Tumors harm the digestive, nervous, and circulatory systems; they release a hormone that alters a persons' body functions.

There are two different types of tumors: benign and malignant. Benign is the kind of tumor you would rather have, other than having no tumor at all. Benign tumors stay in one spot of the body and are slow growing. A malignant tumor is the more dangerous of the two. Malignant tumors are known to metastasize, which means it can move to other parts of the body. Medical News Today describes two occurrences of malignant tumors:

1. a cancerous cell manages to move throughout the body using the blood or lymph systems, destroying healthy tissue in a process called invasion
2. that cell manages to divide and grow, making new blood vessels to feed itself in a process called angiogenesis.

### **WHAT CAUSES CANCER?**

There is no real certainty of what causes cancer. All we know is that it is a disruption in the normal cell process.

Your body creates new cells every day, mostly to repair, grow, or replace your old cells. This cell growth is controlled by your genes, not the ones you wear.

Sometimes, these genes get damaged, or mutated, and too many cells are produced. This cluster-bomb of damaged, mutated cells forms a tumor.

Another explanation describes the process of apoptosis, which is programmed cell death. Your body has an order as to when normal cells will be created, grow, and die. When this process fails to repeat, cancer forms. These cells do not die; instead, they keep growing and divide into more cancerous cells. This leads to a tumor.



**CHAPTER 2**  
**YOUR**  
**BRAIN TUMOR**  
**BOARD**

## WHAT IS A BRAIN TUMOR BOARD?

A brain tumor board is a team of physicians you put together for advisement on the decisions you will make regarding the treatment of your child's brain tumor.

Every hospital has a brain tumor board. Those doctors are there to oversee the care of patients with brain tumors at that specific hospital. Your brain tumor board will consist of doctors across the country, hopefully. There is a good chance you will not even meet half of the doctors you will be talking to.

You need as many different opinions from as many different doctors as you can get. My dad had 32 doctors he called regarding my sister.

The kinds of doctors you'll need:

- Neurologist
- Neuroradiologist
- Neuro-oncologist
- Neurosurgeon
- Neuropathologist

This is very important: You will need two (minimum) of these kinds of doctors. Each one should be from a different major center (a different, not connected hospital). Why? If you get two hospitals that are connected (take for example CHOC and Mission Hospital), then you are going to get similar methods. You need different major centers for different opinions.

How do you create your brain tumor board? That is an easy answer. You call and call until people are calling you back. Think of it like this. You're a salesman/woman. Would it be better for you if you were selling to 10 or 100 people? 100 people. That way you have more of a chance that someone will buy from you.

When you are calling, do not flat out say "I would like you to be on my brain tumor board." Imagine a representative from a charity asking you to donate money to their cause. Would you be very interested if someone came up to you

and said: “Donate money. It’s a worthy cause”? I didn’t think so. It’s better if they explain how it’s worthy and why you should donate.

It’s the same thing here. Describe to these doctors your situation. They will want to listen. Then, mention something about them that you read (in other words, flatter them) and how it could benefit your child. After that, they will want to help.

There is a good chance that they will not respond to your call right away. They are doctors; they work night and day to save lives. So, if after 72 hours (at most) they do not call you back, call them again. Your persistence may be annoying, but it will show that you care.

Once you have your team, use them for everything you can. Call them regarding which treatments would be best at the moment. Do not go to them for infections or fevers, they will tell you to go to your own doctor for that. Make sure that you call the right doctor for the situation you are in. And make sure you call several of the same kind of doctor to get different opinions on it. If they come to the same conclusion, you have your answer.

# **CHAPTER 3**

# **BRAIN TUMOR**

# **FACTS**

# FACTS ABOUT BRAING TUMORS

Used with permission by the Jeffery Thomas Hayden Foundation.

- Pediatric Brain Tumors are the leading cause of cancer related deaths in children 18 and under
- 3,200 new childhood primary malignant and non malignant and central nervous systems tumors are expected to be diagnosed in 2004. Of those, 2,450 will be in children under the age of 15
- In 2004 it is anticipated that there will be 12,690 deaths due to primary malignant brain tumors
- Brain tumors are the second leading cause of cancer related deaths in males ages 20-39
- Brain tumors are the fifth leading cause of cancer-related deaths in women ages 20-39
- Five year survival rates are a mere 27.9% in males and 30.1% in females
- Every day, an estimated 50 adults are diagnosed with a brain tumor in the United States
- 33% of patients diagnosed with brain cancer will survive five years
- Approximately 40,000 individuals in the United States will be diagnosed with primary brain tumors; of this total, more than 18,000 will be diagnosed with malignant primary brain tumors
- Metastatic brain tumors (cancer that spreads from other parts of the body to the brain) occur at some point in 10-15% of people with cancer and are the most common type of brain tumor.
- In the United States, the overall incidence of all primary brain tumors is 14.1 per 100,000 people.
- There are over 120 different types of brain tumors, making effective treatment very complicated.
- Brain tumors can be malignant or benign, and in either case can be life threatening.

- Brain tumors in children are different from those in adults and are often treated differently. Although as many as 69% of children will survive, they are often left with long-term side effects.
- Enhancing the quality of life of people with brain tumors requires access to quality specialty care, clinical trials, follow-up care, and rehabilitative services. Improving the outlook for adults and children with brain tumors requires research into the causes of and better treatments of brain tumors.

# **CHAPTER 4**

## **THE**

### **SYMPTOMS**

## WHAT ARE THE SYMPTOMS?

Here I thought if you are new to this, you are going to want a place where you can see the symptoms instead of scrolling through so many different kinds of brain tumors. So here I have provided a list of common ones. If your child is experiencing any of these, go to your doctor.

*(from National Institute of*

*Health: <http://www.nlm.nih.gov/medlineplus/braincancer.html>)*

- Very bad headaches in the morning
- Nausea and vomiting
- Ability to talk, hear, or see is changed
- Problems with balance and/or walking, almost as if drunk
- Problems with memory and/or thinking
- Muscle jerking or twitching
- Numbness, or tingling in arms/legs

When Misha was three months old, she displayed many symptoms of having a brain tumor. While she slept, her right eye would remain open, with the eyeball rolled up in the back of her head (see picture to the left). She would also cry for no reason at all. The pediatrician's explanations for these happenings were "Babies are quirky" and "Babies cry".

It was when Misha was four months old when she began throwing up more than usual. Immediately after the third or fourth bottle my parents would give her, she would throw up all her formula. When this happened my parents did not know if they just fed her too much or played with her too hard (Misha like to play a lot when she was a baby). The pediatrician gave his curt response: "You're over feeding her." Not once did he listen to my parents when they said something was wrong. In fact, he once asked my mom, "Mari, do you want your daughter to be sick?"

There was one instance in particular when the pediatrician finally listened. My family was at a restaurant they owned at the time in Laguna Beach. It was an



extremely hot day (and when it's hot, your face gets flushed, right?). Misha's face was only half flushed. There was a line down the center of her face that showed the contrast in skin color: the right side was flushed red, the left was not. This was definitely not normal.

This time it was my dad who called the pediatrician instead of my mom. He told him, "You will see my daughter on Monday." And he did. They went in that Monday, and after close examination the pediatrician concluded that it was Bell's Palsy (a disorder of the nerve that controls the movement of facial muscles. Damage to this nerve causes paralysis in the facial muscles). Misha was referred to a neurologist at Children's Hospital of Orange County (CHOC), Jeffery Levine, who also said it was Bell's palsy. Dr. Levine ordered an MRI for Misha, just in case. One week later, a tumor the size of a golf ball was discovered in her brain.



# **PART 2**

# **TYPES OF**

# **BRAIN TUMORS**

# **CHAPTER 5**

## **ACOUSTIC**

## **NEUROMA**

Thank you to the National Brain Tumor Society for these facts!

## **ACOUSTIC NEUROMA**

These tumors are considered very slow-growing and benign, meaning it won't spread to other places. It has some common symptoms: "drunken"-like movement, change in hearing, dizziness, headaches, and numbness.

An acoustic neuroma is also known as a schwannoma, vestibular schwannoma, or neurilemmoma.

### Characteristics

- Arises from cells that form a protective sheath around nerve fibers
- Typically grows around the eighth cranial nerve, but can be found around other cranial or spinal nerves

### Symptoms

- Hearing loss in one ear
- Dizziness or vertigo
- Tinnitus (ringing in the ear)
- Tingling or numbness in the face
- Walking and balance problems
- Lack of coordination

### Treatment

An acoustic neuroma may be observed in order to monitor its growth, or surgery may be performed. The goal of surgery is the complete removal of the tumor without harming the seventh cranial nerve (which controls facial movement) or causing hearing loss. Radiosurgery can be a viable option for many patients. This focused, high-energy radiation prevents the growth of acoustic neuromas, but actual shrinkage of the tumor may never occur or may take several months.

# **CHAPTER 6**

## **ASTRO- CYTOMAS**

## **GRADE I – PILOCYTIC ASTROCYOMA**

Also called Juvenile Pilocytic Astrocytoma (JPA)

This is the kind of tumor that doctors on the east coast thought Misha had before it was officially diagnosed as an oligodendroglioma. These tumors are generally benign; they don't grow and are not cancerous.

### Characteristics

- Slow growing, with relatively well-defined borders
- Grows in the cerebrum, optic nerve pathways, brain stem and cerebellum
- Occurs most often in children and teens
- Accounts for two percent of all brain tumors

### Treatment

Surgery is the standard treatment. If the tumor cannot be completely resected, radiation or chemotherapy may be given. Chemotherapy may be given to very young children instead of radiation therapy to avoid damage to the developing brain. Some of these tumors can progress to a higher grade, so it is important to be diligent about following up with the medical team after treatment.

## **GRADE II – LOW-GRADE ASTROCYTOMA**

These tumors are not very common, as they are very low-grade compared to a glioblastoma.

An astrocytoma is a type of glioma that develops from star-shaped cells (astrocytes) that support nerve cells. The WHO classifies a low-grade astrocytoma as a grade II tumor.

### Characteristics

- Slow growing
- Rarely spreads to other parts of the CNS

- Borders not well defined
- Common among men and women in their 20s-50s

#### Treatment

Treatment depends on the size and location of the tumor. The doctor will most likely perform a biopsy or surgery to remove the tumor. Partial resections or inoperable tumors may be treated with radiation. Recurring tumors may require additional surgery, radiation and/or chemotherapy.

### **GRADE III – ANAPLASTIC ASTROCYTOMA**

An astrocytoma is a glioma that develops from star-shaped glial cells (astrocytes) that support nerve cells. An anaplastic astrocytoma is classified as a grade III tumor.

#### Characteristics

- Grows faster and more aggressively than grade II astrocytomas
- Tumor cells are not uniform in appearance
- Invades neighboring tissue
- Common among men and women in their 30s-50s
- More common in men than women
- Accounts for two percent of all brain tumors

TreatmentTreatment depends on the location of the tumor and how far it has progressed. Surgery and radiation therapy, with chemotherapy during or following radiation, are the standard treatments. If surgery is not an option, then the doctor may recommend radiation and/or chemotherapy. Many clinical trials (experimental treatments) using radiation, chemotherapy, or a combination are available for initial and recurrent anaplastic astrocytomas.

### **GRADE IV – GLIOBLASTOMA**

The glioblastoma is the most common and most malignant of the astrocytomas. It is estimated that 60% of the 17,000 or so diagnosed brain tumors are glioblastomas.

An astrocytoma is a glioma that develops from star-shaped glial cells (astrocytes) that support nerve cells. A glioblastoma multiforme is classified as a grade IV astrocytoma. It is also referred to as a glioblastoma or GBM.

### Characteristics

- Most invasive type of glial tumor
- Commonly spreads to nearby tissue
- Grows rapidly
- Includes distinct genetic subtypes
- May be composed of several different kinds of cells (i.e., astrocytes, oligodendrocytes)
- May have evolved from a low-grade astrocytoma or an oligodendroglioma
- Common among men and women in their 50s-70s
- More common in men than women
- Accounts for 17 percent of all primary brain tumors

**Treatment**Standard treatment is surgery followed by radiation therapy or a combination of radiation therapy and chemotherapy. If surgery is not an option, the doctor may administer radiation therapy followed by or in conjunction with chemotherapy. Many clinical trials (experimental treatments) using radiation, chemotherapy, or a combination are available for initial and recurrent GBM. Clinical trials using molecularly targeted therapies showing success in other cancers are also being tested in GBM patients.



# **CHAPTER 7**

# **CHORDOMA**

The chordoma tumor is malignant, but grows slowly. Usually when it spreads, it spreads to the lungs.

