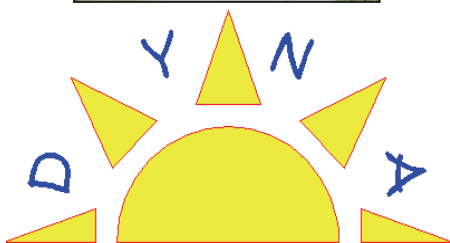


**Your Child is
Diagnosed with a
Dysautonomia
Condition:
A Resource for
Immediate and
Extended Family**



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

“ A Ray of Hope ”

Purpose

Having a child with a dysautonomia diagnosis can be unsettling, confusing and stressful. Basic comprehension of the condition will help you to better support your child and allow you to explore the various medical and educational options available. When provided with the right support tools, caregivers become informed, responsible, and empowered, and everyone in the family copes and manages better.

Childhood illness changes the family lifestyle; secure plans for the future may suddenly be uncertain. Your child may not be able to depend on his or her body for now. You may feel besieged with new responsibilities. Illness affects not only your child's medical status, but also family life, family stability, financial resources, and the health and well-being of the entire family. Coping with a childhood illness can be complicated for the parents, the family members, and especially for the child. You can find ways to cope, discover measures of control, and help your family to accommodate to the changes childhood illness can bring.

DYNA is a non-profit organization dedicated to serving children afflicted with dysautonomia conditions. This pamphlet specifically addresses pediatric issues associated with dysautonomia. This brochure will answer many of your questions and offer suggestions which will enable you to proceed in the direction of optimized health for your child and balance for yourself and your family.

Please talk to your physician regarding questions you may have and feel free to visit our web site www.dynakids.org for additional information.



Call it What You Will

Are you confused by the medical terminology you have been hearing lately? You are not alone! There is an on-going debate within the medical community as to the specific terminology to utilize for conditions involving dysregulation of the autonomic nervous system. These debates happen with many other medical conditions too, and are not unique to dysautonomia conditions. Our organization uses the term *dysautonomia*, but your physician may not. The umbrella term utilized for these conditions is not what is important to DYNA, and thus we elect to move forward without entering into the name debate. Call it what you will—we just want to help your child.

The following diagnostic terms may be issued to children with dysregulation of the autonomic nervous system or dysautonomia:

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Neurocardiogenic Syncope (NCS)
- Neurally Mediated Hypotension (NMH)
- Vasovagal Syncope
- Post-Viral Dysautonomia
- Non-Familial Dysautonomia
- Generalized Dysautonomia
- Familial Dysautonomia (FD is a very distinctive form of dysautonomia that has been identified in individuals of Ashkenazi Jewish extraction. These children have their own organization that takes very good care of them.)



What is dysautonomia?

Dysautonomia is an umbrella term utilized for a dysregulation of the autonomic nervous system (ANS). The ANS is responsible for controlling all the unconscious functions of our bodies (the things we don't have to think about and that just happen automatically). Dysautonomia conditions can affect boys and girls, men and women of any age. It can be present at birth, manifest over a gradual period of time, or appear suddenly. Cases can be very mild to very severe, and in extremely rare situations fatal. Dysautonomia conditions may impact the patient's life minimally or radically. The conditions may be acute (lasting a few months to a few years) or chronic (long term). These conditions are unpredictable and can lapse, relapse, and present intermittently.

Each case of dysautonomia is unique and must be recognized, respected and treated as such. Your dysautonomia physician is in the best position to assist you with understanding the details of your child's specific medical situation. It is critical that you and your child relay accurate observations to your doctors and are always honest with them. Never hold back information.

Your child may have been issued any one of a set of medical terms or sub-sets of various medical diagnoses relating to a dysregulation of the ANS. Dysautonomia is a term which incorporates all.

Sometimes medications can assist the patient with symptom control. Life-style modifications are a crucial factor for the patient and his or her family. Just as each case is unique, so will be the medications prescribed and the life-style adjustment modifications. Dysautonomia conditions tend to fluctuate and be unpredictable in specific symptom occurrence, intensity, and frequency. Flexibility is needed and will work in your favor.



What are the symptoms?

