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DeWitt student inspiration despite congenital heart defect

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February 25, 2007

by Lauren Krupar

Reporter

Cuyahoga Falls -- A "little miracle" was born at a hospital near Cleveland less than eight years ago.

"My son was born with a congenital heart defect that was undiagnosed at birth," Cuyahoga Falls resident Gina Gatian said of her son Dylan, who has Hypoplastic Left Heart Syndrome .

"He was whisked away at birth. I was able to see him eight hours later. He looked like a little baby in an aquarium with all the tubes and wires."

She didn't get to hold her son, her and her husband Doug's first child, until almost two weeks later. They welcomed their son home almost a month after he was born.

Dylan now is 7 1/2 years old and attends DeWitt Elementary School. His favorite classes are math and gym. He likes science so much that he purchased a book on how the human body works and another about what causes weather conditions when a book sale visited DeWitt.

"He's got some big ideas for a little guy," Gina said. "The stuff he comes up with, we ask if he's really only 7."

He enjoys baseball, particularly hitting long, high balls for home runs, and dreams of becoming a race car driver.

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He and his sister Sarah, 5, fight and tease each other, tearing through the house so much that the family cat often runs to hide. Both of them love swimming at Water Works, especially the giant slides.

"To see him, you would think he is your typical, normal child," Gina said. "It's hard to tell people how difficult it is for him."

She said the family gets second looks from strangers when they pull up to a handicapped parking space, even through they have a sticker. Dylan gets winded from walking longer distances from the car to a store so the handicapped sticker is needed.

"We really get some nasty looks but they don't know," Gina said. "If anyone asks, I tell them that Dylan has undergone three open heart surgeries. He has half a heart."

Dylan doesn't let that stop him.

"I just keep going along," Dylan said.

"He can get tired going up and down the stairs, but you can't tell him that," Gina added.

Dylan has undergone three open heart surgeries as part of the Norwood procedure and numerous other surgeries to correct his heart defect. When he was born, doctors discovered he had two chambers in his heart -- most people are born with four.

"One in 10,000 has the heart defect my son has," Gina said, adding HLHS causes the heart to beat twice as fast. Until 1983, the heart defect was considered lethal. "Seven and a half years ago, I never knew what a congenital heart defect was. Now, I know."

Increase awareness

Gina and her family are part of a Pennsylvania-based organization -- the Congenital Heart Information Network -- that raises awareness about congenital heart defects and provides a community for families impacted by congenital heart defects.

In the years since Dylan has been born, the Gatians have volunteered to help mentor other parents who are in similar situations. They have met other children similar to their Dylan and parents similar to them.

"It's the parents that have the struggles," Gina said. "The children don't have the issues. They are just loving life."

Their efforts to raise awareness increase in February, which the American Heart Association has named National Heart Awareness Month, and the week of Valentine's Day, which the CHIN calls Congenital Heart Defect Awareness Week.

"People need to know that just because a child looks healthy doesn't mean that he or she is," Gina said. "I want to increase awareness because I never even knew a baby could have a heart defect before."

According to the American Heart Association, at least eight in 1,000 infants born each year have a heart defect -- which could be either congenital or acquired. An acquired heart defect develops during childhood and includes Kawasaki disease, rheumatic fever and infective endocarditis, according to the American Heart Association.

The first step Gina said she advises parents of is to have a prenatal screening done and make sure that the child has four chambers in the heart.

"We had an ultrasound but the technician said she just couldn't get a good view of the heart," Gina said.

"My son was born with two chambers of the heart and not four so of course she wasn't getting a good view."

Additional screenings and tests were done before her daughter was born and the tests found nothing.

"She's perfectly fine," Gina said. "When she was first born, I was so worried that I was looking for something to be wrong."

While Gina said it is not clear if congenital heart defects are hereditary or caused by environmental factors, families with a history of heart defects should visit a pediatric cardiologist.

The steps are a hard lesson she and her husband have learned since the birth of their son.

"It may not be the easiest road," Gina said. "My son's future is unknown. We're not sure how long his heart will last."

A future heart transplant could be a possibility, she added. Despite the struggles, Gina said her son continues to be her inspiration.

"He's my little miracle," she said, adding she and her husband have tried to balance knowledge against fear when Dylan asks about the future.

"We tell him that we don't know if he is going to need another surgery but if he does, it's only going to make him bigger and better," Gina said.

For more information, visit www.americanheart.org or www.tchin.org. A donation page -- www.tchin.kintera.org/dylan -- also has been established for Dylan and his family.

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