

What is Dysautonomia?

Dysautonomia is a medical term utilized for a group of serious and complex conditions that are caused by a malfunction of the autonomic nervous system (ANS). The ANS regulates all of the unconscious functions of our bodies. This includes, but is not limited to; our cardiovascular system, gastrointestinal system, metabolic system, and endocrine system. A malfunction of the ANS can cause debilitating symptoms and may pose significant challenges for effective medical treatment. **Orthostatic intolerance** (the inability to remain in the upright position) is a hallmark of various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating and, on rare occasions, can be life threatening.

Symptoms of dysautonomia can be unpredictable, come and go, appear in any combination, and vary in severity. Often patients will experience an increase in symptoms after a stressor or physical activity. Patients may find themselves involuntarily limiting their life-style activities in order to compensate for the conditions. Symptoms can be so severe that some children may require placement in homebound teaching programs for health impaired students; others will be able to attend school, often with limitations and modifications in their educational plans. The social isolation experienced by not being able to attend school or community activities is one of the hardest things for youth with dysautonomia conditions to deal with.

Management of these conditions must be individualized to the specific patient. Treatment may include pharmacological and non-pharmacological methods. Treatment must be fine tuned as the patient physiologically develops.

What are some of the diagnostic terms?

Postural Orthostatic Tachycardia Syndrome (POTS), Neurocardiogenic Syncope (NCS), Neurally Mediated Hypotension (NMH), Vasovagal Syncope, Mitral Valve Prolapse Dysautonomia, Non-familial Dysautonomia, Generalized Dysautonomia, and Post-Viral Dysautonomia are some of the diagnostic terms issued to youth within our organization.

What is DYNA?

DYNA is a 501 (c) (3) non-profit organization dedicated to serving young people diagnosed with various dysautonomia conditions. DYNA is a dynamic group of positively focused and empowered individuals. Without exception, DYNA members face each day with profound courage and incredible strength. Our members have joined together in an attempt to make a difference in the future. Instead of feeling sorry for themselves, DYNA members are taking action by promoting awareness of these life impacting conditions and by helping others afflicted with them.

DYNA is:

- Accurate Information
- Community Activities
- Informative Professional Website
- Dysautonomia Awareness Campaigns
- Professional Medical Advisory Board
- Networking with Leading Physicians
- Enlightening Newsletters
- Supportive Literature
- Physician Endorsed
- Private Member Conventions
- Private, Secure Internet Clubs
- Postal Outreach Program
- Professional Educational Advisory Board
- Youth Social Programs

Dysautonomia Symptoms:

- Orthostatic Hypotension
(excessive drop in BP when one assumes upright posture)
- Orthostatic Intolerance
(inability to maintain upright posture)
- Tachycardia (rapid heart rate >100bpm)
- Extremely Low Blood Pressure
- Wide swings in blood pressure
- Sudden drops in blood pressure
- Syncope /near syncope (fainting)
- Palpitations
- Chest Discomfort
- Lightheadedness
- Dizziness
- Excessive Fatigue
- Exercise Intolerance
- Gastrointestinal Problems
- Nausea
- Visual Disturbances
- Weakness
- Shortness of Breath
- Mood Swings
- Anxiety
- Vertigo
- Migraines
- Tremulousness
- Noise /Light Sensitivity
- Insomnia
- Frequent Urination
- Temperature Regulation Problems
- Cognitive Issues/Brain Fog /Forgetfulness

The manifestations of dysautonomia occur internally, and although the symptoms are quantifiable and verifiable medically they often are not visible to the untrained eye.



DYNA MEMBER ASHLI

Donate to DYNA

Mail to: DYNA
Debra Dominelli, President
1301 Greengate Court
Waldorf, MD 20601

My name is: _____

My address: _____

Telephone: _____

E-mail: _____

Amount Donated: \$ _____

My donation is made in honor of:

Name: _____

Address: _____

Telephone: _____

Please donate by check payable to: DYNA
Donations are tax deductible.

DYNA strives to help youth with dysautonomia by providing them with the necessary support and outreach and by working towards awareness of these life impacting conditions. We are able to provide a "ray of hope" to these exceptional individuals only because of people like you.



DYNA MEMBER CHELSEA WITH DAUGHTER SAMANTHA

*If I can stop one heart from breaking
I shall not live in vain;
If I can ease one life the aching,
Or cool one pain,
Or help one fainting robin
Unto his nest again,
I shall not live in vain.*

Emily Dickinson



"I used to feel alone until I found DYNA. Even though I am on the other side of the world, the support and strength DYNA gives me is incredible. DYNA has inspired and motivated me not just to carry on living with my illness but to still follow my dreams no matter how out of reach they may seem."