#### Characteristics

- Rare and low grade
- Occurs at the sacrum, near the lower tip of the spine, or at the base of the skull
- Originates from cells left over from early fetal development
- Invades the bone and soft tissues but rarely the brain tissue
- Can block the ventricles, causing hydrocephalus (water on the brain)
- Can metastasize (spread) or recur

#### Symptoms

- Double vision
- Headaches

#### Treatment

Surgery and radiation therapy are the common forms of treatment. Chordomas at the base of the skull can be difficult to remove. Surgical resection may be possible if the tumor is located in the spine.

# **CHAPTER 8**

## **CNS**

### **LYMPHOMA**

CNS Lymphoma is a type of cancer that develops in the lymphatic system. The lymphatic system is a network of small organs called lymph nodes and vessels (similar to blood vessels) that carry a clear, watery fluid called lymph throughout the body. This fluid supplies cells called lymphocytes that fight disease and infection. To correctly diagnose primary CNS Lymphoma, staging must be done. Staging is the process of using CT scanning to examine many parts of the body. Staging helps to confirm where the cancer originated and how far it has spread.

### Characteristics

- Very aggressive
- Usually involves multiple tumors throughout the central nervous system (CNS)
- More common in people whose immune systems are compromised
- Often develops in the brain, commonly in the areas adjacent to the ventricles
- Can be primary (originating in the brain) or secondary
- Most common among men and women in their 60s-80s, but incidence is increasing in young adults
- More common in men than women
- Accounts for about two percent of all brain tumors

### Symptoms

- Headaches
- Partial paralysis on one side of the body
- Seizures
- Cognitive or speech disorders
- Vision problems

### Treatment

Radiation therapy, chemotherapy, and steroids are the most common forms of treatment. Surgery is rarely an option because there are usually multiple lesions. However, a biopsy at the start of steroid treatment can be critical to ensure the correct diagnosis.

# **CHAPTER 9**

## **CRANIO- PHARYNGIOMA**

The craniopharyngioma is a benign tumor that usually develops in the pituitary gland, a pea-sized organ at the base of the brain.

#### Characteristics

- Most common in the parasellar region, an area at the base of the brain and near the optic nerves
- Also grows in the regions of the optic nerves and the hypothalamus, near the pituitary gland
- Tends to be low grade
- Often accompanied by a cyst
- Originates in cells left over from early fetal development
- Occurs in children and men and women in their 50s and 60s

#### Symptoms

- Headaches
- Visual changes
- Weight gain
- Delayed development in children

#### Treatment

Surgery is the most common treatment. Radiation therapy may be used.

**CHAPTER 10**  
**DIFFUSE**  
**INTRINSIC**  
**PONTINE**  
**GLIOMA**

The DIPG is one of the rarer forms of brain stem gliomas.

Characteristics:

- Located in the pons
- Normally forms in children aged 5 to 10
- Grows in between and around normal cells
- Difficult to treat because of it's location
- Accounts for 5 out of every 100 brain stem gliomas diagnosed

Symptoms:

- Muscle weakness on one side of the body,
- Swallowing problems
- Speech problems
- Crossed eyes
- Drowsiness
- Hearing loss
- Personality changes

Treatment:

"These tumors are treated with radiation therapy, which are high-energy X-rays that destroy tumor cells. This treatment can reduce symptoms significantly, but there may be some permanent damage caused by the tumor which can't be helped. Steroids, another type of drug, are often given to improve some of the symptoms. Surgery is not part of the standard treatment because the tumor has grown within a part of the brain where resection is impossible. The effectiveness of chemotherapy is still uncertain" ("Reflections of Grace Foundation")



# **CHAPTER 11**

## **OTHER GLIOMAS**

## **BRAIN STEM GLIOMA**

Brain stem gliomas occur in the brain stem, as the name shows. It has many common symptoms. Misha's tumor formed itself on her brain stem. These kinds of tumors are dangerous because the brain stem controls many of your bodily functions, such as alertness, movement, and breathing. If during treatment, the surgeon was to damage the brain stem at all, things could get very bad.

### Characteristics

- Named for its location at the base of the brain
- Can range from low grade to high grade
- Occurs most often in children between three and ten years of age, but can occur in adults

### Symptoms

- Headaches
- Nausea
- Speech or balance abnormalities
- Difficulty swallowing
- Weakness or numbness of the arms and/or legs
- Facial weakness
- Double vision

Symptoms can develop slowly and subtly and may go unnoticed for months. In other cases, the symptoms may arise abruptly. A sudden onset of symptoms tends to occur with rapidly growing, high-grade tumors.

### Treatment

Surgery may not be an option because the brain stem controls vital life functions and can easily be damaged. Radiation therapy can reduce symptoms and help slow the tumor's growth. Low-grade brain stem gliomas can have very long periods of remission.

## **EPENDYMOMA**

Ependymal tumors begin in the ependyma, cells that line the passageways in the brain where cerebrospinal fluid (CSF) is produced and stored. Ependymomas are classified as either supratentorial (in the cerebral hemispheres) or infratentorial (in the back of the brain). Variations of this tumor type include subependymoma, subependymal giant-cell astrocytoma, and malignant ependymoma.

Ependymoblastoma, which occurs in infants and children under three years, is no longer considered a subtype of ependymoma. For ependymoblastoma, see primitive neuroectodermal tumor (PNET) in the Non-glial Tumors section.

### **Characteristics**

- Usually localized to one area of the brain
- Develops from cells that line the hollow cavities at the bottom of the brain and the canal containing the spinal cord
- Can be slow growing or fast growing
- May be located in the ventricles (cavities in the center of the brain)
- May block the ventricles, causing hydrocephalus (water on the brain)
- Sometimes extends to the spinal cord
- Common in children, and among men and women in their 40s and 50s
- Occurrence peaks at age five and again at age 34
- Accounts for two percent of all brain tumors

### **Symptoms**

- Severe headaches
- Nausea and vomiting
- Difficulty walking
- Fatigue and sleepiness
- Problems with coordination
- Neck pain or stiffness
- Visual problems

### **Treatment**

The doctor will perform tests to determine if it has spread to the spinal cord. Surgery followed by radiation therapy is the usual course of treatment. A shunt may be needed to treat hydrocephalus caused by blockage of the ventricles.

## **MIXED GLIOMA**

A mixed glioma is often a combination of an astrocytoma and an oligodendroglioma (see oligodendroglioma for more).

### Characteristics

- Composed of two or more types of glioma cells
- Graded according to the most aggressive type of tumor cells
- Common among men and women in their 20s-50s
- Accounts for one percent of all brain tumors

### Symptoms

- Headaches
- Seizures
- Weakness or paralysis
- Nausea and vomiting
- Visual problems
- Behavioral and cognitive changes

### Treatment

Mixed gliomas are generally treated for the most anaplastic (cancerous) type of cell found in the tumor. For example, in the case of a tumor composed of an anaplastic astrocytoma and a low-grade oligodendroglioma, the treatment would be based on the anaplastic astrocytoma – the more aggressive of the two cell types.

# **CHAPTER 12**

## **OPTIC NERVE**

### **GLIOMA**

These tumors can grow in various parts of the brain. They affect the optic nerve, which carries information to the eye.

### Characteristics

- Named for its location on or near the nerve pathways between the eyes and the brain
- Can range from low grade to high grade
- Occurs most often in infants and children, but can occur in adults
- Symptoms
- Headaches
- Progressive loss of vision
- Double vision

### Treatment

Surgery is standard treatment, usually followed by radiation therapy or chemotherapy. Chemotherapy may be given to very young children instead of radiation therapy to avoid damage to the developing brain.

# **CHAPTER 12**

## **SUBPEN- DYMOMA**

This tumor forms from ependymal cells, and is a variation of an ependymoma. Ependymal cells are cells line the passageway in the brain where cerebral spinal fluid (CSF) is produced and stored. Ependymal tumors are classified as either supratentorial (in the cerebral hemispheres) or infratentorial (in the back of the brain). See "Ependymoma" for more information.

### Characteristics

- Slow growing
- Usually located in the fourth and lateral ventricles
- More common in men than in women

### Symptoms

- Headaches
- Nausea
- Loss of balance
- Sometimes no symptoms occur and tumor is detected incidentally

TreatmentSurgery will be performed when possible. Radiation therapy may be used if the tumor progresses or recurs. A shunt may be needed to treat hydrocephalus (water on the brain).



# **CHAPTER 13**

## **MEDULLO- BLASTOMA**

The medulloblastoma is a tumor in the cerebellum, which controls your balance and motor skills.

### Characteristics

- A type of primitive neuroectodermal tumor (PNET) (see below)
- Often located in the cerebellum or near the brain stem
- Can spread to the spinal cord through the cerebrospinal fluid (CSF)
- May obstruct the fourth ventricle, causing hydrocephalus (water on the brain)
- Occurs most often in children under the age of ten, but may occur in adults
- Slightly more common in males than females

### Symptoms

- Headaches
- Early morning vomiting
- Lethargy or sleepiness
- Lack of coordination
- Double vision
- Behavioral or personality changes
- Signs of pressure seen behind the eye when examined with an ophthalmoscope

### Treatment

Surgery is the standard treatment when possible. Chemotherapy is usually part of the treatment plan. Radiation of the brain and spine is often recommended in adults and children over three years of age. A shunt may be needed to treat hydrocephalus. This tumor may recur years later if not totally resected.

# **CHAPTER 14**

## **MENINGIOMA**

These tumors grow from the meninges, the layers of tissue covering the brain and spinal cord. As they grow, meningiomas compress adjacent brain tissue. Symptoms are often related to this compression of brain tissue, which can also affect cranial nerves and blood vessels. In some cases, meningioma growth can also extend into the bones of the head and face, which may produce visible changes. Most meningiomas are considered nonmalignant or low grade tumors. However, unlike nonmalignant tumors elsewhere in the body, some of these brain tumors can cause disability and may sometimes be life threatening. In many cases, meningiomas grow slowly. Other meningiomas grow more rapidly or have sudden growth spurts. There is no way to predict the rate of growth of a meningioma or to know for certain how long a specific tumor was growing before diagnosis. Meningiomas are graded from low to high. The lower the grade, the lower the risk of recurrence and aggressive growth.

The WHO classification divides meningiomas into three grades:

Grade I: Benign Meningioma

Grade II: Atypical Meningioma

Grade III: Malignant (Anaplastic) Meningioma

#### Characteristics

- May arise after previous treatment from ionizing radiation or excessive x-ray exposure
- Common among women and men in their 40s-50s, but can occur at any age
- Twice as common in women as in men
- Accounts for 34 percent of all primary brain tumors
- In very rare cases, can invade the skull or metastasize to the skin or lungs
- Women with meningiomas can experience tumor growth during pregnancy
- In rare cases, multiple meningiomas can develop at the same time in different parts of the brain and/or spinal cord

#### Symptoms

- Seizures

- Headaches
- Nausea and vomiting
- Vision changes
- Behavioral and cognitive changes
- Sometimes no symptoms occur and tumor is detected incidentally

#### Treatment

If there are no symptoms, the doctor may monitor the tumor with MRIs.

Otherwise, surgery is the standard treatment. If the tumor cannot be completely resected or if it recurs, radiation therapy may be given as well. Chemotherapy for unresectable, aggressive, atypical, or recurrent meningiomas is being tested through clinical trials. Follow-up scans are needed indefinitely, because meningiomas can recur years or even decades after treatment.

# **CHAPTER 15**

## **OLIGO- DENDRO- GLIOMA**

This is the kind of tumor Misha had: a grade III oligodendroglioma. It is very uncommon, making up 3% of the diagnosed brain tumors in a year.

This tumor type develops from glial cells called oligodendrocytes.

### Characteristics

- Occurs frequently in the frontal or temporal lobes
- Can be classified as low grade or high grade
- Common among men and women in their 20s-40s, but can occur in children
- More common in men than women
- Accounts for two percent of all brain tumors
- May be associated with 1p or 19q chromosomal losses

### Symptoms

- Seizures
- Headaches
- Behavioral and cognitive changes
- Weakness or paralysis

Treatment options depend on the grade of the tumor. If the tumor is low grade and symptoms are not severe, the doctor may decide to perform surgery, then “watch and wait” and evaluate tumor growth through MRIs. There is a malignant form called anaplastic oligodendroglioma and a mixed malignant astrocytoma-oligodendroglioma. The common treatment for these high-grade tumors is surgery followed by radiation therapy and/or chemotherapy. Both low- and high-grade oligodendrogliomas can recur. If a tumor recurs, the doctor will evaluate it for a second surgical procedure, radiation, and/or chemotherapy. Gene expression studies are used to classify gliomas based on certain characteristics, or genetic profiles. Oligodendrogliomas can be identified by deficiencies in certain chromosomes named 1p and 19q. Genetic profiling of oligodendrogliomas provides a more accurate predictor of prognosis and treatment options than does standard pathology.

