

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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Constance Blanchard with her family

May 2019

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Events

Head for the Cure Kickoff Event

Hear from the Head for the Cure Foundation team and get ready for this year's race on Saturday, Oct. 12.

Thursday, June 13
6 to 8 p.m.

Pappasito's Cantina
2515 S Loop W
[headforthecure.org/
content/houston-5k-
kickoff-event](http://headforthecure.org/content/houston-5k-kickoff-event)

Together in Hope

A conference for brain tumor patients and their families

Aug. 2-4

Doubletree Houston-Greenway Plaza
[mdanderson.org/
conferences](http://mdanderson.org/conferences)

10-year glioblastoma survivor: Get busy living

BY CONSTANCE BLANCHARD

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

Rare. Unusual. Anomaly. All of these words are synonymous with being a long-term glioblastoma survivor. All statistical data suggests that I shouldn't be here. Only 10% of people with glioblastoma survive five years. However, here I am, 10 years after being diagnosed with the most aggressive form of brain cancer, and I'm not only surviving – I'm thriving.

Looking back is surreal. Some things seem like a dream to me, as if I was floating above watching my life unfold beneath me. Other memories are so vivid that I am instantly brought back to the time and place, and I can recollect the smallest details.

My glioblastoma diagnosis and recurrence

After my glioblastoma diagnosis, I was extremely hopeful, yet realistic. I had every medical advantage for a person diagnosed with brain cancer: one of the best neurosurgeons in the country, Dr. Sujit Prabhu, who removed 99% of the tumor in MD Anderson's state-of-the-art BrainSuite®; excellent neurological exams; and peak health condition for my age. But I still knew that it was possible, or more than highly likely, that I would have a recurrence.

My tumor returned less than a year after my initial diagnosis, and my life changed the moment I stepped out of MD Anderson after my second surgery. Even if it meant multiple recurrences and craniotomies, I would fight as long as possible for my husband, my daughter, my family and my friends.

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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. 2014-0899

Phase I/II

CMV-stimulated adoptive
T cells

*Newly diagnosed and
recurrent glioblastoma*

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Study No. 2015-0953

Phase I

Bone Marrow Human
Mesenchymal Stem Cells
loaded with DNX-2401

*Recurrent high-grade
gliomas*

.....

Study No. 2012-0358

Phase I

WP1066

*Recurrent malignant gliomas
and melanoma brain
metastasis*

.....

Study No. 2017-0615

Phase II

Capecitabine, ONT-380,
Trastuzumab

*HER2-positive breast cancer
with leptomeningeal disease*

Can immunotherapy treat glioblastoma? Understanding the latest study

BY MEAGAN RAEKE

Read the full story in the [Cancerwise blog](#).

A new study has revived hope for the role of immunotherapy in treating glioblastoma, the most aggressive and deadly form of brain cancer in adults. The study used a type of immunotherapy known as checkpoint inhibitors, which train the immune system's T cells to fight cancer. Although checkpoint inhibitors have greatly increased overall survival for some types of cancer, such as melanoma, early clinical trials failed – until now – to show any benefit for glioblastoma.

We sat down with John de Groot, M.D., professor and interim chair of Neuro-Oncology, who led the MD Anderson portion of the study, to learn more about the latest progress in immunotherapy for glioblastoma.

How did this clinical trial work?

The Phase II randomized clinical trial was led by researchers from UCLA and conducted at six other institutions, including here at MD Anderson. We enrolled recurrent glioblastoma patients – people whose tumors had returned after their initial treatment. Nearly all glioblastomas recur, and when this happens, median survival drops to less than a year.

The study had two different arms. In one arm, patients received pembrolizumab, an immune checkpoint inhibitor, both before and after surgery. In the other arm, patients only received the drug after surgery.

How was this study different from previous clinical trials studying immunotherapy in glioblastoma patients?

