Teen has 'miraculous' recovery from unusual tumor disorder

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In mid-March, Dottie Davis thought something was off when her typically unsentimental 13-year-old daughter sobbed with joy while riding a new horse on the family's farm in Hixson.

"She cried the whole time she rode the horse, and she rode for like 30, 45 minutes," recalled Mrs. Davis, a business owner and personal trainer. "She was like, 'I'm just so happy.' "

A day later her daughter, Chance, couldn't remember a trip to IHOP earlier in the morning and uncharacteristically snuck out of the house at night.

"It scared me to death," Mrs. Davis said.

Chance was admitted to T.C. Thompson Children's Hospital on March 23, Mrs. Davis said.

During her hospital stay, Chance displayed a range of emotions and symptoms that varied by the hour, at times mirroring schizophrenia and, at other times, autism or cerebral palsy, her mother recounted. During agitated fits, Chance would bite her tongue and mouth. At one point, Chance insisted upon crab-walking across the hospital floor. Inexplicably, she spoke in an uncanny Cajun accent at times.

It wasn't until a CT scan was ordered by a doctor who'd seen similar symptoms in a 13-year-old girl earlier this year that Chance got a diagnosis.

Chance had two teratomas -- tumors in each ovary that contained hair follicles, cartilage and brain tissue.

'stem cells gone wild'

Typically benign, teratomas commonly occur in the ovaries or testes when stem cells -- the basic cells from which all other cells develop -- go haywire, said neurologist Dr. David Rankine, who ordered the CT scan. The tumor's name is derived from the Greek word for "monster" because the tumors contain unusual tissues such as hair, teeth and often brain cells.

"It's stem cells gone wild," he said.

In January of this year, Dr. Rankine had worked on a nearly identical case in another 13-year-old female patient. It was 10 weeks before that patient was diagnosed at Vanderbilt Medical Center with an autoimmune disorder triggered by a teratoma, Dr. Rankine said.

When he took a look at Chance's symptoms, the similarities struck him immediately.

"I said, 'Man, these are the exact same symptoms as the first case,' " he said. "I'm sitting there thinking, 'Lightning doesn't usually strike twice in same place, but I missed the first one (and) the second one I'm not gonna miss.' "

In rare cases, the immune system recognizes the tumor as a foreign body and creates antibodies to attack it. The antibodies target the brain cells found both in the tumor and in the brain, leading to encephalitis and bizarre symptoms, Dr. Rankine said. If undiagnosed, the disorder can be fatal.

Chance -- an avid soccer and volleyball player who loves going to the mall with friends -- already was in a comatose state by the time Dr. Rankine got hold of her case file.

"I didn't think she had but a few more days, she was getting so bad," her mother said.

After surgery to remove the tumor and blood-plasma cleansing to rid Chance's blood of the offending antibodies, her recovery was "miraculous," Mrs. Davis said.

After two weeks of immunotherapy treatments and blood plasma exchanges, Chance had regained consciousness and began to talk again.

Just four weeks after her May 5 discharge from the hospital, Chance has made a near full recovery and has since made the high school volleyball team at Hixson High School, which she will attend in the fall.

Although she cannot remember anything about her hospital stay, Chance said she still has nightmares about it.

"It doesn't make sense because I was healthy. I never really had any problems with my ovaries," she said.

She added that she just hopes "nobody dies from what I had."

Unknown before 2005

Chance's disorder is significantly less exceptional than previously thought, said Dr. Josep Dalmau, professor of neurology at the Hospital of the University of Pennsylvania. He is leading the research on the autoimmune disorder, which he has named anti-N-methyl-D-aspartic acid receptor, or anti-NMDAR, encephalitis. The name signifies the type of receptor in the brain under attack by the immune system.

"This disease essentially was unknown before 2005," Dr. Dalmau said. "It's amazing how much more we know in a couple of years."

In the past, the rigidity of afflicted patients' muscles and grinding of the teeth led to misdiagnosis of rabies or tetanus, Dr. Dalmau said. Personality changes were misdiagnosed as psychosis or drug abuse, and some patients ended up in mental hospitals, he said.

Since he has published studies on his findings and developed a diagnostic test to identify these particular antibodies, new diagnoses of this condition have grown rapidly, Dr. Dalmau said.

The total number of reported cases has grown from just four in 2005 to 10 in 2007, to 100 last year, to a total of 250 cases to date, he said. Most patients are young women under 35, he said.

At the Children's Hospital of Pennsylvania, Dr. Dalmau is seeing one new patient for the disease per month, he said.

About half of the cases are triggered by a teratoma, Dr. Dalmau said, though he's discovering a growing number of cases in which a teratoma is not present and the trigger is unknown. He theorizes that the patients may have a genetic tendency toward autoimmune disorders.

Spreading the Word

It took doctors weeks to determine a cause for Chance's bizarre symptoms. A spinal tap revealed a general inflammation of the brain, called encephalitis, which is often caused by a virus. Tests for herpes and other viruses that cause encephalitis came back negative, one after another, until the CT scan that resulted in a diagnosis.

Erlanger physicians are now highly attuned to the symptoms of a teratoma, following a lecture presentation on Chance's case that Dr. Rankine gave to hospital staff and residents two weeks after her recovery.

"Everybody was kind of like, 'Wow,' " Dr. Rankine said. "The important thing for everyone to realize is, if you have an encephalitis ... and the patient isn't getting better with standard therapy, we need to be looking for these other, more uncommon things."

The experience has shaken Chance's parents, who hope their daughter's experience contributes to the growing awareness about this disorder.

"Chance suffered so much for weeks. I would hate for another child to suffer needlessly" for want of a diagnosis, Mrs. Davis said. "Something good needs to come out of something bad that happened to her."

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