

Speakout: May 1-7 a time to lift awareness of child-killing brain tumors

STORY TOOLS

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By **Liz Holzemer**
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Raising awareness about life-threatening diseases is a competitive business. There's an awareness day, week or month devoted to breast cancer, heart disease, prostate cancer . . . and the list goes on.

In May alone, there are more than 40 different recognized health awareness issues ranging from Childhood Depression Day to Food Allergy Awareness Week to Better Sleep Month.

There's a particular week I'd like to focus on that sadly nets very little attention. It's called National Brain Tumor Action Week and it's celebrated every year during the first week of May. This year's 9th annual observance is May 1-7.

You might be surprised to know that brain tumors are the leading cause of death in children under 18 and that 190,000 children and adults will be diagnosed with a brain tumor this year. That's a brain tumor every three minutes and, tragically, someone dies from a brain tumor every 20 minutes. These are frightening statistics.

Having survived two craniotomies for a life-threatening baseball-sized brain tumor called a meningioma, I have a vested interest in generating more awareness about them. It's what led me to create Meningioma Mommas, an online support group that has members from across the world. We provide support to the newly diagnosed, their families and caregivers, and we also soften what I call the "brain tumor journey."

I was shocked by how little information there is about meningiomas and the lack of attention they receive considering they account for nearly a third of all primary brain tumors. So how is it that the most prevalent tumor is the least known and discussed?

Lack of awareness and visibility. Oh, and the fact that they are labeled "benign." I think most would agree with me that any type of growth in your head is not benign by any stretch of the imagination. Would any of you consider paralysis, epilepsy, or other permanent life-altering deficits benign?

It seems many are shy about uttering the words, "I have a brain tumor" - whether it is a meningioma, astrocytoma, oligodendroglioma, medulloblastoma or schwannoma to name just a few of the more than 120 tumors. I know I was surprised at the number of prominent people who have been afflicted with brain tumors - Elizabeth Taylor, Gene Siskel, Lee Atwater, George Gershwin, Bob Marley and, last year before it claimed his life, Johnnie Cochran, who preferred to call his tumor "a neurological condition requiring a procedure."

These reasons alone motivate me to educate the general public and generate dialogue about brain tumors and their life-altering impact.

Washington, D.C., hosts a week-long event with activities including meetings with senators and representatives and a candlelight vigil, sponsored by the North American Brain Tumor Coalition, which focuses on raising awareness and demanding more funding for research to discover a cure for this devastating disease. Those who've lost their battle will be remembered and honored while the rest of us, who still have a voice, can speak up even louder.

The coalition's annual Faces of Brain Tumors will be distributed to members of Congress so they can have a firsthand look at how a brain tumor forever changes lives. This moving collection of stories from all over the country pays tribute to lives lost and those still fighting to keep theirs.

And for the third time, the "Hidden Under Our Hats" project will be on display near the Capitol. Each of the collected hats represents either a survivor or someone whose life was claimed by a brain tumor.

While I don't doubt each of us has a cause dear to our hearts, I encourage *News* readers to spread brain tumor awareness so that we can eradicate this disease "head-on."

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