

**This article was written for the Childhood Brain Tumor Foundation, Germantown, MD.**

## **Small but Mighty**



After the age of three, Vanessa really started slowing down in growth. Soon her younger sister caught up to her and then grew taller than her. They were wearing the same size clothes and for a while I was dressing them as if they were twins. Then Vanessa fell behind even further. I questioned her pediatrician and told him that we were worried, and he told us she was just going to be small. She also began having headaches. First the pediatrician told us it was probably allergies, then that we were maybe giving her too much chocolate. He told us she was too young to know what a headache was, and that we could give her Tylenol if we thought she really needed it.

The following year her headaches increased and in first grade, was markedly smaller than all of her classmates. We insisted on some sort of testing, and a somadamedin-C test showed that she had almost no growth hormone. We went to a pediatric endocrinologist in Boston where it was confirmed that she had growth hormone deficiency, and then we were sent for an MRI "just to make sure" that it wasn't a tumor. Well, unfortunately it was. This was on May 2, 1997. We also took her for a thorough eye exam, and the ophthalmologist discovered that she had lost peripheral vision in her left eye.

After much research in a VERY short time, we ended up flying from Boston to Los Angeles for Vanessa's surgery. The surgery was performed by Dr. Martin Weiss and Dr. Michael Levy, our heroes. It was transsphenoidal surgery -- through the sinuses, and was done on May 18, 1997. Dr. Weiss informed us that the tumor came out encapsulated, all in one piece. He was able to peel the tumor away from the optic nerve, and it just dropped right out. She did have a leak of cerebral spinal fluid, but they were able to patch it with a fascia lata graft, using fat from her right thigh to the area of the sella where the leak was. Vanessa has about a 4-inch scar on her right thigh where this procedure was done. The patch held great. She was out of the hospital within 5 days. Vanessa did contract meningitis about 9 days later and was back in the hospital for 15 days, which was actually scarier than her surgery!

Post surgery, Vanessa began medications, but on the lowest possible doses of levoxyl, cortef, and DDAVP that you can have. She does, however, take a healthy dose of growth hormone (genotropin). Her follow-up exam with the neuro-ophthalmologist showed that not only did her lost peripheral vision return, but Vanessa's vision is actually incredible. She is still very small, not quite on the growth charts for height or weight, but growing along on a nice curve. Being small is the thing that bothers her the most. People do not realize how old Vanessa is and tend to treat her a lot younger. There has been no follow-up treatment other than yearly MRIs and exams. She has just passed the seven-year mark of clean MRIs. Vanessa has tons of energy and is very athletic. She is a beautiful, skinny little kid. The next hurdle will be putting her through puberty, and then some day the fertility issues, but we will cross those bridges when we come to them. We are truly blessed with Vanessa's outcome, and pray for the same for all children diagnosed with brain tumors.

*Written by Lisa Genatossio  
Mom to Vanessa, age 14*

