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Tori a symbol of hope

By: Carrie Kreisler, Leader Staff Writer
02/21/2007

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Three-year-old Tori Hrupek was telling people for a week that she was going to meet Bellevue Mayor Ed Babbitt.

But when the time came for the Mayors' Mile kickoff last Wednesday, the excitement may have been a bit overwhelming.

Tori kept hiding in her mom's lap, letting her shyness distract her from painting her heart art made of chicken wire and plaster. But eventually she and Mayor Ed Babbitt put on the finishing touches, just in time for him to haul it away for display at City Hall.

And more importantly, just in time for Tori's introduction as one of five area children with heart disease who will represent their cities in the Mayors' Mile walk in May.

The ceremony was held in conjunction with Congenital Heart Defect Awareness Day. Congenital heart defects are the most common form of fatal birth defects in Nebraska.

Tori was born with a congenital heart defect known as Pulmonary Artresia with Ventricular Septal Defect, or VSD. Pulmonary Artresia means she was missing a heart valve, and VSD means she had a hole in her heart.

Usually, the condition is detected shortly after birth, but Tori was 3 months old when it was discovered.

She went for a regular checkup and the doctor noticed a sporadic heart murmur. Just as a precaution, the




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doctor sent Tori and her mom, Traci, to Children's Hospital to have the murmur evaluated. Three doctors and two hours later, Traci and her husband, Toby, were told Tori did not have a heart valve and that she would need surgery.

Two weeks later, Tori had open-heart surgery in which doctors implanted a shunt.

"They had to redo her plumbing, as they told me," Traci said.

There are different kinds of Pulmonary Arteresia and very few kids are set up the way Tori is, Traci said. Doctors told her and Toby they had a better chance of winning the lottery than Tori's condition occurring.

"It was a complete stroke of luck," Traci said.

Tori's first surgery was quite an ordeal in and of itself, but there were complications afterward, as well.

"It was a really rough go off of her first surgery," Traci said.

Tori was in the hospital for a month. She got a "really nasty infection," Traci said, which caused her to be on at-home antibiotics for 13 weeks. Those cost \$100 a day.

She also developed severe acid reflux after surgery and stopped eating. She had to have a feeding tube for about four months.

The total expenses resulting from Tori's first surgery were about \$700,000, Traci said. St. Matthew Parish helped the Hrupeks a lot during that time by hosting a spaghetti dinner fundraiser. The church also held a breakfast shortly after Tori's second surgery.

When Tori was 13 months old, she had an artificial heart valve put in. That second operation went much smoother than the first, Traci said. She was in and out of the hospital in six days.

Then last March, Tori had an angioplasty done because of narrowing of her arteries. Things have been looking up, though. She still visits Children's Hospital every three months to have blood work done because of medicine she takes. She also sees a cardiologist annually. In the next year or two, Tori will have another surgery to replace the valve, because she will have grown out of her current one.

"She is very small for her age," Traci said, and doctors tell her that will always be the case. "It takes a long time for her to gain weight."

Despite all she's been through in her almost four years of life, Tori is full and energy and brightens the room with her contagious smile.

"She's doing so well now," Traci said, adding that it is almost hard to believe that she has been through so much. She will start preschool in the fall, and it seems she won't let anything hold her back.

"She's starting to ask more questions ... about her scar," Traci said. She said other kids at day care will ask her what it is and she will tell them, "That's my scar."

Also, her family helped her plan for the most recent procedures. When she had her last surgery in March, her grandma got her a suitcase with new pajamas in it. She knew those were her "hospital pajamas."

Tori's brother Tyler, 6, has adjusted well to the situation, also, Traci said. It was hard when Tori was a baby because her mom had to be with her all the time. She even had to quit working for four months during that time. Things at the Hrupek household are much more normal now.

"She's kickin' butt," Traci said.

In fact, "ornery" is the word Tori's parents often use to describe her, even though shyness can sometimes set in. All in all, they are just glad she is doing so well.

Having Tori be chosen for the Mayors' Mile has been a real honor, Traci said. When she got a call at work a

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couple months ago from Children's Hospital, she was nervous at first. She thought it was bad news, but after her heart started beating normally again, the woman on the other end told her the good news.

Tori had been selected to represent Bellevue in the Mayors' Mile before the 2007 Omaha-Council Bluffs Heart Walk.

"I was completely shocked," Traci said.

She was told Tori was chosen from about 100 Bellevue kids.

Tori stuck out in the minds of Children's Hospital representatives. Traci said the caller told her, "We all kind of remembered her and you're such a nice family and we all love Tori."

So on Valentine's Day, the Hrupeks joined the four other child survivors and their families for the kickoff. Children's Hospital President and CEO Gary Perkins and Director of Cardiology Dr. John Kugler both said a few words, noting the Mayors' Mile is about recognizing that heart disease affects people of all ages, and children are making a stand for heart research.

Then, Perkins introduced the children and mayors or mayor representatives from Bellevue, La Vista, Papillion, Council Bluffs and Omaha and presented them with a certificate for their participation.

Traci said even Tori has grasped the idea that being a part of this event is special.

"She's been very excited about it," she said. "She's a pretty sharp little girl."

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