

Kicking leukemia gives teen a better sense of self

May 12 2011



Katelin Ivison awoke on her 14th birthday, Jan. 13, 2010, with a sore throat. She and her mother Adella had fun plans to go shopping and out to dinner to celebrate Katelin's big day, but first, Adella had scheduled an appointment for herself and her daughter with the family physician. Adella had strep throat and she figured Katelin did too, but they would soon learn that something much more serious was afoot.

Katelin's skin color looked off to the physician and blood work revealed a startling prognosis. Katelin might have leukemia. She needed to get to Golisano Children's Hospital at the University of Rochester Medical Center (URMC) right away.



"I pride myself in staying calm and focused when something stressful happens or if there's an emergency, so at that point, it hadn't really sunk in," Adella said. If you asked Adella's children about the frantic 40-minute drive from Byron to Golisano Children's Hospital though, they might tell you otherwise, she quipped.

Adella's husband John arrived at URMC's Pediatric Emergency Medicine Department soon after Adella, Katelin and Katelin's brother Jacob. The family was told that Katelin probably had a form of cancer called acute myeloid <u>leukemia</u> (AML) which, when it occurs at all, is usually found in older patients.

"The family is incredible," said Denise Casey, M.D., assistant professor of Pediatric Oncology/Hematology at Golisano Children's Hospital. "They were just very trusting. Throughout Katie's entire treatment, they would say, 'You just let us know what we have to do and we'll do it."

Katelin was given a birthday cupcake in URMC's Department of Pediatric Emergency Medicine before being whisked upstairs for what would be a seven-week stay at Golisano Children's Hospital. The health care team on 4-1400, which Adella insisted is "where the best nurses in the whole entire world are," welcomed Katelin to her temporary new home with a birthday cake and balloons.

Katelin had AML with high-risk cytogenic factors, meaning her chromosomes were changing at rates linked with worse outcomes, so she needed very intensive treatment. Katelin briefly faced some complications during her stay and needed to be moved from 4-1400 to the pediatric intensive care unit, where she was given oxygen and fed intravenously. Katelin's family struggled with seeing Katelin so seriously ill, especially when she had seemed perfectly fine just a few weeks prior. "It was a horrific time," Katelin's mom recalled.



The Ivisons found ways to get through the experience together, leaning on their friends and family for help. Adella's mom flew in from Michigan to help take care of the Ivisons' other two children Jacob and Cora, while Adella and John took turns taking the 40-minute drive to and from Golisano Children's Hospital. Friends and neighbors held a fundraiser for Katelin. The family also started a Caring Bridge page and Katelin's dad attended CURE meetings with other parents of children being treated for cancer.

"Once we got into the hospital, we tried to keep everybody's life as normal as possible," Adella said. She was focused on being there for Katelin, but made a point to spend one-on-one time with Jacob and Cora too. She and John each found different ways to cope with the experience. John liked getting the details, whereas Adella like hearing a more general overview. John shared his experience with others while Adella preferred taking a more private journey. In the end, they made a great team.

"They always had good questions and a positive attitude," Casey said.

After the first seven weeks and two rounds of chemotherapy, Katelin was able to go home. Katelin surprised her friends by making a special appearance to her eighth grade dance on Valentine's Day.

Katelin's health care team and the Ivisons had known from the beginning that a bone marrow transplant would be the best option for Katelin. The family worked closely with Laurie Milner, M.D., associate professor of Pediatric Hematology/Oncology, to find a match and plan Katelin's preand post-transplant therapy.

Katelin's brother and sister were matches for each other, but not for her. A near match was found on the bone marrow donor registry list, so they decided to schedule the transplant for May 5. Katelin was doing well and



in remission at that point, but she was in danger of relapsing without a transplant.

"I don't know who the donor was. I just know that she was a 20-year-old girl and I just wonder: What 20-year-old would do that? To have to go through all that she did...this girl is a hero to us," Adella said.

Katelin's body fought the transplant at first. She was ill around Thanksgiving and the holidays as well.

"She has a great attitude and bounced back more quickly mentally than physically," Casey said, "She's a teenager and they so often think they can take on the world. Her parents are wonderful though and they pulled the reigns in." Adella and John encouraged their daughter to take things slowly and let herself heal.

Katelin returned to school in January and comes to the hospital every four weeks for check-ups. Her <u>bone marrow</u> transplant was a success and as time goes on, she will continue to get stronger and healthier.

"If attitude has anything to do with a child getting through aggressive treatment, you just knew that Katie was going to be a survivor," said David Korones, M.D., a pediatric oncologist at Golisano Children's Hospital who was on the team that helped treat Katelin. "She faced everything head on and even when things got scary, she had a smile."

Katelin's mom explained that she is much more mature and much surer of herself after her experience. She chose to "rock the bald" rather than wearing a wig during her treatment and stopped caring so much about what others thought of her.

"Katie has really come into her own," said Adella. "She doesn't waste her time on frivolous stuff...She knows what she likes."



Katelin surprised her parents by changing from a reluctant participant in the local Teens Living with Cancer (TLC) support group to a very active member, who participated in last year's national leadership conference. She is an avid reader, loves school and her close group of friends and is considering joining a sport. The 15-year-old miracle knows who she is and what she stands for. She recently told her mom, "Mom, I never want to do drugs. I've done enough of them already."

Golisano Children's Hospital is proud to recognize such a resilient, optimistic and inspiring young lady as Katelin Ivison. Watch out world, here she comes.

Provided by University of Rochester Medical Center

Citation: Kicking leukemia gives teen a better sense of self (2011, May 12) retrieved 9 May 2024 from <u>https://medicalxpress.com/news/2011-05-leukemia-teen.html</u>

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