

DYSAUTONOMIA INTERNATIONAL



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DYSAUTONOMIA INTERNATIONAL HOSTS LARGEST GATHERING IN THE WORLD ON AUTONOMIC NERVOUS SYSTEM DISEASES

HERNDON, VIRGINIA (July 13, 2015) – Shannon Linford had no idea why, as a previously healthy 8-year-old, she couldn't keep up with her peers. Sitting straight at piano lessons was painful. Attending gym class was unbearable. All of the normal physical activities a child of her age would perform remained out of reach for Shannon. Her parents struggled for years to find a cause and a cure, but help seemed as elusive as their child's once boundless energy.

After years of searching for an answer, she finally received one. Shannon, now 22, has Postural Orthostatic Tachycardia Syndrome (POTS). POTS, a deregulation of the autonomic nervous system, can occur after an infection, an accident or surgery, or, as in Shannon's case, it can come out of nowhere.

"It's like having the flu every day of your life," Shannon said. "What's worse is that most doctors have never heard of POTS, and think it's just all in your head." Most patients with POTS suffer a wide array of symptoms due to dysfunction of their autonomic nervous system including: dizziness, chest pain, migraines, gastrointestinal disturbances and more.

Lauren Stiles, Esq., president of Dysautonomia International, notes, "POTS is not well-known, but it is not rare. Mayo Clinic researchers estimate that POTS impacts one in 100 teens. Including adult onset patients, POTS is estimated to impact over 1 million Americans."

"It's the most common medical condition you've never heard of," said Stiles, who was diagnosed with POTS at the age of 31. "In fact, you probably know someone with POTS who is currently undiagnosed. POTS patients endure an average six-year diagnostic delay due to a lack of awareness about the condition."

To help increase public and physician awareness about POTS and other forms of dysautonomia, Dysautonomia International is holding its **2015 Conference & Lobby Day, July 17-20 at the Hyatt Dulles**. During the conference, Mayo Clinic researchers, led by Dr. Wolfgang Singer, will conduct a POTS research study. Researchers will screen serum from

POTS patient volunteers for antibodies that may be causing POTS symptoms.

Conference speakers include the world's leading experts on POTS and other forms of dysautonomia, and special guest, ***New York Times* columnist, Dr. Lisa Sanders, who inspired the TV show *House M.D.***

Shannon Linford, a student at Northern Virginia Community College, is interning for Dysautonomia International and is eager to participate in research. "Anything I can do to help find a cure, I'm happy to help!"

About the 2015 Dysautonomia International Conference & Lobby Day

Held **July 17-20, 2015** at the Hyatt Dulles at Dulles International Airport in Herndon, VA (outside of Washington, DC)

Dysautonomia International is hosting its third annual Conference & Lobby Day this summer. Participants will join in on educational seminars, engaging speakers, social events and grassroots Dysautonomia advocacy. **With over 450 guests, this is the largest international conference on autonomic disorders**, bringing together patients, caregivers, researchers, physicians, allied health professionals, industry representatives, non-profit leaders and government policy makers. On Monday, July 20th, participants will head to Capitol Hill for Dysautonomia Lobby Day.

"This year, **Dr. Blair Grubb** (University of Toledo) will receive the **2015 Physician of the Year Award** for devoting his career to the study of autonomic nervous system disorders," stated Dysautonomia International Board Member, Clover Yordanova. "Dr. Grubb is highly-skilled, compassionate, and always goes above and beyond for his patients."

About Dysautonomia International

Founded in 2012 by a dedicated group of patients, caregivers, physicians, and researchers, Dysautonomia International is the leading 501(c)(3) non-profit focused on assisting patients and families impacted by autonomic nervous system disorders. The organization funds research, physician education, public awareness and patient empowerment programs.

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