# **CHAPTER 16**

## **PITUITARY TUMORS**



The pituitary gland produces hormones that affect growth and the functions of other glands in the body. Certain pituitary tumors secrete abnormally high amounts of their respective hormones and cause related symptoms. Other pituitary tumors do not secrete hormones, but grow and compress brain tissue, causing other symptoms.

### Characteristics

- Named for its location on or near the pituitary gland, located at the center of the brain behind and above the nose
- Can range from low grade to high grade
- May cause excessive secretion of hormones
- Common among men and women in their 50s-80s
- Accounts for about 13 percent of all brain tumors

### Symptoms

- Headache
- Depression
- Vision loss
- Nausea or vomiting
- Behavioral and cognitive changes
- Cessation of menstrual periods (amenorrhea)
- Leaking of fluid from the breasts (galactorrhea)
- Hair growth in women
- Impotence in men
- Abnormal growth of hands and feet
- Abnormal weight gain

### Treatment

If the tumor is large or compressing the optic nerve, standard treatment is surgery. This can be transphenoidal surgery, which gets access to the tumor by entering

through the nasal passage. Radiation therapy may also be used. Some pituitary tumors may be treated with medication, and/or observed with MRI scans. Certain drugs can block the pituitary gland from making too many hormones. Follow up with an endocrinologist may be necessary to manage hormonal changes.

# **CHAPTER 17**

## **PRIMITIVE NEURO- ECTODERMAL TUMOR**

There are several tumor types in this category. Names of specific PNETs may be based on the tumor location. Examples include pineoblastoma (located in the pineal region, a form of pineal tumor), medulloblastoma (located in the cerebellum), and cerebral cortex PNET (located in the cerebral cortex).

### Characteristics

- Highly aggressive and tend to spread throughout the CNS
- Grow from undeveloped brain cells
- Commonly include cysts and calcification (calcium deposits)
- Tend to be large

### Symptoms

- Can vary depending on location of tumor
- Weakness or change in sensation on one side of the body
- Morning headache or headache that goes away after vomiting
- Nausea and vomiting
- Seizures
- Unusual sleepiness or lethargy
- Behavioral or personality changes
- Unexplained weight loss or weight gain

### Treatment

Surgery is the standard treatment when possible. In adults and children over three years of age, surgery may be followed by radiation therapy to the whole brain and spinal cord, and chemotherapy. In children under three years of age, surgery may be followed by chemotherapy or a clinical trial of chemotherapy to delay or reduce the need for radiation therapy.

# **CHAPTER 18**

# **SCHWANNOMA**

This tumor is benign. It covers nerves, called the nerve sheath.

Also known as vestibular schwannoma, neurilemmoma and acoustic neuroma (see acoustic neuroma).

### Characteristics

- Arises from cells that form a protective sheath around nerve fibers
- Typically grows around the eighth cranial nerve, but can be found around other cranial or spinal nerves

### Symptoms

- Reduced hearing in the ear on the side of the tumor when eighth cranial nerve is involved Tinnitus (ringing in the ear)
- Balance problems
- Deficits depend on the nerve that is affected

### Treatment

Surgery and radiotherapy are the most common forms of treatment. If the tumor is not completely removed, recurrence is likely.

# **CHAPTER 19**

## **PINEAL TUMOR**

A malignant form of pineal tumor is called pineoblastoma.

### Characteristics

- Named for its location in or around the pineal gland (near the center of the brain)
- Can range from low grade to high grade
- Can produce an excess of melatonin, a hormone that controls the sleep/wake cycle
- Can block the ventricles, causing hydrocephalus
- High-grade pineal tumors can spread to the spinal cord through the CSF
- Common types include germ cell tumors, pineal parenchymal tumors, and gliomas
- Occurs most often in children and young adults

### Symptoms

- Headaches
- Nausea and vomiting
- Fatigue
- Double vision
- Memory problems

### Treatment

Surgery is standard treatment when possible. Radiation therapy may be used as primary treatment in adults and children above age three. Chemotherapy may be given to delay the use of radiation therapy in very young patients. A shunt may be needed to treat hydrocephalus (water on the brain) caused by blockage of the ventricles. Treatment for high-grade (malignant) pineal tumors such as a pineoblastoma may involve radiation to the brain and spine to control spread through the CSF. Clinical trials using chemotherapy or biological therapy following radiation therapy are being investigated.



# **CHAPTER 20**

## **RHABDOID**

### **TUMOR**

Rhabdoid tumors are the most aggressive and lethal malignancies.

### Characteristics

- Rare
- Highly aggressive and tends to spread throughout the CNS
- Often appears in multiple sites in the body, especially the kidneys
- Difficult to classify; may be confused with medulloblastoma or PNETs
- Occurs most often in young children but can also occur in adults

### Symptoms

- Vary depending on location of tumor in the brain or body
- An orbital tumor may cause the eye to protrude
- Balance problems may occur
- External tumors cause noticeable lumps; internal tumor symptoms vary based on location

### Treatment

Whenever possible, surgery is performed to remove as much of the tumor as possible. This is usually followed by chemotherapy and radiation therapy. In children under three years of age, surgery may be followed by chemotherapy alone. Clinical trials are being studied using autologous bone marrow transplantation after high-dose chemotherapy for recurrent or multiple rhabdoid tumors.

# **CHAPTER 21**

## **OTHER BRAIN RELATED CONDITIONS**

## **Cysts**

A cyst is a fluid-filled sac that may encapsulate (surround) or be located next to a tumor. Based on its location in the brain, a cyst can cause symptoms such as headache, pain, seizures, or a neurological deficit. Cysts can be surgically removed or drained. If a cyst is not causing neurological difficulties, the doctor will conduct ongoing MRI and CT scans to observe its growth pattern.

## **Neurofibromatosis**

Neurofibromatosis is a genetic disorder that can cause tumors in various parts of the central nervous system (CNS). There are two types of neurofibromatosis. Type 1, the more common kind, usually occurs outside of the CNS. Type 2 occurs within the CNS. Type 2 neurofibromatosis causes multiple CNS tumors, including neurofibromas, multiple meningiomas, bilateral vestibular schwannomas, optic nerve gliomas, and spinal cord tumors. Symptoms include loss of balance, tinnitus, total hearing loss, facial pain or numbness, and headache. Surgery is the standard treatment.

## **Pseudotumor Cerebri**

This condition is not a brain tumor, but its symptoms mimic a brain tumor. Pseudotumor Cerebri most commonly afflicts obese adolescent girls and young women. Symptoms include headaches, blurred vision, dizziness, and a slight numbness of the face. The symptoms are caused by a buildup of cerebrospinal fluid (CSF). Treatment is given to relieve the symptoms, particularly visual impairment. Treatment may include repeated lumbar punctures or medications to decrease CSF. In severe cases, a shunt may be needed.

## **Tuberous Sclerosis**

Tuberous Sclerosis is a genetic disorder that causes numerous neurological and physical symptoms, including tumors of the CNS, eyes, and kidneys. Most cases occur in children under 20 years of age. About fifty percent of tuberous sclerosis patients develop brain tumors. Subependymal giant-cell astrocytomas are the most common type, but other tumor types are also associated with this condition. Most patients suffer from seizures. Treatment may involve inserting a shunt to prevent hydrocephalus (water on the brain). Surgery is another treatment option.

# **CHAPTER 22**

# **TREATMENT**

# NEUROSURGERY

Neurosurgery is the most common form of treating a brain tumor, especially if it is benign. Benign tumors are easier to take out because they are in one part of the body. They are unlike malignant tumors, which spread to other parts of the body.

Neurosurgeons can also help diagnose and prevent a brain tumor. In their experience, some tumors, depending on the area of origin, can specify what type of tumor it is. And based on their research, are able to prevent it with new or recurring treatments or drugs.

For some patients, their tumors can be removed completely during surgery. However, there are some, which may be deep in the brain, which need several surgeries before it is completely removed. These surgeries are called debulking. Debulking reduces the size of the tumor.

Tumors can be difficult to remove because it spreads and fixes itself to the surrounding tissue. Going about removing the tumor must be done carefully, as to not damage the tissue.

The best doctors for your team when starting surgeries are:

- Neuro-oncologist
- Neurologist
- Neurosurgeon

Misha had gone through 17 surgeries, each removing more of the tumor. However, Misha's tumor was very fast growing; it was malignant. So each time the doctors would go in to remove the tumor, there would be more of it than the last time

Her tumor had started roughly the size of a golf ball. Later it quintupled in size. Because of the tumors growth and hydrocephalus, Misha's brain had been pushed forward. At one point, the tumor was bigger than her brain.

Now, Misha's tumor was on her brain stem (she had an exophytic brain stem glioma). This made it extremely difficult to remove the entire tumor because if you cut or touched the brain stem, it could lead to severe brain damage.

# CHEMOTHERAPY

Chemotherapy uses drugs to kill cancer cells and stop their reproduction.

If someone you know has a *low-grade* brain tumor, it is not best to use chemotherapy as the initial treatment. The drugs cannot go through the blood-brain barrier (a system whose purpose is to protect the brain from molecules that want to reach the nervous system).

The one thing about chemotherapy is that not all tumors respond to it.

Chemotherapy is usually the treatment that follows neurosurgery and radiation therapy. One important thing to know is that chemotherapy is not used for benign tumors. It is used on malignant and metastatic tumors only. These are tumors that can and will spread to other parts of the body.

There are many side effects to chemotherapy:

- Hair loss
- Nausea
- Vomiting
- Diarrhea
- Risk of infection from low white blood cell counts
- Fatigue from low red blood cell counts
- Easy bruising and bleeding from low blood platelet counts

Now, how does it work. In the words of Cancer Treatment Centers of America:

“Chemotherapy drugs enter the bloodstream and reach areas throughout the body. Chemotherapy drugs may be administered orally in pill form, or injected into the vein. For some types of brain cancer, chemotherapy drugs may be given directly into the cerebrospinal fluid (CSF), either in the brain or spinal column.”

# **RADIATION THERAPY**

Radiation therapy is uses high-energy radiation, like x-rays, gamma rays, and other charged particles, to shrink tumors and kill cancer cells. Almost every patient with cancer uses radiation as a form of treatment.

You may be asking: how does radiation kill cancer cells, exactly? Radiation damages the DNA, either by full on attacking it or planting some charged particles in the cells and attacking it from there. In other words, it keeps the cancer cells from multiplying. With enough radiation therapy, the body's natural processes can kill the cancer cells on it's own.

There are two general types of radiation: external and internal. External radiation uses radiation to treat tumors in your head, bone, abdomen, chest, and other organs.

Despite the benefits of radiation therapy, there are some side effects. The radiation also attacks normal cells and tissues. This means that more sensitive areas on your body, reproductive organs and hair follicles, are damaged more easily than the bones. Doctors take this into account before they suggest radiation therapy for the patient.

Some side affects of radiation on the brain:

- headaches
- swelling of the brain
- hair loss
- nausea
- vomiting
- fatigue
- hearing loss
- skin and scalp changes
- Memory loss and trouble with speech



- seizure

Now down to the nitty-gritty details. The doctor who specializes in radiation therapy is a radiation oncologist, and for a brain tumor it would be a radiation neuro-oncologist; or just a neuro-radiologist. The types of scans used are computed tomography (known as a CT), magnetic resonance imaging (MRI), positron emission tomography (PET), and ultrasound scans.

After the scan(s), the radiation oncologist determines the exact area for treatment and exactly how much radiation is required. Radiation doses are measured in grays (Gy), which is "a measure of the amount of radiation energy absorbed by 1 kilogram of human tissue" ([www.cancer.gov](http://www.cancer.gov)).

Radiation can be considered, although very effective, very dangerous. If an area in the body has received radiation, there is a chance that radiation cannot be received in that area again. This all depends on how much radiation was received during the initial treatment.

There are many kinds of radiation therapy:

"Intensity-modulated radiation therapy (IMRT): Uses hundreds of tiny beams for a single dose of radiation. The goal is to increase the radiation dose to the needed areas and reduce radiation exposure to specific sensitive areas of surrounding normal tissue.

Image-guided radiation therapy (IGRT): Scans are repeated to identify changes in a tumor's size and location after treatment. This allows the position of the patient or the planned radiation dose to be adjusted during treatment as needed

Tomotherapy: Capture CT images of the patient's tumor immediately before treatment sessions, to allow for very precise tumor targeting and sparing of normal tissue.

Stereotactic radiosurgery: Delivers one or more high doses of radiation to a *small* tumor.

Stereotactic body radiation therapy: Delivers radiation therapy in fewer sessions, and specifically to tumors that lie outside the brain and spinal cord.

Stereotactic radiotherapy: refers to a single or several stereotactic radiation treatments of the brain or spine. SRS is delivered by a team involving a radiation oncologist and a neurosurgeon

[\*Misha had this kind of radiation for her treatment.]

