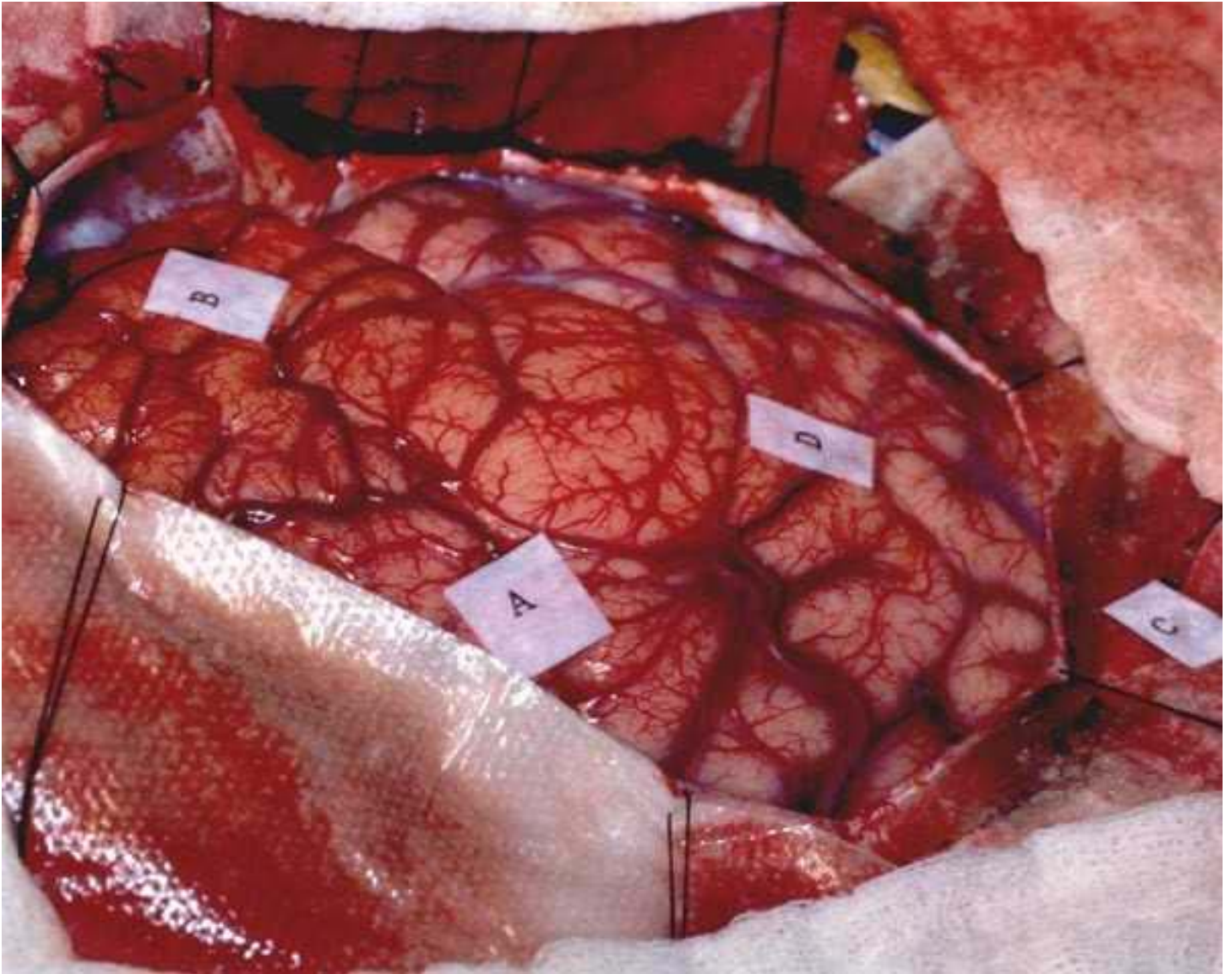


**A mind is a terrible thing to waste—  
on a brain tumor**



Shannon O'Brien's first craniotomy  
June 20, 1994  
showing her grapefruit-sized  
oligodendroglioma brain tumor

Deepest gratitude to our hero Dr. H. Richard Winn for giving Shannon this amazing operating room slide of her brain during surgery—and for saving Shannon's life—twice!

# NEWS

**Media Contact:**

Jan OBrien

job03@comcast.net

253-759-1534 or 253-226-0818

Mother of Shannon O'Brien  
Ten year brain cancer survivor  
Tacoma, Washington

## FOR IMMEDIATE RELEASE

### **FAMILY OF TACOMA BRAIN CANCER PATIENT DESPERATELY SEARCHING FOR ANSWERS**

**Tacoma, Washington, April 22, 2005** - Up to 200,000 people in the United States each year will be diagnosed with a brain tumor. Many will die. Most who survive will be disabled. And that includes Tacoma resident Shannon O'Brien.

