

# East Moriches woman draws attention to dysautonomia

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By DEON J. HAMPTON [deon.hampton@newsday.com](mailto:deon.hampton@newsday.com)



Photo credit: Daniel Brennan | Lauren Stiles, 35, is the president of Dysautonomia International, a non-profit organization dedicated to raising awareness for the neurological disorder known as Dysautonomia. (Oct. 24, 2013)

An East Moriches woman has been working overtime to raise the national profile of dysautonomia, a group of neurological disorders resulting from a malfunction of the autonomic nervous system.

Since Lauren Stiles, 35, started a nonprofit -- Dysautonomia International -- from her home last October, the group has opened offices in Chicago, San Diego, New York and Washington, D.C.

"I had been healthy my whole life. And you don't hear of people just waking up sick," said Stiles of her early frustration with the disorder, which took years to diagnose. "I don't want anyone to go through what I had to go through."

The nonprofit -- one of a few groups dedicated to raising awareness of dysautonomia -- has recruited hundreds of volunteers -- from as far as England, California, Hawaii and Arizona -- hosted a national conference, launched its first national patient research registry and organized two lobby days on Capitol Hill.

Brookhaven Town issued a proclamation naming October as Dysautonomia Awareness Month. "We wanted to raise awareness about the devastating disorder because it affects many people," Supervisor Edward P. Romaine said. The state of Texas declared Oct. 23 as Dysautonomia Day. Cities such as La Crosse, Wis., and Olive Branch, Miss., have had similar proclamations, Stiles said. The nonprofit has raised \$50,000, part of which goes toward a cure for the disorder, and hosted a fundraiser Thursday night at Stone Creek Inn in East Quogue.

Stiles says she fell ill near the end of a ski and snowboarding trip to Vermont in 2010. She found herself bedridden as puzzled neurologists struggled to diagnose her disorder. Stiles, who used a wheelchair for the next two years, visited hospitals on Long Island and in Manhattan before physicians in Ohio identified her condition as Postural Orthostatic Tachycardia Syndrome (POTS), a form of dysautonomia.

The autonomic nervous system, which the ailment affects, controls heart rate, digestion and blood pressure, and it can cause lightheadedness and fainting.

According to [medicalnewstoday.com](http://medicalnewstoday.com), symptoms can also include extremely fast heart rate, slow heart rate, palpitations, chest pain, dangerously low or wide swings in blood pressure, the inability to remain upright, excessive fatigue, gastrointestinal problems, nausea, insomnia, shortness of breath, anxiety, tremulousness, frequent urination, convulsions, and migraines.

Brent Goodman, neurologist specialist in autonomic disorders at the Mayo Clinic in Arizona said the illness is becoming increasingly common. He said 80 percent of those diagnosed are female.

"Just out of the blue [it came]," said Stiles, who was stricken with POTS at age 31.

Stiles, a Riverhead-based environmental and real estate lawyer, uses medication to treat the disorder and no longer needs a wheelchair.

"I was misdiagnosed by several doctors, but the disorder causes so many symptoms that it mimics other illnesses," she said. And that makes it difficult to diagnose, health experts say. Jennifer Samghabadi, a nurse practitioner at John T. Mather Memorial Hospital in Port Jefferson, said vague symptoms such as an increased heart rate are hard to pinpoint when they only last a few minutes. She said an accurate diagnosis can take years.

Megan Loughran, 17, of Rocky Point visited 15 doctors before being diagnosed with POTS two years ago. "Living with it, the problem I have is that there isn't a good treatment. The medicine doesn't always work," she said, adding she has stopped taking medication and hopes for a cure.