

# Saved from 'Sleeping Beauty Syndrome'

Sleep used to rule her life. Now,  
she's taking it back.

Getting enough sleep is important for good health. Yet uncontrolled, excessive sleep (hypersomnia) interferes with everyday living.

For example, a Lynbrook teen has lost about 700 days of her life to hypersomnia since 2013, according to her mother.

Getting to the root of the problem was Sarah Hastings' first hurdle – a big one. No one knew what was wrong when her troublesome symptoms began.

"She started sleeping a little more, eating a little more," said Amy Hastings, her mother. "She was dizzy, getting headaches."

Those early episodes worried Sarah, then 10, her older brother, Maxwell, and her mother. "I would try to wake her up for school and she would be unable to speak," said Ms. Hastings.

The mystery deepened as the symptoms persisted. During some of

her most extreme experiences, Sarah would be awake for only 30 minutes out of 24 hours. Episodes could last a few weeks. When they subsided, she couldn't remember any of it.

The quest for a diagnosis was long and often frustrating. Sarah once went to an emergency department yet received no clear answers after three days of tests. She returned to normal, but then symptoms came back nearly a month later.

## Hope awakens

"I met with an infectious disease doctor, an endocrinologist, a psychologist, a psychiatrist, a neurologist, a pediatrician. I really wanted everyone to look at her and rule out everything," said Ms. Hastings. Some clinicians chalked up Sarah's symptoms to behavioral health issues, but her mother was sure they were wrong.



Sarah fulfilled her quest for the right diagnosis and treatment at Cohen Children's. She is living proof of the hospital's high standards for pediatric neurology and neurosurgery.

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In January 2014, Shefali Nakul Karkare, MD, Sarah's pediatric neurologist at Cohen Children's Medical Center, referred Sarah to her mentor, Sanjeev Kothare, MD, director of pediatric neurology at the hospital, and the East Coast's leading specialist on neurologic sleep disorders.

With new blood work and a sleep study test, Dr. Kothare diagnosed Sarah with Kleine-Levin syndrome (KLS), a rare neurological disorder. Sarah and her family were grateful to get a conclusive answer.

The primary hallmark of KLS is repeated periods of hypersomnia — sometimes more than 12 hours a day for weeks — with increased appetite, irritability, disorientation and amnesia. Its cause is unclear, and there is no standard treatment.

KLS occurs in one or two people in a million — usually adolescent boys. Since Sarah's a tween, she's even more exceptional.

Dr. Kothare prescribed lamotrigine, which is often used to treat bipolar disorder and epilepsy. Because Sarah is a girl, he prescribed this medication rather than the usual ones for KLS — valproate or lithium. "Valproate can affect girls' ovaries, and there can be serious side effects with lithium," he said.

The KLS episodes haven't stopped altogether, but the medication has helped to shorten and regulate them so Sarah's life is more manageable.

"The lamotrigine prevents Sarah from being catatonic. But unfortunately, other symptoms remain," said Ms. Hastings, adding that her daughter's behavior regresses to that

of a toddler's during a bout of KLS. "But at least now, with this medication, I can take her to a school meeting."

Sarah experiences fewer episodes now, Dr. Kothare said. "She used to have attacks about every 21 days for a few weeks. Now it's about every two months for about 10 days," he added. "When we see Sarah in the clinic, she acts so normal, even during an attack. But later, she doesn't remember anything."

## Facing the future

For Sarah, KLS means "Keep Living Strong." She focuses on catching up with schoolwork as much as possible while she feels well. She works hard, and often sees a tutor after a full day of school.

Sarah monitors how she feels and sees Dr. Kothare regularly to manage her condition. Before an episode, she now experiences symptoms like dizziness or feeling under the weather, so she and her family know to prepare.

While they walk a challenging path, Sarah and her mother stay positive and determined. And they're glad they can share her experience with others.

"Sarah told me that one person could hear her story and it could change things. You never know who could read about her and get a grant to work on a cure."

In the meantime, the family forges ahead. "Whenever Sarah hears 'Fight Song' by Rachel Platten," her mother said, "it reminds her to Keep Living Strong even on the toughest of days."