Sophie, 18, New Zealand

"I am still going to do what I want to do in life, even though I may have to do it in a different way than everyone else. DYNA has taught me that I can achieve great things in spite of the fact that I have dysautonomia."

Melissa, 15, IN

"DYNA has helped me through some really rough times. In DYNA, we all support each other. We are truly a family. These are people I can always count on."

Juli, 17, OH

"My friends in DYNA are always there to support me and understand. In DYNA, we do not believe in leading "pity parties" but we do believe in leading awareness campaigns!"

Kim, 18, FL

"I have been living with dysautonomia for five long years and it has totally changed my life. Before I found DYNA I thought I had to fight the battle alone. My DYNA friends are some of my closest friends because they truly understand and do not judge me. In DYNA, we all support each other, we never pity ourselves, and we strive for dysautonomia awareness. DYNA has helped me to become a stronger and better person."

Heather, 22, PA

"Before DYNA I thought I was all alone, I now know that there are many other kids with dysautonomia and it is great to be able to talk to them."

Whitney, 12, AK

"DYNA has a Postal Outreach program for kids like me who don't have access to the Internet. The reliable information that DYNA provides through this program has helped my family tremendously."

Becky, 15, PA

"DYNA has helped me realize that I am not alone. As I live with this condition everyday, it's so comforting to know that my friends in DYNA are going through similar things and that we are all willing to support one another through the difficult times. It is nice to have each other."

Meghan, 20, IL

"It was the DYNA members who taught me that dignity is something you keep inside for yourself, and no matter what anyone says or does to you, whatever twists and turns your illness takes – once you have that self-belief, no one can take it away from you, however hard they try."

Erin, 21 Scotland

"In DYNA, when we get dizzy and fall - we still know how to keep on dancing!"

Mary, 18, IL

"When I got my first DYNA newsletter and read the story of another girl my age, tears filled my eyes. It sounded so much like what I was going through. I emailed her right away and since then I have made countless friends through DYNA."

Katie, 19, NC

"Dysautonomia is a state of physical being; DYNA is a wonderful state of mind."

Megan, 22, VA

"It is assuring to know that someone else knows what you are going through."

Meredith, 17, NC

"DYNA helped me find a good doctor. Now I know that other kids have POTS too – and it's more common than most people think. It's great knowing that I'm not alone."

Katherine, 10, WI

"I am not going to let dysautonomia take away what life I can have. It helps to know that I am not alone and it helps to have the friends I have made through DYNA."

Mandy, 15, MD

"With DYNA I have learned to make adjustments in my life to deal with my dysautonomia. It amazes me that DYNA was started by one courageous person that had a goal to help others; the result has been a fantastic and supportive community. Both online and literally around the world."

Diana, 17, TX

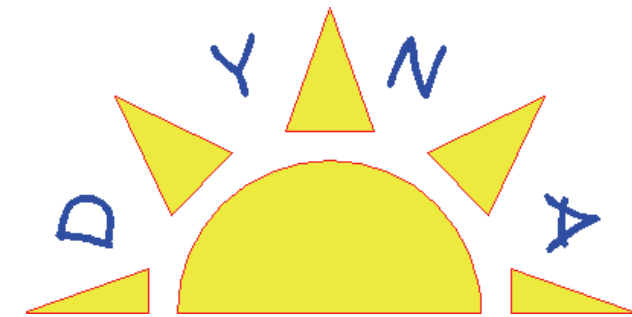
"Life is like a hundred meter race...dysautonomia is just one huge hurdle that we have to get over...we all wish it wasn't there but it's part of who we are."

Tegan, 16, Australia



"Kids with dysautonomia are still normal kids but we are normal kids with a medical condition. Please don't treat us differently."

Ally, 9, MI



**Dysautonomia Youth
Network of America, Inc.**

"A Ray of Hope"

Priorities of DYNA

- ☺ To give young people with dysautonomia conditions hope for their future.
- ☺ To provide a positive support network to young people with dysautonomia conditions.
- ☺ To help young people with dysautonomia conditions adapt to the stress, trauma, and life-style changes that they often experience.
- ☺ To help young people with dysautonomia conditions manage the social isolation and loneliness they may experience.
- ☺ To help young people with dysautonomia conditions learn to deal with their medical situations in a positive and productive manner.
- ☺ To provide information on dysautonomia conditions and on the educational rights of students with dysautonomia to parents so that they can become their child's advocate.
- ☺ To heighten awareness of dysautonomia conditions within the Pediatric and Adolescent medical communities so that others can get diagnosed earlier and obtain proper medical treatment.

www.dynakids.org