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Palm Beach Gardens woman who lost daughter to rare disease raises money to help pediatric nurses

Ask anyone what they would do if they knew their time on earth was limited. Their answers might include grand plans, elaborate trips or daring adventures. But for one woman who knows her time as Mom will be short, the answer is simply to spend as much time as possible being "Mom."

"Mikey is terminal. But he is so happy, and that's all that matters. It's about quality, not quantity," said Trish Armand of Palm Beach Gardens.

And quality for Armand includes helping others in similar circumstances have as much time with their children as possible. She is the mother to two children born with a rare metabolic storage disorder.

Her daughter, Olivia Grace, died two years ago this month, just before her 5th birthday. Mikey, who turned 5 in April, weighs 16 pounds. Smaller than a toddler, he crawls and still eats baby food. But he prattles with Mom, plays hard and remembers his big sister "Ee-ya," especially when Mom tears up.

Both children were born with Mucopolysaccharidosis II, or I-Cell, a disorder in which children lack the lysosomal enzymes essential for breaking down complex carbohydrates. It's caused by a rare recessive gene, which both Trish and her husband carry. Life expectancy is less than 10 years.

The Armand children were two of perhaps fewer than 20 in the United States with the disorder in the past decade. And the Armands realized that is why so few people had heard of it and why it's often misdiagnosed. They reached out to other families, creating a support system and information exchange.

To honor her short but vibrant life, they created the Olivia Grace Armand Foundation. It spreads the word and provides scholarships for nurses to further their education in pediatrics. It awarded one Dec. 12 to Mary Prokop at St. Mary's Medical Center in West Palm Beach.

"Her daughter has leukemia," Armand said. "She was so inspired that she became a nurse."

It was a nurse's suggestion of genetic testing for the Armands that led to an accurate diagnosis of I-Cell in Olivia. By that time, Olivia was 2 and Trish was pregnant with Mikey. Both children had bone marrow transplants to provide the enzymes that their

bodies lacked. It's not a cure, but it allows the children a better quality of life, Armand said.

Olivia made remarkable progress for an I-Cell child. She could talk, feed herself, say her ABCs and even walk with assistance. Most I-Cell children aren't so fortunate. By the time they're diagnosed, it's often too late for a marrow transplant, Armand said.

"When Olivia was born, she looked perfect. But at 11 months, she wasn't making some (development) milestones and her features were starting to look a little coarse," a characteristic of I-Cell children, Armand said.

Part of the goal of the scholarships is for medical professionals to have more knowledge about I-Cell.

The 63 days in the hospital for Olivia's bone marrow transplant were the first of many Trish spent surrounded by nurses.

"It takes a special breed to be that type of nurse," Armand said. "I watched these nurses cry. They have such a connection. You get such an attachment to the people there."

Mikey has been in hospitals so many times that Trish has lost count. Sometimes it's Miami Children's, but often, it's St. Mary's, where Olivia died and where the nurses know the Armands well.

"A lot of people ask how I do it," Trish said. "I'm a mom. I just do. If you were in my shoes, you just would."

Giving out the fourth scholarship in her daughter's honor is a rewarding way to remember Olivia's boundless love, she said.

Armand asks one favor of the scholarship recipients: "Stay in touch, spread the word about I-Cell, and pay it forward."

For details about the Olivia Grace Armand Foundation visit oliviagracearmandfoundation.com.

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