



Dysautonomia Youth Network of America, Inc.

"A Ray of Hope"

Awareness Campaign:



Standing Up For Dysautonomia Patients!

The purpose of this campaign is to facilitate change: change in improving the lives of childhood dysautonomia patients and their families, change in the community-at-large to foster awareness and a better understanding of dysautonomia conditions, and change in the future, to encourage compassionate care, efficient diagnosis, and reliable treatment of dysautonomia conditions.

Facts:

- Dysautonomia, is a group of little known and even less understood medical maladies that are more recently being diagnosed in children, teenagers and young adults.
- It has been less than a decade that POTS, a complex form of dysautonomia, was officially named and diagnosed.
- Until quite recently, very few pediatricians / pediatric medical professionals have encountered the official diagnosis in a patient.
- Presently, there are too few medical professionals who recognize the symptoms of most dysautonomia conditions, or know how to properly treat the patients afflicted.
- Once aware, most medical professionals can recall past case histories of patients who were tragically left undiagnosed (or were misdiagnosed).
- In the amount of time it takes someone to finish a cup of coffee, they can learn about this group of life altering medical conditions that are tragically afflicting young people across the world. Please become informed by referring to: www.dynakids.org
- DYNA is a professionally structured 501 c 3 non profit organization that is dedicated to serving children diagnosed with non-familial dysautonomia conditions. DYNA works with the big picture: networking with medical professionals, educating medical institutions, promoting and endorsing patient advocacy, providing information to educational facilities and spreading awareness of childhood dysautonomia conditions.
- You can contact DYNA at: 301-705-6995 or via email: info@dynakids.org to speak with a Awareness Campaign Liaison and for more information on childhood dysautonomia conditions.

Dysautonomia:

- Dysautonomia is an umbrella term utilized for a group of medical conditions that are caused by a malfunction of the Autonomic Nervous System. The autonomic nervous system regulates all of the unconscious functions of our bodies (such as body temperature regulation, heart rate, blood pressure, digestion, pupil dilation etc.). There are numerous forms of dysautonomia conditions. The degree of impact for each patient is unique and can vary from mild to severe. In the severe cases, patients are unable to attend school or social activities and can become socially isolated. Dysautonomia can be debilitating, life altering, and on rare occasions life threatening.
- When afflicting children, dysautonomia conditions most commonly strike during adolescent and teen years. There is a 5 to 1 female to male ratio.
- The inability to remain in an upright position (Orthostatic Intolerance) is a hallmark of dysautonomia conditions. Orthostatic Intolerance impacts an estimated 500,000 Americans and causes a wide range of disabilities.
- Symptoms of dysautonomia can include but are not limited to: severe tachycardia (fast heart rate), bradycardia (slow heart rate), orthostatic hypotension (low blood pressure) and orthostatic intolerance (inability to remain upright), syncope and near syncope (fainting), migraines, insomnia, seizures, disabling fatigue, gastrointestinal issues, and extreme dizziness.
- The most commonly known form of dysautonomia is: Neurocardiogenic Syncope (NCS). Also sometimes referred to as Neurally Mediated Hypotension and Vasovagal Syncope. Syncope is the medical term utilized for fainting or loss of consciousness. In NCS blood vessels tend to expand, which leads to pooling of blood in the lower parts of the body. As a result, less blood reaches the brain and this causes fainting (which can occur suddenly and without warning). The usual stimulus for this action resides in the nerves of the heart-hence the term neurocardiogenic.
- Over recent years, Postural Orthostatic Tachycardia Syndrome (POTS) has been evolving as a diagnosis. POTS is a less commonly understood and very complex form of dysautonomia. POTS is defined by an increase in heart rate of 30 beats per minute or more upon upright posture (upright posture can refer to both sitting and standing positions for some POTS patients). POTS can be associated with a high degree of functional disability.
- Youth with dysautonomia conditions may face such severe symptoms that they are left tragically ill and socially isolated during the prime of their developing lives. Because the symptoms of these conditions are often invisible to the casual observer, most patients don't look sick. This tends to lead to a lack of understanding and support for the child and their family.
- The financial burden placed upon families can be extremely significant as they continually seek out the best medical care for their children.
- Awareness of dysautonomia conditions is desperately needed and can make all the difference in the future for those afflicted.

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