Darien woman aims to raise awareness of syndrome that affects nervous system

Mayor to proclaim October as Dysautonomia Awareness Month in Delavan

By Michael S. Hoey
CORRESPONDENT

Tawni Boardman has been misunderstood for most of her life. The 21-year-old Darien woman said she has lost friends who did not understand her medical condition, and she has heard classmates say they thought she was anorexic. She has also faced physical challenges since she was in fifth grade.

Boardman has postural orthostatic tachycardia syndrome, or POTS—a form of dysautonomia, a condition in which the autonomic nervous system malfunctions.

The autonomic nervous system controls essential bodily functions like respiration, heart rate, blood pressure, digestion and temperature control.

POTS is a syndrome not a disease.

"It affects anything the autonomic nervous system does, things the body does on its own and we take for granted," said Tawni’s mother, Michele Boardman.

Tawni Boardman hopes to raise awareness of the syndrome during Dysautonomia Awareness Month in October. Mayor Mel Nieuwenhuis plans to issue a proclamation Oct. 14 to bring attention to the cause.

Symptoms
The biggest identifier of the condition is that when an affected person stands up, his or her heart rate often climbs while blood pressure falls, resulting in dizziness or even black outs.

Tawni Boardman said she struggles to stand for any great length of time and doing things like going to the zoo are very challenging.

Other symptoms include gastrointestinal problems, stomachaches, vomiting, restlessness, insomnia, acid reflux and weight loss. Blood can also pool in lower extremities making feet appear purple.

"The brain doesn't send the organs the right messages," Boardman

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Michele Boardman (left) and Tawni Boardman (right) are pictured with Mayor Mel Nieuwenhuis, who will read a proclamation Oct. 14 designating October as Dysautonomia Awareness Month in Delavan. Tawni Boardman suffers from a dysautonomia syndrome.
Boardman

said. POTS has no known cure and no known general cause. Some research indicates that if a cause can be determined for a particular patient, treating the cause can help with overall treatment. Boardman said her doctors were never able to determine the cause for her.

"It could be genetic, from a flu shot, or from a vaccine - they just don't know," she said. No one else in her family has the condition.

The condition is also very unpredictable, Boardman said she can go awhile without any symptoms or they can happen frequently. Michele Boardman likened it to mood swings.

Tawni Boardman said she first noticed something was not right in fifth grade. She got sick a lot and doctors would just say she needed rest and send her home. The symptoms got worse until she started blacking out completely and not being able to get to the bathroom in the morning.

A correct diagnosis did not happen until Boardman was a sophomore at Delavan-Darien High School.

"We had taken her to a local emergency room and a nurse there had seen someone who had POTS," Michele Boardman said. The nurse recognized the symptoms and suggested Tawni be tested. Several years after first experiencing symptoms, Tawni finally had some answers. And more questions.

Both Tawni and Michele said the diagnosis provided some relief because at least they knew what the problem was. They also found out Tawni's case was not fatal as it can be. Her life was going to be challenging, they were told, but the condition would not take her life.

Tawni said she also had some fear, and the next question was "What now?" At first the doctors prescribed an anti-depressant to create higher serotonin. They failed and caused Tawni to lose 30 pounds in less than a month. At one point she weighed 89 pounds. She was prescribed laxatives for her gastrointestinal problems and salt pills for other symptoms, but both made her sick.

The doctors say she is very chemically sensitive," Michele Boardman said. Tawni said she drank alcohol once and had a seizure shortly after.

Familiarizing others

Tawni is telling her story to raise awareness about a condition few people know about. She said she has learned a lot of people have POTS and other conditions or diseases and can't get the funding they need for treatment or research.

"I can't say enough about the teachers," Tawni said.

Tawni mentioned teacher Craig Lodahl and counselor Laura Becker specifically.

Michele said the doctors told them Tawni would have to be home schooled or at least have a 504 educational plan in school to succeed. Michele did not even know what a 504 plan was. The plans provide special accommodations for students with special needs because extra time to complete assignments.

"The teachers always said they knew she cared because she always did the work," Michele said.

Awaiting relief

Since graduating, Tawni has taken classes at the University of Wisconsin-Whitewater and online classes at a technical school in Milwaukee but has struggled to keep up. Michele said Tawni is taking a break and will ease back into college. Tawni wants to be a dental hygienist if she can handle the classes.

Tawni credits her mother, her father, Jim, and her two sisters, Amanda and Jordan, for helping her get through her condition. She now receives treatment at Froedtert Hospital in Milwaukee but received care at Children's Hospital for most of the time she was diagnosed with POTS. Tawni says Dr. Gisela Chelinsky helped a lot.

Michele said the staff at Our Redeemer Lutheran Church with School and the Rev. Robert Rickman and his wife, Susan, were of great help as well in Tawni's years at that school.

"They prays a lot for us," Michele said.

As for a prognosis, there is no cure but research indicates the condition, while lifelong for some patients, stabilizes

for others, most often in the mid to late 20s. "It hasn't stabilized for me yet," Tawni said.

"It's a waiting game," Michele said. "I'm still hoping one day she will wake up and it will be gone."

Tawni is pregnant and due in late November. She said her condition makes things a bit more difficult than if she was healthy. Sometimes it is hard to tell if she is experiencing morning sickness or her regular symptoms.

Looking back on how the condition has affected her life, Boardman said she had to give up playing sports and performing in musicals and she lost most of her friends because they didn't understand her condition. When friends would call to invite her to do things she would often have to decline because she just couldn't do whatever they were doing. Eventually they stopped calling.

"I don't blame them," Boardman said. "They just didn't understand." Michele said Tawni was a good athlete in basketball and volleyball and a good dancer.

"She did well in whatever she did," she said.

Tawni worked very hard to get through high school. Michele said many kids with POTS can't, so it was a great accomplishment.

"The teachers at the high school were very accommodating," Michele said.

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Lasting effects

Today Tawni Boardman has gone natural - eating gluten-free foods, drinking soy milk and using other all-natural products. She still has symptoms, but things are better.

Looking back on how the condition has affected her