Shannon is a brain cancer survivor. First diagnosed with a benign brain tumor in 1994, Shannon had a recurrence in 2000. The new tumor was malignant. Shannon and her family learned about Brain Tumor Action Week, a yearly lobbying effort organized by the North American Brain Tumor Coalition,<sup>1</sup> and began going to Washington DC every May to ask the legislature for increased funding for brain tumor research, as well as needed improvements in the clinical research system. Shannon meets personally with her Senators and Congressman, who have been very supportive.

This year would have been Shannon's fifth consecutive year, but she can't go. Shannon is in poor health, suffering from a late effect of the radiation treatment she had 10 years ago. In December Shannon and her family learned something had shown up on her MRI. After follow-up MR Spectroscopy and PET scans, Shannon's doctors agree that the suspicious area on her scans is most likely not recurrent tumor. Instead, they believe it is more likely radiation damage, just now showing up, ten years after her radiation treatments.

Certainly, "most likely not recurrent tumor" are good words to hear for any cancer survivor. But Shannon has been having gradually increasing difficulties, including ever present pain; daily headaches/migraines; neuropathy; depression and anxiety; motion sickness; medication related side effects; extreme sensitivity to smells, tastes, and noise; chronically recurring infections; chronically recurring bouts of dehydration requiring emergency room visits; chronically recurring gastrointestinal disturbances; premature peri-menopause (beginning at age 32); extreme fatigue; and cognitive and memory problems. Shannon and her family are in a desperate search for answers—consulting with world renowned brain tumor doctors for second opinions, seeking a more definitive diagnosis, and researching treatments for Shannon's condition.

Shannon's story powerfully demonstrates the reality that even when a brain tumor doesn't kill, it often devastates one's life.

Brain tumors are the leading cause of childhood cancer death, accounting for almost a quarter of cancer deaths in children up to 19 years of age, and are the third leading cause of cancer death in young adults ages 20 to 39. Shannon's interest in brain tumor advocacy sprang largely from her compassion for the children who contract this devastating disease. When Shannon first attended Brain Tumor Action Week in 2001, she met a baby, on life support, in its mother's arms. This is why Shannon became a brain tumor advocate/activist - because of that baby and all the child "angels" and child survivors that baby represented.

Brain tumor cancer research is one of the most under funded areas of cancer research in this country, receiving only about one-tenth of the funds going to breast cancer research or one-fifth of colorectal cancer funding. Of the ten priority areas for research, brain tumors come in at the bottom for funding.

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<sup>1</sup> <http://www.nabrainumor.org/>

Survival rates for glioblastoma multiforme (the most common brain tumor) are dismal, with large numbers of people dying within the first year of diagnosis and many within months.

Those “lucky” enough to survive a brain tumor rarely survive without tremendous impact on their quality of life. Many are crippled, blind, unable to speak, read or write, unable to drive, tormented by seizures, memory loss and personality changes and other incapacitating results.

Yet, in spite of the tremendous impact brain tumors have on the North American population, many people know very little about brain tumors. The wide range of symptoms, benign versus malignant, the often devastating results of even “benign” brain tumors. The incredibly disabling outcomes, the relatively primitive state of medical treatments for brain tumors, the shockingly poor survival rates.

And this lack of public awareness about brain tumors can have dire consequences, resulting from delayed diagnosis and treatment. Many having brain tumor symptoms and not recognizing the potential serious cause of their symptoms, do not promptly see a physician; others may see a physician but are misdiagnosed, sometimes waiting years before receiving a correct diagnosis, when it may be too late. Often a brain tumor patient, when finally diagnosed, will undergo immediate emergency surgery, with little to hope for beyond prolonging the fatal moment.

This year’s Brain Tumor Action Week is scheduled for May 1 through 7. In addition to legislative visits, the lobbying week includes two events of special meaning to the participating brain tumor patients and loved ones:

**Hidden Under Our Hats** - Exhibit of nearly 2000 hats representing brain tumor survivors and brain tumor “angels” (those who have died from brain tumors)

Monday May 2nd, 11 a.m. to 5 p.m.

Senate Fountain (Upper Senate Park) in Washington, D.C.

**Candlelight Vigil** - Annual ceremony of healing, honoring all those who are diagnosed with a brain tumor at all stages of this difficult journey and also honoring the dedicated caregivers, health professionals, and researchers

Monday May 2nd, 5-6 p.m.

Senate Fountain (Upper Senate Park) in Washington, D.C.

