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‘She’s just a little sunshine’

Adopted from China, LiLi Santee, 8, is fighting a rare blood disorder one transfusion and one smile at a time.

By: Alyssa Allen | April 24, 2021

Beth Kurt, MD, will always remember the first time she met little LiPing Santee.

September 2019.

LiPing, or LiLi, then age 7, had recently arrived in West Michigan after the Santee family adopted her from China.

The Santees, of Wayland, Michigan, had been told LiLi suffered from aplastic anemia.

But Dr. Kurt, a pediatric hematologist with Spectrum Health Helen DeVos Children’s Hospital, would soon diagnose her with Diamond-Blackfan anemia.

Kati and Andy Santee adopted LiPing, or LiLi, knowing their little girl was fighting a rare blood disorder. LiLi's anemia requires regular blood transfusions. (Chris Clark | Spectrum Health Beat)

It’s a rare blood disorder that occurs when the bone marrow doesn’t make red blood cells, which carry oxygen to the body’s tissues.

LiLi didn’t speak English. She barely uttered Chinese the day she met Dr. Kurt.

But the doctor knew she had severe anemia and needed a transfusion.

And judging by the condition of the veins on her arm, LiLi had been through this many times in her young life.

“When the nurses went to start an IV, LiLi sat there silently with tears streaming down her face and held her arms out,” Dr. Kurt said. “She didn’t try to fight. You could see just how difficult it was for her.

“I’ll never forget it,” she said. “It was one of the saddest things I had ever seen.”

The scar tissue in LiLi’s arms made it difficult for the health team to place a needle into her arm, said LiLi’s mother, Kati Santee.

It proved a struggle for even the most veteran nurses in the pediatric intensive care unit. A doctor finally managed to access a vein with the assistance of an ultrasound.

“She was not complaining,” Kati said. “That is very much her demeanor. She had been through years of needing to be strong and take care of herself and not complain.”

LiLi’s hemoglobin level stood at 4.6. Normal is 12 to 16.

Two blood transfusions later, she could finally return to her new home with the Santees.

Girls’ day

LiLi’s family and the health team began to map out a long-term plan for her care.

The first step: insert a port so she wouldn’t need to undergo traumatic pokes. She could receive the transfusions directly through the port.

“It was the best decision,” Kati said.

Nowadays, LiLi sits with a smile on her face before her transfusions.

“She has no tears,” Dr. Kurt said. “It’s just so awesome to make a difference for her in terms of her quality of life.”

Giving LiLi a blood transfusion every 21 days keeps her hemoglobin at 9 or above, Dr. Kurt said.

Every three weeks, her family takes her to the lab at the Spectrum Health South Pavilion on 68th Street to undergo a blood draw. The next day, she heads to the infusion clinic at Helen DeVos Children’s Hospital for a transfusion, which takes about six hours.

Kati and LiLi make it a girls’ day, complete with snacks, crafts, homework, books and more.

“She really is amazing,” Kati said. “It’s mind boggling to me. The average child in this country would not handle one month of what she does.”

But Dr. Kurt also had to address another problem.

Chronic blood transfusions can lead to a buildup of iron in the blood.

Dr. Kurt ordered a FerriScan, a state-of-the-art MRI that measures liver iron concentration. LiLi’s readings came in astronomically higher than normal.

“Iron in high levels is toxic to the body, so we felt some urgency to get her iron levels down,” Dr. Kurt said. “It has to be treated and treated promptly.”

Doctors use chelation therapy to treat the condition.

In LiLi’s case, this required multiple medications per day.

She also sleeps with a chelation pump attached to her. She wears it in a pink backpack until bedtime.

“She has cried one time, the first time, because she was scared of what the machine was,” Kati said.

Ideally, the chelation treatments will end this spring or summer. Then she’ll only need oral medications.

But for now, she’s doing remarkably well with the treatments, Dr. Kurt said.

“I just could not be more pleased,” Dr. Kurt said. “It’s not easy to take these medications, swallowing multiple pills every day and sleeping with a needle under her skin and keeping it there for 10 to 12 hours.

“She’s just so brave,” she said. “She’s really a remarkable girl.”

Had the iron continued to build up in LiLi’s system, it would have led to multiple complications, including organ failure, Dr. Kurt said.

A gift

LiLi’s family and doctors hope she can enjoy life as a normal kid.

“I hope she can focus on important things, like what she’s going to do with her friends or what she’s learning in school—rather than worrying about her health on a day-to-day basis,” Dr. Kurt said.

LiLi and her family hold a special place in Dr. Kurt’s heart.

“It’s just really neat to see how LiLi has fit into her new family so beautifully and just what a gift she is for them,” Dr. Kurt said. “And certainly I would say she’s a gift for me, too.

“I love, love seeing her,” she said. “She’s just a little sunshine.”

Kati said she and her husband, Andy, knew that adopting LiLi would be the right path.

“She will have a life because she is here,” Kati said. “Our job is just to love her and make her life as fulfilling as possible.”

On their first date, Kati and Andy had talked about adoption.

When they had two sons—Ty, now 9, and Ari, now 6—it came time to think about having a third child.

They decided to adopt.

“We thought, ‘We have a very blessed life, so let’s see what we can do,’” Kati said.

In August 2017, they applied for adoption, indicating they were open to children with a variety of medical conditions.

In 2018, Kati saw LiLi's picture on the Facebook page of a woman who had been to China. That individual advocated for the adoption of children with medical needs.

"Hearing the way she described her in this writeup, I thought, 'This is my daughter.' I can't even describe it," Kati said.

She texted LiLi's photo and the description to her husband and asked him if they should request more information.

He wrote back, "Is this our daughter?"

'B positive'

Kati immediately began researching LiLi's medical needs.

Would they have access to what she needed in West Michigan?

"It felt so calming through this whole process," Kati said. "I thought this is what it feels like to have the hand of God saying, 'I've got you. You can do this.'"

Since LiLi's adoption, she has embraced countless opportunities.

She loves skiing. Sledding. Snowmobiling. Coloring. Arts and crafts.

She's a thriving first-grader at St. Stanislaus Catholic School in Dorr, Michigan.

"There's really not much that this child is not open to at least trying," Kati said. "When she feels really good, she is all smiles and being sassy with all of us."

On her bad days, when she's feeling weak and tired, she's quieter.

"I like when she's a little naughty because it means she feels good," Kati said.

LiLi sees other specialists, including a cardiologist, ophthalmologist, audiologist and endocrinologist.

She may one day be eligible for a bone marrow transplant. For now, the transfusions are doing their job.

And the health teams at Spectrum Health continue to help LiLi.

"There's not been a single person who we have interacted with who has not brought me peace of mind," Kati said. "They do everything in their power to support children and families. I can't sing their praises enough."

Kati is also quick to point out that LiLi's life depends on blood donors.

"That has become our family's passion and mission," Kati said. "LiLi loves nothing more than when someone we know goes to donate blood, takes a picture and sends it to her."

LiLi has B positive blood, just like her dad.

Every time she’s at a transfusion, LiLi asks her mom to check the bag of blood to see if it matches her father’s donor identification number.

“Literally, every 21 days, someone with B positive blood is saving LiLi’s life,” Kati said. “Now, that has become a saying we use: ‘Today, we are going to B positive.'”

Learn more about the pediatric specialty care available at Spectrum Health Helen DeVos Children’s Hospital.
Consider donating the gift of life at a local blood drive.