Proton therapy: The use of protons reduces the exposure of normal tissue to radiation, possibly allowing the delivery of higher doses of radiation to a tumor."  
(from **www.cancer.gov**)

The second type of radiation therapy is internal radiation therapy. Internal radiation therapy is the kind of radiation that is *placed* in the affected area, either temporarily or permanently. This type of therapy delivers a high dose of radiation. Depending on the kind of cancer, the radioactive material is either placed directly into the affected area or in a sealed plastic container, which is known as an implant.

Internal radiation therapy is also called brachytherapy, or seed implantation for those non-doctor speaking people out there. These "seeds" are placed in the infected area. From there, it slowly releases radiation.

These seeds can remain in a single place for the patient's life, or until they have lost their radiation (which is usually after a year). This therapy is not necessarily used to treat brain tumors. It is usually used for breast, cervical, ovarian, pelvic, head and neck, lung, perianal, and prostate cancer.

# IMMUNOTHERAPY

To put it simply, immunotherapy uses the patient's immune system or their own cancer cells to attack the tumor.

Immunotherapies are used for one of two reasons. First, it is used to work up the immune system to go against the brain tumor. Or second, for targeting specific abnormalities in brain tumor cells that involved in the tumors growth.

Basically, immunotherapy boosts the immune system so the patient is more able to fight against the cancer.

Immunotherapy is better for some cancers than others. For some, this is the only treatment you want to use. For others, it is best used with other treatments like chemotherapy, radiation, and neurosurgery.

The side effects of immunotherapy are:

- fever
- chills
- nausea
- appetite loss
- rashes or swelling on injected site
- possible decrease in blood pressure
- fatigue
- bone pain
- allergic reactions

There are several different types of immunotherapy:

"Biological Response Modifiers: Substances that trigger the immune system to indirectly affect tumors.

Colony-Stimulating Factors: Substances that stimulate the production of blood

cells. They do not directly affect tumors but through their role in stimulating blood cells they can be helpful as support of the person's immune system during cancer treatment.

Tumor Vaccines: Researchers are developing vaccines that may encourage the patient's immune system to recognize cancer cells. These would in theory work in a similar way as vaccines for measles, mumps and small pox. The difference in cancer treatment is that vaccines are used after someone has cancer. The vaccines would be given to prevent the cancer from returning or to get the body to reject tumor lumps (Cleveland Clinic).

Monoclonal Antibodies: Laboratory-produced substances that can locate and bind to cancer cells wherever they are in the body. They do this by reacting against tumor-associated proteins on the surface of the cancer cell. These antibodies can be used to see where the tumor is in the body (detection), or as therapy to deliver drugs, toxins, or radioactive material directly to a tumor (Cleveland Clinic)."  
(from **Cleveland Clinic**)

## **BONE MARROW AND BLOOD STEM CELL TRANSPLANT**

Blood and bone marrow stem cell transplants replace unhealthy stem cells with healthy stem cells.

Now, stem cells are found in bone marrow. What is bone marrow? Bone marrow is the substance inside the bones. (Have you ever eaten ribs, or seen a rib bone, and looked in the middle of the bone? That's bone marrow.)

The stem cells that are found in the bone marrow are red blood cells (which carry oxygen throughout the body), white blood cells (which fight infections), and platelets (which help blood clot).

Stem cells can also be found in the blood *and* the umbilical cord and placenta after a baby is born. From there, the blood is frozen and stored at a umbilical cord blood bank for later use.

There is one stem cell, the embryonic stem cell, which can develop into *any* type of cell. These kinds of cells are not found in the bone marrow.

There are two main types of stem cell transplants: autologous and allogenic.

Autologous transplants store the stem cells for later. Even though you are sick, you will still have enough healthy stem cells. Cancer cells are removed and destroyed from the cells that were collected.

In an allogenic transplant, stem cells are received from a donor, like a relative or someone you do not know.

You may be asking how do they collect the stem cells?

One way of collecting cells through a donor is through a process called apheresis. During this process a needle is placed in the arm to draw blood, which is then passed through a machine designated to filter the stem cells from the blood. After that, the blood is then returned to the donor.

# **CHAPTER 23**

# **DOCTORS YOU**

# **WILL NEED**

# PEDIATRICIAN

A pediatrician is a physician who works with babies, children, and teenagers. Mostly they maintain the child's health, give checkups, and occasionally prescribe medicine. For the first year of the baby's life, pediatricians provide seven checkups to the baby. After that, they can stay with the doctor until they are twenty one years old. These doctors you should have around you even if your kid does not have a serious illness.

They are also there for children who have acute or chronic illnesses. For my family, our pediatrician was our saving grace, our advocate. She helped us through my sisters treatment, giving support and check ups to make sure she was alright.

In the beginning, Misha had a pediatrician that was very uncooperative. When she was 3-4 months old, he did not listen to my parents when they told him something was wrong (to read the full story, look under Symptoms). Only when my dad demanded of him to see Misha is when he finally took some action by sending her to a neurologist.

## **Your pediatrician has to listen to you.**

After Misha's first surgery, my dad told the pediatrician that something was wrong. Her head was swollen. The pediatrician said that it was just the flu. At one point, he told my mother to just let Misha die and not let her suffer anymore.

There was a time when my dad did a fake phone call to the hospital, where he pretended he was a doctor. He said that Misha (who was well known at the hospital now) was his niece, and he suspected that she might have hydrocephalus and ordered an MRI for her. The MRI showed that it *was* hydrocephalus and the tumor had quintupled in size. They said that the hydrocephalus was so bad that they had a day to do a VP shunt.

Misha's old pediatrician dropped the ball with her. He refused to take any accountability. Afterwards, our family got two *amazing* pediatricians, one of which was Asha Misra. She blew the other pediatrician out of the park.

As you can see, you need a pediatrician that will work with you and listen to you, even if it's just for a common cold or flu. It's rare that you'll find a tumor, but sometimes you hit the lottery (in a bad way).

In the beginning, your pediatrician **must be an advocate** for you and with the insurance companies. They should submit authorization forms for the insurance company. They are at the center of chaos through treatment and insurance. They should be there for everything your child is going through.

You go to your pediatrician with basic questions. They will be there for doctor stuff you need that will not be done at a hospital.

## NEUROLOGIST

Neurologists perform examinations (to test muscle strength and movement, balance, ambulation, reflexes, sensation, memory, speech, and language) on the head, neck, spine, and the nerve endings in them. They perform diagnostic tests such as CT and MRI scans.

Neurologists do not only work with brain tumors. They treat disorders the brain, nerves, and spine:

- Cerebrovascular disease (stroke)
- Demyelinating diseases of the central nervous system (multiple sclerosis)
- Headache disorders
- Infections in the brain and peripheral nervous system
- Movement disorders (Parkinson's disease)
- Neurodegenerative disorders (Alzheimer's disease, Parkinson's disease, and Amyotrophic Lateral Sclerosis (Lou Gehrig's disease))
- Seizure disorders (epilepsy)
- Spinal cord disorders
- Speech and language disorders

There are two main divisions of neurology: the central nervous system (brain and



spine) and peripheral nervous system (ears, eyes, skin, and other sensory receptors).

These are the doctors that identify the problems in a patient's nervous system. They are not the ones who will perform surgery on the patient. They determine the area that needs to be treated and refer you to a neurosurgeon.

A neurologist is one of the most important doctors you should have. After treatment, it is wise to follow up with a neurologist for long term care.

Pediatric neurologists have an interesting field of work; their patients nervous system is still growing and developing. So, the determination of the cancer may seem uncertain.

## **NEURO-RADIOLOGIST**

Neuroradiology is the diagnosis and treatment of the nervous system using x-rays, magnetic fields, radio waves, and ultrasound. In other words, they use MRIs, x-rays, and CT scans to diagnose if there is anything wrong with your nervous system.

A neuroradiologist is a doctor who specializes in these diagnoses. They are trained to interpret medical images. The images are attained by using “x-rays (radiographs, CT, fluoroscopy), or radioactive substances (nuclear medicine), others by means of sound waves (ultrasound) or the body's natural magnetism (MRI).” (RadiologyInfo.org)

These kinds of doctors can determine where the tumor is in your body. After periods of times, they can also determine whether or not the surgeries have shrunk the tumor or if it has grown. If it has grown, they will tell you where it is so treatment can be begun to get rid of it.

## **NEURO-ONCOLOGIST**

A neuro-oncologist is similar to a neurologist; in fact, a neurologist may double as a neuro-oncologist.

Neuro-oncologists treat and diagnose brain tumors in the nervous system. They manage benign and malignant brain tumors, specifying which ones need treatment and which ones do not. These doctors understand the types of tumors, and that each tumor is different (even if it is the same kind of tumor).

When you go to a neuro-oncologist, they will supply you with many things. They give you the details of your child's tumor and your options from thereon out.

It is important that you follow up with your neuro-oncologist. They have a similar role as your neurologist; however, they have a deeper understanding of brain tumors.

\*neuro: brain    onc: tumor    ology: study of  
neuro-oncology: study of brain tumors

## **NEUROSURGEON**

Neurosurgery is the treatment through surgery of the brain and spinal cord. These include diseases and injuries such as:

- Cerebral hemorrhages
- Cerebrovascular conditions including aneurysms and vascular malformations
- Brain and spinal cord tumors
- Spinal cord injuries
- Traumatic brain injuries
- Spinal surgeries including laminectomies and fusions

*(taken from Baylor College of Medicine)*

Neurosurgeons diagnose and treat surgical disorders and/or injuries of the nervous system. They examine the neurological structure of the body, perform surgery on the main systems of the nervous system, and perform radio surgery. Radiosurgery is the medical procedure that allows treatment of benign and malignant tumors.

Benign: tumors that is not cancerous.

Malignant: is cancerous; grows very fast and multiplies, spreading to other parts of the body and infecting other areas.

## **NEURO-PATHOLOGIST**

Neuropathology is the branch of medicine dealing with diseases of the nervous system.

The typical tasks a neuropathologist has:

- Study brain tumors and other tissues and fluids
- Diagnose and classify tumors as malignant or benign
- Study the results of pathological analyses of patient's cerebro-spinal fluid to determine nature and extent of a disorder
- Identify the presence of pathological blood conditions or parasites
- Advise neurologists and neurosurgeons of the results
- Write reports on study results.

*(from SchoolsInTheUSA.com)*

Neuropathologists specialize in diseases of the brain and spinal cord, and also make definitive diagnosis of brain tumors. Much like how neuroradiologists use CT scans, MRIs, and x-rays, neuropathologists use “electron microscopes in pathology labs to determine the nature and type of tumor in a patient’s brain or other type of neurological problem” (SchoolsintheUSA.com). They also look for any changes in any neurological disorders, which will lead them to establish a diagnosis.

These doctors perform microscopic examinations of tissue from the tumor. They ask themselves questions (such as 1) what type of brain cell did the tumor come from? and 2) does the tumor show rapid growth?). These questions help further determine what kind of tumor the patient could have.

Once the neuropathologist has determined the type of tumor, the neurologist is informed so they can give treatment advice, a prognosis, and health-care information to the family.

## NEURO-PSYCHOLOGIST

Neuropsychology is the study of the relationship between behavior, emotion, and cognition on the one hand, and brain function on the other. It studies how the brain and nervous system affect how we function on a daily basis.

A neuropsychologist is a psychology professional with expertise in the behavior of relationships in the brain. "Clinical neuropsychologists use this knowledge in the assessment, diagnosis, treatment, and/or rehabilitation of patients across the lifespan with neurological, medical, neurodevelopmental and psychiatric conditions, as well as other cognitive and learning disorders" (Advanced Psychological Assessment, P.C.).

Basically, a neuropsychologist uses psychology to rehabilitate, treat, or diagnose a patient with neurological disorders: "evaluate patients' neurocognitive, behavioral, and emotional strengths and weaknesses and their relationship to normal and abnormal central nervous system functioning" (Advanced Psychological Assessment, P.C.).

## QUESTIONS TO ASK

There are always questions you should be asking your doctors, other than the obvious "Why did this happen to me?" Here is a list of some questions you should ask:

1. What should I know from the very beginning?
2. What are the normal treatment options available for brain tumors?
3. What sort of tests will be given my child?
4. How important is getting the correct diagnosis to determine the proper treatment?
5. When do you recommend surgery? Radiation? Chemotherapy?

6. What are the alternative treatment options?
7. Regarding quality of life, how do you balance that and trying to save your patient?
8. What is done to help a child with the pain?
9. Is there a time you recommend to not to do any treatment?
10. What are the most common brain tumors?
11. Which ones have the worse prognosis?
12. What should I do when I first find out my child has a brain tumor?
13. When I meet with you for the first time, should I record the meeting?
14. Should I tell the child about the diagnosis, especially if it is very bad?
15. What is your role after all the treatments are done?
16. For you personally, what do you find most rewarding about your job?
17. Did I forget anything? Is there anything else I should add?

