# **Brain and Spine Tumor News**

Making Cancer History®



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**

# Walk with the Doc

Join John de Groot, M.D., for a walk through Hermann Park

Saturday, May 20 9 a.m.

**Details** 

# **Brain Tumor Support Group - The Woodlands**

A special edition of MD Anderson BEST

May 25, 2017 6 to 7:30 p.m. South County Community Center

#### Survivorship Week

Join MD Anderson for a week of activities to celebrate cancer survivors and their caregivers

June 4-10

# Brain tumor patient finds support, friendship in other survivors

Like many men, Jeff Gerber admits he was never very fond of visiting the doctor. Still, on his 35th birthday, the father of three decided it would be responsible to go in for a thorough "head-to-toe checkup," just in case. The checkup revealed something he never expected: a left frontal lobe brain tumor.

"When I saw the mass on the MRI scan, I went blank with shock," Jeff says. He called his wife and headed to the ER. After surgery, they learned it was glioblastoma, the most aggressive form of brain cancer in adults.

Jeff came to the Brain and Spine Center and completed the standard of care treatment: chemotherapy (Temozolomide) and six weeks of radiation therapy. But after just a few months, the tumor returned. Neurosurgeon Frederick Lang, M.D., performed a craniotomy to remove the brain tumor recurrence in 2010. Jeff has remained stable since then, under the care of Barbara O'Brien, M.D. – and with the support of other brain tumor patients.

"There aren't many people who know what we're going through," Jeff says. "We're a tight-knit community of survivors."

#### Making connections

During an appointment at MD Anderson, Jeff heard about Together in Hope, a biennial conference for brain tumor patients and their families.

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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

#### Study No. 2015-0869

Phase IIb/III
Treatment agent:
ABT-414
Newly diagnosed
glioblastoma

#### Study No. 2015-0864

Phase II
Treatment agent:
Crenolanib
Recurrent glioblastoma

#### Study No. 2016-0330

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Phase III
Treatment agents:
Lomustine and Eflornithine
First recurrence of grade III
anaplastic astrocytoma

#### Study No. CERN09-02

Phase II
Treatment agents:
Bevacizumab
Recurrent ependymoma

#### Support, friendship

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Jeff and his wife attended for the first time in 2009. While the conference included plenty of treatment information and research updates, Jeff enjoyed the informal breakout sessions the most.

"In the small group sessions, I really started to connect with people," Jeff says. He and his wife exchanged phone numbers with a few other couples who'd had similar experiences. Over the years, they have grown close, meeting up several times a year, usually for dinner at someone's home.

"It's not like we sit around and just talk about the c-word," Jeff says. They chat about everything from family life to sports, and provide an outlet for each other to discuss both the big and small challenges that come with being a cancer survivor.

#### Caregivers need support too

"If you try to go through this by yourself, it's a lot harder," Jeff says. That goes for caregivers too.

When Jeff was diagnosed with glioblastoma, his oldest daughter was 5 years old and his

youngest was just 7 months. Within their group of survivors, Jeff's wife also found support from other couples with kids around the same age. They understood what it meant to suddenly find yourself caring for young children, plus a spouse with cancer – and worrying about what you would do if they were gone.

"I feel like the caregivers are more of a patient than the patient themselves," Jeff says. "When you're in a relationship you rely on each other. My wife put her life on hold for me. It's just as important for the caregiver to get support."

#### New best friends

Jeff and his wife now count their network of brain tumor survivors and caregivers among their best friends. Every other year, they return to the Together in Hope conference and make a few new friends.

"The hardest part is seeing friends pass and people suffer," Jeff says. "We may not have a cause or cure yet for brain cancer, but by going through the battle together, we know we're not alone."

For those interested in meeting other caregivers and survivors, see the list of MD Anderson BEST support group meetings on the next page.



## **Together in Hope 2017 Recap**

Thank you to all who attended the 2017 Together in Hope conference for brain tumor patients and their families, April 28-30, at the DoubleTree Greenway Plaza in Houston. Over three days, more than 60 attendees heard expert lectures, took part in support groups and talked to our doctors one-on-one.

