

About 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 Autonomic Nervous System 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 without symptoms) is a hallmark of various forms of Dysautonomia.

Dysautonomia conditions can range from mild to debilitating and, on very rare occasions, can be life threatening. Symptoms of Dysautonomia can be unpredictable, wax and wane, appear in any combination, and vary in severity.

Management must be individualized to the specific patient and each patient's situation is unique unto itself.

Some children may require temporary placement in homebound teaching programs for health impaired students; others will be able to attend school, often with 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 cope with. Educational facilities, parents and physicians should take steps to ensure that the student remains connected to their peers.

For additional information visit our website at:

www.dynainc.org

Treatment, Coping, Recovery

Treatment includes pharmacological and non pharmacological methods and will usually require fine tuning as the patient physiologically changes. Frequent adaptations, patience and flexibility will be necessary for all involved.

Many families are unprepared to cope with the impact of Dysautonomia conditions and the seemingly overwhelming demands of the recovery process. Recovery requires a positive attitude, perseverance, dedication, and support.

It is common for patients to experience an increase in symptoms after physical activity and/or upright posture. Patients thus often involuntarily limit their physical activity and modify their lifestyle in order to accommodate their uncomfortable and often overwhelming symptoms. Severe limitations can enable the condition to progress and disable the recovery process. Many patients will require the guidance of a qualified physical therapist.

With medical guidance, successful pharmacological management, physical therapy and conditioning, patients eventually begin to re-engage in activities which will contribute positively to their recovery process. Physical therapy and conditioning should take priority and should be directed by medical professionals knowledgeable of Dysautonomia.

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 the DYNA 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 Website

Dysautonomia Awareness Campaigns
Professional Medical Advisory Board
Networking with Leading Physicians
Supportive and Accurate Literature
Physician Endorsed

Private Member Conventions
Private, Secure Internet Clubs
Outreach Programs

Professional Educational Advisory Board
Youth Social Programs

DYNA Mission

The DYNA mission is to facilitate change; to improve the lives of young Dysautonomia patients and their families; to foster awareness, support, and a better understanding of Dysautonomia conditions in the community at large; to encourage compassionate care, efficient diagnosis, reliable treatment, and re-search of Dysautonomia conditions.

Dysautonomia Symptoms:

- Orthostatic Hypotension
(excessive drop in BP when one assumes upright posture)
- Orthostatic Intolerance
(inability to maintain upright posture without symptoms)
- Tachycardia (rapid heart rate)
- 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



INVISIBLE DISABILITY

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



*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

Donate to DYNA

**Please donate to DYNA via our web site
Justgive.org link at www.dynakids.org
or call our office for directions.**

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.

**Without your financial assistance DYNA
will not succeed.**

“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, Age 21, Scotland

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

Mary, Age 25, Illinois

“DYNA has taught me to embrace what health I do have, and to be empowered to change my situation to make my life better both now and for the future. DYNA has done this by providing me with a safe environment to share my thoughts and concerns, and by providing me with reliable, trustworthy, medically endorsed information on my condition.”

Adele, Age 24, England

“The resources, coping skills, and positivity that I have gained through DYNA have been invaluable for living with a chronic illness and for life in general.”

Breanne, Age 25, Wisconsin

“DYNA empowers me to see beyond my illness and know my strengths.”

Kate T, Age 22, Illinois

“In DYNA we live our recovery and not our illness.”

Sophie, Age 25, New Zealand

“One of the best things about being a DYNA Youth Ambassador is having the opportunity to help others.”

Danna, Age 16, Iowa

“When I first got a diagnosis, I wasn't sure where to turn or what information to trust. After I found DYNA, I knew that I didn't have to worry anymore.”

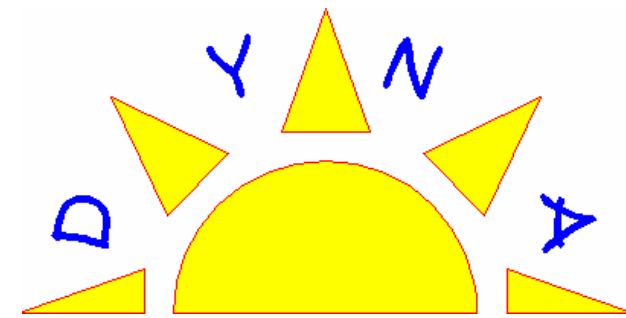
Ariel, Age 19, Indiana

“DYNA has truly taught me to focus on my abilities rather than my disabilities!”

Caroline, Age 13, Ohio

“The DYNA Summer Chill conference is always such a profound weekend for me. My first Chill was the first time I'd felt “normal” since my diagnosis! It is an amazing time of support, information, and fun. I look forward to it all year!”

Katie J. Age 23, Virginia



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

“A Ray of Hope”

Priorities of DYNA

- ☺ To enable the recovery process not the illness.
- ☺ 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 better cope with the stress, trauma, and life-style changes that they experience.
- ☺ To help young people with Dysautonomia conditions manage the social isolation and loneliness they sometimes experience.
- ☺ To help young people with Dysautonomia conditions learn to deal with their medical situations in a positive and productive manner.
- ☺ To provide accurate, reliable and medically endorsed information on Dysautonomia conditions.
- ☺ To heighten awareness of Dysautonomia conditions and the patient population afflicted with them.



www.dynainc.org



DYNA
301-705-6995
www.dynainc.org
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A 501 (c) (3) non-profit organization
established for youth with Dysautonomia.
Contact us for information.