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***Photo by Laura Lennie***

Kaitlyn Terrana was recently diagnosed with Kleine-Levin syndrome. The 17-year-old Cardinal Newman Catholic Secondary School Grade 12 student is making it her mission to raise awareness about the rare sleeping disorder.

Student seeks to awaken awareness of ‘Sleeping Beauty syndrome’

[*By Laura Lennie, News Staff*](mailto:llennie@hamiltonnews.com)

Kaitlyn Terrana dreams of attending McMaster University in hopes of entering the medical field.

But the 17-year-old Cardinal Newman Catholic Secondary School Grade 12 student says the reality of having a rare sleeping disorder, sometimes called Sleeping Beauty syndrome, makes realizing that dream seem almost impossible.

The disorder, officially known as Kleine-Levin syndrome, is characterized by recurring, but reversible periods of excessive sleep.

Symptoms occur as episodes, typically lasting a few days to a few weeks. The cause is unknown. There is no definitive treatment.

“Living with KLS means missing school for weeks at a time; it’s a struggle to keep up with my school work because the episodes happen so frequently,” Kaitlyn said. “Whenever an episode hits, it sets me back, so I’m always worrying about the future because all I can think is, ‘How am I going to get into the school I want, the program I want if this keeps happening?’ I know there’s nothing they can do, I just have to somehow live with it, make the best of it and not give up.”

Kaitlyn’s mother Kathy says her daughter’s episodes usually last for 10 days. They begin with her being extremely tired and unable to focus, she added.

“When she starts to have an episode, the sleeping is around the clock; she sleeps for up to 22 hours and won’t wake up, so I have to wake her up to make sure she goes to the bathroom and drinks water. Sleeping for that long usually lasts two to three days,” Kathy said. “Around the fourth day, she will sleep for about 16 hours straight, get up, go to the cupboard, eat everything in sight and go right back to sleep. During that time, she doesn’t interact with anybody; she’s basically sleepwalking.”

Doctors confirmed Kaitlyn had Kleine-Levin syndrome in late June after two years of tests and a couple of wrong diagnoses.

Her symptoms began in October 2010.

“I was so tired and couldn’t focus,” Kaitlyn said. “When I was in Grade 10, my math mark dropped 15 per cent from where it was in Grade 9 because I missed two or three units at least. Math had always been one of my strongest subjects.”

Kathy said she knew something was “off.”

“Kaitlyn was a teenager, so I didn’t know if something had been going on at school, if it was that that was causing her to be this way or something else,” she said. “Our doctor was doing all kinds of tests on her. They did everything and they couldn’t find anything.”

In November of that year, Kaitlyn had what doctors thought was a seizure during a blood test, which led to a misdiagnosis that she was suffering from complex partial seizures.

She also later was misdiagnosed with depression.

“I was on different medication and because I continued to have the episodes the neurologist would continue to up my meds,” Kaitlyn said. “I missed months of school and the medication only made me feel worse. It wasn’t even working. It was a really difficult time.”

Kathy said things got progressively worse.

“As a parent, you want what’s best for your kids,” she said. “When they kept increasing all her meds and she was getting worse instead of better, I was like, ‘There’s something wrong here.’ I went into the doctor’s office and said, ‘As a group, we all have to get together and do something because this is not working.’”

Kaitlyn was referred to a new neurologist at McMaster Children’s Hospital. She waited six months and finally met with the neurologist in early June.

Two days later, Kaitlyn experienced another episode, so the neurologist ordered an electroencephalogram (EEG), which showed no irregular brain activity. The neurologist concluded she had Kleine-Levin syndrome.

Kaitlyn, who had never heard of the syndrome, said she’s been collecting information about it.

“The most shocking thing I’ve learned is that there’s only 1,000 known cases worldwide,” she said.

Kaitlyn said she’s also read that complex partial seizures and depression are common misdiagnoses.

“It’s not doctors’ fault for misdiagnosing it,” she said. “If there was more awareness about it then there would probably be more cases that are properly diagnosed. I don’t want the next person to have to wait two years or four years to finally get diagnosed, I don’t want them to have to be stuck on medication that’s not helping them and, instead, just bringing them down.

“There’s nothing I can do about having it, but I can try and make the best of it and hopefully raise some awareness in the process.

“If one other person gets properly diagnosed because of that then at least I know I’ve made the best of it.”

For more information on how you can help Kaitlyn in her quest to raise awareness of Kleine-Levin syndrome, email kaitlyn\_terrana\_13@hotmail.com.