

'Sleeping Beauty Syndrome' doesn't keep Santa Rosa teen down

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When one of Claire Olney's sleeping spells takes hold, nothing will wake her up — neither clock radio, nor fire alarm, not even a bucket of water will do the trick. Give her a dose of modafinil, a stimulant used by fighter pilots and shift workers to avoid even a moment of disastrous shut-eye, and she'll sleep right through it.

When a spell comes over her, and they do about twice a year for weeks at a time, Claire is asleep for up to 22 hours. Time essentially stops for her.

The two hours she's awake feel "like walking through water," and are spent as efficiently as possible eating, showering and going to the bathroom. The rare sleep disorder is known as Kleine-Levin syndrome, or KLS. Some also call it "Sleeping Beauty Syndrome" because the primary manifestation is hypersomnia, with an average sleep time of about 18 hours a day.

"I've learned to live with it," said Olney, 17, who lives in Santa Rosa's Bennett Valley neighborhood. "I wish I didn't have to."

The condition's onset happens around puberty and usually doesn't last longer than 10 years, said Kirsten Olney, Claire's mother.

But, she said, "during that 10-year period, it could be life devastating."

Claire said her first episode began about four years ago, during spring of her freshman year of high school. The first episode was frightening, she said. Her parents thought she had a bad case of "teenagerism."

"When we didn't know what was happening, when I'd wake up I'd kind of be scared and worried," the teen said. "I didn't know what was going on."

The first episode coincided with a case of the flu. Claire had a high fever for about five straight days and suffered from recurring headaches. They tried throwing water on her to wake her up and even dragging her out of bed. Nothing worked.

Then came the battery of tests.

"They tested her for pregnancy, drug use, all sorts of hormonal things," said her mother, adding that the second stretch of sleeping episodes came about four months after the first. The teen has had a total of six episodes since then, the majority of them — four — occurring between the end of December and the end of February.

During an episode, with only about two waking hours between sleeping spells, life pretty much goes on without Claire, who at the time in the ninth grade had a large group of friends.

"Her friends were off doing their own things at school," said her mother, adding that while Claire has struggled to keep up with her grades, she still manages to pull straight A's at Montgomery High School, where she'll be a senior.

"She really cares about her grades and classes. My husband and I say all we want is for you to pass."

Dr. Amit Malhotra, a pediatric neurologist at Kaiser Permanente Oakland Medical Center who is treating Claire, said that while underlying mechanisms of the disorder are not fully known, there is "some evidence for genetic or immune-based etiology" or origination.

Speaking generally about the condition, he said KLS affects an estimated one to five in a million people.

"The disease can be debilitating and cause difficulty performing typical everyday tasks," he said.

In a 2014 paper published in the Journal of Nature and Science of Sleep, Stanford researchers Mitchell Miglis and Christian Guilleminault wrote there are only about 200 reported cases documented in scientific literature.

"It is a disease predominantly of teenagers, and boys are four times more likely to be affected than girls," the researchers wrote.

A proper KLS diagnosis came only last year, after she went to see Malhotra in Oakland. Aside from modafinil, her doctor has prescribed the use of a light therapy device that mimics the sun's light. She uses the powerful lamp during her waking periods, shining it on her face while she's eating breakfast, for example.

During her initial episode of KLS, Claire often woke up at random times. But by the second episode, the schedule became a little more regular, her mother said, waking between 3 and 8 p.m.

During that period, Claire is put into what's known as a "home hospital" program, where an instructor visits for about an hour to keep Claire on track academically. Her studies suffered during initially, but Claire was determined to not fall victim to her condition.

She has stayed positive, though she knows because of the way the disorder works another episode is likely to strike later this year.

"I really don't want to be in another episode," she said. "I want to be able to get up and take care of business."