



The Dirks Family

The Dirks family (above l-r), Mom Erin, 17-year old Stoneham High School senior Kayla, 13-year old Connor and Dad Oscar. The family has seen Connor through his bout with KLS (Kleine-Levin Syndrome). Connor sleeps for hours, and when awake can be spacey, forgetful and irritable. The family will be holding a fundraiser on March 7 to help with the medical bills

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Stoneham boy lives with sleep problem

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In today's hectic, fast-paced world, many people struggle to get the required eight hours of sleep each night. Some get by with just half that thanks to work, kids and other commitments. For one young boy in Stoneham, getting eight hours of sleep isn't a problem. The problem arises when it's time to wake up, because many times he can't.

Connor Dirks has what is known as KLS (Kleine-Levin Syndrome). It's a rare and complex neurological disease that causes him to sleep for hours at a time while affecting his behavior. The 13-year old Stoneham boy can sleep for upwards of 26 hours before waking up.

His mother, Erin, said that when he gets tired she knows it's time to get him into bed. There's no waking him up, either, she said, though she has admitted to getting him up for sips of water at times.

When he sleeps, his head goes back, he gets very white and his breathing becomes shallow. She said it's completely different from normal sleep.

Unfortunately, the disease has affected his health. Before, he was a normal boy who played sports. Now, his mother said, he's very thin and pale. Thankfully, playing sports gave him more of an athletic build and muscle tone that's helped him over the past few months as the disease has taken hold.

How it began

According to his mother, Connor had been sick off-and-on since March of 2011. The family thought he had mononucleosis, a common viral illness (known as the "kissing disease"). Prior to him first getting sick, his mother said he was very energetic.

Connor was a typical young boy, "very silly and goofy" his mother said. While some parents might think their kid was just lazy, his mother knew something was wrong, because "lazy was the exact opposite of who Connor was."

Once the family realized something was going on, they took him to a specialist at Tufts Medical Center for testing. They performed sleep studies, but all the tests came back negative.

At this point, Connor's mother was getting frustrated. Not knowing what else to do, she posted on Facebook a message about Connor constantly sleeping. Fortunately, in what has to be something of a miracle, as the disease is so rare that approximately 1,000 people have been diagnosed with it, another mother from Stoneham whose son also has KLS responded to Erin's Facebook post suggesting she see a neurologist.

With things looking up, the Dirks family went to Boston Medical Center for an MRI. During the procedure, Connor actually fell asleep. Though the doctors were worried, his mother assured them that it happens all the time.

Since August of last year, Connor has dealt with these sleeping episodes. Typically, he can go a couple of days between episodes. The longest he's gone is seven days.

Fortunately, his mother said, he'll outgrow the disease. However, it might not be for 10-12 more years meaning that he'll miss out on many rites of passage for a teenage boy including getting his driver's license.

His mother hasn't brought that up yet, as stress can contribute to his condition. She said she wants to focus on now and not worry about the future.

How he lives

Connor tries to live life like any ordinary child. He's been to school 18 times this year. Thankfully, the school has worked with the family to allow Connor to show up when he's able. When he's home he has the help of a tutor, though at times he's fallen asleep during his session.

He works out when he can, his mother said. She tries to get him to exercise when he's awake. Unfortunately, his awake periods don't always last long, which has contributed to his thin frame and pale skin.

Connor tends to eat at weird hours, sometimes in the middle of the night. Many times, the 13-year old is awake when everybody else in the house is asleep. His mother said he'll watch TV or find other ways to entertain himself.

One thing he misses is sports. Connor had made the AAU baseball team prior to developing the illness, but had to drop out once KLS set in. He also doesn't get to many sporting events, either.

Though it seems like a hard life - constantly sleeping, missing out on time with friends - his mother said he takes it as it comes. Though, it does get to him some days.

"I just want to get better," he'd tell his mother.

Connor has been fortunate to have great friends and a great support system. His biggest fan might be his sister who's a senior at Stoneham High School. His mother said they're really close and she enjoyed attending his hockey games.

Since the disease is so rare, very little is known about it. In that regard, Connor's mother has decided on a holistic approach to battling the illness. He takes 25 vitamins every day, which his mother said have helped.

He just started a gluten free diet, his mother said. It's also been suggested by his doctor that he start aerobics to help the endorphins fire.

How KLS affects lives

According to the KLS Foundation website (www.klsfoundation.org), the cause of KLS is not known. What is known is how badly it can affect those who suffer from it and their loved ones.

As his mother points out, when awake Connor can appear “spacey” or out of it. Sometimes he does things, then forgets he did them. Other times, he appears irritable, especially when overwhelmed by visitors.

A personality change that could happen, though hasn’t yet, is hypersexuality. Connor’s mother said she’s not looking forward to that if it takes effect.

The worst part about KLS may be what could happen, i.e. the KLS Foundation says that “affected individuals may go for weeks, months, even years without experiencing any symptoms, and then they reappear with little warning.

“In between episodes those diagnosed with KLS appear to be in perfect health with no evidence of behavioral or physical dysfunction. However, they function daily with the frightful reality that they could become sick again at any moment. KLS episodes may continue to reoccur for a decade or longer with devastating effects on the adolescent’s life and family.”

While on the outside KLS may look like any other sleep disorder, it is vastly different. As Connor’s mother mentioned, waking someone up during an episode can have unintended consequences. It may cause the person to suffer hallucinations. She said that one time Connor thought his parents were trying to kill him.

Although the disease is serious, it can offer moments of levity. One time while out in the backyard with his puppy, Connor had fallen asleep. When his mother looked out the window and saw Connor, still holding the leash, being dragged along the ground by the dog, she couldn’t help but laugh.

Fundraiser

KLS does not come cheap. Thanks to a number of tests, many not covered by the family’s insurance including a DNA test, the family’s finances have been drained. Therefore, a “Night of Inspiration” will be held on March 7 at the Faith Quest Community Church, 50 Central St., Stoneham, from 7 - 9 p.m. There is a \$20 suggested donation with 100 percent of the proceeds going to Connor’s medical bills.

For those not able to attend the event, but who would like to support Connor and his family, there are two ways to help:

- A benefit fund has been established. Donations can be mailed to: Connor Dirks Benefit Fund, c/o: StonehamBank, 80 Montvale Ave, Stoneham, MA 02180
- Raffle items can be donated by contacting Caroline Colarusso at 781-279-1197 or by e-mail at notforgotten3@gmail.com

According to his mother, Connor will most likely not be attending the event.

For a boy who at one time played six sports, now sleeping through most of the day can only be described as a jarring transition.