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A tumor on my mind

By Liz Holzemer

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May usually has people thinking about Mother's Day and planting flowers. I'm thinking about meningiomas instead.

A meningio-*what*? That's the reaction I had eight years ago, when I was diagnosed with a baseball-sized brain tumor that could very easily have claimed my life. I survived two craniotomies and went on to have two healthy children, which I was told was unlikely to happen.

Meningiomas are the most prevalent primary brain tumor. Of all the patients diagnosed with one, 65 percent are women. According to Dr. Peter McLaren Black, professor of neurosurgery

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at Harvard Medical School, meningioma is diagnosed in about one in 1,000 people each year and that at least 138,000 people in the U.S. are living with one.

This is Brain Tumor Action Week, begun 11 years ago to raise awareness about the affliction.

Many misconceptions surround meningiomas, one of them being that they are harmless because 90 percent are classified as benign. Benign tumors can cause permanent disabilities and be life-threatening. They also have a 15 to 20 percent recurrence rate, so survivors must be monitored for the rest of their lives — always in fear that they'll return. I undergo an MRI every January to ensure there are no signs of regrowth.

Preliminary research has indicated that meningiomas could be hormonally fueled. I was constantly told it was all in my head, that I was just hormonal and stressed out. They are also slow-growing and are often misdiagnosed, especially since some of the symptoms can be attributed to menopause, or are not detected until they start causing serious deficits.

When I was diagnosed I felt alone, isolated and frightened. I knew of no one who had survived a meningioma, let alone a brain tumor. Those feelings were aggravated by the fact that they are often discounted by those in the medical profession. I'm still told by some doctors that I had the "good" brain tumor. As far as I'm concerned, there is nothing "good" about any growth in your head.

Meningiomas can cause blindness, deafness, paralysis, cognitive changes, severe mood swings and more. But I feel like I got off lucky with minimal side effects: epilepsy, chronic fatigue and facial pain.

Meningiomas have claimed the lives of far too many. Since I established a non-profit group called Meningioma Mommas, I've lost a handful of women friends to this so-called "benign brain tumor," most recently Karen Peak, a 44-year-old wife and mother from Salina, Kan. Karen found the tumor 10 years ago, and just lost her battle. In the words of her husband, Tim, "So ravaged by these tumors, Karen became a shell of herself."

I'm proud of the fact that my organization — which now has more than 3,000 patients, caregivers and family members — has raised \$90,000 to fund meningioma research for the Brain Science Foundation and the Meningioma Lab at the University of California-San Francisco.

Thankfully, the newly diagnosed will have a better outcome and prognosis because of the doctors there and elsewhere in the world who have committed their lives to treating, removing, curing, understanding and researching meningiomas.

So while I can't deny I'd enjoy a nice box of chocolates for Mother's Day or beautifully arranged gerbera daisies from my garden, I'd prefer a cure to an underfunded and little-known brain tumor. It's May — and I've got meningioma on my mind.

Liz Holzemer (info@lizholzemer.com) of Highlands Ranch is author of "Curveball: When Life Throws You a Brain Tumor."

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