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## 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  
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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

**“It affects anything the autonomic nervous system does, things the body does on its own and we take for granted.”**

**- Michele Boardman, describing postural orthostatic tachycardia syndrome**

ic 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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MICHEAL S. HOEY *Delavan Enterprise*  
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 (Continued from front page)

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 needed help getting 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 a son who had POTS," Michele Boardman said. The nurse recognized the symptoms and suggested Tawni be tested. Seven 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 now knew what the problem was. They also found out Tawni's case was not fatal as some 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. That 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 chemical sensitive," Michele Boardman said. Tawni said she drank alcohol once and had a seizure shortly after.

### 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

life, Boardman said she had to give up playing sports and performing in musicals and she lost most of her friends because they did not 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.

"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 like 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, Amber 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 Chelimsky helped her 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 prayed 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.

### 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. Tawni said one good organization people could contribute to is Dysautonomia International, a network of top doctors that does much research on the condition.

"It is a worthwhile organization," Michele said.

Michele said that they recently were looking into ways to bring more attention to the condition and found that October is Dysautonomia Awareness Month. Michele found out local governments can issue proclamations designed to bring awareness to the cause, so she contacted Nieuwenhuis and asked if he would be willing to do so at the Oct. 14 Common Council meeting. Nieuwenhuis agreed.

"I had never heard of it before," Nieuwenhuis said. "I asked around and no one else I talked to had either."

Nieuwenhuis said he has read up on it and is very willing to do whatever he can to raise awareness.

The proclamation reads in part: "Now, therefore, I, Mayor Mel Nieuwenhuis proclaim this month of October to be Dysautonomia Awareness Month in the City of Delavan. I urge our community to support our local citizens stricken with this condition and applaud the profound courage and incredible strength they must possess every day."

"The challenges Tawni has to deal with can't be fun," he said.

Nieuwenhuis said it was great that teachers at D-DHS understood and helped her, and it was too bad more of her friends didn't understand.

"She struggled to get through her day and then she had to deal with that," he said.

Tawni said one thing she learned while coping with POTS was not to judge anyone by how they look on the outside.

"Everyone is struggling with something," she said.