

‘We pray, we cry, we cuss.’

BY STEPHANIE DOYLE

Day No. 1. Monday, March 5. David Miles' son, Daniel, walked into his father's office at Process Machinery, Inc., in Shelbyville, a dazed expression across his face. It was 10 o'clock in the morning. Both their days – their months, their lives – were about to take a tragic turn.

“I thought he was coming to get me as we were scheduled to go visit a customer,” David Miles recalled. “He told me what he knew and walked out of my office, got in his truck and drove to Kosair (Children’s Hospital).”

David’s granddaughter Addison had just been to her pediatrician for a routine wellness checkup. The family was expecting to find out how much the 4-month-old weighed and how many inches she had grown. Instead, they learned that she had a large mass in her belly. They found out she needed a spinal tap. And they learned she had leukemia.

“In less than a two-hour window of time, this beautiful little baby’s entire life (and her parents’ lives) came unraveled, and it hasn’t been the same since,”

David Miles said.

Within an hour, David and his wife, Linda, who live in Shelbyville, and Daniel and daughter-in-law Rachel, who live in Finchville, gathered at Kosair with other family and friends to be near little Addison Lynn Miles. She was diagnosed with Acute Lymphoblastic Leukemia Type B.

On Tuesday, day No. 2, doctors withdrew fluid from her spine. On day No. 3, Addison started chemotherapy. On day No. 4, and every day since – day No. 45, day No. 58, day No. 75 – Addison has been fighting in a Kosair cancer unit on the 7th floor called simply 7 West.

“She is unbelievably tough,” David Miles said. “It is heartbreaking to watch what this baby has been through since March 5th, yet she complains very little and keeps fighting back. She is truly an inspiration.”

Addison tried her first green beans in 7 West. She tried her first carrots in 7 West. On good days, there is no nausea and the veggies stay in her tummy. On

www.bethematch.org

bad days, there are as many as six outfit changes.

And 7 West is where Addison waits. Waits to have her sick bone marrow – the spongy tissue found in bones – replaced with the bone marrow of someone else, healthy marrow, so that she can live. It was May 17, day No. 73 in 7 West, when doctors decided Addison’s only hope to live meant a bone marrow transplant.

“It is her only hope for survival,” David Miles said.

Now the family’s mission has somewhat shifted – to encouraging anyone and everyone to get on the National Marrow Donor Registry. Addison’s mother, father and older sister already have. They were not a match for Addison. If a child does not have a sibling or other family member who is a close match, doctors begin searching for an unrelated donor through the national registry.

They found four matches for Addison but don’t consider any of them a “best match” for her. The Miles family is on a mission now to let as many people as possible know that entering the national registry is a fast, convenient and free process. They tell anyone who will listen that all they have to do is simply request a kit, swab their cheek cells with a Q-tip and

mail the kit back.

“They will test your DNA and log this info into the donor registry,” Miles said. “That’s all there is to it.” From there, if a match is made for someone in need, marrow donors never incur any expenses and the recovery time after transplant is two to seven days.

A bone marrow registry drive for Addison will be held in Shelby County on June 17 at Shelby Christian Church. Those who want to help can get tested at the church.

“The chances of us finding a match for Addison through donor drives is very difficult to predict,” David Miles said. “If we don’t try, we have no chance. This is a numbers game. The larger the number of people who test, the greater the chance for success.”

“In the meantime, if we are successful and this effort leads to another 10,000 to 20,000 donors or more registered in the donor pool, we may save other children’s lives. I can live with that. I cannot live with not trying and not giving it our very best effort.”

Doctors, meanwhile, are working to destroy Addison’s abnormal marrow. “Her bone marrow results came back yesterday with 6 to 8 percent disease left,”



Before day No. 1. February 28, 2012.



Day No. 1.



Day No. 2. Blood transfusion.

Bone Marrow Registry Drive for Addison

9 a.m. to 4 p.m. Sunday, June 17
Shelby Christian Church (gymnasium)



Day No. 19.



Day No. 36. Post-surgery No. 5.



Day No. 77. Playing doctor.

www.caringbridge.org/visit/addisonmiles

Rachel Schlensker Miles, Addison’s mother, on said May 25. “She has come a long way. Before she can receive a transplant the doctors will give her more chemo to get the disease down to 0. We are hopeful that she will respond and this will happen!”

David Miles said he tries to get up every day and make something positive happen for Addison – work on a bone marrow drive, help out with childcare, assist Daniel with his workload at Process Machinery, etc.. Meanwhile, Addison battles everything from nausea to mouth and stomach ulcers.

“Every emotion that you can imagine runs through you,” he said. “It is never not on your mind. We pray, we cry, we cuss. Above all, we just cherish our time with Addison. She is an absolute joy to be with. The kid is tough-minded as nails, yet she is as sweet and gentle as the most cuddly kitten that you ever held. She is extremely intelligent as if she understands what is going on and refuses to give up.”



Day No. 79. A rare day at home in Finchville.

Purchase a 1-, 2- or 3-Year Subscription to Shelby County Life in the month of June and ALL PROCEEDS will go towards Addison’s Bone Marrow Drive Registry costs.



Subscriptions will be sold at the Downtown Shelbyville Street Party Concerts June 29 & 30. OR call 502-437-5237