# **CHAPTER 24**

## **TO THE SIBLINGS**

I have realized the growing need for a section for the siblings on this website. So I have decided to tell about my time growing up and what I felt as my sister was going through her treatments. I encourage all brothers and sisters of a child with cancer to read this, or have it explained to them by their parents.

I was born 17 years ago. By that time my sister's tumor was almost gone, but I was still involved with her cancer from the moment I was born. At two months old I was taken on a plane to fly to places like Boston and Alabama. Of course, being two months old I do not remember this at all.

It wasn't until I was around the ages of 3-5 when I had a real understanding of what my family was going through. I knew that my sister would be in the hospital most days out of the week, and finally (at that age) I slowly figured out that my sister had cancer. She had "something bad" in her head.

Being born into this, I knew from a young age that I would not be put first most of the time. I knew that my sister's needs came before mine. So I could not get angry if my parents were paying attention to my sister more than to me. There were times, though, when my sister was going through her facial reconstruction process (to fix her smile) when it really started nagging at me. I would yell at my parents and be so mad at them. Sometimes I told them that I wish I had been born with cancer too, so that they would pay as much attention to me as they did to Misha.

The siblings can, and *will*, start thinking these things. They are going to be very angry at the parents and start saying things bad about them and their sibling with cancer. Parents: this is not the time to be scolding that child. Do not yell at them for being inconsiderate or selfish, or remind them that their brother or sister has cancer so they need to have a little more respect. Do not do that. The siblings, despite being angry, actually do care about their brother or sister in the hospital.

Even though I said all those things about my sister having more attention, I would always be there to take care of her if need be. I would always be the first one out the door if one of my parents was taking me to the hospital to visit my sister. There was one time when I woke up in the morning and my mom told me "We're going to see Misha today." From what my parents tell me, I ran to the door and ran down the stairs (we lived in an apartment) still in my pajamas and diaper. I had not eaten or anything. I just looked up at my mom and said "Let's go."

When everyone gets older, and the child survives their cancer, there are going to be a lot of opportunities for them. People will praise them for surviving and tell them

they "are such a miracle." This has happened to my sister since she was three, when the tumor was officially gone. Of course I got jealous whenever such things happened. My sister had a miraculous story to tell. But what did I have? I had to sit and help her through so much during that time. I realized then that like my sister and her story, I would need to make a story for myself. I needed to do something miraculous, too. That is why I created this website: to do something miraculous. Maybe I wasn't the one who survived a brain tumor, but I can sure help other people try to survive theirs.

To this day, I'd do anything to help my sister. It's just the mind-set that I have had since I was a baby. Showing false emotions (that can also have a little truth behind them) is a siblings' way of coping with the situation. At least, it was in my case.

The siblings need to know that they are not forgotten. Their parents still love them and will make time for them. Parents: you need to make sure you spend quality time with that child as well. Don't let them feel how I have felt since I was a child. They'll realize after a while that what they're going through was a little selfish, but the parents do not need to be the ones to tell them that. I have figured it out, and gotten over it.

If you ever need a fellow sibling of a child with a brain tumor to talk to, don't hesitate to email me at [amritoch@gmail.com](mailto:amritoch@gmail.com). I'll always answer with advice or be there if you just want to talk about what is going on.



# **CHAPTER 25**

## **EDUCATION**

I am not an expert in education, only when it comes to receiving it. Instead of writing something that would basically copy what is on the internet already, I decided to ask my high school's principal, Machele Kilgore. She gave a summary of how a brain tumor patient can go through their schooling while still in the hospital.

"When students are medically fragile, it is often difficult for them to attend school on a regular basis. The traditional school system is based on seat-time attendance, which means the student needs to be in their seat every morning in order for the school to get the daily attendance financial support. For students moving in and out of hospital appointments, this will equate to many absences and lost credits.

At the time of the illness, a student's well being is obviously the primary focus. Often school and academic assignments can bring a sense of familiar, and can often help the transition back into a traditional school when the student is ready to return. Earning a few credits, completion or partial completion of courses can help the student maintain grade level expectations.

I would suggest looking into several alternative education programs. The California Department Education's website will be a great resource. Also, your public school may have some options for you to consider as well. Talk to everyone to discover what alternatives are available to your student.

A few options may include Independent Study, or Home Hospital programs.

- Independent Study is offered by most school districts and is usually an option for students to complete their school assignments at home, often under the guidance of a credentialed teacher. The student is able to earn credit and/or grades based on the completion of the work assigned. This can include local Charter Schools and online programs.

- Home Hospital is for more seriously ill students and offers support by a credentialed teacher to the student for minimal assignments each week. The links below will help lead you to a school option that will best suit your needs.

**Independent Study** (Ca. Dept. of Ed.) <http://www.cde.ca.gov/sp/eo/as/>

**Home Hospital** (Ca Dept of

Ed.) [http://www.cde.ca.gov/search/searchresults.asp?cx=001779225245372747843:gpfw5rhxiw&output=xml\\_no\\_dtd&filter=1&num=20&start=0&q=Home%20Hospital](http://www.cde.ca.gov/search/searchresults.asp?cx=001779225245372747843:gpfw5rhxiw&output=xml_no_dtd&filter=1&num=20&start=0&q=Home%20Hospital)

### **Charter Schools (Ca Dept. of**

Ed.) [http://www.cde.ca.gov/search/searchresults.asp?cx=001779225245372747843:gpfw5rhxiw&output=xml\\_no\\_dtd&filter=1&num=20&start=0&q=charter+school&submitgo=Go](http://www.cde.ca.gov/search/searchresults.asp?cx=001779225245372747843:gpfw5rhxiw&output=xml_no_dtd&filter=1&num=20&start=0&q=charter+school&submitgo=Go)

### **Online**

**schools** [http://www.cde.ca.gov/search/searchresults.asp?cx=001779225245372747843:gpfw5rhxiw&output=xml\\_no\\_dtd&filter=1&num=20&start=0&q=online+california+schools&submitgo=Go](http://www.cde.ca.gov/search/searchresults.asp?cx=001779225245372747843:gpfw5rhxiw&output=xml_no_dtd&filter=1&num=20&start=0&q=online+california+schools&submitgo=Go)

### **Private School Affidavit**

If you have a teaching credential, one can also consider creating their own private school by filing an affidavit with the Ca. Dept. of Education. <http://www.cde.ca.gov/sp/ps/rq/affidavit.asp> "

# **CHAPTER 26**

# **INTERVIEWS**



## **DR. JOHN CRARY: NEURO-PATHOLOGIST**

“These patients, we see their biopsies. So my perspective will be quite different from the people that see brain tumor patients in the clinic.”

**Me: To what extent are you involved in brain tumors? Because I know you said your focus is in neurodegenerative diseases. So what is your knowledge of brain tumors?**

**Dr. Crary:** So, 80% of my time is devoted to neurodegenerative research, and 20% of my time is devoted to clinical service. So of that 20% of my time, I spend basically spend it looking at brain biopsies and I try to figure out if they are tumors or not tumors. And every week I go to a tumor board conference, where they have the neurosurgeons, neuroradiologists, neurologists, neuro-oncologists, and the neuropathologists and we have a discussion about every single patient about what the diagnosis is. Even though it's only 20% of my time, it's every week I'm at these meeting.

**Me: Regarding the parents, what would you have them know about a neuropathologists role in their child's treatment?**

**Dr. Crary:** A neuropathologist's role is essential in dictating what the treatment is going to be. Before the biopsy, they don't know if it's a tumor or something else. They don't know the degree of the tumor; they don't know how aggressive it is going to be. So it is a key branch point in clinical decision making. If the neuropathologist says it's a benign tumor, you're going to go off in one direction for treatment. Whereas, if the neuropathologist says it's a malignant tumor, you're going to get a more aggressive treatment. The neuropathologist may help to decide, even at the time of the biopsy, while the patient is still in the operating room, the neurosurgeon will often ask the neuropathologist to come down and do a quick read, which we call a frozen section. So the surgeon will hand over small pieces of tissue to the neuropathologist. They'll freeze it, and cut slides quickly under the microscope. They can usually finish this in about 20 minutes. But the frozen tissue is not ideal to making a diagnosis because of water frozen in the tissue. It's a tricky read but it can help you triage the patient. During the frozen section, we might tell the neurosurgeon that it is benign region, in which case it might be more aggressive during surgery. Which is counterintuitive, but the logic is the benign region is more aggressive, and the malignant tumor is more likely to spread

throughout the brain, there will be a less radical surgery. Because they'll know if there's going to be additional treatment later on, after the fact. So that's the first time the neuropathologist comes into play. Then, sometime over the next couple of days, they'll study the tissue under the microscope. It's very important that you get an actual neuropathologist to look at the tissue. There is often a hospital generalist, who specializes in pathology but may not be an expert in the brain. And most centers do not have an active neurosurgical unit. You really need to be at a center where they treat a lot of the infected patients. Then you can be sure that a neuropathologist has actually looked at the slides. Now, if there is any question, you can always request that the slides be read by a *second* neuropathologist to get a second opinion. If you ever have a biopsy, always ask that it be reviewed at a major center. They do this all the time. Just ask for a second opinion. You may get a different wording, from different styles and customs, and pretty much a different diagnosis, the treatment is often the same. The thing about pathology that is important for everybody to know is that it's the gold standard for making a diagnosis.

Your brain is a vital organ. No one wants a neurosurgeon to dig a hole in your brain. But if there is a tumor in there, more people are willing to do it. If the tumor is in a hard to reach spot, the neurosurgeon may be reluctant to take out a large piece of tissue, and can only take out a really, really small piece. And the neuropathologist will have a really tough time deciding if it's a high-grade tumor, a low-grade tumor, or if it's a tumor at all.

**Me:** When my sister was getting her treatment, there were doctors on the east coast saying it was a juvenile pilocytic astrocytoma, and doctors on the west coast saying it was an grade 3 oligodendroglioma. But a week later after they said that, the tumor quintupled in size. But the doctors on the east coast still saying it was a JPA. So what do you do in situations like that?

**Dr. Crary:** It's very frustrating when dealing with uncertainty. In biopsies, you don't have the whole thing. So you're looking at a small piece of what's happening. The pathologist can only make a diagnosis on the piece of the tumor that they have. Now, why wouldn't they be able to know what the rest of it looks like? Well, tumors are all different. Everyone is a little bit different, but even in one person's tumor they could have parts that are more aggressive and parts that are less aggressive. So even within something that seems like it would be a benign tumor, there would be parts of it that would be aggressive. And what a tumor basically is one cell that is trying to divide uncontrollably. And so all of the offspring, all of the daughter cells, of the cell that is dividing, all of the daughter

cells are undergoing changes of their own that could potentially make them more aggressive. If one of those daughter cells “takes off”, you could have a very ugly tumor, but just in a subset of the cell. But when a surgeon takes out a biopsy, they grab the less aggressive part of the tumor. That’s why those clinical-pathological correlations are so important. Because what happens is a radiologist will say “This looks very, very aggressive” and the neurosurgeon says “Well, this is what I took.” And the pathologist will say “This is what you gave me, and what you see under the microscope is not aggressive.” So then they say A plus B does not equal C, even though it’s supposed to, so what’s missing? And then they’ll have to fill in the details.

**Me: How important is getting the correct diagnosis to determining the proper treatment?**

**Dr. Crary:** Right now there are only a couple things we can do for a patient with a brain tumor. We can do surgery. Surgery is great if you can remove the whole thing. There are certain types of tumors that are outside the brain that are immune to surgical resection alone. Unfortunately, in the brain the tumors can’t always be removed completely. Surgery alone works if the tumor is benign. If it’s a malignant tumor, they’ll require often chemotherapy and or radiation. Now it’s important, as a neuropathologist I don’t do these treatments, but I do know that there are a lot of side effects. It’s important to know that there are a lot of side effects, and people are scared of the side effects. And they should be! For example, radiation in the brain. It can get rid of tumors, but it can also cause tumors. Radiation is good because it is very effective at killing cancer cells. So it’s a balance. You don’t want to radiate a benign tumor. There’s a major source of medical liability in neuropathology. There are cases of misdiagnoses when a pathologist thought they were aggressive and called it a malignant tumor and they get it radiated and they turn a benign tumor into a malignant tumor. You don’t want that to happen. The other thing is chemotherapy. Chemotherapy also has side effects associated with that, like bleeding in the brain, nausea, vomiting, losing your hair. So making that decision, that’s really essential. You don’t want to treat a benign tumor with all these aggressive treatments with all these side effects. And with an aggressive tumor, it’s also the best chance that you have for extending life.

