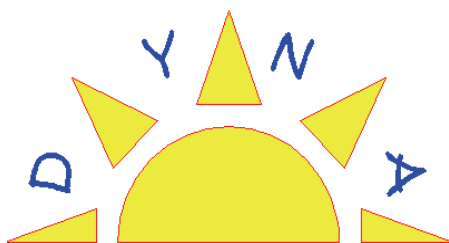


Your Pediatric Patient is Diagnosed with Dysautonomia: A Guide to Understanding Autonomic Dysregulation



Dysautonomia Youth
Network of America, Inc.

“ A Ray of Hope ”

Purpose

At DYNA we recognize that the study and practice of medicine is continually changing. Within the last decade the study of dysautonomia (autonomic dysregulation) has advanced dramatically. This pamphlet will assist community physicians and their staff with the basics they will need to better understand and serve their dysautonomia patient. Please recognize that for purposes of brevity, this pamphlet provides overly-simplified, yet highly beneficial material.

The Challenge

Living with a dysautonomia condition is a far cry from reading a medical abstract about it or hearing about it in the exam room. The balancing act for the patient and the patient's family can be extremely difficult. Dysautonomia conditions can be overwhelmingly stressful, life impacting, and life changing.

Medical science has proven that when patients have a respectful, understanding, and supportive relationship with their physician, their medical treatments will yield optimal results.

Successfully treating a youth afflicted with a dysautonomia condition takes a thoughtful, caring physician who is willing to transcend standard care. There are numerous challenges and tremendous rewards when treating a childhood dysautonomia patient. Begin your appointment with a clean slate and an open mind. Take the time to listen to your patient and to empower him or her in his or her own care. The most important predictor of success is trust in the doctor, and that begins with communication.



Introduction

The symptoms of dysautonomia conditions are usually “invisible” to the untrained eye. To their school systems, neighbors, and friends, childhood dysautonomia patients may outwardly appear as healthy as other children. Physicians obviously recognize that the manifestations are occurring internally and that the diagnosis is certified medically by a qualified specialist—not visually by a casual observer. Tragically, due to the invisible nature of these conditions, the relative rarity, and the lack of knowledge regarding the pathophysiology, there can be psychosocial consequences for the patients and their families. They sometimes face gossip, ostracization, disbelief, wrongful accusations of depression, drug abuse, malingering or laziness.

Along with being invisible, the symptoms of dysautonomia can be unpredictable, wax and wane, appear in any combination, and vary in severity. Children may push themselves beyond their capacity level just to please others who may have no concept of the illness. Children are experts at discovering ways to work through an activity via adrenalin. They develop creative and inventive techniques to hide their symptoms and then suffer the consequences afterwards. Sadly, they can thus jeopardize their medical progress. With communication, understanding, support, and compassion from those around them, children with dysautonomia conditions will eventually learn to find a balance in their lives. **They quickly learn to simplify, to appropriately pace themselves, to know when to respect their limits, and when to push their limits. Parents, society, physicians, and educators eventually learn to respect their judgment and accept their input.**



What is Dysautonomia?

Dysautonomia is a medical term utilized for a group of complex conditions that are caused by a dysregulation of the autonomic nervous system (ANS).

The ANS regulates all of the unconscious (involuntary) functions of our bodies, including our cardiovascular system, gastrointestinal system, urinary system, metabolic system, and endocrine system. A malfunction of the ANS can pose significant challenges for effective medical treatment.

Orthostatic intolerance is a hallmark of the various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating and, on rare occasions, can be life threatening. Each dysautonomia case is unique, and treatment must be individualized to the patient.

The following diagnostic terms may be issued to children with forms of 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 distinctive form of dysautonomia that has been identified in individuals of Ashkenazi Jewish extraction.)



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

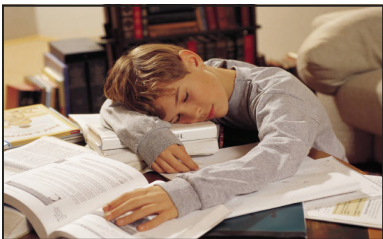
SEIZURES / CONVULSIONS

- 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.



