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Elmwood student's story helps bring awareness for syndrome

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Nine-year-old Max DiFrisco, a student at Elmwood Elementary School, can do most things any typical boy his age can do.

However, when comes to the physical aspects of certain activities, Max faces certain limitations.



Max DiFrisco, 9, a student at Elmwood Elementary School, thrives despite the physical and medical challenges of prune belly syndrome.

(Photo courtesy of Marianne DiFrisco)

"It's harder for me to do things like play basketball, baseball and do pushups," said Max, who was born with the disorder known as prune belly syndrome, or Eagle-Barrett syndrome.

Characterized mainly by deficient or absent stomach muscles, a large bladder and undescended testicles, the syndrome occurs in about 1 in 40,000 births and affects males at a 95 percent higher rate than females.

"The doctors believe it's genetic," Marianne DiFrisco said. "If this is genetic then my three sons,

including Max, could be carriers."

Dr. Derek Matoka, a pediatric urologist at Loyola University Medical Center in Maywood, said it's not known why the syndrome occurs, but there are noted high risk factors.

"Prune belly syndrome often occurs with younger mothers, mothers who carry twins, and there is an increased frequency in African-American women" Matoka said.

It's reported that while in the womb, a developing child's abdomen swells with fluid. The fluid disappears after birth, leading to a wrinkled abdomen that looks like a prune, an appearance more noticeable due to the lack of abdominal muscles.

"At 9 months, Max, like other children, had to have abdominal reconstructive surgery," DiFrisco said.

"The issues Max deals with today, is that he doesn't have a strong cough due to lack of stomach muscles and so he often gets pneumonia. He also gets kidney infections and has an oversized bladder and he wears a binder to protect his organs."

One of the most challenging times for Max occurred when he was 3 years old and spent three and a half weeks in intensive care.

DiFrisco shares the story on a website she created that chronicles Max's journey.

"Max spent three and a half weeks in intensive care," she wrote on the website. "He had to be put into a drug-induced coma so that they could keep him on a ventilator to breathe for him. Half way through his stay he went through severe withdrawals from the drugs and ended up aspirating into his lungs and getting a new pneumonia."

The new pneumonia resulted in Max going back on the ventilator.

"Two and a half weeks later, he was ready to try things on his own," the site reads. "The vent came off and he gave us all a thumbs-up."

It took a week or so to get his voice back and he had to relearn to walk, DiFrisco said, but Max's smile came back immediately.

Despite his illnesses and physical limitations, DiFrisco said Max is a happy, well-adjusted, talented child.

"I'm speaking out because people are being told to abort (fetuses diagnosed with this syndrome)," DiFrisco said. "I want people to know these kids are worth having their life. I found out that Max had the syndrome at 20 weeks (into my pregnancy) through ultrasound. We think it happens at 9 to 10 weeks, but people don't get ultrasounds at that stage."

As to doctors encouraging abortion when a fetus is diagnosed with the syndrome, Matoka said he is not aware of that.

"It's not something I would do," Matoka said. "I'm surprised that would happen. These children can go on to lead very productive lives."

DiFrisco is also speaking out to raise funds to help find a cure and for genetic testing for the family, including Max and his two brothers.

Max cannot do a sit-up or ride a bicycle because he lacks core muscle strength.

"Max has to use his neck (muscles) versus his diaphragm," DiFrisco said. "The fact that he cannot ride a bicycle is very frustrating for him."

A network dedicated to providing information and support offers encouragement via its website at www.prunebelly.org. You can also make a donation via the website.

Unlike some kids with PBS, Max can eat regular food.

In addition to choreographed wrestling shows, Max also enjoys Web design, something he learned in a club at school.

Max loves the Beatles and created a website dedicated to them. He also helped design the website dedicated to him.

"I just hope people can find a cure," Max said.

To read more of Max's story, go to www.wix.com/difriscom/maxPBS.