

WHAT IS DYSAUTONOMIA?

Dysautonomia, (pronounced dis'-aw-tuh-no-me-ah) is an umbrella term used to describe various conditions that cause a malfunction of the Autonomic Nervous System. The Autonomic Nervous System controls most of the essential functions of the body that we do not consciously think about, such as heart rate, blood pressure, digestion, dilation and constriction of the pupils of the eye and temperature control. People with dysautonomia have trouble regulating one or more of these systems in the body, due to the malfunction of their Autonomic Nervous System.

Dysautonomia can occur as a primary condition or as a secondary condition in association with other diseases such as Parkinson's Disease, Sjogren's Syndrome or Diabetes. Some of the more common forms of dysautonomia include Neurocardiogenic Syncope, Postural Orthostatic Tachycardia Syndrome and Orthostatic Intolerance. Some of the less common forms of dysautonomia include Pure Autonomic Failure, Multiple System Atrophy, Familial Dysautonomia, Baroreflex Failure, Autoimmune Autonomic Ganglionopathy and Dopamine Beta-Hydroxylase Deficiency. This is not a fully inclusive list, as there are many different forms of dysautonomia.

HOW MANY PEOPLE HAVE DYSAUTONOMIA?

It is not known exactly how many people around the globe have dysautonomia, but it is likely in the tens of millions. In fact, one form of dysautonomia, Postural Orthostatic Tachy-

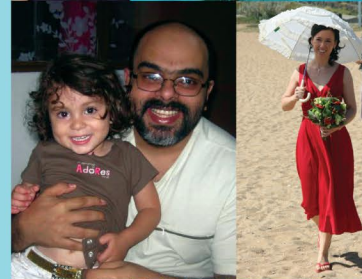
cardia Syndrome (POTS), is estimated to affect 500,000 individuals in the United States alone. If other countries have similar rates of POTS, that would mean an estimated 11 Million people worldwide have POTS. And that is only one form of dysautonomia.

All of these people have dysautonomia. Most look "normal" and "healthy" on the outside, but some of them are quite ill. Some dysautonomia patients lead active lives and can participate in normal activities like work, school and sports, while other dysautonomia patients are so sick they can barely sit up or stand.

IS THERE A CURE?

There is currently no cure for dysautonomia, but secondary forms caused by an underlying disease may improve with treatment of the underlying disease. There are many symptomatic treatments available to improve quality of life,

including medications, dietary changes and lifestyle adaptations. After individualized medical treatment,



some patients are able to function normally. However, even after trying all treatment methods available, some patients remain quite disabled and may even be unable to work or attend school. Again, each person is unique.

WHERE CAN I OBTAIN MORE INFORMATION?

For more information about dysautonomia, please visit our website:

www.DysautonomiaInternational.org

There you will find the most up to date scientific information on the known causes of dysautonomia, treatment options that are available through your doctor, lifestyle adaptations, exercises meant to help with orthostatic symptoms and more. You can also sign up for research studies, learn how to connect with other patients and find local support groups.

We also have resources for physicians and researchers, including research updates and a large compilation of peer-reviewed journal articles on various autonomic conditions – from basic summary articles to detailed technical research articles. We also raise funds for autonomic research and physician education programs.



WHAT IS DYSAUTONOMIA INTERNATIONAL?

Dysautonomia International is the first global dysautonomia advocacy organization. We have a Medical Advisory Board of expert physicians and researchers, a talented Patient Advisory Board and an outstanding group of volunteers (our "Awareness Army").

Our Mission

To identify the causes and cures for all forms of dysautonomia and to enhance the quality-of-life of people currently living with these illnesses.

Our Goals

- To raise funds for research on various forms of dysautonomia, including but not limited to, Postural Orthostatic Tachycardia Syndrome, Neurocardiogenic Syncope, Multiple System Atrophy and Pure Autonomic Failure;
- To raise awareness of dysautonomia within the medical profession and to provide accurate information to practitioners on the latest diagnostic methods and treatment options available, in order to improve patient care;
- To empower patients and caregivers by providing them with useful tools, resources and information about dysautonomia; and
- To increase awareness and recognition of dysautonomia amongst the general public.

We love to hear from patients, caregivers, physicians and researchers. If you would like more information, or if you would like to learn about our volunteer opportunities, or how to donate to dysautonomia research, please visit our website or contact us.

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WHAT IS DYSAUTONOMIA?

A guide for
newly diagnosed patients,
family members, friends,
employers and educators.



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