TACHYCARDIA (FAST HEART RATE)

BRADYCARDIA (SLOW HEART RATE)

ORTHOSTATIC HYPOTENSION (LOW UPRIGHT BLOOD PRESSURE)

ORTHOSTATIC INTOLERANCE (INABILITY TO REMAIN UPRIGHT)

SYNCOPE AND NEAR SYNCOPE (FAINTING)

SEVERE DIZZINESS

EXCESSIVE FATIGUE

EXERCISE INTOLERANCE

MIGRAINES / HEADACHES

GASTROINTESTINAL ISSUES

NAUSEA / DIARRHEA / CONSTIPATION

INSOMNIA

JOINT / MUSCLE PAIN

JOINT HYPERMOBILITY

MUSCLE WEAKNESS

MENSTRUAL IRREGULARITIES

SHORTNESS OF BREATH

THERMOREGULATORY ISSUES

ANXIETY

LOW MOOD

TREMULOUSNESS

FREQUENT URINATION

COGNITIVE IMPAIRMENT (BRAIN FOG)

VISUAL BLURRING OR TUNNELING

SEIZURES / CONVULSIONS

- Each dysautonomia condition has its own set of symptoms that apply.
- Each patient will experience different degrees of symptoms and have various systems impacted.
- Like all medical conditions, patients are afflicted to a different extent.
- Each case is unique unto itself.



The Child

Obviously, your child is not feeling well. Whatever set of symptoms is impacting your child, he or she is definitely not up to par. Your child may be frightened and confused and may even be frustrated and angry. You may feel the same way yourself. Many children experience a sudden dissolution of their social life as their ability to attend school and extra activities is impacted. Many schools are ill-equipped to deal with the complexities of these conditions. Sometimes local physicians are not familiar with the conditions and may not be up to date with the current treatment modalities and will have to be willing to take the extra steps to become informed. It is not unusual that the very people who will be guiding these children through their formative years may have little or no current knowledge or experience with dealing with these impacting conditions. **You, the parent or guardian, are in the driver's seat to assist your child and carry or guide him or her through this life crisis. Your child needs you to remain calm, take control and pave the way.**

The Parent

We all have the ideal notion of a perfect family working together to overcome a crisis. In reality, however, demands on our time, finances, and emotions create stress that can be overwhelming under the best of circumstances—much less in times of crisis. Make no mistake—a childhood diagnosis of a dysautonomia condition can be a stressful situation with complex ramifications for your child's life-style and the life-style of your family. At this time, society has not kept pace with awareness, understanding, and support with regard to childhood dysautonomia conditions.



DYNA is working hard to change that. DYNA will need your involvement, and your child needs you to be pro-active in your community and throughout the world. **Awareness is the answer to a brighter future for all children afflicted with dysautonomia conditions.**

You may be feeling a variety of emotions similar to what your child is experiencing. Additionally, you may be experiencing guilt, denial, loss of a sense of control, grief, financial concerns, and fear for your child's future. The best thing you can do right now is to stay calm, assess your situation, arm yourself with qualified and accurate information, and surround yourself with the proper resources.

Unless you and your child were very fortunate, you may have experienced an amount of difficulty in determining the proper diagnosis for your child. Physicians, friends, family, and even your school community may have let you down. The stress of the situation can take its toll on marriages as well. Frequently the main care-giver will be more attuned to the illness and the other may find it more difficult to understand.

Now is the time for both partners to educate themselves about dysautonomia—the nature of the condition, how it impacts their child specifically, and how the family will proceed. It is in the child's best interest for all parties to understand the condition, be supportive of the child and one another, and to calmly pursue the changes that will become necessary to overcome this challenge.

A serious diagnosis of one's child constitutes a crisis for the child, parents and family. In addition to managing the illness, it is very important to recognize and deal with the emotional factors and family dynamics that occur. Professional chronic illness counseling can often be beneficial for families and couples. Your doctor can provide you with details.



Short-Term Plan

The most difficult part of this journey is behind you. Now that you have the appropriate diagnosis, you can learn how to proceed.

First of all, calm yourself. Do whatever you need to do to clear your mind: talk to a friend, cancel any immediate commitments, clear your schedule.

Comfort your child with the certain knowledge that you will overcome this challenge together. Assure your child that as the parent you will support him/her and accept the responsibility to secure medical care and arrange any necessary educational accommodations. Your child's job is to heal and participate in life to the best of his or her ability. **Your child still needs to be a child—allow them that opportunity.**

Take the necessary time to focus on your child and your family and the change that has arrived in your life. Make the time now to collect your thoughts. Relax and allow your mind, body, and soul to regroup.

