



In the News...

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Go Grey in May Campaign kicks off in South Carolina

The "Go Grey in May" Campaign kicks off in the home state of The Brain Tumor Awareness Organization (BTAO) -South Carolina.

May 1st, Cancer centers serving South Carolina's brain tumor populations will proudly display the Governor's Proclamation of Brain Tumor Action Week and Brain Tumor Awareness Month.

Beginning with Brain Tumor Action Week (BTAW), May 4-8; several centers will share information about this time when advocates from around the country meet with legislators in Washington, DC on behalf of brain tumor patients and professionals. The Brain Tumor Awareness Organization will sponsor a slideshow display about BTAW so that local patients, caregivers and professionals can learn how to support and get involved in the North American Brain Tumor Coalition's event.

Support groups and brain tumor survivors are also invited to participate in "The Hidden Under Our Hats" display which travels the nation as a visual awareness display and returns annually around the Upper Senate Fountain in DC. The hats will be displayed at various centers throughout the state during the month of May before becoming part of the National display.

Brain tumor **Angels** and **Warriors** are remembered during our annual Vigil which is hosted in DC by The Healing Exchange B.R.A.I.N. Trust and remotely throughout the world. Please submit your names to us so that we may include them in this year's vigil.

In an effort to raise awareness and funds for those affected by brain tumors, our **Go Grey in May** campaign informs the community about **National Brain Tumor Awareness Month** which was proclaimed by House Resolution 1124 last year. The goal of The Brain Tumor Awareness Organization is to increase outreach efforts within the community to promote May as Brain Tumor Awareness Month and increase funding for support programs and research.

Grey Ribbon Medallions will be offered at \$1 and \$5 to the public by community sponsors to raise awareness about the Grey Ribbon Campaign and gap funding necessary for brain tumor survivors.

The first annual **Grey Ribbon Ride-Craniums Converging on Caesars Head** will be held on May 9th, 2009 in Marietta, SC and offers a 50 mile mountain ride with an optional 25 mile scenic loop ride.

The **10th Annual Melvin McCall "Strokes for Progress" Golf Tournament** will be held May 18th, 2009 at Pebble Creek Golf Club and is the annual fundraiser for The BTAO.

The **Donate Your Plate on the 28th** campaign will benefit the BTAO through the support of area restaurants who donate a portion of their proceeds generated from patrons visiting their locations on the 28th of May.

The first brain tumor support group in the Upstate will begin the last Monday of May at First Presbyterian Church, Downtown Greenville at 6 pm.

To volunteer or become a **Grey Ribbon Sponsor**—please check out these information sheets:

Awareness...

- [Governor Sanford's Proclamation for SC](#)
- [May Awareness Activities](#)
- [Go Grey in May](#)
- [Grey Ribbon Campaign](#)
- [Donate Your Plate](#)
- [Drive Awareness Home](#)
- [Online Fundraising Opportunities](#)
- [Sponsor Levels](#)

Advocacy...

- [NABTC Position Papers](#)

Connected...

- [Hidden Under Our Hats](#)
- [Brain Tumor Vigil](#)
- [Scroll of Names](#)

United...

- [The North American Brain Tumor Coalition \(NABTC\)](#)
- [The International Brain Tumor\(u\)r Alliance \(IBTA\)](#)
- [The Canadian Alliance of Brain Tumor Organizations \(CABTO\)](#)

Did you know?

The American Brain Tumor Association has over 6000 participants in their 4th Annual Path To Progress Walk?

Thousands of motorcyclists from across the country **Ride For Kids** and benefit the Pediatric Brain Tumor Foundation?

A brain tumor survivor flew his own plane around the country and raised \$50,000 for brain research?

Joggin' for the Noggin' founder wins NYC Marathon
Ya Gotta Believe!

Be a Brain Tumor Advocate-Raise funds online through our affiliate programs!

Online giving has become the tool that non-profits in today's economy depend on to supplement their grants cycles. The BTAO has some great partners that provide you access to our community and social networks while driving funds to the organization.

Please support us through our partner programs:

[Download our community toolbar](#)- get immediate access to brain tumor news, support groups, a live chat room while raising funds! Powered by Google, this ad-free, spyware free toolbar installs in your browser and with each search or download, the BTAO benefits!

Facebook-Join our cause! Our goal is \$6000 until the end of May and we are building now on 600 members and recruiting every day!

<http://apps.facebook.com/causes/150096>

[Firstgiving.com](#) - is our online registration processor for events and also to allow you to make direct donations as well as create fundraising pages for us!

Join our affiliate program and allow us to assist you in your campaigns to promote awareness and raise funds to establish patient assistance programs in your community. [Email us!](#)

[ClickInks.com](#) provides excellent customer service and donates 25% of each purchase to us. You will find great savings for your inks purchases by visiting their site.

