

## e-Currents

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## Meet Sophie



Sophie was born at 33 weeks weighing a mere 4 pounds. After over a month in the NICU, Sophie's family was given the news that she was finally able to go home. But, something wasn't quite right. "Once we were home, Sophie was always crying, didn't want to eat, was constantly stretching to her right and was gasping for air," shares Jesenia, Sophie's mom. "At first, doctors thought she just had acid reflux, but a mother's instinct told me something was wrong."

It was then that Sophie began having seizures. "Everything took a turn. Sophie starting having seizure after seizure," says Jesenia. "We didn't know where they were coming from because she didn't have any trauma to her brain."

At 10 months old, Sophie was diagnosed with TBCK syndrome, a genetic intellectual disorder that can have an impact on things like speech, motor development, the respiratory system, and can cause epilepsy. "In a way, the diagnosis gave us piece of mind because we finally knew exactly what was wrong," shares Jesenia. "We knew how to properly treat her."

After three surgeries and getting a tracheostomy tube, Sophie was transferred to the S.S. La Rabida. "At La Rabida, Sophie gets a lot of therapy. She is doing so well here," says Jesenia. "The staff here has given us so much hope."

Since arriving to La Rabida, Sophie has made great improvements. "Sophie is not having the seizures that she would before," shares Jesenia. And for a child who once relied on a ventilator around the clock, Sophie is making strides to breathe on her own. "She's now off the vent for about 7 hours throughout the day and has been able to communicate with us a lot more."

These improvements are helping with Sophie's overall development. "She is much more active and is very alert when people speak to her. Sophie is sleeping through the night as well – she didn't do that before. I can tell that she is very, very happy here," shares Jesenia.

Having been at La Rabida for nearly four months, Sophie has become a part of the La Rabida family. "When I can't be here, I know that she is in good hands," says Jesenia. "My anxiety level has gone way down knowing that she is in such a positive, safe environment. I have peace of mind knowing that she is safe. Being at La Rabida has been the best experience. I don't want to leave!"

## Happy Valentine's Day!



Roses are red. Violets are blue. This Valentine's Day was special, thanks to friends like you!

Our friends from SHE 100.3 and CD One Price Cleaners once again helped spread the love to the patients and families of La Rabida by hosting a Valentine's Day card drive. SHE 100.3 asked their listeners to create thoughtful handmade valentines and deliver them to their nearest CD One Price Cleaners. Jay Stiles and the SHE 100.3 team hand delivered the cards to our patients and families. With over 20,000 cards collected and distributed, our kids sure felt the love this Valentine's Day.

La Rabida also welcomed our friends from the Chicago Police Department's Third District and Grand Regency of South Shore to our Gem on the Lake this Valentine's Day. The officers and representatives from the Grand Regency of South Shore visited with patients aboard the S.S. La Rabida and delivered toys and gift bags to our families.



Thank you SHE 100.3, CD One Price Cleaners, Chicago Police Department's Third District and the Grand Regency of South Shore for bringing love to La Rabida!

## Life with a Feeding Tube



Nearly 1/2 million people rely on feeding tubes, and 40% of them are children. If a child is not able to eat safely or cannot consume enough food or liquids by mouth, feeding tubes can provide the nutrition and hydration needed.

"When a child is not eating enough by mouth and is losing weight or not gaining weight, feeding tubes can relieve the pressure, take away some of the worry and alleviate fears regarding dangers of malnutrition and dehydration," shares Allison Lee, La Rabida's Chief of Speech Language Pathology.

Feeding tubes help kids, kids like Junior, get the nutrition they need thrive. Junior was born prematurely at under one pound and required a trach and a feeding tube. After spending some time in the NICU, Junior was transferred to La Rabida where he has been for the last six months.

Junior has used a g-tube, one of the many types of feeding tubes, for the majority of his life. "Junior's experience with the g-tube has been nothing but positive," shares Joanna, Junior's mom. "The therapists at La Rabida have been great in helping us both learn."

Since being at La Rabida, Junior has made great progress. "He's learned sign language to help him communicate, he smiles, and, most importantly, has started tasting real food," shares Joanna. "He has become very interested in feeling the food, playing with it, and putting it in his mouth. He is going to be an eater. I just know it."

"I have La Rabida to thank for all of Junior's progress. The staff has been so wonderful with helping us through the experience with the g-tube and now exploring real foods," shares Joanna. "We are happy beyond words."

