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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Events

CureFest Fishing Tournament
Benefiting brain cancer research at MD Anderson

March 24-25, 2017
San Leon, Texas
curefest.com

Run for the Rose
Benefiting brain cancer research at MD Anderson

Sunday, April 2
NRG Park
runfortherose.com

Together in Hope
A conference for brain tumor patients and their families

April 28-30, 2017
Houston, Texas
Registration coming soon!
mdanderson.org/conferences

Cammie Shaddock

February 2017

My brain tumor story

This story originally appeared on MD Anderson's Cancerwise blog.

By Cammie Shaddock

My brain tumor diagnosis came suddenly. I had no pain, headaches or any kind of warning. On Oct. 3, 2016, I had difficulty conveying my thoughts during a casual conversation at lunch. By 5 p.m., I just didn't feel right and had difficulty communicating and texting. Our son, a physician, suggested I go to the ER for a CT scan.

My husband and I did just that, and the world changed at 6 p.m. when the radiologist confirmed I had a large brain tumor. We headed to MD Anderson two days later.

My brain tumor surgery

At the MD Anderson Brain and Spine Center, we met with the most amazing and empathetic neurosurgeon, Sherise Ferguson, M.D. I immediately felt at ease knowing I was getting the best care available. She scheduled a craniotomy for the following Friday.

I had no symptoms, so I went shopping on Saturday and to dinner that night. But on Sunday morning, I awoke confused and weak. We immediately went to the MD Anderson Emergency Center.

After an MRI on Sunday, my surgery was moved up to the next day: Oct. 10. Dr. Ferguson operated on me for 12 hours and removed more than 95% of the brain tumor, which turned out to be glioblastoma.

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Clinical Trials

We have many clinical trials available. A few open trials are listed below. See more trials, details and enrollment information:

mdanderson.org/ neuroclinicaltrials

Study No. 2016-0252
Phase II
Treatment agent:
VAL-083
Unmethylated MGMT recurrent glioblastoma
This trial is only available at MD Anderson

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Study No. 2016-0355
Phase II
Treatment agent:
Tesevatinib
Recurrent glioblastoma

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Study No. 2016-0330
Phase III
Treatment agents:
Lomustine and Eflornithine
First recurrence of grade III anaplastic astrocytoma

My brain tumor story

Continued from page 1

When I awoke, she told me that she had done her job and that my job was to listen to the therapists, do my therapy and rest. She said my husband was in charge of everything else. I am so lucky to have had his love and support through all of this.

Regaining mobility after my craniotomy

I didn't feel any pain when I awoke after surgery, but I couldn't move my right leg or arm. I could only wiggle my right thumb a little bit. Three days later, I was released from the ICU into recovery, then rehab.

The results from that point on were nothing short of miraculous. My days started with speech and cognitive therapy with Jaimie. Then I would do an hour of physical therapy with Liz, Reggie and Hillary, have lunch, and Taylor would start another hour of occupational therapy.

Within a few days, I could move my arm, then leg a little bit. Two weeks after surgery, I was getting my hair done, walking with a walker and writing to-do lists for my husband! Many people wanted to visit me, but my days were so full of therapy and exercise that I refused all requests. Instead, I completely focused on Dr. Ferguson's orders to listen to my therapists and rest. By Oct. 27, I began walking without the aid of a walker and was soon walking all over the hospital. I even participated in a hospital-wide scavenger hunt!

The therapists taught me not just to exercise, but the fundamentals of safety as well. They even brought the car to the front door so I could practice getting in and out. I was discharged on Nov. 2 and released from speech therapy, but I continued my occupational and physical therapy as an outpatient. Thank you, Raymond, Lejoe and Shammi!

My amazing doctors, nurses and therapists took excellent care of me and pushed me to get better each day. Their positive attitudes were contagious. Everyone from the receptionists to the car valets were considerate and truly caring.

Soon after discharge, I met with radiation oncologist Jing Li, Ph.D., and neuro-oncologist Carlos Kamiya Matsuoka, M.D. Together they planned a six-week regime of radiation and chemotherapy, which I completed just before Christmas.

Life after brain tumor treatment

Today, I am home and fully mobile. Thanks to my therapists, I can even carry my 18-pound, 5-month-old grandson around the house. I continue to do my exercises and feel even better every day. My faith, family and friends are my rock.

While I know everyone's experience is different, I feel blessed to have never felt bad from surgery, radiation or chemotherapy. I know I have a second chance after my craniotomy, and I look forward to spending time with family and friends every day.

Save the Date
April 28-30
Houston

mdanderson.org/ conferences

Brain Cancer Q&A

On Friday, Feb. 10, John de Groot, M.D., professor and chair, ad interim, of Neuro-Oncology, and Jeffrey Weinberg, M.D., professor of Neurosurgery, answered questions about brain cancer in a live Q&A broadcast on Facebook and Twitter. Thank you to all who watched and submitted questions!

If you weren't able to catch the video live, click here to watch it now. Follow MD Anderson Brain and Spine on Facebook (/MDAndersonBrainandSpine) to see future live Q&As. Here are a few highlights from the event:

Why hasn't there been more progress in brain tumor survival rates?
JdG: This is something that keeps us awake at night. There are many challenges when it comes to treating brain cancer. One challenge is that gliomas are very heterogeneous, meaning there are a lot of differences between the individual tumor cells. Coming up with a therapy that can attack all of those different molecular aspects at once is a challenge. This is something that newer approaches, like immunotherapy may be able to overcome.