When your mind is clear, you will probably want to gather accurate and medically certified information regarding your child's diagnosis. At a time when so much seems to be unknown, be very careful to avail yourself of facts and be wary to not be drawn into dramatic, inaccurate, anecdotal information. Talk directly to your physician if you have specific questions regarding the accuracy of information you have collected.

As the parents you will need to understand the nature of the diagnosis issued. You will have to assess your child's specific symptoms and various emotional and medical needs. Do not allow yourself to be unduly influenced or intimidated by others. **YOU know your child better than anyone else. Trust your instincts.**



- Consult with a medical specialist in the field of childhood dysautonomia.
- Inform your child's Pediatrician or G.P and provide them with DYNA brochures **well in advance of your appointment** so that they have time to review the material in depth.
- Notify friends and family. Their support, understanding, and compassion can be very beneficial.
- Notify all pertinent parties of your child's diagnosis. Follow through with providing hard copy information and refer them to the DYNA website for details.
- Set up meetings to begin an educational action plan for your child. If the situation requires, request a 504 Plan from your school guidance counselor.
- If your child is homebound, notify school officials, extra-curricular leaders, spiritual/religious leaders.
- Most likely your child has been prescribed medications. You will need to establish a system to administer them as directed. If age—appropriate, teach the older child to take responsibility for his or her own medications. Fully supervise them. Expect to have to modify the medications, their timing, and their dosage.
- Communicate with your child about the condition to the degree that is age/interest appropriate. Answer questions. Encourage input. Allow your child the amount of control that he or she can responsibly handle.
- Remember to take care of yourself. Eat. Sleep. Exercise. New time demands on you may feel overwhelming. Do what you CAN and find satisfaction in that. A five-minute walk in fresh air may be just enough to help you control the stress level. Know that, in time, you will find a workable routine and balance.



Long-Term Plan

The ultimate goal is to find a new balance for your family's life. You will need a cooperative team with each member doing his or her part to contribute to that balance. As you introduce members and assess existing members of that team, choose people who are open minded, willing to learn something new, flexible, supportive and can contribute to making your child's life as healthy and productive as possible. This can mean big changes and tough decisions.

- Educate your immediate circle of family and friends.
- Educate your community.
- Eliminate the stress of negative people and negative situations.
- Participate in as many regular activities as possible, but don't sweat it when you need to opt out.
- Optimize all aspects of healthcare.
- Allow your child time to heal. TIME is essential.
- Be patient.
- Live in hope.

For many parents the crisis of a dysautonomia diagnosis for their child and the personal upheaval associated with it can lead to a tremendous sense of loss and grief. You may experience a wide variety of emotions. It is important that you respect and deal with these feelings for your own health and for the well-being of your child and family. Reach out to others. You and your family are not alone.



Tips For Family and Friends

It is frequently difficult for family and friends of a child with dysautonomia to understand what the child/family is experiencing and how to help.

- Dysautonomia impacts every person uniquely. Even within families, dysautonomia conditions will impact members differently.
- While the distress the child is experiencing is medically verifiable, the signs are often invisible to the untrained eye.
- There is no easy cure for dysautonomia. Medications help control / manage symptoms. There is not a “quick fix.”
- Life-style modifications are critical to successful health maintenance.
- “Normal” schedules and activities may pose significant hurdles for participation and may cause set-backs.
- Energy levels of a child with dysautonomia may be significantly less than those of a healthy individual and may fluctuate day-to-day, minute-to-minute.
- Normal illnesses like the cold and flu pose additional health threats for people with dysautonomia. Reasonable care must be exercised to avoid undue / unnecessary exposure.
- The immediate family is absorbing extra burdens and is likely operating at a heightened level of stress: physical, emotional, financial.
- Dysautonomia is completely unpredictable. Making secure plans and maintaining routine schedules is a frustrating challenge. Flexibility must be factored into the child / family schedule.