Treatment

Treatment of dysautonomia conditions is based on the condition, the sub-type, and the patient specifics and must be individualized. Treatment often includes pharmacological and non-pharmacological methods. Fluid intake of 2 liters a day along with an increased sodium intake of 3–5 grams is often recommended to help increase the patient's blood volume. Various medications are commonly utilized and each is fine tuned to the particular patient. Medications will also typically require ongoing adaptations as the patient physiologically develops and changes. The hope is to be able to obtain enough symptom relief to initiate a gentle reconditioning program. Although, reconditioning is important, it must be undertaken slowly. Forward progression can be an extremely frustrating and arduous process for dysautonomia patients. Recognizing the numerous obstacles faced by these patients is essential to success. Along with their medical treatments, school-age children have educational responsibilities, a tremendous desire to maintain their level of academics, and an essential need to maintain some degree of a social life. **First and foremost, it is absolutely necessary that they discover the ways and means to still be children in spite of their illness.**



Patients may require moderate or significant adaptations to their educational plans. We recommend parents request a 504 Plan.



Establishing a Medical Team

All involved physicians will need to recognize the impact the condition places on the patient and the family.

Local Pediatrician or General Practitioner

A local pediatrician or general practitioner will be necessary to provide high quality general care and medical maintenance. It is important to note that dysautonomia impacts ALL childhood health issues and should be an additional consideration when treating common childhood ailments in the dysautonomia patient.

Local Cardiologist / Electrophysiologist

A local cardiologist will most likely be needed. This doctor should have a good professional working relationship with the pediatrician or general practitioner. When necessary, they should also be willing to initiate communication with the dysautonomia specialist in order to supervise treatment.

Dysautonomia Specialist (Autonomic Disorders)

A dysautonomia specialist is up to date with the most current treatment modalities. This needs to be a physician who has had long term exposure to the conditions and who has treated numerous patients through the duration of their illness. This exposure enables these specialists to have a broad scope of the variances and degrees of the conditions and treatments. Most patients will need to travel for this consult.

Additional Specialists

Additional specialists will be required as needed. Depending on the additional health issues, neurologists, gastroenterologists, nutritionists, endocrinologists, physical therapists and other medical specialties may need to be involved.



Open Discussion

Most dysautonomia patients experience complex and varied symptoms. It is imperative that physician(s) and their office staff(s) are prepared for and open to listening to the patient's and the family's numerous concerns.

- Schedule appointments appropriately in order to allow the time to provide the opportunity for unhurried and thoughtful discussion.
- Encourage and support open discussion. Otherwise, the patient and the family will become hesitant to communicate in order to avoid being labeled as difficult.
- Make it a standard office policy, that you always offer the opportunity for private discussion during each appointment. Sometimes the parent or the child have private matters they wish to share with you or want to ask you about without the other present. It will be beneficial to everyone involved if you allow opportunity for private discussion on an automatic basis.
- Without a secure doctor-patient relationship, patients and family members may not feel comfortable enough to disclose essential information. Medical care will thus not be optimal and treatment will not be productive.

Dysautonomia brings special considerations. The conditions are unpredictable and the circumstances are always changing. Each patient is unique and each case should be addressed and assessed individually.



Considerations

- Childhood developmental stages (especially adolescence) can be extremely stressful when you add in the complications of illness. A supportive relationship with a compassionate, understanding physician can make all the difference.
- Sometimes patients cease use of a beneficial medication due to initial side effects that would resolve if given appropriate time. It is important to discuss this with your patient and prepare them for the possibility of initial side effects. When starting a new medication, close communication will be necessary.
- Common sense lifestyle adjustments are a critical factor both in the initial and long-term healing process and in the maintenance of optimal health and daily function.
- Given opportunity most children are very capable of taking responsibility for their condition. If allowed, they will learn to recognize their body's signals, respond appropriately and properly pace themselves.
- The symptoms and concerns that the child expresses should be respected by the adults assisting with decisions in the child's care.
- Energy can be quickly and unexpectedly depleted and may require an extended period of rest to regenerate. Inappropriately pushing the patient during these periods may cause an unproductive exacerbation of symptoms causing a protracted extension of time to recover—with the increased risk of additional and/or amplified symptoms.



- Seasonal as well as meteorological factors can influence dysautonomia symptoms. Barometric pressure changes may cause an exacerbation of symptoms.
- Blood pressure is lowest in morning hours and thus most patients function better in the afternoon.
- Often patients have strong sensory sensitivities. Noise, lights, odors and tactile sensations can be factors.
- It is sometimes hard for these patients to multi-task.
- Impact on life can be mild, severe, or anything in between. Often frustrating variances exist as the conditions wax and wane.
- With support and understanding these children will learn to adjust to their medical condition and situation. They are often very successful individuals.
- Implementation of physical exercise may require a creative approach. The hope is to be able to obtain enough symptom relief to initiate a gentle reconditioning program. Reconditioning is important but must be done slowly and can be an extremely frustrating and arduous process. Patience and scheduling flexibility are required.
- Respectfully allow the emotionally healthy patient to find the right balance of activity, and recognize that each patient is individual, as is each life situation.
- Authority figures must respect and honor the patient's needs with cooperation and without adverse judgment.
- Hormonal factors will influence symptoms.