“Hidden Under Our Hats,” a project of the Brain Tumor Action Network,<sup>2</sup> began with 850 hats in 2002, originally springing from the grief of one bereaved woman, a Sumner, Washington mother who lost her little girl to a brain tumor. The size and impact of this exhibit continues to grow as more and more survivors and bereaved loved ones contribute their hats. Each hat is hand decorated and donated by a brain tumor survivor or loved one, or by the bereaved in memory of a loved one lost to a brain tumor. Between its annual display in Washington, DC during Brain Tumor Action Week, the “Hidden Under Our Hats” exhibit travels across the U.S. raising brain tumor awareness. Shannon and her family were instrumental in bringing “Hidden Under Our Hats” to Seattle and Portland last fall, as part of their ongoing advocacy for brain tumor patients and families.

Shannon O’Brien is available to give interviews and is willing to ask her Senators and Congressman to give interviews as well.

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<sup>2</sup> <http://www.btan.org/>

# Shannon O'Brien



**Before Brain Tumor**



**After**

## Together in Remembrance and Hope



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. Carsick 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. 37 years old. Former dancer and gymnast. Soon to be eleven-year brain cancer survivor. Self-advocate and brain tumor activist.

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 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 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, six weeks, a lifetime dose. I had 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. Recurrence, after six years. Brain surgery again, June 2000. Again, 100 percent resection by my brilliant Dr. Winn. But my tumor had “progressed”—**anaplastic** oligodendroglioma, a more aggressive tumor. My neuro-oncologist Dr. Alex Spence, now advised chemotherapy. I completed 12 grueling months of Temodar.

But there was a benefit from my brain tumor recurrence in May of 2000: My family and I discovered our purpose. We discovered brain tumor advocacy and activism at a national level, and it has been the main focus of my life ever since. My Aunt Christy is a natural advocate and activist, and she took me to our country’s capitol in Washington DC. It was the first week of May 2001, and it was Brain Tumor Action Week in Washington. We met other survivors and loved ones who gathered together in Washington DC to meet with our United States Senators and Representatives. We became citizen-lobbyists and we felt powerful. Finally, powerful. We traveled from all four corners of our country, and even from Canada, hoping to raise awareness about this devastating disease known as brain tumors. I traveled with Aunt Christy all the way to Washington DC from my home state of Washington—the “other” Washington. I prepared to meet my government head-on for the very first time in my life.

And we all became **family**, right there in DC, in May of 2001. A “family” of brain tumor patients and survivors, and those grieving the unimaginable loss of their loved ones. I have been returning each May for BTAW because I have learned that I have a loud voice in Washington. I can speak for the children who cannot speak for themselves. I represent thousands of brain tumor survivors and “angels” in Heaven. I always try to honor the children.

In 2002, Our “family” of survivors and loved ones was finally successful in bringing about an important new law. After much hard work by the community of brain tumor activists, the Benign Brain Tumor Cancer Registries Amendment Act was passed on August 2, 2002 and became Public Law No. 107-260 on October 29, 2002. Success! This law now requires all 50 state cancer registries to collect the data on both benign and malignant brain tumors. This information is essential to medical research because both benign and malignant brain tumors are incurable and deadly. Deadly. We were heartened, encouraged, energized. We had changed the law of our country! I will continue to return to Washington DC, **and I will continue to speak for the children.**

During the summer of 2002, my brain tumor journey was side-tracked. When I went to my neighborhood Walgreen’s on Sunday to pick up my prescription for pain medication, I was **arrested, hand-cuffed and taken to jail** by two cops who did not believe me. They read me my rights, put me in the squad car, and drove me downtown to the jail and booked me.

These officers would not believe me. I told them I am a brain cancer patient and I was simply trying to fill my prescription for my headaches, just like I had done month after month for many years, at my “friendly” neighborhood Walgreen’s Pharmacy. They did not believe me. I showed them my **brain tumor awareness tee-shirt** I was wearing. They did not believe me. I showed them my medical alert card in my wallet, which states I have brain cancer. They did not believe me. I asked them to call my doctor, my long-time neuro-oncologist at the University of Washington who signed my prescription. They did not believe me. The police thought I had committed a crime. They thought I was guilty. I have never committed a crime. Never.

Those cops treated me like I was a criminal. A guilty criminal! **I was never even sent to the principal’s office,** not once. I was an honor student, a cheerleader, and the Stadium High School Tiger mascot.

I thought, “**If only my grandpa were alive,**” because he was a deputy sheriff. Surely the police would listen to him. But he could not speak for me. Who would help me? I was crying and humiliated, embarrassed and sick, and nobody helped me. Walgreen’s is only one block from my mom’s, where I grew up, but she couldn’t help me. **My mom did not even know the police had arrested me,** her only daughter, her terminally ill daughter. The cops took the word of a young Walgreen’s pharmacist over my word that I had not done this. Over my word that I have cancer, brain cancer! The police didn’t even bother to look at my records at my own neighborhood Walgreen’s Pharmacy. If they had, they would have learned that I am a brain cancer patient and “long-term” survivor of an incurable, terminal illness. The police would have learned that I purchased all of my many medications from this pharmacy, just two blocks from my home. They would have seen that my records included chemotherapy medications that I purchased at this very pharmacy. The police would have learned, if they had bothered to ask, that the other employees at the pharmacy knew me. They knew me and they know I have cancer.

