

Teen with sleep disorder wants to help other sufferers



Dr. Steven Manuli with his daughter Stephanie Manuli

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Stephanie Manuli was copying notes in 8th grade math class when something odd, but all-too-familiar happened.

Suddenly Stephanie was lost -- as if some part of the lesson had slipped away without her knowing.

She glanced down at her notes, and instead of her usually neat handwriting, she saw scribbles. Stephanie had obviously moved her pencil during the time lapse, but her work was indecipherable.

Stephanie later learned she had been in a state of "microsleep," where her eyes were open, her hand was moving, but she had no memory of what she had done.

Doctors would later diagnose her with narcolepsy, a chronic neurological disorder that deprives the victim of restful sleep.

Now at age 16, Stephanie is taking steps to help others who have the disability and may not know it. She is junior ambassador for the Narcolepsy Network, a national nonprofit dedicated to spreading information about the disorder, supporting people who suffer from it, and promoting research for treatment and a cure.

Her duties include speaking at schools, civic clubs, health groups and other organizations about her experience in hopes of helping people who are not diagnosed yet. Earlier this year, Stephanie, a rising junior at Northeastern High School, spoke to her biology class about her experience.

Her diagnosis was neither easy nor fast. Most doctors have little training in how to recognize narcolepsy and are reluctant to prescribe controlled substances that are part of the treatment, said her father, Dr. Steve Manuli, an internist in Elizabeth City.

Part of the difficulty in diagnosing narcolepsy is that the symptoms - sleepiness, tiredness, depression, inability to stay focused - mimic other health problems.

Before she was diagnosed, Stephanie said she remembers being tired and drowsy all day, no matter how much she slept.

"For me it was just normal. I didn't think anything about it," she said.

Her parents misunderstood her constant dozing and need for naps at first.

"Before I was diagnosed, they would always call me lazy," she said.

Steven Manuli said he suspected a problem while driving Stephanie to River Road Middle School one day. When she started nodding off, even after a full-night's sleep, he recalled symptoms he read about while becoming certified earlier for sleep medicines.

Even with the warning signs, doctors did not arrive at an answer immediately.

Stephanie was first tested for sleep apnea, a common disorder where a person stops breathing while asleep. The results were negative.

Next, she went to a psychologist for depression.

Stephanie agreed that she was depressed.

"Honestly, being tired all the time really is depressing," she said.

Doctor visits would continue for several years before Stephanie was finally diagnosed with narcolepsy.

A Multiple Sleep Latency Test at Children's Hospital of the King's Daughters helped pinpoint the problem. The test involves asking patients to take daytime naps. Normally, a fully rested person takes 15 or 20 minutes to fall asleep. In contrast, Stephanie was asleep in a fraction of that time, falling into deep REM (Rapid Eye Movement) sleep - which does not usually happen for most nappers.

Dr. Michael Strunc, a CHKD pediatric neurologist and sleep specialist, said when he met Stephanie, she was sad and mad and was struggling in school. Treatment and some lifestyle changes have made a big difference, he said. She's now making straight A's and has big plans for the future.

Strunc said most people with narcolepsy can live a mostly normal life with treatment. The problem is that many people with it are not diagnosed or improperly diagnosed, he said.

Besides sleepiness, Stephanie experienced hallucinations and "sleep paralysis" as a result of narcolepsy.

When she awoke some mornings, she could not move right away. The "sleep paralysis," a condition where her brain was awake but not her body, would last for five to 10 minutes.

"I would have to just keep calm and wait for it to wear off," she remembered.

Steven Manuli explained that normally the brain sends messages for the body not to move during REM sleep. It keeps a person from running, jumping and kicking when they dream. In Stephanie's case, her body was still in that mode even though she was mentally awake.

At other times, Stephanie would have hallucinations just before falling asleep. She remembered one creepy sensation that someone was in the corner of her room. She knew it was only her coat hanging there, but she could not shake her fear.

Her father called it a "dream intrusion into wakefulness."

Being diagnosed has given Stephanie more tools to help her deal with her condition, which is partly genetic. There is no cure yet.

She takes two doses of medicine, one before falling asleep, another four hours later, so that she can sleep more deeply. She also schedules strenuous tasks early in the day when her mind is fresher. If she gets tired, she's still allowed to take naps, but they are not as frequent.

The regimen restricts what she can do, especially at nighttime, but she's happy about the benefits.

Now she's making As in school instead of Bs and has plans for college.

"I think the future feels so much wider," said Stephanie.

Mother Cindy Manuli said she's also happy that Stephanie is more alert.

The family can sit down at the dinner table without seeing Stephanie suddenly slump in her chair or "zone out" in mid-sentence, she said.

"I've got my exuberant daughter back," said Cindy, who noticed a change in Stephanie starting in third grade.

Stephanie said her happier life makes her want to help other people who may be suffering from the same problem and not know it. The Narcolepsy Network estimates one in 2,000 people are affected but getting a proper diagnosis often takes years.

Stephanie said she's one of the lucky ones to get diagnosed early. Many people live with the condition 10 or even 15 years before finding the source of their problem, if ever, she noted. That's why she wants to help spread awareness about narcolepsy.

"It's not really fair for people to go 10 years not knowing what is going on with them," she said.

(If you would like to contact Stephanie to set up a speaking engagement or are interested in participating in a narcolepsy support group, contact Steven Manuli's office at 338-5183.)