

New website battles mysterious illness

By JENNETT MERIDEN RUSSELL

Laura Stiles's crippling symptoms, nausea, dizziness and fainting – that left her weak and unable to work, are markedly improved since emerging two years ago. But it wasn't without a bewildering journey of misdiagnoses, persistent research, and finally doctors at Weill Cornell Medical Center in New York City who concurred with her findings and treated her for postural orthostatic tachycardia syndrome. POTS is a form of dysautonomia, a general term used to describe a malfunction of the autonomic nervous system. Her quest has pushed her and a group of fellow patients to launch a new organization, Dysautonomia International as well as a website.

The site also offers a variety of resources for patients and family members to connect with experts in the field and keep tabs on, and contribute to continuing research on dysautonomia.

Stiles, an East Moriches attorney, contends that research thus far shows dysautonomia is fairly common, just misunderstood, a fact that she hopes to change. "Our organization is dedicated

to increasing awareness of this group of conditions, so that someday 'dysautonomia' will be a household word, even if it is really hard to pronounce," Stiles said.

"There are more people living with dysautonomia than there are with multiple sclerosis or Parkinson's." Ellen Kessler of Maryland was one mother who was thankful to discover Dysautonomia International. Her

two children, Jordan, 13, and Daniel, 15, were both diagnosed with POTS. Although the two were treated with a variety of medications, the pair still struggled with POTS, Kessler said. She finally found help at the Mayo Clinic in Minnesota. Kessler said she is grateful to have finally found aid for her children and wants to help others fighting the illness to find the proper care, as well. "There are so many patients dealing with this illness who have no access to information," Kessler said. "So, I was happy to join Dysautonomia International where there's a firm structure where we can disseminate accurate information and provide a formal channel for people who desperately need this information." According to research, POTS tends to strike those between the ages of 15 and 50. Women are five times more likely to develop the condition than men, studies showed, and dysautonomia can run in some families. Phil Fischer, M.D., medical director of Mayo Clinic's children's hospital and a POTS specialist, conducted a retrospective study of teenagers in

2007 and his findings were staggering. He concluded that one in 100 teenagers suffer with POTS.

"This is a small study,

but it is an important step because POTS is not well understood even within the medical community," Dr. Fischer explained. "POTS is a real syndrome in which the patient's heart rate accelerates abnormally when moving from lying

For more information, log on to dysautonomiainternational.org, where people can find information about dysautonomia, as well as connect with other patients dealing with the disease.

down to standing up, and it causes a whole cascade of symptoms from fatigue to stomach upset that are often mistaken for depression. This study points to the important role medications can play, in conjunction with other changes, to help these mostly high-achieving young people get their lives back." Stiles said the Dysautonomia International website was launched in September and quickly received thousands of hits from patients and doctors around the world dealing with the illness. One feature of the Dysautonomia International website is it shows a world map that points out the growing locations of POTS patients and doctors specializing in the disease.

Citing that there are millions of people around the world suffering with POTS, Stiles said one of Dysautonomia International's main goals is to advance

scientific knowledge on disorders of the autonomic nervous system. "There is a lack of funding for autonomic research, and that the need is tremendous, as there are millions of people across the globe living with dysautonomia," Stiles said. "We want to encourage the development of better treatments, and keep pushing the science forward until we eventually find a cure for each form of dysautonomia. That is our ultimate goal." ■

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