When my parents were finally able to bail me out of the jail, I just broke down and cried like a baby. I was mad and I was sick and it was late and I had been in the same county jail where my grandpa had fingerprinted and photographed many criminals. This must be a dream, a **nightmare.** I thought I could no longer trust my police department. They had arrested me, a brain cancer patient and a good citizen of Tacoma. If it could happen to me, **it could happen to anyone** who tries to fill a prescription. Those police officers did not do their job’s right.

The next morning we had to go to court for my arraignment. Before we left home for the courthouse, my mom called my doctor’s nurse. My neuro-oncologist could not believe it! He immediately faxed a letter to the court saying this was a big mistake and that I did not need to be **traumatized** anymore than I already am with my brain cancer. The judge did not believe the fax from my doctor. Here we go again! **The judge said if I could forge a prescription, I could forge a fax!** He held me over for trial. He limited my travel. And he ordered me into drug rehabilitation treatment to begin the very next day—even though I had not been convicted of any crime.

My parents and I ran out of that courtroom and hired the **best lawyer** we could find. My lawyer, Mike Withey, immediately got all charges dropped and my criminal record sealed. My mug shot, my fingerprints and my police report, all sealed. Now Mike Withey is my new hero because he was able to stop the wheels of justice from rolling over and over me!

At my third Brain Tumor Action Week, in May 2003, I had the good fortune to make the acquaintance of a brilliant neurosurgeon, Dr. Rolando Del Maestro of McGill University, Montreal, Canada. Dr. Del Maestro spoke at education day, enthraling me and my mom and aunt with his presentation on the genetics of brain tumors. He announced right at the start that he would focus on oligodendrogliomas, and believe me, we sat up and took notice—he was talking about my own tumor type! We spoke with **the good doctor** after his talk, and he encouraged me to get my tumor tissue genetically typed. After some months of struggling with Medicare and the University medical system, I did eventually get the testing, receiving the good news on **St. Patrick's Day**: My tumor does have the 1p/19q deletion. As Dr. Del Maestro had explained to us, this means a better prognosis.

Still, I have lost a lot due to my brain tumors and the damaging treatments. Before my brain tumor, I was a dancer, a gymnast, and a very independent woman. Now, I live with daily severe headaches, fatigue, pain, depression. I have been unable to return to full-time employment, although I have tried again and again. I have memory deficits that make it very difficult to manage my life independently. And it is likely I will be unable to have children of my own, which **breaks my heart**.

Since completing my year of chemotherapy in November 2001, my quarterly MRI scans showed no visible tumor—until last summer, August 2004, when an “area of enhancement” appeared on my MRI scan. When it appeared to be larger in December 2004, my doctor gave me the news. Maybe radiation damage, maybe recurrent tumor. In order to help determine which, Dr. Spence ordered another kind of scan, an MR Spectroscopy. After that scan, the tumor board met to review my case, deciding that the suspicious area was probably radiation damage as a late effect of radiation treatment. **My family was shocked**. We had no idea radiation damage could show up so much later. My radiation treatment was ten years ago! The tumor board still could not rule out the possibility of recurrent tumor. My mom kept asking for a PET scan, and my doctor finally agreed. While the PET scan did not rule out possible recurrent tumor, it did provide important information. My doctor was able to determine that a more aggressive tumor was not presently growing in my brain. In addition, at our meeting with radiation-oncologist Jason Rockhill, I learned that my pituitary gland was “absolutely hit” by the radiation I received ten years earlier. He said when the brain is irradiated, the pituitary gland—which is in the center of the brain—almost always gets hit by the radiation. Dr. Rockhill recommended that I see an endocrinologist. Finally! I have been asking for a referral to an endocrinologist for years.

But this journey continues to take twists and turns. My latest MRI, on April 20, 2005, showed a “change.” My doctor said he would order another MR Spectroscopy ASAP. **Oh please let this not be another recurrence!**

Brain tumors, whether “benign” or malignant, are devastating. The present treatments for brain cancer are not curative, and they often cause great harm. 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 brain tumor survivors.

Will I live a long and full life? That could be up to you. Lawmakers, I implore you: Please do everything in your power to help. **PLEASE HELP CURE BRAIN CANCER!!!**

Together in Remembrance and Hope  
Shannon O'Brien  
April 2005

[Note: Shannon's story will be hand delivered to her U.S. Senators and Congressman during Brain Tumor Action Week this May.]