

Brain and Spine Tumor News

Making Cancer History®

THE UNIVERSITY OF TEXAS
MD Anderson
Cancer Center

Our mission is to provide support and education to patients, families, caregivers and friends of individuals with brain and spine tumors.

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Suzanne Mesa and her husband

February 2019

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Events

Run for the Rose
5K supporting brain cancer research at MD Anderson
Sunday, March 31
NRG Park
runfortherose.com

Stand-Up for Brain Cancer Gala
Annual fundraiser from the Broach Foundation for Brain Cancer Research
Thursday, April 18
River Oaks Country Club
thebroachfoundation.org

Swim Across America
Open water fundraising swim supporting adult and pediatric brain tumor research at MD Anderson
Saturday, May 4
Lake Houston
swimacrossamerica.org/houston

How a spine tumor changed my perspective

BY SUZANNE MESA

This story originally appeared on MD Anderson's [Cancerwise blog](#).

My life changed forever on the morning of Nov. 6, 2016. I'd felt some pain in my lower back, and decided to go to the emergency room at the hospital where I work as a nurse manager. I thought I would get some fluids for hydration and be sent back home to my husband and two babies. But God had different plans for me.

Instead of fluids, I had CT and MRI scans of my spine. When the ER physician said, "Ms. Mesa, you have a lesion at L2," I knew immediately that tumor on my spine was cancer. I could see it all over his face.

Why I chose MD Anderson

In that moment, my husband, mom, dad and I shared a look. We knew we would go straight to MD Anderson. For us, there was no option other than the best cancer hospital.

MD Anderson has an exceptional reputation and outcomes, so I didn't mind making the five-hour drive from my home in Louisiana. I knew it was the right decision, because from the first time I walked through the doors, I was treated like the most important person in the world. In MD Anderson's [Brain and Spine Center](#), I met my superheroes: neurosurgeon [Dr. Laurence Rhines](#) and Laurel Westcarth, his nurse practitioner. They treated me like my life mattered more than anything else.

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Clinical Trials

We have more than a dozen clinical trials available, including newly diagnosed and recurrent glioblastoma, meningioma, ependymoma and brain metastases. A few open trials are listed below.

See more trials, details and enrollment information:

[mdanderson.org/
neuroclinicaltrials](http://mdanderson.org/neuroclinicaltrials)

Study No. 2016-0867

Phase I/II
Atezolizumab
*Newly diagnosed
glioblastoma*

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Study No. 2017-0555

Phase I
EDO-S101, radiation
*Newly diagnosed MGMT
unmethylated, IDH wildtype
glioblastoma*

.....

Study No. 2012-0358

Phase I
WP1066
*Recurrent malignant gliomas
and melanoma brain
metastasis*

.....

Study No. ALLIANCEA071601

Phase II
Cobimetinib, Vemurafenib
*BRAF V600E mutation
positive Papillary
Craniopharyngiomas*

Glioblastoma myths

BY SHIAO-PEI WEATHERS, M.D.

See more myths in the original story on MD Anderson's [Cancerwise blog](#).

[Glioblastoma](#) is the most common and aggressive primary [brain tumor](#) in adults. Although it's considered a rare cancer, with about 12,000 new diagnoses each year, it's gained increased visibility recently with the diagnoses of a few high-profile people.

As a neuro-oncologist and the clinical medical director of MD Anderson's [Brain and Spine Center](#), part of my job is to make sure glioblastoma patients and their families understand this disease and how it will affect them. Unfortunately, as I've learned, there are many myths and misconceptions about glioblastoma.

Here's the truth about several glioblastoma myths I commonly hear.

Myth: Cell phones cause glioblastoma.

Fact: Cell phones don't cause brain cancer. Several different studies have failed to find clear evidence of a link between cell phone use and brain cancer. The number of people diagnosed with glioblastoma has remained largely stable over the past decade, while cell phone use has continued to increase.

Myth: There's nothing you can do for an "inoperable" glioblastoma.

Fact: A tumor that's considered "inoperable" at a hospital without specialized brain tumor programs may actually be operable if you seek treatment at a cancer center with the right expertise. Here at MD Anderson, our neurosurgeons successfully operate on many patients who thought their tumors were inoperable. We treat glioblastoma patients every day and have a great deal of experience and expertise in safely removing tumors. This includes glioblastomas involving brain regions responsible for important functions, such as language or movement.

