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Nikki Rauscher made the most of her short life



Nikki at Disney World with Disney characters Lilo and Stitch. Rauscher Family Photo

By [Michael Yeoman](#), Dispatch Correspondent

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Since preemie clothes were too big for her, Nikki wore Cabbage Patch doll clothes. Rauscher Family Photo

ONEIDA >> Nikki Rauscher was only on this Earth for 18 years, but in that time she touched the lives of people locally and globally.

The Oneida city girl was born with Cornelia de Lange syndrome (CdLS) - a rare genetic disorder with no cure and no effective treatments. Her battle with the disease ended on Feb. 2.

“She was never able to speak but developed her own sign language to communicate her thoughts,” said her brother, Josh. Through this sign language and other gestures she displayed, those around her were able to understand what she was thinking and what she needed. Josh said she had a gift for entertaining those around her through her motions.

Josh said Nikki was diagnosed with the disease at birth. As with most babies who have CdLS, she had very low birth weight. “We were not able to find baby clothes to fit her,” Josh said. When preemie clothes were still too big, Nikki was dressed in Cabbage Patch doll clothes, which were more suited to her small stature.

In addition to slow growth before and after birth, those diagnosed with Cornelia de Lange syndrome typically have distinct facial features, development issues, problems with the digestive tract, seizures, heart defects, eye problems, and skeletal abnormalities.

While Nikki endured many medical setbacks and challenges – she did not let the fact that she had a “disability,” by definition, slow her down. Josh said his sister did pretty much anything she set her mind to. She loved four-wheeling and the outdoors. Her favorite place to visit was Disney World and she made several trips there during her lifetime.

A student with the Madison–Oneida BOCES Special Education program, she was described as having a true spirit about her. According to Josh, her teachers at Vernon-Verona-Sherrill had a balloon launch to honor Nikki shortly after learning of her death. “Everywhere that Nikki went she made an impact on people that she met,” he said.

In November, her symptoms intensified as she experienced a perforated stomach caused by an obstruction in her small intestine. With the exception of a short stay in Brigham and Women’s Hospital in Boston, Mass. to esophagus surgery, she spent most of the remainder of her life since November at Upstate Golisano Children’s Hospital in Syracuse. The disease also necessitated the removal of her entire stomach as well as the removal of portions of her small and large intestines, and her spleen.

Nikki’s parents said that her siblings - sister Kristen Evans, and brothers, Josh and Jason Rauscher and Sean Evans - were a big part of Nikki’s day-to-day life. “They did a lot for her and were able to learn from her. She helped us grow as individuals as well as a family. We are a close family,” they said.

Josh said the family has endured quite a bit – emotionally and financially as they sought care for Nikki. “My parents (Rolfe and Dawn Rauscher) have always been the type of people who did so much for others and never wanted anything in return. Initially they objected to any type of a fundraiser to help with expenses, but agreed when we combined the fundraiser with a celebration of Nikki’s life,” Josh said.

Nikki would have been 19 on March 1 and the family is using this date to celebrate her life and hold a community fundraiser. The event will be held from noon until 5 p.m. at the Owl’s Club on Vanderbilt Avenue in Oneida. There will be a DJ, food, drinks, desserts and raffles along with special displays and a slide show highlighting Nikki’s life and the lives she touched. Josh also hopes a representative from the CdLS Foundation will be available to discuss the disease and answer questions. Donations will be \$10 for individuals and \$15 for a couple. Those unable to attend can also send or drop off a donation to the Nikki A. Rauscher Benefit c/o Americu Credit Union - 280 Genesee Street, Oneida, NY 13421.

Nikki’s life has already been celebrated through Team Nikki on social media and the CdLS Foundation. “She is still touching thousands of people with her story. We have heard from people as far away as Austria and the United Kingdom,” Josh said.

To continue Nikki's legacy, her parents and siblings intend to continue to raise awareness for CdLS by working directly with the CdLS Foundation – an organization which provides support, education, resources and research for those afflicted by this disease.

Team Nikki on Facebook: <https://www.facebook.com/celebrationoflifefornikkirauscher>

About the Author



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