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## FAMILIES

### Family faces challenge of two sons with brain tumors

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Having one child with a brain tumor could be enough to devastate a family.

Having two children with brain tumors is almost unimaginable.

Yet somehow Chaun and Jodie Steiner of Toledo keep it together, one day, one doctor visit, one bill at a time.

When they learned their first born, Braeden, had a brain tumor, he was 16 months old.

"Our world was turned upside down when we found out about Braeden. I mean, we didn't know what to do," Jodie said.

Their second child, Bronson, was diagnosed with his tumor at 18 months of age, shortly before Chaun lost his job in January 2008.

"We were dumbfounded and again devastated. Braeden had just finished chemo in June 2007, and Bronson was diagnosed in September 2007. It was like we hit rewind and we had to go through it again," Jodie said.

"My thought was, 'I didn't smoke, I didn't drink, I didn't do anything wrong. I ate healthy and I took my vitamins and did everything I should for the pregnancy, and my kids have brain tumors.'"

Both Braeden and Bronson have neurofibromatosis (NF), a genetic disorder that affects 100,000 Americans, including Jodie. All three have the NF type 1 variety.

The disorder affects people differently. Jodie never had any complications, besides pea-sized bumps on her stomach that first appeared during pregnancy.

"We did go see a geneticist before we had Braeden," Jodie said. "Our chances were 50-50 that the child would have NF and there was like a 4 percent chance they would have a worse case than what I did."

Both boys have optic nerve glioma because of the genetic disorder. Optic nerve glioma is a brain tumor on the optic nerve, the nerve that controls vision. Braeden is legally blind in one eye and wears glasses to preserve his vision in his good eye; Bronson has no vision problems. Braeden also has bowing of his leg and wears a brace because of the fragility of his tibia. One day, the bone will have to be replaced with a steel rod.

"Having a second child, we thought the odds of him having the brain tumor were impossible," Jodie said.

'The little bump'

A day in the life of the Steiner family is ordinary in every way, minus the many trips to the University of Michigan Health System.



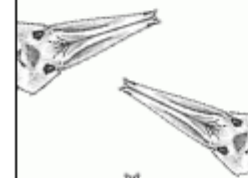
Jodie, Braeden, Bronson and Chaun Steiner.

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“We tell them everything that is going on with them,” Jodie said. “We talk about the tumors; we call it the ‘little bump’ in their head. That is why they have to have the MRI, and we tell them they are going to get their sleepy medicine.”

Braeden’s chemotherapy stabilized his tumor for now, while Bronson’s chemo is reducing the size of his tumor. When it’s not chemo, it’s MRIs for both boys, visits to the optometrists and other checkups that will continue for the rest of their lives.

Braeden, now 5, attends all-day kindergarten at Wildwood Environmental Academy in Maumee, while Jodie is a stay-at-home mom with Bronson, now nearly 3.

“He doesn’t have any trouble giving anything a try,” said school leader Elizabeth Lewin of Braeden. “He does well on the playground. He tries really hard with American martial arts. He has been just fabulous.”

The boys love to play all kinds of sports, including baseball, basketball, floor hockey, swimming and soccer. They also like playing Wii and rough-housing with dad.

“What I really appreciate in Mr. Steiner, and so many of other parents, is that they still incorporate the medical piece into their lives, but they don’t let go of the childhood pieces of life,” said Sheila Morris, a child life specialist for the University of Michigan Comprehensive Cancer Center.

While dad loves to be home with his boys, he said getting back to work is paramount. Chaun lost his job as a health insurance claims manager a year ago because of downsizing. He has been looking for work since, making do with unemployment, which is about to run out, and help from family, friends and strangers. They pay more than \$1,000 per month for Cobra health insurance, which runs out in this spring. The boys also have Medicaid.

“That is kind of how we have stayed afloat, but it is becoming harder,” Jodie said, noting that severance, savings and money from a benefit for the boys are gone or about gone. “We don’t spend foolishly; we take care of our kids. That is all we do.”

Wolverines at heart

The Steiners do not consider traveling to Ann Arbor several times per month, if not week, inconvenient.

“We went and got several opinions,” Jodie said after Braeden was diagnosed with his tumor. “We talked to doctors in Toledo; we talked to doctors at the Cleveland Clinic and we talked to doctors at the University of Michigan.”

For the Steiners, they felt best about the care in Michigan. It’s become a home away from a home, a place their sons look forward to visiting.

“When you have a family who is not playing victim, it is so inspirational for staff; it is so inspirational for other families,” said Kelly Parent, parent coordinator for the University of Michigan Health System. Chaun serves on the Mott’s Patient and Family Advisory Council, which meets regularly to identify opportunities to improve relationships among patients, family and staff.

Parent said the Steiners consider themselves lucky. That often happens with families coping with illness, she said. They realize it could be even worse.

Both boys have a good prognosis as far as living, but learning disabilities are common with their disorder, in addition to more tumors, which may never go away.

“I would change nothing,” Jodie said. “Our kids are wonderful and are perfect. I wouldn’t change anything about them. They have awesome personalities, distinctive laughs and love life and they make it a lot more enjoyable.”

“We would take 100 more just like them,” Chaun added.

### **What is neurofibromatosis (NF)?**

The neurofibromatoses (NF1, NF2 and Schwannomatosis) are a set of distinct genetic disorders. Individuals with NF1 are prone to develop benign tumors that grow on the nerves anywhere on or in the body. NF1 can also affect other tissues, including bones, skin, blood vessels and eyes. Nearly 50 percent of all people with NF1 have learning disabilities.

## How many people have it?

NF1 affects about one out of every 3,000 births. NF2 is less common, affecting about one out of every 40,000 births. In 50 percent of cases, NF is inherited from a parent. The remaining NF cases occur as the result of a mutation in the sperm or egg cell.

## Signs of NF1

- \* Family history
- \* Six or more light brown spots on the skin
- \* Freckling under the arms or in the groin area
- \* Small pigmented bumps on the eye's iris
- \* Optic glioma
- \* Skeletal abnormalities

*Source: Children's Tumor Foundation*

## Ways to Help the Steiner family

Team Steiner will again run events on May 2 and May 3 at the Flying Pig Marathon in Cincinnati to raise money for Children's Tumor Foundation (CTF).

CTF funds NF research, as well as promotes awareness for NF and supports people with NF.

Chaun Steiner is team captain for the Flying Pig this year. To donate for the marathon, or to help the family in general, contact Chaun Steiner at [chaunsteiner@yahoo.com](mailto:chaunsteiner@yahoo.com).

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