

‘A LITTLE FIGHTER’

Fundraiser to help family pay for infant’s liver transplant

By Stephanie Butzer | Enterprise Staff Writer Jun 11, 2017



Annabelle McKinney, who was born in 2016, was diagnosed with Propionic Acidemia shortly after her birth. Her family is now raising money for a liver transplant. Photo courtesy of Jennifer Limbaugh of JL Photography & Design. SPECIAL | HPE

HIGH POINT — Like the parents of any newborn, Mike and Charity McKinney are loving and protective. They make sure their daughter has fun with her toys. They play with her long and rebellious hair. They make sure she’s eating enough protein to grow strong.

But not too much. Because unlike other babies, for 8-month old Annabelle, too much protein is deadly.

After a normal pregnancy, Charity gave birth to their first daughter on Tuesday, Sept. 20, 2016. The couple and their new addition left the hospital that Thursday around lunchtime with what nurses had dubbed a “perfect baby,” said Mike, a teacher at Ledford Middle School.

But shortly after 11 p.m. that same day, they were at Brenner’s Children Hospital with Annabelle, who was breathing, but unresponsive. Her temperature read 95.

“It was like she was still breathing, but if you put the bottle in her mouth she wouldn’t suck or anything,” Charity said. “She wouldn’t open her eyes. At one point, (Mike) was holding her and you could pick her arm up and it would go just limp. That was scary.”

Hours passed at the hospital.

“It was one thing after another, going on all night long,” Mike said. “Finally around 7 or 8 o’clock that morning, they finally came in and said, ‘Everything is checking out good, but we found something we want to keep an eye on.’”

Annabelle's ammonia levels had skyrocketed, indicating a possible metabolic disorder, doctors said. With the help of experts at Duke University Hospital, the doctors at Brenner's recommended starting dialysis.

"That was really scary for us as the parents," Charity said. "All of a sudden we're talking about dialysis. With as small as she was, they said there was a risk."

The newborn was in surgery later that night to have ports put in for the dialysis. She remained hooked up to the machine until the following afternoon.

As scary as the experience was for the new parents, doctors finally presented them with a reason.

Propionic Acidemia. If Annabelle eats too much protein, her body doesn't break it down and it builds up in her system. That increase in the level of ammonia can cause brain damage. On the flip side, if she doesn't eat enough, her body can start breaking down her own protein. It's a rare disease, and as far as they know, she's the only, or one of a very small number of children in the state who has it, Charity said.

The family moved to the NICU at Duke University Hospital for the following two weeks, where genetics doctors and specialists studied Annabelle's condition and operated on her to insert a gastrostomy tube to help with the specialized feeding she would need moving forward.

After weeks in hospital rooms, the family finally came home on Oct. 11, 2016. They returned with not just a healthier child, but new skills and schedules to perfect to keep her that way.

Just a few days after she was born, Annabelle McKinney was back in the hospital. Here, she is undergoing dialysis. She now needs a liver transplant. SPECIAL | HPE

As the McKinneys settled into their new life at home, still while making frequent doctor visits, another surgical procedure started to become more of a possibility.

Doctors first mentioned a liver transplant in November, and again, with more seriousness in December. While not a complete cure, the transplant would make her day-to-day life better and more manageable.

They carefully weighed the odds. If they did chose to look for a transplant, they'd be looking at a long first year of complications. But it would likely grow easier over time and Annabelle could live a more normal life as a vegetarian.

If they didn't decide on a transplant, they'd be looking at a life in a bubble. Constant management of her diet, which would be restricted to veganism. Her immune system would be weaker if she got sick. She'd need a lab-made, expensive special formula every day.

"We feel like by making the decision for a liver transplant, we're giving her the best quality of life we can give her," Mike said. "This opens up the opportunity for her to go to school and be around other kids."

They decided to pursue the option, and made a trip to Children's Hospital of Pittsburgh in Pennsylvania in April for a transplant evaluation. They were impressed by the facilities and doctors, but geneticists told them there was a sense of urgency.

It wasn't a matter of if Annabelle would have brain damage from high levels of ammonia, but rather when it would happen, they told the family. The hospital had done more than 330 metabolic transplants.

"We felt like it was the best place to go, even if it was kind of far away," Charity said.

After learning the immense cost of a transplant, plus the after-care, the couple learned about, and turned to, the Children's Organ Transplant Association, or COTA.

COTA is a national charity dedicated to organizing communities in raising funds for a child's transplant-related expenses. It works to ensure that no child or young adult is denied a transplant due to lack of funds. One hundred percent of the funds raised through COTA go toward the person's transplant.

So far, two yard sales are planned, both for June 10. One will run 8 a.m.-1 p.m. at 4239 Kernersville Road, Kernersville, and the other is 8 a.m.-noon at Union Cross Moravian Church, 1780 Union Cross Road, Kernersville. The latter is selling spaces to vendors, and will also have breakfast available for purchase.

The funds raised will go to COTA, in honor of Annabelle. They'll help pay for not just the transplant, but the annual visits back to the Pittsburgh hospital, lifetime medication and more. All donations are tax-deductible. The first donation came in on May 8, and the total hovered around \$9,200 as of Friday afternoon. The total cost of transplant-related expenses is expected to be \$50,000, according to [Annabelle's page on the COTA website](#).

When will the family get the call that a transplant is ready? COTA estimated it may take 2-3 months when they first partnered with the organization in early May, but the call could come at any minute.

Either way, they're prepared.

The home's dining room is filled with suitcases already packed with clothes and necessities, all the medical equipment. Everything is ready to go, down to a sealed bag of new toys for Annabelle to play with in the hospital.

"I went to Wal-Mart and bought seven \$3 shirts," Charity said. "Lounging sweatpants, seven of those. My outfit will be the same every day. But colors will change."

Mike explained the rest of the trip's logistics: He had a shuttle to the airport ready to pick him and Annabelle up anytime. They had a medical flight arranged and an airport pickup service that would take them straight to the hospital.

"They want us there within four hours of the call," he said.

Charity will pack the car and drive up with suitcases and other items too bulky to take on the plane.

The family will spend anywhere from three to six months in Pittsburg, she said. That includes a 1-2 month stay in the hospital and a few months outside of it. They will stay in the area until doctors believe Annabelle is stable enough to return home.

"It's been a hard, long battle," Mike said. "A bit learning curve. Every time something happens, whether we go to the hospital or whatever, we always just react. We jump in. You don't even think, you just do what needs to be done. For us, personally, it's really helped us to grow in our faith. Just to trust in the Lord through all of this. That's how we sought comfort."

They would pray about the struggle and then something would happen that encouraged them to keep their head up, he said.

"We're very impressed," Charity said. "She's a little fighter and she's doing really well. She's beat a lot of odds."

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Want to donate?

Donations can be mailed to the Children's Organ Transplant Association, 2501 West COTA Drive, Bloomington, Indiana, 47403. Checks or money orders should be made payable to COTA, with "In Honor of Annabelle GM" written on the memo line of the check. Donations are also accepted at www.COTAforAnnabelleGM.com. Visit the COTA for Annabelle Facebook page at www.Facebook.com/COTAforAnnabelleGM for updates.