[Download our online opportunities document](#)



**The Inaugural Grey Ribbon Ride
Craniums Converging on Caesars Head**

May 9th 2009

a fundraising ride to establish patient assistance funds

Learn [more](#) about Grey Ribbon Ride!

Mark Your Calendars:

May is Brain Tumor Awareness Month in South Carolina

May is National Brain Tumor Awareness Month

["Focus on Brain Tumors"](#) Conference
Biltmore Estate, NC
May 1st, 2009

[The Grey Ribbon Ride](#)
"Craniums Conquering
Caesars Head
May 9th, 2009

[Brain Tumor Support Group](#)
Hollings Cancer Center
2nd Wednesday of each month
12:00 pm

[The McCall Golf
Tournament](#)
May 18th, 2009

May is Brain Tumor Awareness Month in South Carolina

[Trident Health System](#)
Brain Tumor Support Group
3rd Tuesday of each month
5:30

[Donate Your Plate
on the 28th](#)
Check for area restaurants
May 28, 2009

[Upstate Brain Tumor
Support Group](#)
Beginning Wednesday May 27th
6:00 pm
First Presbyterian Church
Downtown Greenville



“Heads Up To Heroes” Daring ❖ Surviving ❖ Thriving

June 15, 1994. Grand mal seizure. My eyes rolled. I turned blue. Stopped breathing. My husband was terrified. He thought I was dying. Rushed to ER. Woke up in a wheelchair. Nurse, in my face, loud: “Do you know where you are?” Hospital, I knew. “Do you know what happened to you?” Not a clue. Car sick from the frantic car ride, still fuzzy from the seizure. Stood up and nearly fell over. Waiting on a gurney in the hallway. Young doctor stops by: “We think you have one of three things: a brain infection, a brain cyst, or a brain tumor - most likely a brain tumor.”

I am Shannon O'Brien. Self-advocate and brain tumor activist. 26 years old at diagnosis, now 41 and a 15-year brain cancer survivor. At the time all this took place, I was living in Seattle, working as food server at a Japanese restaurant. No medical insurance. The hospital decided to discharge me. I had received no tests or treatments of any kind. Luckily, my Aunt Molly was there. She went to find a doctor. Bless the luck of the Irish, the doctor she found turned out to be world-renowned neurosurgeon Dr. H. Richard Winn. He declared my case an emergency, and five days later performed my emergency 8-hour brain surgery, successfully resecting my huge tumor, 100 percent.

I remember waking up in my hospital bed. Music on the little radio, cello and piano, my two favorite instruments. My life flew before my eyes. I just cried. It all came out. I felt the time ahead would be the toughest time of my life. And it has been ...

Diagnosis: oligodendroglioma, grapefruit-sized, right frontal lobe. Radiation therapy (external beam focal), six weeks, a lifetime dose. I went through rehabilitation at UWMC, re-learning to walk and talk all over again. My memory of this part of my journey is kind of patchy. I did have to stop working and go on welfare, then Social Security disability. Marriage ended. Between the tumor, the seizure, the surgery and radiation, I now had a lot to cope with: depression, short-term memory loss, headaches, fatigue, pain. Somehow I began putting my life back together. Six years went by. I dared to hope the nightmare was behind me.

But no. **May 2000.** My first recurrence, after six years. Same diagnosis. Brain surgery again, June 2000. Again, 100 percent resection by my brilliant Dr. Winn. But my tumor had “progressed” - anaplastic oligodendroglioma grade 3, a more aggressive tumor. My hero, neuro-oncologist Dr. Alex Spence, now advised chemotherapy. I completed 12 grueling months of Temodar between 2000 and 2002. I decided to quit after one year of Temodar because it was killing my spirit.

After four or five years of clear MRIs, a confusing period followed in 2004-2005, with something showing up on my MRIs that my doctors thought might be from the late term effect of radiation treatment ten years earlier. I also got second opinion consultations with several other doctors, but the diagnosis remained uncertain.

Finally in **May 2006** they confirmed. My second recurrence. Since I was having MRI scans every month or every other month, it was diagnosed when it was still relatively small. Both UWMC and UCSF recommended radiosurgery for this recurrence, but Dr. Del Maestro recommended conventional surgery. My medical team at UWMC agreed, and I had my third brain surgery on May 18, 2006. By this time, my beloved Dr. Winn was no longer with UWMC. Dr. Silbergeld performed my surgery. He said he performed a gross total resection of all visible tumor. I went through another year of Temodar, completing that course of chemotherapy in June of 2007.