Most glioblastoma clinical trials only give the new drug at the time of recurrence, usually without surgery. Previous studies of pembrolizumab in glioblastoma that were



[WATCH: John de Groot, M.D., explains the study.](#)

designed this way haven't shown a survival benefit.

One of the goals of this study was to look at the drug's effect on tumor biology. In order to do that, we had to design a "window of opportunity" clinical trial, where the drug is first given several weeks before surgery and continued afterwards. Researchers studied the tumor tissue removed during surgery to see how the drug affected the immune cells within the tumor.

Because this trial included two arms, researchers were also able to compare the impact of the drug on the tumor tissue and patient survival between the two treatment approaches.

What did the clinical trial find?

Surprisingly, the study found that glioblastoma patients who received pembrolizumab before surgery survived much longer than those only receiving it after surgery. We didn't expect for one group to live longer than the other.

The study also found more activated immune cells, including T cells, in the tumor tissue from those who received the drug before surgery.

What does this mean for glioblastoma patients and caregivers?

There is hope that there might be a way moving forward to use immunotherapies more strategically for the treatment of glioblastoma.

One of the most important things to remember about this scientific data is that it needs to be repeated to know if the results are really true. It may only apply to patients who are able to have surgery after treatment with immunotherapy.

10-year glioblastoma survivor

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Taking advantage of the gift of time

After a few years passed with no more recurrences, I felt foolish for not taking full advantage of being a young, healthy cancer survivor. I decided then that I would push myself to achieve goals that I thought were out of reach, and make as many new memories as I possibly could with the extra time I'd been given.

I earned my bachelor's degree in English. I also ran two half-marathons and completed my first full marathon in January 2018. And, most importantly, I made wonderful memories with my family and friends. I've visited more places in the last 10 years than I had ever imagined. I saw ancient Mayan Ruins, played in the clear blue waters of the Caribbean, explored incredible caverns and visited Disney World twice.

Long-term glioblastoma side effects

However, long-term glioblastoma survival doesn't come without inconveniences. I suffer daily with anxiety, thinking about the "what ifs." I've come to terms with being on a mild anti-anxiety medication. It's better than trying to fight through crippling panic attacks. Also, it's become extremely awkward for me to begin new relationships with friends or work colleagues. I never know when I'll need to explain why I have to travel to MD Anderson — or that I have bald spots beneath my long hair from radiation. I sometimes feel uncomfortable sharing my experience. I don't look sick. So, why would anyone think that I'm a cancer survivor?

Learning to deal with survivor's guilt

I also suffer from an indescribable survivor's guilt. I think of people I've connected with along the way who are no longer here. Every time I hear someone has been diagnosed with any type of cancer, I cringe, thinking someone else might say, "Well, you know Constance is a cancer survivor," as if I've experienced every aspect of every cancer. (I haven't!) But these are minor problems for living much longer than expected, and I'm grateful to my care team that I'm even here to experience these inconveniences.

Embracing life after glioblastoma

The past 10 years have felt like a lifetime. It also feels like they've gone by in the blink of an eye. My memories are like a roller coaster ride of highs and lows, but mostly highs thanks to my care team and support system of family and friends. Like everyone, I have bad days. But I try my very best to be optimistic and happy on a daily basis, no matter what the world throws my way. See, that's where cancer loses. We may not have much control over the hand we're dealt. But glioblastoma doesn't have control over my life. I've faced every day since my diagnosis head on, and I've learned to embrace every waking moment with all of my being.

To quote one of my favorite movies, "The Shawshank Redemption," you either have to get busy living, or get busy dying. Every day that we wake up, regardless of our current health, we are both living and dying at the exact same time. We can make the ultimate decision to embrace every moment and live our lives to the fullest, or we can choose to let life get the best of us. I choose to get busy living, and my advice to every survivor is to do the same.



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:

May 14: Expert panel on primary brain tumors

June 11: Navigating relationships

July 9: Advance care planning and disability

Questions, registration and/or request online access:

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