JW: Brain tumor cells are smart and they figure out ways to outsmart the treatment. They have a lot of escape routes. We're also limited by what we can take out surgically because harming healthy brain tissue can cause serious problems with mobility, speech or vision. However, the more we can take out, the less there is left behind to treat.

What advice do you have for brain tumor patients and caregivers?
JdG: I tell all of my patients that they're not a statistic. We obviously have a long way to go toward curing brain tumors, but not every patient is going to have the same experience as everyone else. It's important to really live every day to its fullest, with the expectation that none of us can predict exactly what's going to happen. Being optimistic is incredibly important.

JW: I have a patient with metastatic lung cancer that spread to his brain. When another doctor told him how much time he had to live, his response was: "I'm not a can of peas. I don't have an expiration date stamped on me." He's still here a number of years later. His "peas" would have expired a long time ago, but in fact, he's doing great. I think it's also important to know that when you're here, it might be your first time, but it's not ours.

MD Anderson BEST

A brain tumor support group

MD Anderson BEST (brain tumor education and support together) is a monthly education and support group for patients diagnosed 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.

BEST is open to all MD Anderson brain tumor patients and their caregivers. Lunch and valet parking validation are provided at no cost to attendees.

MD Anderson BEST
Second Tuesday of each month
12 to 1:30 p.m.
Brain and Spine Center

2017 Schedule

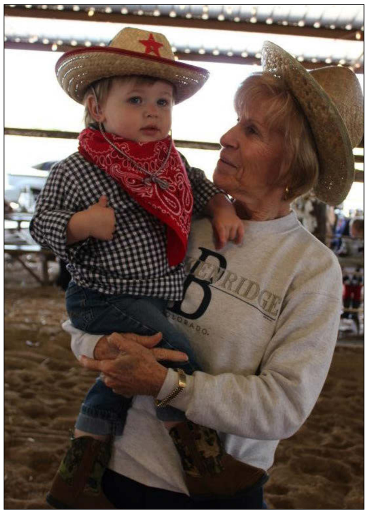
March 14: Side effects
April 11: Rehabilitative therapies
May 9: Radiation
June 13: Cognitive changes
July 11: Communicating with family
Aug. 8: Seizures
Sept. 12: Clinical trials
Oct. 10: Mood and anxiety
Nov. 14: Fatigue
Dec. 12: Resiliency and self-care

Follow the MD Anderson Brain and Spine Facebook page (facebook.com/MDAndersonBrainandSpine) for updates and event reminders about each meeting.

Pre-registration is appreciated, but walk-ins are also welcome.

Questions and registration:
Amy Sheehy, 713-563-7728
Michelle Will, 713-792-0772

Advice from a cancer caregiver



Mary Ellen Flowers with her first great-grandchild, Jennifer's son, Jackson.

Mary Ellen Flowers' granddaughter Jennifer Ratliff and neurosurgeon Amy Heimberger, M.D., describe her the same way: "Very sweet, but a little spitfire too!"

The active 69-year-old from Vicksburg, Mississippi, enjoyed running marathons and kayaking, and had never smoked. So, it was a complete surprise when she was diagnosed with stage IV lung cancer that had already spread to her brain.

It's been nearly a year since Mary Ellen passed away, but Jennifer remains grateful for the care her grandmother received here:

"MD Anderson is such a special place," she says. "Even if you have to travel to get there, it's worth it. When we talked to her doctors, I felt like their entire world stopped to focus on us. We did everything we could – and I was lucky to have her in my life for that amount of time."

Here's Jennifer's advice for making the most of time together when a loved one has cancer and coping with grief:

Be present. Driving from Mississippi to Houston for appointments and treatment meant that Jennifer had three days of uninterrupted time with her grandmother. They would talk about everything and nothing at all, Jennifer says. One memory that sticks out in her mind: Mary Ellen was an avid Downton Abbey fan, but Jennifer had never seen the show. During a long stretch between appointments one day, Jennifer, her mother and Mary Ellen all watched an episode together on her tablet – Jennifer was hooked.

"When the final season aired, every Sunday night, I left my husband and kids and went to her house," Jennifer says. "We watched the show together in our pajamas, just us. I'm so happy I did that. I cling to those 'nothing special' times we had together."

Take notes. Jennifer took turns with other family and friends accompanying Mary Ellen to her appointments. Together, the caregivers shared and managed a single "living, working binder" with notes from each doctor visit and questions for the care team. The notes served as a reference and helped keep all of the rotating caregivers in the loop about Mary Ellen's treatment plan.

"When you leave the doctor's office, sometimes you go, 'Wait – what did they say?'" Jennifer says. "It was useful to be able to go back and re-read our notes from appointments, after we'd had time to digest everything."

Talk to someone about your grief. Jennifer and her grandmother were incredibly close. "She was my person," Jennifer says simply. Understandably, coping with her death has been hard. Talking to a grief counselor helped with the healing process.

"It was helpful for me to talk to someone outside my family and friends," Jennifer says. "My grief counselor recommended that I write down the things I love and miss about my grandmother. Mother's Day was really hard. So, I wrote down what we would be doing if she was still here. I'm going to share it all with my kids one day so they'll know her. It's helped me to know that I'm not going to forget her because it's all written down."

Learn about resources for caregivers at MD Anderson.

Find us online:

Digital Newsletter: www.mdanderson.org/neurosurgery

/MDAndersonBrainandSpine @MDABrainSpine