September 2007. Third recurrence. My MRI showed a large recurrent tumor with some parts enhancing. The UWMC tumor board considered my new tumor inoperable. This terrified me! We sent my scans out to Rolando Del Maestro in Montreal Canada, Mitch Berger at UCSF, and Keith Black at Cedars-Sinai Medical Center in LA. Dr. Del Maestro said “operable.” Dr. Berger said “operable.” Dr. John Yu (Keith Black's Co-Director at The Maxine Dunitz Neurological Institute at Cedars-Sinai in LA) said “operable.” Cedars-Sinai offered a trial including surgery, Gliadel Wafers, and dendritic cell vaccine treatment. I chose Dr. Yu and Cedars-Sinai.

I traveled from Seattle to Los Angeles and underwent my fourth brain surgery on October 17, 2007, performed by Dr. John Yu. The nine-hour surgery was exhausting. The good news: Dr. Yu was able to remove all the malignant (enhancing) areas. Unfortunately, there was a shadowy area in the motor strip he could not remove, but he said it was not a big problem, that it looked like low grade. The pathology showed mixed oligo. I found some of this frightening. Before this, I had always had gross total resection (all visible tumor removed), and my diagnosis had always been pure oligo. Also, during the weeks after surgery, I found the Gliadel Wafers made the recovery from surgery much slower.

Then began the vaccine trial. Once they determined I was eligible for the trial (based on recovering enough tumor tissue), they began with leukapheresis (white cell collection) on December 5, 2007. Then they prepared my vaccine, using my tumor cells and my white cells. The vaccine was administered three times at two-week intervals: December 21, 2007, January 4, 2008, and January 18, 2008. When I went



Shannon O'Brien has displayed beauty and courage as an advocate, survivor and artist.

back a month later for my follow-up MRI after the vaccine trial, on February 27, 2008, I received the best possible news – the MRI showed no visible tumor! All gone, no tumor left in the motor strip. Of course I was thrilled. My doctors at Cedars-Sinai recommended follow-up chemotherapy treatment, which can be administered by my “home team” at UWMC. In June 2008, my latest MRI showed a small spot and my case went before the tumor board at Cedars-Sinai and once again I faced a treatment decision again.

The present treatments for brain cancer are not curative. We need new and better treatments. More funding for research. Legislation to improve the research system and to provide better access to care, treatment, and rehabilitation services for all brain tumor survivors.

PLEASE HELP US FIND A CURE!!!

Shannon



Shannon recently attended the Florida Brain Tumor Association conference “Sharing Hope-Tumor Talk” January 2009

where advocates from across the country gather to exchange treatment news, support and advocacy efforts.

The Brain Tumor Awareness Organization

Contact us:
news@braintumorawareness.org
www.braintumorawareness.org

Want to be a news correspondent for BTAO?

Contact us and we will put you in our newsroom!

Read our newsletter online:
www.braintumorawareness.org/scan.html

Subscription Options:
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[Update](#) your email address or information

The Brain Tumor Awareness Organization was founded by a patient and a caregiver, to provide an interactive resource community. This community will provide access to resources and be enhanced by an advocacy network who uses it to raise awareness and provide support. Bringing talents together in a web community will empower survivors and advocates to provide valuable assistance to those new on this journey—simply by sharing this website! Become a state affiliate and you can host your own web page within this community, update your events here, and raise awareness and funds for your community! Join today and help us develop this advocacy network!

www.advocate.braintumorawareness.org

Founders of the BTAO to appear on “Your Carolina” with hosts Jack and Kimberly

WSPA News Channel 7 awarded the March Caring for the Carolinas Award to Julie Houston, the Founder and President of The Brain Tumor Awareness Organization.

Julie and Keith Houston will appear on **Your Carolina** May 4th, 2009 with hosts Jack Roper and Kimberly Kelly which is a morning show and can be viewed live at www.yourcarolina.tv. They will discuss how they became survivors and have extended that dedication to others. As tireless advocates for brain tumor awareness after Keith’s diagnosis with a grade 3 brain tumor, they have met many who are helpless when trying to navigate a difficult system of employer, insurance, disability, tax, and access to care issues. The internet proved to be a valuable resource for support and they now share these resources through their website—teaching others how to use technology for support and outreach.

This year, The Houstons and the volunteers of The Brain Tumor Awareness Organization kicked off a “Go Grey in May” Campaign to raise awareness about May being proclaimed Brain Tumor Awareness Month and how funding is needed to provide support services and programs for brain tumor survivors and their families. Cancer centers across the state will be hosting Brain Tumor Action Weeks—normally held in Washington, DC during the first week of May but now throughout communities in SC to educate about advocacy efforts.

Videos that inform:

[No One Can Afford A Brain Tumor](#)

[Difference Maker-Beth Rosenthal](#)

[Brain Tumor Center has breakthrough](#)

[Brain Cancer Vaccine in Development](#)

[Clinical Trial at Duke Shows Vaccine Fights Brain Cancer](#)

[Brain Cancer Zapper](#)

[Brain Surgery without a Knife](#)

