

Advertisement

Toddler raising awareness about CdLS

Family hopes more people will understand condition

Updated: Tuesday, 16 Aug 2011, 12:52 PM EDT
Published : Tuesday, 16 Aug 2011, 12:41 PM EDT

CRAWFORDSVILLE, Ind. (WLF1) - A toddler with a rare genetic condition is helping her family raise awareness about the syndrome.

Angie Brown flipped through pictures of her daughter Addison as an infant.

"She doesn't have the typical baby book. Her baby book is a journal of nothing but tests," Brown explained.

Little Addison will celebrate her fourth birthday next week, but first, she has to undergo yet another surgery, this time on her hand.

"Moving that thumb down will give her better flexibility and dexterity in her hand," Brown said.

Addison's missing finger is just one of the many symptoms of Cornelia de Lange Syndrome (CdLS). Brown said Addison has to go to Riley Hospital for Children at least once a week.

"She has speech and feeding therapy and physical therapy," Brown said.

Other symptoms of CdLS include slow growth, feeding and eye problems, and developmental delays. According to the CdLS Foundation, about one in 10,000 children have the syndrome. Brown is hoping to make the community aware of CdLS and understand her daughter better.

"As a mom of a child with special needs, I just felt it was important that people understand that they are children too," she said. "Their syndrome doesn't identify them. She is still Addison. She has CdLS, but they are all also just another child in the classroom."

Addison definitely has a personality someone can't help but fall in love with.

"Her determination and perseverance makes it better for me. I think that she is so happy that it makes it easier to know that all the stuff she is going through doesn't seem to bother her as much as it bothers me," Brown said, crying.

The Crawfordsville community is also hosting a fundraiser to not only raise awareness about CdLS, but also help with Addison's growing medical expenses.

"I opened one bill and just broke down. I couldn't believe that it cost that much," Brown said.

The Addison Brown Benefit Concert for CdLS is Saturday, August 20 from 5:00 p.m.- 1:30 a.m. at the Eagles Club at 920 E South Blvd. in Crawfordsville. The event is open to all ages until 9:00 p.m. Many bands will be performing and there will be a raffle and silent auction.