**Me: How does understanding the pathology dictate the treatment?**

**Dr. Crary:** The idea is pathology is all about prognosis. Pathologists are labelers, they’re namers. They will attach a label to every tumor. In the textbooks, it’s really nice and clean. But it’s not always like that in the real world. In the real world what

matters most is the behavior of the tumor. We do our best to fit every tumor into the artificial categories that we have created. But there's the whole idea of coming up with the prognosis. If there's a patient with a tumor, and we tell them patients with similar molecular profiles generally live for about two years, that's a bad prognosis. It's nice to know that versus if we have another set of patients with another set of features with another set of molecular profiles, but those patients live on average up to five years, and we know it's a benign tumor, we can pass that information onto the clinician. The clinician, being the neurologist and neuro-oncologist, will be able to better balance the side effects of the treatment versus the extension of life. So they know that the treatment will extend life a certain number of years on average paved on previous clinical research. So it's all about us prognosticating on what the chances of living and being cured are.

**Me: What is your role with the patient after their treatments are done?**

**Dr. Crary:** Once they've been treated, brain tumor patients are generally followed; they really need to be. You need to have a relationship with your oncologist, neurologist, and neurosurgeon. You really need to come back and get rescanned periodically to see if the tumor has come back. The pathologist, after the first diagnosis is made, if the tumor comes back then they may need a second surgery. And we can be useful to determine whether the features of the tumor have changed. We'll compare the original tumor with the second resection. That'll be useful for a couple of reasons. Number one, it'll tell you if it's taken off, so to speak, if it's done worse. If the tumor has evolved it can become more aggressive. We can give that information to the clinician and they can alter the treatment. The other thing that happens is that some patients, not all (it's a minority, but it's not insignificant), have cancer syndromes in their family, and they're prone to multiple tumors. So they may have a new tumor that is now rising up, and that is important to know. We can diagnose a second tumor; usually that doesn't happen though. The other thing is they may have a recurrence that can be many many years later, and the neurosurgeon comes in and takes out the tumor. And when we look at the histology, there's no tumor there. It's kind of a trick. What happens is these are almost always patients who were treated with radiation. And the radiation can have a side effect of damaging the tissue, we call it radiation necrosis. It can appear to the radiologist of being a recurring tumor. But in reality it's just a small piece of tissue dissolving, so to speak, as a result of the radiation treatment. That's really useful, because if it's a recurring tumor, the patient may want to get another round of chemotherapy.

**Me: What do you find most rewarding about your job?**



**Dr. Crary:** The thing is there are two different aspects of it. The research is the most rewarding. The opportunity of making a lasting difference that can affect everybody is really really valuable. It's what keeps me going. It's very hard to be a scientist and a doctor at the same time. And there aren't that many fields where it's easy to do it. Unfortunately, it's sad as a pathologist that we never see the patients, we never see their faces. They never get a chance to thank you. There's a classic story of the tumor board. And the neuropathologist shows up at the tumor board. When it happened, there was a frozen section the previous week and it was really tricky. The neuropathologist said "This doesn't look right" and the neurosurgeon thought it was a glioblastoma. And the neuropathologist put in all this extra work and did all these extra levels and figured out that it wasn't a glioblastoma, and figured that it was some other tumor that was benign and he was very proud of himself. He went home patting himself on the back. And the next week at the tumor board, all the fellows have new watches. And the neuropathologist said "Why are you guys all wearing new watches?" And they said "Well remember that guy last week who had a really tough case? Well he owns a watch store and he gave us all new watches because we cured him." And the neuropathologist said "Does anyone want to give me their watch?" and nobody did. Nobody knows about the neuropathologists, no one really knows that they even exist. So we do get a lot of satisfaction, but it's not directed from patients. But it's knowing that you're doing science that's the most important thing. Because your impact could potentially be beyond what you're doing that that moment. It has the potential to reverberate to change care across the whole country. And that is a great feeling.



## **DR. HENRY FRIEDMAN: NEURO-ONCOLOGIST**

**Me:** If a parent calls you and they have found out that their kid has a brain tumor, what would you tell them in the very beginning? Where should they start?

**Dr. Friedman:** Alright, what they want to be sure is that they're at a center of excellence. There are a lot of centers of excellence and there are an incredible number of organizations that are out there. But you need to make sure that you Google brain tumor organizations because they're all over the world, all over the United States. But what I'm talking about are academic organizations that give out information. They're all over the place. So Google brain tumor organizations, brain tumor resources. Do a number of searches. You'll pick up a lot of different organizations. And what you want to tell the people is you want to approach the situation, don't rush in, and get yourself a sensor. That's what your dad did; he got me, one of the leading sensors in the world who was willing to help him.

**Me:** Could you explain your role in the patients' treatment?

**Dr. Friedman:** The neuro-oncologist is the one who brings to them the differences to treat somebody, to diagnose and treat somebody with a brain tumor. You want to get a neuro-oncologist from day one and they will help with the selection of surgeons, radiotherapists if necessary, and the actual medical treatment if needed; you want to get somebody that is familiar with the treatment of a brain tumor. Not somebody that has no idea what's going on.

**Me:** How important is getting the correct diagnosis to determining the proper treatment?

**Dr. Friedman:** In most cases it is extraordinarily important. On the other hand, if you're not going to do therapy, if you're only going to watch because you don't think there is anything there you need to deal with then you don't need to have a diagnosis immediately. The diagnosis is only if you're going to do therapy. Or if you think it's going to impact on the need to do therapy. But if you're confident you're dealing with something that is a low grade tumor that's been there for three years and you just happened to pick it up three years ago but you don't want to get

tissue, you don't need tissue. You don't need to when you don't know what it is and it has an unpredictable biology and when you want to do therapy. Then you got to know.

**Me: What do you when you have two different diagnoses?**

**Dr. Friedman:** If you have two different opinions from two different major centers, which do not happen often, then you need a tie breaker.

**Me: In your opinion where is the hope for brain tumor research?**

**Dr. Friedman:** The hope is all around you. There are new things that are coming with therapy, with better diagnostics, with the use of molecular analyses. Everywhere you look there is hope for better treatment which means better outcomes. The most important thing that anyone can give a family is what I made sure I gave your dad is hope.

**Me: What is your role with the patient after all the treatments are done?**

**Dr. Friedman:** The fact that the patients frequently have consequences from the tumor and side effects of the therapy and to ensure that their quality of life is at it's greatest. So it's not just treating the children, it's treating the patient. You're fighting for the quality of life. It's the maintenance of quality of life.

**Me: What do you find most rewarding about your job?**

**Dr. Friedman:** Calls like from you. Calls where I get somebody who's telling me that somebody I spoke to seventeen years ago has done well and is doing great and now has a younger sister who wants to give back to the field. That is the most rewarding thing in my life. And your call today came in a week that has been particularly grim for a number of different things that have been sad. Getting this call has made it a much better day.



## **DR. ISAAC YANG: NEUROSURGEON**

**Me:** Can you explain what a neurosurgeon does? Say I'm a parent with a sick child, or a patient, how would you explain your role to me?

**Dr. Yang:** So a neurosurgeon is a doctor who does surgery. That means he opens people up and puts them back together. And a neurosurgeon is a surgeon who focuses on problems of the brain and spinal cord.

**Me:** I was doing a little research, can you explain to me a little bit about Gamma Knife Radiosurgery?

**Dr. Yang:** Gamma Knife Radiosurgery is a type of stereotactic radiosurgery. So it's kind of like a brand, like Toyota, Honda; brands of a car. There's Gamma Knife, there's Linac, there's Novalus; there's different kinds of stereotactic radiosurgery. Overall, radiosurgery just needs highly focused, highly precise radiation. You get high doses of radiation focused on one spot while you leave all the normal tissue to lower doses of radiation.

**Me:** I know that in radiation, the surrounding tissue gets damaged. The Gamma Knife doesn't do that?

**Dr. Yang:** It minimizes the damage.

**My sister:** You said before you work on the brain. Obviously the brain stem can't be operated on. So how do you operate on that?

**Dr. Yang:** Very carefully. The deeper a lesion is the harder it is to access it. So you do your best to weigh the pros and cons on how careful you ought to be based on how deep the tumor is.

**Me:** Are you going through any research right now? Is there anything you can tell us about your research?

**Dr. Yang:** We're looking at using different kinds of therapy and technologies to

attack brain tumors. We're looking at stem cells, nanoparticles. We're always looking at different ways at using that technology to attack brain tumors.

**Me: You had worked on a vaccine for a glioblastoma, can you explain that a little bit?**

**Dr. Yang:** Vaccines work by recognizing different proteins. So if you recognize a protein on a bacteria or a cell that's wrong, the vaccine recognizes that and goes after it. So what we're trying to do is use different kinds of therapies. Right now I'm trying to work on a nanoparticle vaccine in terms of trying to find different kinds of proteins that can help the immune system recognize the proteins on brain cancer. And then your body can fight brain cancer.

**Me: Have you done any trials?**

**Dr. Yang:** Clinical trials are going on right now at UCLA and UCSF.

**Me: How are you involved with the family's journey? Obviously, you operate in their brain. Are you involved with anything else with them?**

**Dr. Yang:** I usually meet the patient's before surgery. I talk with them, I let them know. I call it a journey. Brain tumor treatment is not In-n-Out. I like In-n-Out hamburgers, but it's not "in and out". It's a journey. Once you get diagnosed with a brain tumor, you're going to be fighting it for the rest of your life. Even if it's quote-on-quote "cured", you're still going to get MRIs for the rest of your life. So I look at them and say, "You and I are going to be friends for pretty much the rest of your life. Maybe even the rest of my life. We're going to be friends no matter what. It's a journey." So what I think about with my patients is it's a journey we go on together. And if you want to go to go this way, we have to discuss so we can go together. And as long as we both agree to go we can move forward. And that's what I think about with my patients. The brain tumor therapy is a journey that I go on with my patients.

**My sister: What would be the biggest mistake a patient can make with their cancer? Or the biggest mistake a parent can make?**

**Dr. Yang:** I think the biggest mistake I think I see patients make are doing something that A, they're not comfortable with. So if you don't know what's going on, you have to ask. And I know it's hard too, because doctors are kind of scary but you have to ask. On both of us. Patients have to have more voice to speak up

and doctors need more of a voice to make it comfortable to speak up. So I think the biggest mistake is doing something they're not comfortable with. And so you have to make sure that you're comfortable and that you have everything explained to you.

**Me: Misha had a brain stem glioma, what would be a treatment option be for her? She can't have radiation anymore, and chemotherapy isn't an option. Other than surgery, what could she do for treatment?**

**Dr. Yang:** There are newer medications, versus twenty years ago. There is something called Avastin, which helps shrink tumors. It's experimental; it only works for a short time. If it came back, we'd be very desperate. You can't keep shooting radiation so we'd try something like Avastin. You could consider surgery, but if it's deep and in the brain stem, it would be not a good idea to do surgery.

**Me: Last question, I ask this to every doctor, what do you find the most rewarding about your job? Getting to save a life is always a great thing, but is there anything else?**

**Dr. Yang:** The best thing about my job by far is connections. It's the friendship, it's the relationship. It's the journey. Because I can't always save their life. That's the sad thing about it. Sometimes they have a really deep brain cancer, and there's not much else we can do in terms of medical therapy, chemo, and radiation. But I refuse to believe that there is nothing else I can do. I can make them feel more comfortable. I try to make them smile. If they want to hug me, I let them hug me. It's remarkable what a hug can do. What a warm smile, what that relationship can do. I have found out through my life and through my job, that death is not the worst thing. I know, death is horrible. I am not minimizing death. But it's not the worst thing. The worst thing is not having those connections. Not having that opportunity to say goodbye, to say you love someone, to say you forgive someone and they forgive you. Being able to help families, to help patients through that process, they really like me for that. We have a super deep connection through this thing we're going through. Because I am going with them on this journey. They feel very connected to me. And I have to say that is a very fulfilling, very rewarding, sometimes a little overwhelming experience. But that's what I enjoy about my job.



## **DR. GEORGE JALLO: NEUROSURGEON**

**Me:** I know what a neurosurgeon does. But let's say that I am a patient, and I just found out that I have a brain tumor and I have no idea what your role is in my treatments. Could you explain to me what your job is as neurosurgeon?

**Dr. Jallo:** Sure. My role is, as a neurosurgeon, is to cut. That means I operate in the brain and provide tissue to, one, determine the diagnosis to know exactly what the tumor type is. And two, for a lot of tumors if you can take them out, it makes other treatments all that much easier. And in some cases, if you are able to remove the entire tumor you don't need any other treatments such as radiation or chemotherapy. So, the neurosurgeons have a major part in the care of the child who has a brain tumor. You can almost say that they become the first line approach. Once they can safely remove the tumor, we send it to the pathologist. The pathologist reviews it and makes the diagnosis. And once we have a diagnosis we discuss it with the neuro-oncologist to come up with a plan for the patient. If they need chemotherapy, the oncologist will take over. If they need radiation, the radiation-oncologist will take over. The neurosurgeon will take a "backseat" knowledge in case there are problems that develop or, in the case of a malignant tumor, if it grows back and it needs another operation, then we step up to the plate again.

