

The Not So Dainty Fainting Lady

There are an estimated 500,000 to one million Americans living with Postural Orthostatic Tachycardia Syndrome (POTS). Despite being just as common as Parkinson's Disease or Multiple Sclerosis, most people have never heard of POTS. Could you or someone you know have this condition?

Most people who develop POTS are women of childbearing age. Mayo Clinic experts estimate that 1 out of 100 teenagers will develop POTS before adulthood. Often, people who have POTS go through many years of misdiagnosis before they are properly diagnosed.

POTS was first identified by Mayo Clinic neurologists in 1993, so many physicians have not heard of it yet.

Each person may have slightly different symptoms, but POTS symptoms can include lightheadness, dizziness, fainting, tachycardia (a racing heart beat), shortness of breath, chest pain, shakiness, nausea, headaches and migraines, fatigue, constipation or diarrhea, flushing of the skin, an increased sensitivity to medications, erratic blood pressure (too low or too high), heart palpitations, exercise intolerance, coldness or pain in the hands and feet, and brain fog. Many of the symptoms are relieved by laying down and get worse when the person stands, particularly the tachycardia and lightheadness.

POTS is a form of dysautonomia. Dysautonomia is a class of disorders that are caused by a malfunction of the Autonomic Nervous System (ANS). The ANS regulates the functions of your body that you don't have to think about, like your blood pressure, heart rate, breathing, digestion, kidney function, etc. POTS occurs when the ANS has a hard time responding to orthostatic stress. When a healthy person stands up, the blood vessels in our legs constrict, countering acting the effect of gravity, to help push blood upwards towards the heart and brain. In POTS, the blood vessels do not constrict properly and the POTS patient ends up with blood pooling in their legs and not enough blood returning to their heart and brain. This can trigger the long list of POTS symptoms described above.

POTS is not a fatal condition, but it can be quite debilitating. Physicians who specialize in treating POTS have compared it to the quality of life seen in patients who have congestive heart failure or chronic obstructive pulmonary disease (COPD). There are medications and lifestyle adaptations that can help manage POTS symptoms better, but there is no cure to date.

I was a healthy, athletic, 31 year old attorney, and I developed POTS symptoms out of the blue during a ski trip in 2010. I went from snowboarding and cross-country skiing one day, to barely able to stand without fainting a few days later.

I developed almost all of the POTS symptoms listed right away. When I went to the Emergency Room for the first time, having severe chest pains, shortness of breath and feeling like I was going to faint, the doctor dismissed me as if I was just having a panic attack. I had no history of anxiety or any other mental health issue. I knew he was wrong and refused the Valium he offered me. It took nine more months of being bounced from one doctor to the next before a team of neurologists at Cornell diagnosed me with POTS and severe autonomic nerve damage. After I was properly diagnosed, we

were able to start treating my POTS correctly. I finally started to feel better.

I was angry that so many doctors had misdiagnosed me for so long. Before I was diagnosed with POTS, one particularly arrogant doctor told me that I "was doing this to get attention from my husband because I was 31 and didn't have babies yet."

How offensive and absurd. Unfortunately, sexism is alive and well in the medical profession. I hear stories like this from women with POTS and other serious health problems all the time. Some doctors still cling to that Victorian era image of a dainty fainting young lady, swooning when a good looking man walks in the room. Oh, please. There is a reason we don't wear bone-crushing corsets and 50 pound dresses anymore. When I first developed POTS, I was wearing my well worn snowboarding boots and baggy pink and white camouflaged snowboarding pants. *Dainty fainting lady I am not!*

I didn't want another young woman to needlessly suffer for months or years because her doctor never heard of POTS, so after I started feeling a little bit better, I founded an organization to raise awareness about POTS and other autonomic disorders. I found thousands of other POTS patients online, and teamed up with some of them to form Dysautonomia International. Dysautonomia International is based on Long Island, but we are the first global non-profit dedicated to raising funds for autonomic research, educating physicians about autonomic disorders, and raising awareness about these conditions amongst the general public.

You can learn more about POTS and other autonomic disorders on our website, www.dysautonomiainternational.org. We regularly host awareness and fundraising events on Long Island and in the New York City area. If you would like to get involved, or for more information, please contact info@dysautonomiainternational.org.

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT



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