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Montgomery couple remembers the daughter they lost to DIPG

BY ROBYN BRADLEY LITCHFIELD • NOVEMBER 22, 2009

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Looking back, Elizabeth Adams recognizes all the little changes in 3-year-old Madeline's behavior as symptoms of diffuse intrinsic pontine glioma (DIPG).

There were restless nights, more potty accidents, eye blinking that just seemed a bit "off," but nothing that seemed serious enough to warrant a trip to the pediatrician. Then, in January 2007, when Madeline was 3 years and 9 months old, she woke up and her entire left side was limp. At first, Adams thought her youngest child had had a stroke.

They did a CT scan in the pediatrician's office and could tell something was in the brainstem, but they had to send her to Children's Hospital of Alabama (Birmingham) for an MRI to more closely examine the area. When the results were ready, Madeline's neurologist -- a seasoned specialist, Adams added -- broke the news, her hands trembling.

"And here I was, thinking that leukemia was the worst things that could happen to a child, but my child has something much worse," said Adams, who lives in Cloverdale. Actually, 90 percent of children who have leukemia survive, which is the opposite for children with DIPG.

Treatment included radiation and two drug tests, but the tumor started growing back, which was one of the most disheartening, devastating parts of it, she said.

As Madeline was treated, the Adamses felt helpless. At one point, said her father, Pat Adams, "We have a better chance of sending her to the moon."

Elizabeth Adams said it was a truly humbling experience to learn that they had absolutely no



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control over what would happen. Physicians did all they could, yet they could not save Madeline. Or any of the other children with DIPG.

During the last 11 months of her short life, little Madeline gradually lost the ability to swallow, speak or communicate. She became completely paralyzed on the left side. She was just miserable in her own body, her mom said.

What she and kids like her endured makes The Cure Starts Now Foundation's work that much more important, said Elizabeth Adams, who is the director of the foundation's Alabama chapter, while Pat Adams



Madeline and Ellie Adams are all dressed up for Easter Day 2007. Madeline was diagnosed with brainstem glioma when she was 3 1/2.. (Contributed)

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serves on the foundation's national medical board as a parent representative. It also helps the Adamses move forward.

The memories of Madeline, of course, also help. Adams loves sitting back and listening to her children -- Cole, 9, and Ellie, 8 -- talk about Madeline, and some of the things they share are new even to their mom and dad.

"It's comforting to know that they remember her," Adams said.

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