**Me:** How heavily does the type of treatment depend on what kind of tumor it is?

**Dr. Jallo:** Absolutely. If it is a benign low-grade tumor and you take it out, it may not need any other treatment, just imaging—MRIs now and then to make sure it doesn't grow back. If it's malignant, it may need chemotherapy, radiation, or a combination of the two. If it's a benign or slow growing tumor sometimes we do nothing but surgery. And even if it comes back again, we'll go in and re-operate to get it all out or as much of it as possible, trying to avoid all the other modalities from chemotherapy and radiation. They also have some side effects associated with them.

**Me:** Are there any other treatment options besides surgery, chemotherapy, or radiation, such as a vaccine, for example?

**Dr. Jallo:** There are some vaccines under trial now that are being opened for children. There are vaccine trials for malignant tumors in adults but currently there are one or two vaccine trials for children for low-grade tumors and high grade tumors. And sometimes vaccine trials need some catheters inserted in that location so they can deliver the drugs.

**Me:** Do you have any current research that you are conducting at the moment that you could tell me about?

**Dr. Jallo:** Yes, I am doing research on brain stem and spinal cord tumors; these are really difficult tumors. What we do is creating the tumors in animals and then I am trying to treat them by putting in catheters and delivering drugs. So we're trying to treat them with that surgery, just with the delivery of chemotherapy agents.

**Me:** So you're testing them out on animals first and then on people?

**Dr. Jallo:** Well, yes. You can't just test it in a human trial. So you have to do these safety studies on animals. And we use small animals: mice and rats.

**Me:** That's really interesting. So, I am curious about one thing. My sister had hydrocephalus. I was never told much about it, so there isn't much I know about it other than that it is water in the brain. If you come across a patient who has hydrocephalus, do you remove it? Or do you work around it? Can you explain that to me?

**Dr. Jallo:** Hydrocephalus, it's actually very common in children. One, there are some children who are born with it. Two, the children develop it once they have a tumor. What hydrocephalus is, in a simple definition: *hydro* is water and *cephalus* is brain; so water on the brain. But really what it is is a cerebral spinal fluid (CSF). We all have it in our brain. One, it provides nutrients. Two, it cushions the brain which is confined in the skull. It is a clear fluid so everyone thinks it is water, but it's not. It's full of chemicals and electrolytes inside it, but it provides nutrients to all the brain cells as well as providing the cushions. So what happens is we make about [in comparison] one can of soda a day, but we reabsorb that whole can each day. What happens is, some tumors can cause you to make more cerebral fluid that you can't reabsorb, and an accumulation occurs. And you have hydrocephalus. Some tumors can block the fluid pathways or you make it and it can't get out and get reabsorbed. To treat it we have a couple of options. We can bypass the instruction. Other times we have to put a shunt into the fluid cavity, the ventricles, and run the tube under the skin and put it into some other orient such as



around the abdomen or in the lungs, and sometimes in the heart, to treat the fluid.

**Me: Regarding the quality of life, how do you balance that and trying to save your patient?**

**Dr. Jallo:** Lots of practice. When I first finished my training, it was extremely difficult. I just wanted to be here all the time for my patients and try to be the best physician for them. I think that surgery is actually easier than balancing that.

**Me: After all the treatments over, and the patient is tumor-free, what is your role with the patient thereon out?**

**Dr. Jallo:** So after that, I'm going to have to follow patients. In some cases it could be the oncologist, other times it may be the surgeon. I have followed some of my children with brain tumors for 20 years. I see them once or twice a year just to make sure they are doing okay. So I continue to follow them even though I don't need to do surgery. I am still interested in their lives and how they are developing.

**Me: I have asked every doctor this question. I just enjoy hearing their answers. What is the most rewarding aspect about what you do?**

**Dr. Jallo:** For me, as a surgeon, it's seeing the children tumor-free and trying to live their lives to their fullest potential.

# **CHAPTER 27**

# **INSURANCE**

## THE INSURANCE COMPANIES

This information came from a mom whose daughter died from a brain tumor. She approached me after I emailed her and told me she would write something for the insurance portion of Get Through it Together.

Information provided by Annette McKeon (**Aimee's Army**) Who has a degree in medical insurances, coding, anatomy, and medical terminology and over 20 years experience in the medical insurance claims industry as a claims analyst.

Annette (angel aimees mom)

**"A ribbon is just a ribbon without a face, add pig-tails and a baseball cap and it becomes a child". Aimee Dickey forever 12**

## MEDICAL INSURANCE

Medical insurance can be a headache for all those involved, from the patient to the provider.

Depending on the type of insurance, depends on the amount of time one has to file a claim. It can range anywhere from 6 to 18 months depending on the policy. Most common is 6 months from the date of service.

**Patients must be fully aware of how their policy works.**

- 1) Verify before any procedure that the provider is contracted with your insurance company before a procedure is done. This will avoid any unexpected out of pocket expenses for the insured.
- 2) Verify with your provider that they do have your correct insurance information, in order to file a claim in a timely manner. This will avoid back and forth calls and billings at a later date.
- 3) Verify with your insurance company that the procedure in question is a covered benefit. Ask if a letter of medical necessity is needed. Just because you have insurance doesn't mean your covered for all procedures. Some policies do carry exclusions. It's best to find out before hand instead of getting hit with a bill later.

## **Main reasons claims are delayed or denied**

1) Inaccurate Coding--ICD-9 and CPT codes are given for every disease and procedure by the American Medical Association. They are a Universal Language used by all providers, and insurance company. When correct codes for the diagnosis and procedure are inaccurate or don't match the insurance company will pend the claim for further information from the provider. Therefore, delaying the payment of the claim. Everything is based off of the codes used for both diagnosis (ICD-9) and procedure (CPT). Every part of your body has a universal code in which the diagnosis (disease, condition) is based. Codes are assigned based on anatomy.

EX: Brain Tumor --code 191 (neoplasm of the brain) however, since the brain is divided into many parts/sections the billing specialist needs to be more specific 191.7 (191=malignant neoplasm of the brain .7=brain stem) again however the brain stem also has several sections therefore the proper code or way to bill would be to use

the diagnosis code of 191.7 (4) neoplasm of the brain, brain stem, pons (sections of the brainstem) Therefore the analyst processing the claim wouldn't have questions. However, more than likely will pend the claim for medical records to verify.

In most cases in order for the doctors to reach that diagnosis they will perform an MRI or test based on your symptoms. The MRI procedure code (CPT) 70551, however, there are also other codes that can be used based on if the patient has the MRI with or without contrast therefore requiring different codes.

So the DX code is 191.7 (4) and the procedure is 70551 (without contrast). Therefore the procedure code matches the diagnosis code.

Now say the billing specialist transposed the number and used procedure code 07551 which is an invalid code. Therefore, the claim would be denied as invalid coding.

Keying errors are the most common, and easily fixed. Call both your insurance company and provider to have it corrected.

2) Incorrect patient information--These are usually due to information being keyed incorrectly by the billing specialist, common error. Some cases especially on family plans the specialist may bill for a male when the procedure codes are female specific. ICD-9 and CPT codes are also based off of gender, and age of the patient along with the anatomy.

So, if it's billed under the male insured, not the female and the codes are specific to

female patients the claim will again be denied for invalid coding since some procedures, and diagnosis are gender specific

3) If the providers do not correct the information or provide the insurance company with the information they need the claims will be denied, therefore leaving the insured fully responsible for payment.

### **Letter of Medical Necessity**

In some cases the insurance company will request a letter of medical necessity for a procedure before they will approve possible payment on a claim.

This is primarily based off the diagnosis (ICD-9)code, does the diagnosis warrant the procedure (CPT) code.

Or can another less expensive procedure/test be done with the same results. The provider needs to prove that the procedure is the best way to determine your course of treatment. If not then having the procedure done becomes your sole responsible for payment to the provider.

### **Collection Agency**

When your provider is contracted with an insurance company they are under law to accept payment for the allowed amount not the billed.

EX: You visit your doctor, he bills your insurance company \$100.00 for the office visit.

Your insurance company say's no that procedure is only worth \$80.00. Then depending on the policy will pay a percentage of that \$80.00 you are only responsible for the difference. Most major medical policies are 80/20. With an 80/20 policy and the allowed amount of \$80.00 your insurance will pay \$64.00 and you'll be responsible for \$16.00 totaling \$80.00. The provider must write off the other \$20.00 from the total billed of \$100.00.

Most policy have co-pay's which you are responsible for a co-pay amounts usually at the time of service, depending on the terms of your policy. So, if your co-pay for an office visit is \$10.00 you pay that when you arrive. The provider bills your insurance company for the \$100.00, again they allow \$80.00, paid 80% or \$64.00 you all ready paid \$10.00 so the provider may bill you for the remaining \$6.00 of the 20% which is your responsibility. Co-pay amount vary depending on the

policy.

You may also have deductibles which are your full responsibility, prior to the insurance company paying for claims which can range in different amounts depending on the coverage and/or policy terms. If your deductibles are not met you will be responsible for the claim.

This is where some collection agency's come in. Some will go to the providers to get the other \$20.00. That's illegal, especially if they are contracted with your insurance company. However, if your insurance company does deny the claim the provider can then bill you whatever they want for that service. Which can then be in excess of the original \$100.00 and become your total responsibility.

Many people fear non payments being added to their credit reports, so they will pay whatever is billed. Please, verify the dates of service and/or the procedure. Also, verify with your insurance company that no other payment was made by them, and the claim and amount is really your responsibility.

It is extremely important to understand your policy, and read your explanation or benefits (EOB) from your insurance company after a claim has been filed. Match it up with any and all bills you may receive from the provider and or collection companies. This will prevent any error or overpayments on your part that you are not responsible for. When in doubt always ask questions.

There are many different types of insurance.

**Medicare**--federally funded through your Social Security benefits usually for seniors and or disabled.

**Medicaid**--state funded for low income or disabled patients.

**Major Medical**--usually covered a wider range of services but also carries a higher deductible.

**HMO (health maintenance organization)**-- cover a wide range of plans but you must see an exclusively HMO provider

**PPO (preferred provider organization)**--you must get your care from the insurance company's list of preferred providers.

**POS (point of service)** combines elements from both HMO & PPO plans. You must choose a primary care physician you work with to coordinate your care.

**In network providers**-- are providers contracted with your insurance company for your care.

**Out of network providers**--provider not on the insurance company's list of in

network providers. Seeing an out of network provider for your care means your are responsible for the bill. In some case your insurance may pay a portion of the charges depending on the circumstances for going out of network.

**One thing to always remember, you have a right to appeal any denied claim. Just because you receive a bill does not mean it is your responsibility. Make sure it was not a coding error on the providers end and or claims specialist. Also, just because your policy has exclusions doesn't mean those exclusions are not payable.**

**There are exceptions to every rule. Always, always double check when you receive a bill from a collection agency. With insurance fraud, and Identity theft on the rise when in doubt always ask questions. It's better to be safe than sorry.**

**End.**

# **BRAIN TUMOR SUPPORT**



# SUPPORT ORGANIZATIONS

## JOY RX

Here is a brief explanation (taken with permission from the Joy Rx website):

When seriously ill kids and their families need more than medicine, CCA is there with compassion and innovation creating moments of respite and hope, in the hospital and at home. Managed by a professional staff and powered by volunteers, CCA brings soothing music in a time of crisis, friendship in a time of loneliness, resources in a time of turmoil and vital support in the midst of life-threatening illness. **We call it Joy Rx.**

Their website:

<http://www.joyrx.org/>

## RONALD MCDONALD HOUSE

This is a very special charity. The Ronald McDonald House charities provide a home away from home for families with critically ill children. They let you stay with them for \$5-10 per night. And if you can't afford it, they let you compensate for it by cleaning every now and then around the house.

Here is their website:

<http://rmhc.org/>

This charity is very special to me. When Misha was going through her treatments, my dad stayed at the houses in Boston and Alabama.

For the past four years, I have been volunteering at the House in Orange County. I help clean the house and help the staff prepare for events. On occasion, my family and I cook dinners or breakfasts there. It's really remarkable what the staff is able to do for these families. The rooms are always clean, there's never a speck of dust on the furniture, and there is always food in the kitchen.

From the Director of Operations at the Orange County Ronald McDonald House:

"If I had to summarize my experience here at Orange County Ronald McDonald House in one word it would have to be; inspiring. I have been inspired first and foremost by the families that walk through our door. Day after day, I am privileged to witness the resiliency of human nature. Caregivers repeatedly demonstrate strength during their time of adversity. They live life full of hope. Hope for a cure, hope for healing, and hope that it will all work out in the end.