- Children with dysautonomia often suffer periods of cognitive dysfunction along with their fatigue. For accurate impressions at examinations the physician may want to have the patient keep a casual symptom log to bring to appointments. This is likely to make it easier for them to communicate and easier for their physician to understand and better treat their case.
- Warm/stuffy environments exacerbate symptoms.
- It should be noted that patient exam rooms are often warm and stuffy. If the office has an exam room that is cooler, we suggest that the staff consider utilizing that room for their dysautonomia patient. Sometimes leaving the door open to allow air circulation helps.
- Many pediatricians prefer to have these children brought directly back to an available room rather than have them sit in the waiting room. This will enable them to wait their turn in a quiet environment and if necessary to lie down or elevate their feet. It allows the patient to present for a more productive appointment, and it also has the benefit of avoiding unnecessary exposure to germs.
- Patients will find they are more likely to sunburn and should use common sense to avoid exposure.
- Baths/showers should not be overly hot as most patients benefit from lukewarm to cooler water temperatures.
- Dysautonomia patients are particularly susceptible to common illnesses, and care must be taken to eliminate known exposure.



What is DYNA

The Dysautonomia Youth Network of America, Inc. (DYNA) is a 501(c) (3) non-profit organization dedicated to serving young people that are diagnosed with various childhood dysautonomia conditions. DYNA works closely with renowned cardiologists, electrophysiologists, 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 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 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 Convention
- Private, Secure Internet Clubs
- Postal Outreach Program
- Professional Educational Advisory Board
- Youth Social Programs



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 to the patients.



DYNA Video

A professional video production featuring the lectures conducted by renowned dysautonomia physicians at our Summer Chill Conference is available. Patients may find an order form available on our web site. Physicians may contact us directly to receive their copy (301-705-6995).



Reference Materials

**The Fainting Phenomenon:
Understanding Why People Faint and What Can
Be Done About It—Second Edition**

Blair P. Grubb, M.D.,
ISBN # 9781405148412

**The Postural Tachycardia Syndrome:
A Concise Guide to Diagnosis and Management**

Blair P. Grubb, M.D., Yousuf Kanjwal, M.D.,
and Daniel J. Kosinski, M.D.
Journal of Cardiovascular Electrophysiology,
Vol 17, January 2006

**The Postural Orthostatic Tachycardia
Syndrome: A Potentially Treatable Cause of
Chronic Fatigue, Exercise Intolerance, and
Cognitive Impairment in Adolescents**

Barry Karas, M.D., Blair P. Grubb, M.D., Kathy
Boehm, M.D., and Katrinka Kip, M.D.
Medical College of Ohio, March 2000

**Postural Orthostatic Tachycardia Syndrome
Dental Treatment Considerations**

John K. Brooks, DDS; Laurie A. P. Francis, RDH
JADA, Vol. 137, April 2006
American Dental Association

Fainting, Dizziness and Heartache

Debra L. Dominelli, 2007
Dysautonomia Youth Network of America, Inc.

Resources/Mailing List

Numerous articles, resources, and additional related reference materials are available on our web-site: www.dynakids.org.

Physicians and their staff may feel free to contact our office at 301-705-6995 if they wish to be added to our mailing list or to receive additional information or medical articles.



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

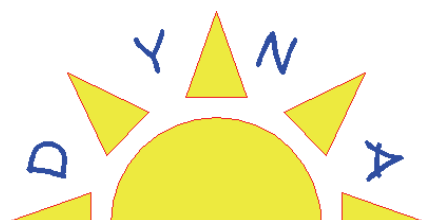
Special Accommodations Medical Card

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

"Patients serve as a unique scientific resource. They report what is wrong and we have to make sense of what they teach. They tell us the truth, so we have to avoid dismissiveness as a defense against our own ignorance."

David S. Goldstein, MD, PhD
Clinical Neurocardiology
National Institute of Neurological Disorders and Stroke
National Institutes of Health





DYNA, Inc.
1301 Greengate Court
Waldorf, MD 20601

Phone: 301-705-6995

Email: info@dynakids.org

Special Thanks To:

Blair P. Grubb, MD
Autonomic Disorders Clinic
Medical University of Ohio

Barbara Straus, MD
Pediatrics
Toledo, Ohio

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