

**The**

# Spotlight\*

Claire Davis



"I had so many thoughts and reservations when we got the diagnosis." Josh Davis is speaking on the phone from his family's home in Franklin on a Sunday evening. Sundays are typically daddy/daughter day for him and his daughter Claire, who is about 18 months old, has Down syndrome, and has been in the hospital more than most people will in their entire lives. Like many parents who get a prenatal DS diagnosis,

Josh did a lot of reading about all of the differences that come with an extra chromosome, but meeting his first child showed him more than his research.

*"When we had her, all that went away," Josh says.*

Josh's wife Kristen gave birth to Claire in October of 2013. Three months later, DS took a back seat to serious health issues. Claire had a major heart defect that required open-heart surgery. She spent nine days in the hospital to start, then after four days home, went back in for almost two weeks. Josh says that after a DS diagnosis, then frequent prenatal imaging visits for growth issues, then a successful operation, "When we got the heart surgery, I thought we were done."

As Claire grew close to six months old, Kristen noticed little red dots on her daughter's skin. Claire's doctor drew blood and found all her counts were low. She took Claire to the oncology clinic. The day after that, Claire had a bone marrow biopsy. Her doctors discovered that Claire had acute myeloid leukemia, which is particularly

aggressive. Compared to the heart defect, the leukemia was especially worrisome. Doctors tell patients and parents exactly what happens with heart procedures, what they fix, and what will happen afterwards. Chemotherapy is different. The outcomes are less certain, more ambiguous.

Claire started treatment at Monroe Carell Jr. Children's Hospital at Vanderbilt five days after her first birthday. Because of the exceptional danger of Claire's leukemia and chemotherapy, she spent her recovery times in the hospital. The Davis family spent three weeks in, then went home for around a week, before returning to the hospital and repeating the process. Nurses measured Claire's vital signs every two hours, and changed her diaper every four hours, regardless of sleep, which often made nighttime rest inconsistent and difficult for her and her parents.

Since Josh and Kristen both work, they didn't get to see each other as much as they would have preferred under such circumstances. Josh says that when one of them arrived at the hospital, the other left: "What are they doing today? What's the schedule? Love you. Bye."

That was life for Claire, Kristen, and Josh for seven months.



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On Saturday, May 23rd, Memorial Day weekend, the Davis family answered the phone and got the news they needed. Claire is cancer-free, and in remission.

"We're still trying to figure out this whole 'raising a kid' thing because we haven't been home long enough to do it," says Josh. He and Kristen can now focus on the development work that comes with raising a healthy little girl who has Down syndrome.

"We never saw any regression in her skills," Kristen says, though she does say the hospital stays slowed Claire down. "We always noticed that the weeks we would go to come home, she would blossom, and then it would slow down again when we went back to the hospital." Regardless of milestones, "She was just herself. She never let it get her down too much, or for too long."

Claire learned to pull herself up to stand while in the hospital, and her speech is starting to sound more like speaking, and less like babbling. She's very close to walking. She's saying bye-bye, mommy, and daddy. Even though she has a post-chemotherapy aversion to solid foods, she's eating an extraordinary amount of Cheerios, and has recently developed a love for refried beans, but only in restaurants.

Even though she loves being home, Claire isn't sure what to think about it. Kristen says "it seems like she's wondering if we're going back there. 'Do we live here?' She's starting to understand that we're home now. It feels like we're free."

Now that she's home, Claire likes to play with her activity table, her stuffed animals and dolls, and things she's not supposed to play with. She loves her 20-lb. mutt, Ranger. If you ask, she'll give you big, sloppy kisses. "You gotta be ready to wipe your mouth," Josh says. Claire is also getting used to not having nurses around, which means better rest, but also less constant attention. Kristen says that it's difficult to get dishes done with a little girl who has brand-new energy, emerging freedom and mobility, and fewer adults to give her attention. In other words, the Davis family is raising a typical little girl.

Kristen and Josh are very grateful for the support of the Down syndrome community in Middle Tennessee.

"The DS community in Nashville has been amazing to our family," says Kristen. I can't describe what having the DS community, with the help and resources, has meant to us. It's just nice to have such a diverse group of people, who have gone through so much, that it seems like no matter what you're going through, there's someone who can help you."

Josh says, "I was indifferent to having kids, and then we had her. She's got such a huge personality. Our family is forever grateful and in debt to all the people, all the families in the Down Syndrome Association of Middle Tennessee. We couldn't have done it without the support. I had lost all faith in humanity until this happened."

"Claire is basically the best thing ever."



## DO YOU KNOW SOMEONE WHO SHOULD BE IN THE DSAMT SPOTLIGHT?

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Email a photo and a short explanation why to [lisa@somethingextra.org](mailto:lisa@somethingextra.org).

Winning submissions will receive \$100 and a special gift!

  
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of Middle Tennessee

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