We appreciate your participation and hope that you learned something new, made valuable connections and had fun! If you missed the event, check out these videos:

- <u>Neuropathology presentation</u> from Gregory Fuller, M.D., Ph.D.
- <u>Laser interstitial thermal therapy</u> <u>presentation</u> from Sujit Prabhu, M.D.

### Chemobrain and cognitive changes



The June MD Anderson BEST meeting will focus on cognitive changes, an important topic for many cancer patients, especially those dealing with brain and spine tumors. Get a preview of the upcoming support group with these questions, answered by Jeffrey Wefel,

Ph.D., associate professor of Neuro-Oncology and chief of Neuropsychology.

#### What is chemobrain?

*Dr. Wefel:* Chemobrain is a term used by patients to describe changes in their thinking, or cognitive function. Depending on the person, "chemobrain" may refer to forgetfulness, slower thinking, difficulty concentrating or periods of mental confusion or "fogginess." It's difficult to pinpoint an exact definition, but it generally describes a feeling that "my brain is not working quite the same as it was before cancer."

#### What causes chemobrain?

*Dr. Wefel:* When we look at cognitive changes in cancer patients, there are two distinct groups. In the first, patients with brain tumors can have changes in cognitive function due to the location of their brain tumor and treatments that directly affect brain tissue.

However, "chemobrain" is often used to refer to cognitive changes experienced by patients in the other group: those without cancer in the brain. While the term "chemobrain" seems to directly blame the problem on chemotherapy, we've actually found that cognitive problems can appear before any treatment begins. Even if cancer is not growing in the brain, it can still disrupt systems in the body that end up affecting mental function. Some treatment, including certain forms of chemotherapy, hormonal therapy and immunotherapy, can also cause cognitive dysfunction, meaning they can directly or indirectly disrupt, damage or alter normal brain function.

Read the full Q&A on the Cancerwise blog.

## Immunotherapy for Glioblastoma

OncoLog is an MD Anderson publication for physicians, but many patients are actively seeking information on this topic too. Read this story from OncoLog to learn about the ongoing laboratory research and clinical trials in development at MD Anderson using immunotherapy for glioblastoma.



#### MD Anderson BEST

A brain tumor support group

MD Anderson BEST (**B**rain tumor Education and **S**upport **T**ogether) 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

June 13: Cognitive changes
July 11: Communicating with family
Aug. 8: Seizures
Sept. 12: Clinical trials

Oct. 10: Mood and anxiety Nov. 14: Fatigue

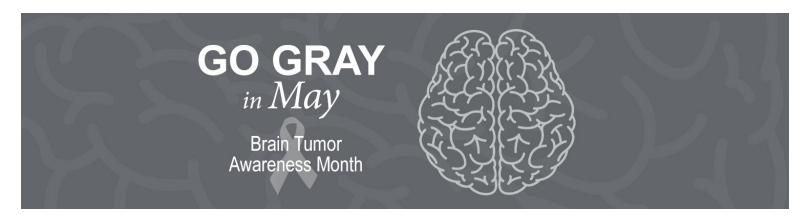
Dec. 12: Resiliency and self-care

Follow the MD Anderson Brain and Spine Facebook page (<u>facebook.com/MDAndersonBrainandSpine</u>) 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



May is Brain Tumor Awareness Month. Doctors, nurses and staff in Neurosurgery, the Brain and Spine Center and the Brain Tumor Research Program wore gray this month to support Brain Tumor Awareness Month.

We invite you to **#GoGrayinMay** with us by:

- Wearing gray in May.
- Telling others about your connection to brain tumors.
- Using #GoGrayinMay and #BTAM on social media.
- Sharing our #GoGrayinMay posts on Facebook or Twitter.
- Supporting brain tumor research.
- Giving a brain tumor patient, survivor or caregiver a hug.







# Thank you!

We are grateful to all who helped make the Dr. Marnie Rose Foundation's 15th Annual Run for the Rose in April a success. The event helps fund brain tumor research at MD Anderson. (Near right)

In March, the David Senez Jr. Foundation donated \$4,000 to brain tumor research at MD Anderson, in his memory. (Far right)





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