

Almost a Miracle

My life with a rare and incurable neurologic disorder.

BY CHELSEY-ANN LAWRENCE

I was 17 years old in the summer of 2005 when I was diagnosed with a rare disease called central nervous system vasculitis (CNSV). Vasculitis means inflammation of the blood vessels. CNSV occurs when the immune system attacks blood vessels in the brain.

CNSV shows up differently in each person. For most of us, the symptoms start with consistent headaches, as if your brain is on fire. When I told this to my doctor, he thought I had migraines. A couple of days later, my sisters noticed that I had trouble communicating. That afternoon, I picked up a book and found that I couldn't read. I saw the words, but they looked like a different language to me.

I told my mom, and she called my aunt, who is a doctor. She asked me questions such as, "What is your full name? Can you count to 10?" I failed all the questions. My aunt told my mom to take me to the hospital immediately.

On the way, I started having vivid hallucinations that demons were chasing us on the highway. I was so convinced of their reality that I tried to jump out of the car while it was moving. Thank God an off-duty ambulance was driving behind us. My parents pulled over and flagged it down. My last memory was clutching my mom in the backseat of the car in fear and being strapped down to the stretcher.

The day after admission to the hospital, I fell into a coma.

The doctors tested me for everything they could think of but found nothing. Finally, my aunt researched CNSV online and pushed my doctors to perform a brain biopsy, which confirmed vasculitis in my brain. I was put on high-dose steroids and chemotherapy to manage the inflammation and suppress my immune system.

After 32 days in a coma, I woke up. The doctors called me "the miracle child" because they thought I was going to die or at least be a vegetable. I recov-

ered fully, including my ability to walk.

If my aunt had not researched the information in time, I probably would have died in a coma. Until recently, most people with CNSV were diagnosed after death because there was not enough research and awareness about the disease.

I was blessed with six years of remission during which I had no symptoms. But in late spring 2011, at the end of my honeymoon, the disease returned. My left eye went blind. The doctors told us that I had optic neuritis because the vasculitis attacked the optic nerve behind my left eye.

Just when it looked like I was getting better, I had two grand-mal seizures in September—symptoms that were very new to me. At the hospital, I was pumped full of seizure medications. The doctors told my husband that I was at risk of permanent brain damage because

my body was not recovering before a new seizure began. This lasted for almost a week. Finally, the doctors determined that the seizures were being caused by the CNSV and put me on chemotherapy and high-dose steroids. Soon after, the seizures stopped.

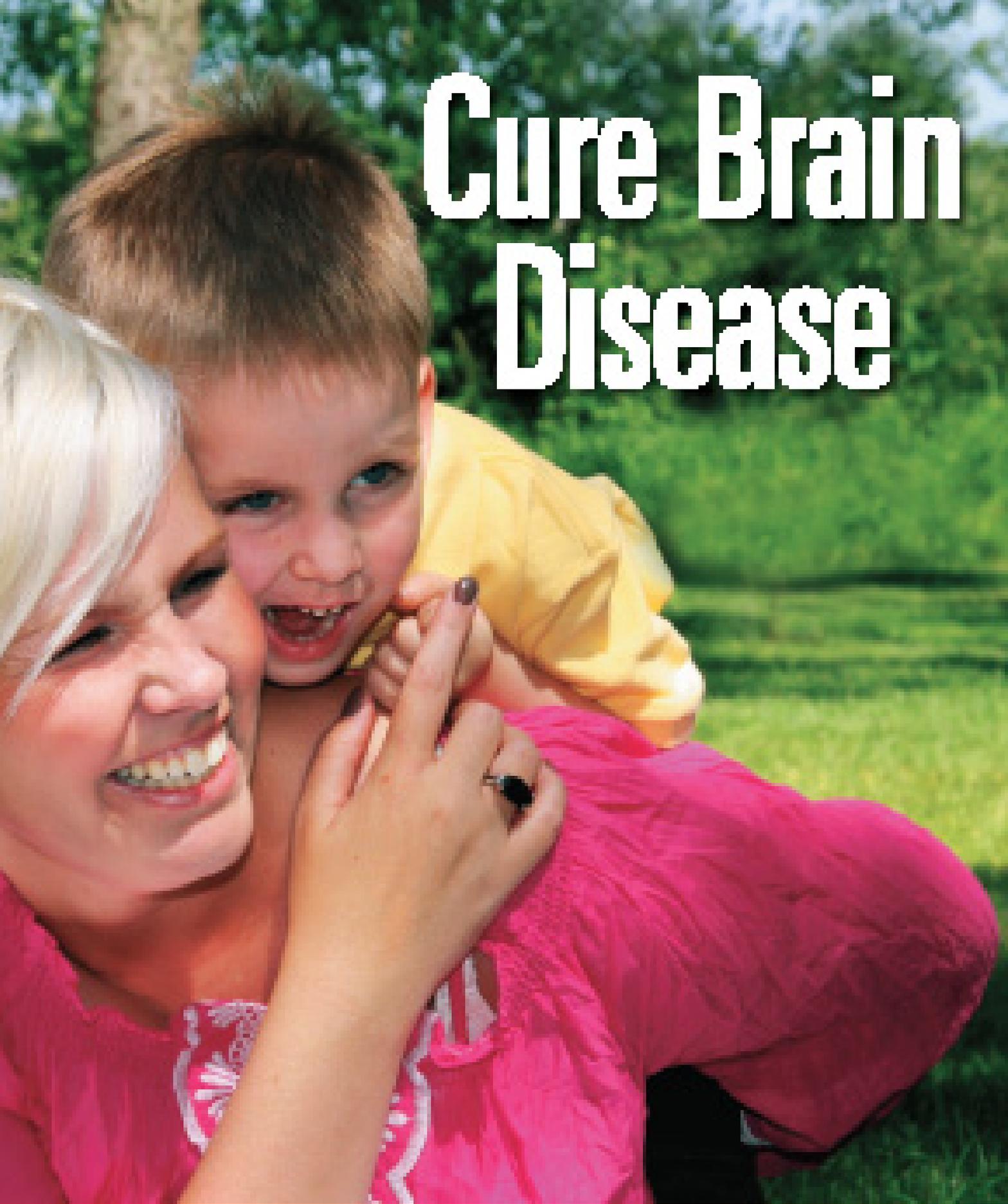
The vasculitis then attacked the visual cortex of my brain, causing vivid hallucinations that lasted for several days. My husband and I came up with a codeword—"pear pie"—so that when I heard it, I knew it was really him speaking and not a hallucination.

People continued to call me "the miracle child" because for some years, it seemed like I was cured. But CNSV has no cure. I live every day knowing that my immune system could attack my brain again. I can only hope to stay in remission for as long as possible. The real miracle will happen when a cure is found.

Chelsey-Ann Lawrence seeks to give to hope to people who live with illnesses through her blog (helpingotherpatientseverywhere.blogspot.com) and the Facebook group Helping Other Patients Everywhere (HOPE).



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