I am inspired by the volunteers, thousands who quietly work behind the scenes preparing meals, serving on our board, writing thank you notes, cleaning the house and yard, answering phones, staffing the family rooms, working special events and the list goes on. Each and everyone of them doing this because "helping others in need" is simply the right thing to do.

I am inspired by the staff who, day in and day out, choose to diligently carry out the mission of our organization providing care, comfort, and support to families. Staff members who endure the reality of this work environment; celebrating the joy of discharge, and mourning the loss of a little loved one.

Lastly, I am inspired by the children, who provide us adults with care, comfort and support by their wide smiles, playful spirits and joyful hearts. Reminding us to value the gift of life: to Live, Love and Laugh."

Noel Burcelis

**Director of Operations**

[nburcelis@ronaldhouseoc.org](mailto:nburcelis@ronaldhouseoc.org)

## **CANDLELIGHTERS**

A brief explanation on the program (used with permission):

Their mission to the community and to the families affected by childhood cancer covers four essential areas: support, education, advocacy & hope.

Candlelighters For Children With Cancer supports families whose children have or have had cancer. We work through all the stages: discovery, diagnosis, treatment and remission, and can also help with other issues, such as those that arise when a child dies. Our motto is, "It is better to light one candle than to curse the darkness."

Their website:

<http://www.4kidswithcancer.org/>

## **HOPE & HEROES**

A brief explanation on the program (used with permission from the website):

In spring 2007, the division became the largest pediatric oncology program in the tri-state area (New York State Department of Health, SPARCS statistics). To meet the needs of our patient populations, we raise money from grateful families and friends, community organizations, foundations, corporations and concerned individuals.

Their website:

<http://www.hopeandheroes.org/>

## **AMERICAN CANCER SOCIETY (ACS)**

This website is a very good one for support. It gives you a list of a support and treatments, research, an explanation about cancer, and ways to get involved. They are as dedicated to you as I am, and therefore a really great place to get help.

Their website:

<http://www.cancer.org/>

## **LOTSA HELPING HANDS**

Lotsa Helping Hands offers free tools designed to make life easier for caregivers and volunteers. The hallmark of the service is the caregiver-focused Help Calendar, which enables members to schedule and sign up for tasks that provide respite for the caregiver including meals for the family, rides to medical appointments, and visits. Members can also communicate with one another through message boards, post personal blogs, share photos, and send well wishes to the family. And Coordinators can safely store and retrieve vital information for the family – from medical and health records to financial and legal documents. Caregivers benefit from the gifts of much needed help, emotional support, and peace of mind, while volunteers find meaning in giving back to those in need. Learn more or create a community for someone you love today.

## **SARA'S SMILES**

This foundation was built on the story of little Sara Burke. She fought her battle with a malignant brain tumor, but passed away in May of 2008. The Sara's Smiles Foundation wants "to extend a loving hand in creating a positive environment and upbeat experiences." They provide places to "hang out" and offer fun times to the children with cancer.

<http://www.saras-smiles.org/index.html>

## **AIMEE'S ARMY**

A little about Aimee's Army (used with permission):

"Aimee's Army is a 501 ( c ) ( 3 ) non-profit, who's mission is for education, research and family support for childhood cancer.

It was Aimee's dream and desire to raise awareness and educate the community into the devastation of all childhood cancers. In the hopes, by doing so, funds will be raised for much needed research, which will lead to a cure, and offer hope for children. She felt that finding a cause, and away to prevent it was key to finding the cure. So we focus more into a way to prevent it from happening, as well as coming up with away for early detection. In the hopes that no parent will ever have to hear your child has cancer and there is NOTHING we can do. Together we can make a difference. Let us all be soldiers in this fight. Be a child's voice today so they will have a future tomorrow."

The link to Aimee's Army:

<http://www.aimeesarmy.com/>

## **THE KORTNEY ROSE FOUNDATION**

The mission of the Kortney Rose Foundation (used with permission):

"The Kortney Rose Foundation is a 501(c)(3) organization that is dedicated to raising funds to support research and education related to the treatment and cure of pediatric brain tumors. Enhancing the quality of life of children with brain tumors requires access to excellent specialty care, clinical trials, follow-up care, and rehabilitative services. Improving the outlook for these children requires research into the causes of better treatments of brain tumors. The goal is to find a balance between the best available treatments with the best quality of life.

Our fundraising efforts will directly benefit the pediatric brain tumor research being done at The Children's Hospital of Philadelphia (CHOP)."

The link: <http://www.thekortneyrosefoundation.org/>

## **WHOLE CHILD LA**

WCLA is a non profit clinic and foundation based on a pain management model created by Dr. Lonnie Zeltzer, UCLA Professor of Pediatrics, who established one of the first interdisciplinary mind-body pediatric pain programs in the country at UCLA in 1991. WCLA employs a holistic approach based on a well-researched understanding of the developmental needs of children and the needs of their families. WCLA incorporates an integrated, broad array of medical, physical, psychological, and complementary therapies specifically for use in combatting chronic pain.

Their website is [www.wholechildla.org](http://www.wholechildla.org).

## **NICKI LEACH FOUNDATION**

About the Nicki Leach Foundation (used with permission):

"We provide educational scholarships to young adults who have cancer (age 17-25) so that they can have a normal college experience.

Our grants can be used to assist with college related expenses such as, tuition, books, or a computer. Funding may also be used for living expenses, a cell phone, or car related costs."

I encourage you to apply for their scholarships. It is very useful for brain tumor patients.

Their link: <http://www.nickileach.org/index.htm>

## **TALI'S FUND**

A little information on Tali's Fund:

Tali's Fund is an organization that raises funds for paediatric brain tumor research. This fund was

created following the tragic passing of the Doron family's daughter, Tal, at the age of 4. Tali's Fund raises money by collecting donations, hosting fundraising events, and selling items such as cards with paintings on the front made by Tali, herself. Through the help of Tali's Fund, a research project is now underway at the Arthur and Sonia Labatt Brain Tumour Research Centre in Toronto, and this in turn has led to a large collaborative project with many Canadian and international pediatric cancer centres around the world.

Link to website: [www.talisfund.org](http://www.talisfund.org)

Link to donate: <https://secure.e2rm.com/registrant/donate.aspx?EventID=16748&LangPref=en-CA&Referrer=http://www.taldoron.com/>

## **STUDENTS SUPPORTING BRAIN TUMOR RESEARCH**

Students Supporting Brain Tumor Research began in 2002 and has skyrocketed into its second decade. SSBTR provides unique opportunities for students to be involved in their community, primarily to raise awareness that one in every three adults has had or currently has a brain tumor. The organization is entirely run by students whose efforts every year leads up to the five SSBTR walks in Arizona. The next event will be taking place at Saguaro High School in Scottsdale in February 2013. Additional walks will occur at ASU in Tempe, NAU in Flagstaff, U of A in Tucson, and the U of A Medical School school Phoenix campus.

Their link:  
<http://www.ssbtr.org/>

## **CHILDREN'S BRAIN TUMOR FOUNDATION**

Children's Brain Tumor Foundation, a non-profit organization, was founded in 1988 by dedicated parents, physicians and friends. Our mission is to improve the treatment, quality of life and the long term outlook for children with brain and spinal cord tumors through research, support, education, and advocacy to families and survivors.

Here is their link: <http://www.cbtf.org/>

## **PEDIATRIC BRAIN TUMOR FOUNDATION**

The Pediatric Brain Tumor Foundation® (PBTF) is a 501(c)(3) nonprofit charitable organization that seeks to find the cause of and cure for childhood brain tumors by supporting medical research, increase public awareness about the severity and prevalence of childhood brain tumors, aid in the early detection and treatment of childhood brain tumors, support a national database on all primary brain tumors, and provide educational and emotional support for children and families affected by this life-threatening disease.

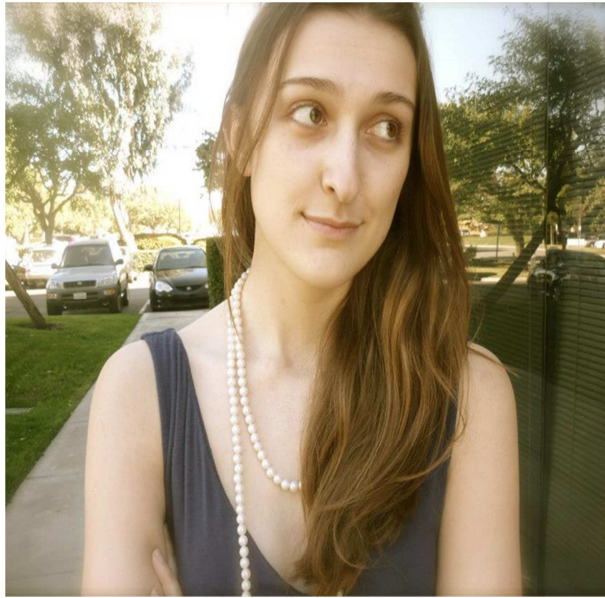
Their link: [www.curethekids.org](http://www.curethekids.org)

## **BENNY'S WORLD**

Benny's World is a 501(c)(3) non-profit foundation established by Benny's parents, Lisa and Brendan, shortly after he was diagnosed with a brain stem tumor. Its purpose is to provide a place where family and friends can feel connected and part of Benny's journey through the Journal. We can all draw strength from each other through the messages of encouragement and support in the Guestbook. Together we can all fight this tumor and help to find a cure. Any life lost to cancer is a waste, to know your child is fighting a diagnosis with such poor odds is heartbreaking.

Their website: <http://www.bennysworld.org/index.php>

# **ABOUT THE AUTHOR**



Hello there! My name is Anna Ritoch. I am a senior at Pacific Coast High School. I find it exciting and scary how fast these last four years have gone by. It seems just last *month* I was a nervous freshman with braces taking her school photo. Now, in a few months (or by the time a lot of people read this) I'll be walking and receiving my high school diploma and going onto the next stage of my life.

These past four years have opened up my mind to many things and proved to me that I could do more than I thought I could. I haven't even graduated from high school yet and I get to say I've written a book and created a website that has helped so many. Not everyone gets to say that and I am glad that I can.

I still stuck with many things that I enjoyed, such as acting, for example. I think I was ten years old when I started my first acting class at South Coast Repertory. From there I was hooked. I was in a lot classes and am now participating in the drama program at my high school.

I've been in plays like *Fiddler on the Roof*, *Thoroughly Modern Millie*, scenes from *Arsenic and Old Lace* (that one was particularly fun; I got to play a deranged old woman who like to kill old men with wine), and now my school is doing a parody of Greek mythology, in which I have the honor of playing Medea and mime giving birth to two kids (not so fun...). I shall trek through it. Now I get to finish my high school acting life in *Wizard of Oz*.

I have a few other hobbies. They include drawing, creating the off video, and writing. My drawing skills are decent. If you give me a photo to look at, chances are I could do a pretty accurate copy. When it comes to doing things myself I just cannot get those squares and circles and lines. I feel like I am drawing a map, and I am terrible at reading maps.

When I was younger I thought I was going to be a famous director and producer. So to pursue this dream I wrote many scripts (I never finished any of them) and filmed small skits with my friends. I realized after some time that I wasn't going to be like Steven Spielberg and decided to commit myself to another hobby. I started writing around the time I started doing those screenplays. I wrote the occasional short story and sometimes went about starting a book. Most of the time I would write something, get writers block, and then read a good book. I spend most of my time now writing for Get Through it Together, and I really enjoy doing that.<sup>4</sup>

Aside from that, I am learning to speak French. I have studied French at the local community college since 2010. Par exemple:

Je parle un peu de français. J'ai pris le classe pour deux ans. C'est quatre ans par la norme de m'école.

Now, my structure and conjugation may be a little off. I don't think so, though.



There are many things I aspire to do and be in the future. I *really* am looking forward to getting accepted into college. There are many schools that I am applying to. Many of them are on the east coast, across the country. When I told Henry Friedman some of the colleges I wanted to go to, he laughed and said that all kids want to get as far away from their parents.

That is not necessarily true in my case. It's my parents who are telling me to go as far away as possible (not in a bad way). They want me to have a change of scenery, place, and life. They don't want to be just an hour car ride or two hour flight from me. I appreciate that from them (Thanks Mom and Dad!).

In the beginning of this long rant about moi, I mentioned that my high school career has allowed me to do things that I never thought I could do. I never thought I'd go through so many different projects and finally pick something that I liked which was right in front of me the whole time (my sister's brain tumor).

And I sure never thought I'd have to pretend to give birth during rehearsals every week in front of thirty people for four months straight. Yeah...that one was sure a surprise.

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