

## What We Do

By supporting patients and working with other non-profit organizations, we aspire to increase the scientific understanding of the relationship between Dysautonomia, autoimmune disorders, connective tissue disorders and Mast Cell Activation Disorder in the hope of finding new treatment options for patients with these clusters of conditions. With a focus to improve the patient experience, we educate and empower those living with chronic illnesses and provide support and resources that enable them to become effective self-advocates. DSN provides a social, online community that addresses the needs of these families and assists them in navigating the health care system, while effectively managing their treatment plan and living well, despite the diagnosis or diagnoses they are facing.

We strive to improve the quality of life of patients worldwide: increasing understanding, awareness and access to appropriate medical care for all patients. We hope to dispel the misunderstanding and prejudice that many medically complex patients face in medical settings and in society as a whole.

## How We Do It

As a volunteer staffed organization, run by patients, DSN provides support, inspiration, training and volunteer opportunities. We focus on how to move forward, despite our limitations. We each have experienced delayed diagnosis time, poor access to knowledgeable medical staff, and decreased quality of life. Powered by our steadfast volunteers, DSN reaches individuals struggling, in all countries. Social media connects them through a keyboard, mobile phone and/or tablet.

## Empowerment

Our special teams of DSN volunteers empower others. Several have entered into these teams in an attempt to connect with others locally and globally to increase awareness, dispel stigmas and enhance the patient experience.

Many volunteers enter our training program feeling hopeless, frustrated by their many limitations and are looking for a way to effect change in their lives and the community. Many become inspired, develop the strength and confidence needed through volunteering to return to the work force or school through service.

The training, teamwork and skill building that happens allows volunteers to be a part of something greater than themselves. Our special teams including Leadership, Advocacy, Media, Tech and Fundraising. Volunteers build skills and increases confidence, while fostering solution based thinking and hope for a purposeful life.

## Empowering members since 2012

To learn more about Dysautonomia and our organization, please visit:

[www.dysautonomiasupport.org](http://www.dysautonomiasupport.org)



QR code--Patient Education Packet

## CONNECT WITH US



**DYSAUTONOMIA**  
SUPPORT NETWORK

**Meetings      Support      Education**  
**Advocacy      Events      Resources**



## What is Dysautonomia?

Dysautonomia refers to a disorder of the autonomic nervous system (ANS) function that generally involves failure of the sympathetic or parasympathetic components of the ANS, but Dysautonomia involving excessive or overactive ANS actions also can occur. Dysautonomia can be local, as in reflex sympathetic dystrophy, or generalized, as in pure autonomic failure. It can be acute and reversible, as in Guillain-Barre syndrome, or chronic and progressive. Dysautonomia also can occur as a primary condition or in association with degenerative neurological diseases such as Parkinson's disease.

DYSAUTONOMIA SUPPORT NETWORK  
SERVICE DOG GRANTS



Hallmarks of generalized dysautonomia due to sympathetic failure are impotence (in men) and a fall in blood pressure during standing (orthostatic hypotension). Excessive sympathetic activity can present as hypertension or a rapid pulse rate. Patients may be misdiagnosed with anxiety as these disorders are not commonly known.

Over 70 million people in the world are living with one or more forms of dysautonomia. Dysautonomia is a word used to describe a group of neurological disorders that involve the autonomic nervous system such as Postural Orthostatic Tachycardia Syndrome (POTS), Neurocardiogenic Syncope (NCS), Orthostatic Intolerance (OI), Autoimmune Ganglionopathy (AAG), Pure Autonomic Failure (PAF), Multiple System Atrophy and others.

Otherwise healthy patients with POTS and NCS, the two most common forms of dysautonomia, often have periods of time when symptoms flare which can be debilitating; and other periods of time when they are able to be fairly active and manage symptoms well with proper medical care, understanding of the disorders, and a good treatment plan.