- Do not take it personally if cancellations occur.
- Studies show that the quality of life for a person with some dysautonomia conditions can be similar to that of an individual with congestive heart failure.
- While dysautonomia is recognized as a specialty field of practice, much of the general medical community is not up-to-date on the recent diagnostic and treatment protocols.
- Many school systems are ill-equipped to deal with the complexities that some dysautonomia cases present for students.
- Dysautonomia conditions can effect every component of the individual's health.
- Physical energy recovery takes an extended time when compared to a healthy individual.
- Every day can present a different set of obstacles to address.
- Symptoms of dysautonomia conditions can be varied, occur simultaneously, and may appear seemingly unrelated.
- The child and the family just want everything to go back to "normal." This is not easy for them.
- Dysautonomia conditions can have active and inactive phases over the course of time. Understand that there can be seemingly good periods for the patient and also set-backs
- Simple life events can setback the health and energy level of the child. Holidays, birthdays, and special celebrations can create extra stress for the families of children afflicted with dysautonomia conditions. Allow the family to accommodate their lifestyle without judgment or hurt feelings.



- Unwisely pushing the child to exhaustion or past their physical capabilities will just exacerbate their symptoms and propel him/her deeper into a state of poor health and detrimental energy depletion.
- To optimize and maintain the existence of a productive lifestyle for the child, serious consideration must be given to maintaining a balance in their life, utilizing gradual and gentle physical reconditioning and allowing opportunity for the natural healing process of restorative rest and relaxation to occur.

About DYNA

The Dysautonomia Youth Network of America, Inc. (DYNA) is a 501 (c) (3) non-profit organization dedicated to serving young people who are diagnosed with various childhood dysautonomia conditions. There are no membership fees. The youth come first in DYNA and are our top priority. DYNA works closely with renowned cardiologists, electrophysiologist, neurologists, pediatricians, chronic illness counselors, psychologists, physical therapists and many other professionals. We provide our youth members with a support and outreach network that is focused on providing positive peer support. We strive to heighten awareness of dysautonomia conditions within the general pediatric and the adolescent medical communities. We aim to promote compassion, support, and understanding of the various challenges that youth with dysautonomia conditions face within society. We empower our members and help direct them to the road of recovery while encouraging the development of a secure, confident, resilient, and independent resolve.



DYNA Conference

DYNA holds an annual conference called our "Summer Chill." This PRIVATE, INVITATION-ONLY event provides a singular resource for DYNA members in-good-standing, their families, and physicians. The highlight of the event is our "Goofy Slipper Lecture on Dysautonomia". This informative lecture provides attendees with the rare opportunity to hear from the field's top-most authorities on childhood dysautonomia conditions. Numerous fun activities exist throughout the event for the children. DYNA is known as a catalyst for promoting dysautonomia awareness and developing better opportunities for accurate diagnosis and improved hope for prognosis. Our Summer Chill event was officially recognized and received the Loudoun Convention and Visitors Association "Humanitarian Award" from Loudoun County, Virginia (a major Washington, DC suburb). This event is supportive, informative, educational and emotionally beneficial.

DYNA Video

Our professional video production from the DYNA Summer Chill "Goofy Slipper" Lecture on Dysautonomia is tremendously beneficial to families dealing with dysautonomia conditions. The video features our DYNA members and highly informative lectures conducted by world renowned physicians in the field of dysautonomia. Please refer to our web site www.dynakids.org for order forms.



Awareness Series Brochures

DYNA INFORMATIONAL BROCHURES:

Your Pediatric Patient is Diagnosed with
Dysautonomia: A Guide to Understanding
Autonomic Dysregulation

Your Child is Diagnosed With Dysautonomia:
A Resource for Family and Extended Family

Your Friend or Classmate is Diagnosed with
Dysautonomia: A Guide to Understanding

Educating the Dysautonomia Student:
An Introduction For Teachers
and Other School Personnel

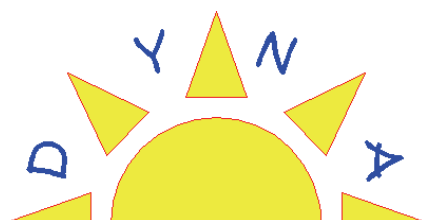
You Have Been Diagnosed With
A Dysautonomia Condition

Special Accommodations Medical Card

Please refer to our web site for information on ordering our materials.

At DYNA, Inc. we value every single donation. Your donation will be used wisely and efficiently. An independent financial audit is conducted yearly, and you can rest assured that your gift is being utilized to its fullest. Administrative costs and overhead are kept to a minimum and various professionals donate their services to the organization in order to make this possible. Please consider making a tax-deductible donation in honor of your child today. Information and various options for donating are available on our web site www.dyndakids.org. Checks should be made payable to DYNA, Inc., and mailed to 1301 Greengate Court, Waldorf, MD 20601.





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In time of test, family is best!

~Burmese Proverb

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