## Teaching the Future Generation

At La Rabida, we take pride in supporting our families through every step of their child's journey. While this traditionally refers to healthcare, it also means through their education. Vicky McClure, La Rabida's resident Chicago Public School teacher, does just that by providing one-on-one instruction to children while aboard the S.S. La Rabida.



The experience of in-hospital education differs from child to child. Some patients come in having been a regular education student for all of their lives, while others are enrolled in special education programs. "Every child is at a different learning level and we work to accommodate their needs," shares Vicky. Working on subjects like math, reading, and social studies, Vicky is able to work with the materials provided by the child's school and modify assignments to fit their abilities. "Some patients do all of their learning verbally," says Vicky. "For others, repetition and visuals are crucial."

Working with patients for one hour each day, Vicky has had the opportunity to get to know each child and their needs. "Recently I was having a challenge getting one of my students to open up. I learned that prior to coming to La Rabida, he took PE as a course and loved it," shares Vicky. "I found out that he really enjoyed basketball, so we started working that into our conversations and I was able to get him engaged."

Vicky works closely with our team of child life specialists, therapists, and physicians to determine the needs of each child. Sometimes instruction is done in the Child Life Pavilion and other times it is done at the bedside. "We are flexible because medical care takes precedent," shares Vicky. "Sometimes a child may be having a procedure or a tough day and that's okay."

"As someone who was a sick child, it is so meaningful that I am able to help these kids through education. These resources were not available to me, so I'm glad I am able to make a difference in their lives."

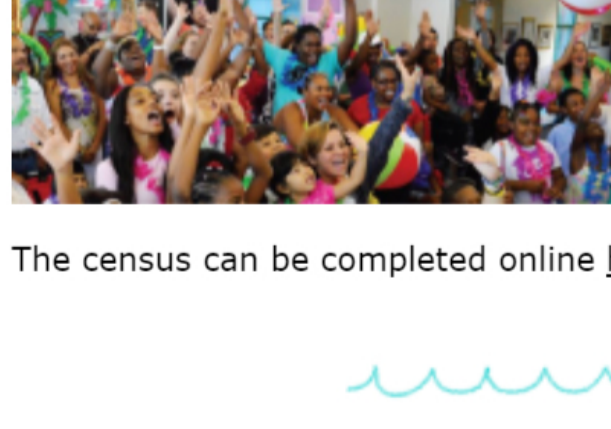
## Invest in the Future of La Rabida

At La Rabida, we understand the needs of children who are living with a variety of complex medical conditions. With a team comprised of the best healthcare providers in Chicago, we provide ongoing, comprehensive care, education and support, and support to families as they face their challenging circumstances head on. One way to provide everlasting support to our hospital and its mission is to leave a gift in your will. Your contribution is an investment in the future of our families and will leave a lasting impact on La Rabida.

If you are interested in learning more, please contact the Development office at 773-753-9606 for more information.

## Every Child Counts in the 2020 Census!

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Children are the most undercounted group in the census. Census responses are 100% protected and confidential.

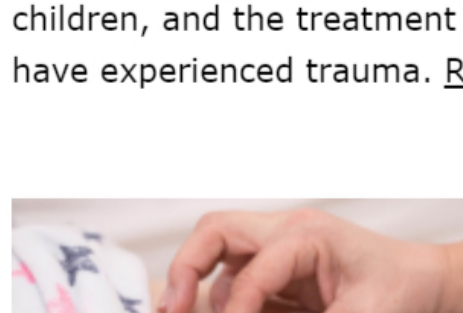
Did you know that census numbers help fund important special services like nutrition assistance, Headstart, special education, Medicaid, and housing assistance?

The census can be completed online [here](#). For questions text: 978-978.

## La Rabida in the News

## US News and World Report

Treating childhood trauma is one of our specialties here at La Rabida. Theresa Valach, Clinical Director of La Rabida's Chicago Child Trauma Center, recently spoke with U.S. News and World Report about what childhood trauma looks like, how traumatic experiences impact children, and the treatment model used to support children who have experienced trauma. [Read here](#).



## Chicago Parent

Children who utilize feeding tubes don't always get to participate in a traditional mealtime experience. At La Rabida, we're changing that. Allison Lee, Chief of Speech Language Pathology, spoke with Chicago Parent about La Rabida's Tube Feeding Task Force and how the initiatives of the interdisciplinary team are transforming the mealtime experiences for children who rely on feeding tubes. [Read here](#).