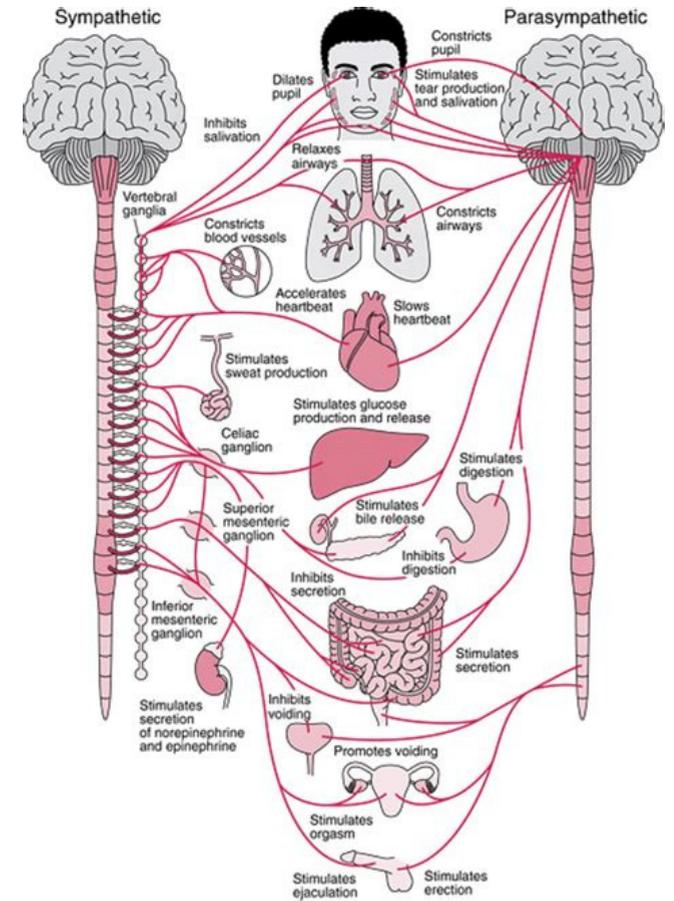
Those that develop dysautonomia secondary to other conditions such as Multiple Sclerosis, Chiari Malformation, Parkinson's, Diabetes, Autonomic Neuropathy, Ehlers-Danlos Syndrome, Celiac Disease, Sjögren's Syndrome,

Mitochondrial Disorders, and Mast Cell Activation Disorders often struggle with managing symptoms for many years. Symptoms tend to wax and wane over time but rarely subside as happens with some teens who develop POTS after contracting an infection.

Symptoms may affect every system in the body, are unpredictable, may come and go, and can be debilitating at times or permanently disabling to some. There is currently no cure but ongoing research is offering hope for better understanding and new treatment options.

#### **Symptoms of Dysautonomia :**

- Abnormally Low (Bradycardia)
- Abnormally High Heart Rate (Tachycardia)
- Extremely Low Blood Pressure
- Narrow Pulse Pressure
- Frequent, Large Swings in Heart Rate or Blood Pressure
- Frequent Bouts of Dehydration
- Chronic Fatigue
- Heart Palpitations
- Dizziness or Vertigo
- Syncope (losing consciousness) or Near Syncope
- Low Blood Volume
- Frequent Nausea and GI Issues (motility issues)
- Difficulty Swallowing or Choking
- Chest Pain
- Shortness of Breath
- Migraines or Frequent Headaches
- Abnormal Pupil Response and Sensitivity to Light
- Difficulty Regulating Temperature



#### **Who We Are**

DSN is a U.S. based 501 (C) (3) non-profit organization providing support, resources, education and advocacy for patients affected by the many forms of Dysautonomia, Connective Tissue Disorders, Chiari Malformation, Mast Cell Disorders, Gastroparesis and other related disorders. Founded in 2012 as Dysautonomia Divas, the organization now runs over 60 groups online, has chapters in all 50 United States and serves patients globally.