

Sickle Cell: A Family Persists



When a child has a sickle cell crisis the pain can be unrelenting.

"He screams and cries and it lasts for days at a time," says mom Valeria.

Her 3-year-old son Tyrone was first diagnosed with sickle cell as a baby. The family has been seeking support at La Rabida ever since.

"A couple months later he had a crisis where he had a high temperature, swelling in his hands and feet, trouble breathing," she says.

"It was very scary."

So when her third child was born, Zion, now three months old, she was praying he wouldn't also have the disease.

"Zion was an unexpected pregnancy. I'm just hoping he doesn't

go through the same pain." With help from the sickle cell clinic, Tyrone's hospitalizations

have been reduced and the family is better able to manage his pain. Zion is now also being treated. Valeria says because of the care her kids consistently receive at La Rabida, she's hopeful their sickle cell journey will be less painful and more manageable as they grow up.

The family is now preparing for their biggest challenge yet.

Tyrone's 7-year-old big sister is planning to donate her bone marrow to her little brother in a procedure scheduled for next March at the University of Chicago.

"She wants to help her brother," Valeria says.

With the support of La Rabida and his sickle cell care team, his mom says she feels prepared.

"They're always on top of things," she says.

For now, Tyrone is enjoying a new school year. His mom says he loves to learn.

"Even on the weekends, he'll wake me up early for school," she says. "He loves puzzles."

September is Sickle Cell Awareness Month. Tyrone's mom says she wants people to understand while it's often called a silent disease, it's still very real, and very painful.

"I just want people to not overlook it because he looks like a regular kid."

This Month on Social

Wagon **Donation**



Schererville, Indiana Boy Scout Adam Lung customized Radio Flyer wagons for patients and donated \$1,000 to the hospital as part of his quest to become an Eagle Scout. He worked with our care teams to make sure the wagons could transport oxygen tanks and feeding tubes. Our patients and their families were thrilled with their new rides.

Heart of the Year



Long-time La Rabida employee, Jeffrey Peebles, won the hospital's annual Heart of the Year Award. In September 2021, he saved a child from drowning off the shores of Lake Michigan while on duty. His positivity and willingness to help out no matter the circumstances embodies so much of what we strive for at La Rabida. Congratulations!

Riley's 1st **Birthday**



Celebrating a big FIRST birthday today on the S.S. La Rabida! Riley is a rockstar! Dressed to impress in all the colors of the rainbow, Riley was showered in love and attention as she celebrated her special day with her parents. Happy Birthday Riley!

Seeking Volunteers and Tutors



Calling all volunteers!

As we resume in-person tutoring for our patients, we're seeking people ages 16+ who are willing to donate their time. We're especially interested in working with high school students and those interested in helping our kids excel at school.

Contact George Hardin for more info at ghardin@larabida.org.

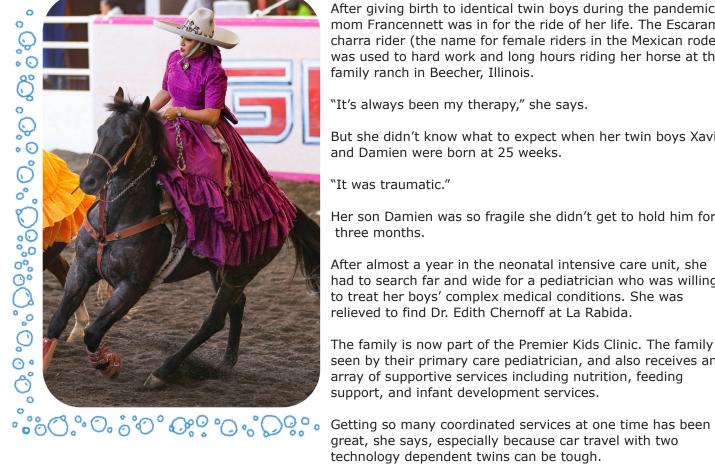
Help Us Help Our Kids

At La Rabida Children's Hospital, our mission is simple: we're dedicated to improving the quality of life for each of our patients who live with complex conditions, disabilities, and chronic illnesses. Children don't choose their circumstances, and we never let those circumstances impact the care children receive. We treat patients regardless of their family's financial circumstances. We are able to do this because of the support of individuals like you.

Help support our mission today by visiting https://larabida.org/donate

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Hispanic Heritage Month: The Ride of Their Lives



mom Francennett was in for the ride of her life. The Escaramuza charra rider (the name for female riders in the Mexican rodeo) was used to hard work and long hours riding her horse at the family ranch in Beecher, Illinois. "It's always been my therapy," she says.

After giving birth to identical twin boys during the pandemic

But she didn't know what to expect when her twin boys Xavier

technology dependent twins can be tough.

and Damien were born at 25 weeks. "It was traumatic."

Her son Damien was so fragile she didn't get to hold him for

three months. After almost a year in the neonatal intensive care unit, she

had to search far and wide for a pediatrician who was willing to treat her boys' complex medical conditions. She was relieved to find Dr. Edith Chernoff at La Rabida. The family is now part of the Premier Kids Clinic. The family is

seen by their primary care pediatrician, and also receives an array of supportive services including nutrition, feeding support, and infant development services.

"In our culture we love our kids and we are very family-oriented," she says. We want to do everything we can for them."

La Rabida, she says, is helping her do just that.