Certain brain tumors that cannot be safely surgically removed may qualify for [laser interstitial thermal therapy \(LITT\)](#). This minimally invasive surgical procedure uses



thermal heat to destroy brain tumors from the inside out. Chemotherapy and radiation therapy are also part of the standard-of-care treatment for glioblastoma.

Myth: Glioblastoma can be completely removed by surgery.

Fact: Even a successful gross total resection for glioblastoma always leaves behind microscopic disease. Glioblastoma has "tentacles" that reach out from the main tumor mass. These tentacles are invisible to the naked eye and even to many of our most advanced imaging technologies.

A gross total resection of a brain tumor is defined as removing at least 98% or more of the contrast-enhancing tumor, which is the part of the tumor that we can see on the MRI scan when the patient is given contrast dye through an IV. An [MD Anderson analysis](#) showed that glioblastoma patients who have a gross total resection tend to live longer. However, invisible cells of cancer are always left behind in the brain after surgery. That's why the standard-of-care treatment for glioblastoma includes chemotherapy and radiation, even after an excellent surgical resection.

Myth: The ketogenic diet can cure glioblastoma.

Fact: No diet can cure glioblastoma. A handful of case studies and internet bloggers have claimed the keto diet may have benefits for brain cancer patients, but the idea that you can "starve" glioblastoma through diet is a myth. While the role of diet in cancer is an area of active research, we know that glioblastoma patients need nutrients – including carbohydrates – to keep their bodies strong through treatment. We recommend a balanced diet based on the [New American Plate guidelines](#) developed by the American Institute for Cancer Research.

How a spine tumor changed my perspective

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My chordoma

After additional testing at MD Anderson, I learned my [spine tumor](#) was a [chordoma](#), a very rare type of [bone cancer](#). Thankfully, Dr. Rhines and his team sat with me and answered every question I had. They didn't rush me, and they explained everything in exquisite detail. Shelly Kennedy, Dr. Rhines' research nurse, was also a great resource.

Surgery is usually the first treatment recommended for chordoma, and that was true for me, too. Because my case was complex, I needed a 20-hour surgery that included multiple different procedures and a team of specialists. On Feb. 14, 2017, Dr. Rhines, along with plastic surgeon [Dr. Alexander Mericli](#) and thoracic surgeon [Dr. Garrett Walsh](#), removed the entire tumor from my spine in one piece, without spilling any cancer cells. Then, they rebuilt my spine. I have rods, screws, a cage and a bone graft, plus three super-impressive, beautiful scars that I couldn't be more proud of.

My path to recovery

Dr. Rhines, Laurel and I had a plan for my successful recovery. I promised I would do everything they asked, if they promised me more time with my beautiful babies and husband. I went to [physical therapy](#) three days a week for six months, then got back in the gym. Now, a year and a half later, I'm a regular in hot yoga classes and am getting certified to teach group weightlifting classes.

Survivorship and emotional recovery

I don't think the magnitude of everything I'd been through really hit me until I was almost fully recovered, about a year after my spine surgery. I was so focused on my physical recovery, I didn't spend time recovering emotionally. I felt absolutely alone, like no one could understand what I was going through. I'm pain-free now, but I can still feel the effects of surgery, and it's a daily reminder that I had cancer.

A different perspective

Everyone told me how proud they were of me and how awesome I'd done in my recovery, but I felt so sad and alone. For them, it was over. But for me, it was just beginning: the constant fear that every twinge was the chordoma returning. That hasn't completely gone away, but through faith and family support, it's getting better. Cancer makes us feel like we're not in control, but we get to decide to make the most of every single day we have.

I still get scared and anxious sometimes, but I also view life differently. I soak up every single minute I have with my family. I relate to my patients completely differently, now that I've been a patient, too. And I thank God for every minute I have, for giving me hope and a future, and for bringing me to my superheroes at MD Anderson.

[Request an appointment at MD Anderson online](#) or by calling 1-877-632-6789.



MD Anderson BEST *A brain tumor support group*

Second Tuesday of each month • 12 to 1:30 p.m. • Brain and Spine Center
Join in person or online from your computer, tablet or smartphone!

MD Anderson BEST (**B**rain tumor **E**ducation and **S**upport **T**ogether) is a monthly education and support group for patients with brain tumors. Each month features a different expert guest speaker, followed by a discussion/support group led by the Brain and Spine Center social work counselors. Lunch and valet parking validation are provided. Upcoming meetings and topics:

Feb. 12: Seizures

March 12: Expert panel on brain metastasis

April 9: Maximizing your function to improve quality of life

Questions, registration and/or request online access:

Amy Bragman, 713-563-7728