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'Sleeping Beauty Syndrome': New Castle native on TV today to discuss her medical condition

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NEW CASTLE — Nicole Delien's mom hopes that for her daughter, 2012 will be a Christmas to remember.

However, that could be a tall order. Nicole can recollect only three of the past 10 Yuletides.

The 17-year-old former New Castle resident suffers from Kleine-Levin Syndrome. When an episode strikes, she will sleep between 17 and 19 hours a day for anywhere from 32 to 64 days.

Because of that, the condition sometimes is called Sleeping Beauty Syndrome.

"But this is no fairy-tale disease," said Nicole's mom, Vicki, who lived in Mahoningtown with her daughter before moving to Pittsburgh in November 2002. "She cannot get up, she can't dress herself, she can't put her makeup on, can't do her hair or bathe herself.

"She misses big chunks of life. She's missed a lot of Christmases and Thanksgivings due to this. She's only been able to attend three Christmases out of the last 10 years."

During an episode, Vicki Delien said, her daughter will get up to go to the bathroom, and she will eat. However, Vicki describes these periods as a "sort of sleep-walking mode."

"Her eyes are all glassy, in a daze; she doesn't know what's going on around her," Nicole's mom said. "And she tends to eat a lot. She'll go to the fridge and whatever she's craving at the time, if it's right in front of her, that's what she's eating, no matter what the amount is.

"One time, she ate almost three pounds of fudge. I try to feed her sometimes, but even if it's something she likes, she might say, 'Ew, I don't like this,' because at that time, she might be craving something else."

DIAGNOSIS

Nicole was just six years old when her first episodes struck. At the time, they would reduce her to an infantile state lasting five to seven days.

Doctors were puzzled, and in the end, it took 25 months before one Pittsburgh physician finally hit upon Kleine-Levin Syndrome.

That's the main reason that Nicole, Vicki and her husband, Harry, will appear at 4 p.m. today on The Jeff Probst Show. The syndicated talk program, which airs on WMPY My Pittsburgh TV, will be featuring people with rare diseases.

"I just want people to be aware of this," Vicki said. "It took us 25 months to find the right doctor to diagnose her with Kleine-Levin Syndrome.

"I know there are so many other families out there going through the same thing, being told that it's bi-polar or that it's just being done for attention. That is not the case. This is a true sleep disorder, and people need to know it exists."

Nowadays, extended periods of sleep have replaced regression as the syndrome's primary symptom. However it has manifested itself, though, KLS has impacted Nicole's family as well as the teen herself.

"I've put myself through school and I've lost externships over this, even jobs," Vicki said. "I can't hold down a job because I need to be here for her. We're now a family of five with one income.

"When she does go into these episodes, we become almost homebound because it's hard to get her up and get out of the house for any family activities or for activities my other children are in. It's hard and it puts a lot of stress on the younger two kids (7-year-old Cameron and 11-year-old Savannah) as well."

LIFE WITH KLS

As one might imagine, Nicole misses a lot of school whenever an episode comes upon her. The West Allegheny High junior — who also attends the Parkway West Career and Technology Center to study digital multimedia — must take classes during the summer to make up whatever she misses during the school year.

Class time, though, isn't the only thing that the condition costs her.

"I hate having KLS. I hate how it steals my life away," Nicole writes on www.klslife.com in an article titled "It's Hard Being a Kid with KLS."

"(It) has not been kind to me in terms of my friendships and relationships. I had one guy who was fond of me, but unfortunately, he lost interest during one particularly long KLS episode."

Nicole writes that she also lost childhood friends whose families found it difficult to comprehend and accept what she was dealing with. She credits her mother with working to share websites and information with her peers to foster understanding.

"I do have a couple of friends who are always there for me during an episode," Nicole writes. "Sadly, there are still kids who make mean comments about KLS because they don't understand it."

Her overriding wish: "I would love to just be a normal kid who can go to school, attend birthday parties and school functions, and participate in school activities. I miss cheerleading so much."

PROGRESSION

Nicole relies on an anti-seizure drug and another medication called provigil to manage her condition. The latter, her mother said, "helps spread her episodes further apart, to every nine months from every two weeks."

However, provigil also costs about \$2,000 a month, and after Nicole's father recently changed jobs, his new health insurance provider has refused to pay for it.

"Hopefully, that will get straightened out soon," Vicki said.

The family has been told that some KLS patients will go into remission after 10 years. While Vicki remains optimistic about that, she hasn't seen much evidence of it in Facebook and other online groups of KLS sufferers.

"I still see 40-year-olds who are having their episodes; they've had it since they were 16, 17 or early 20s," she said. "It would be great if we could go two years without one, then maybe I'll say, 'OK, she's in remission now.'"

"But I've only seen two people who haven't had episodes in the last four years."

Nicole, though, doesn't let that stop her from looking forward to the day when KLS no longer robs her of living.

"After KLS has left, I hope to enjoy everything that life has to offer, including family vacations," she wrote. "My very first family trip was to Disney World, but I don't remember what happened. I got into an episode the day we arrived in Florida and didn't recover until just after we got home.

"My family travels to Florida every year, and it'd be great to go and not have to worry about KLS."

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