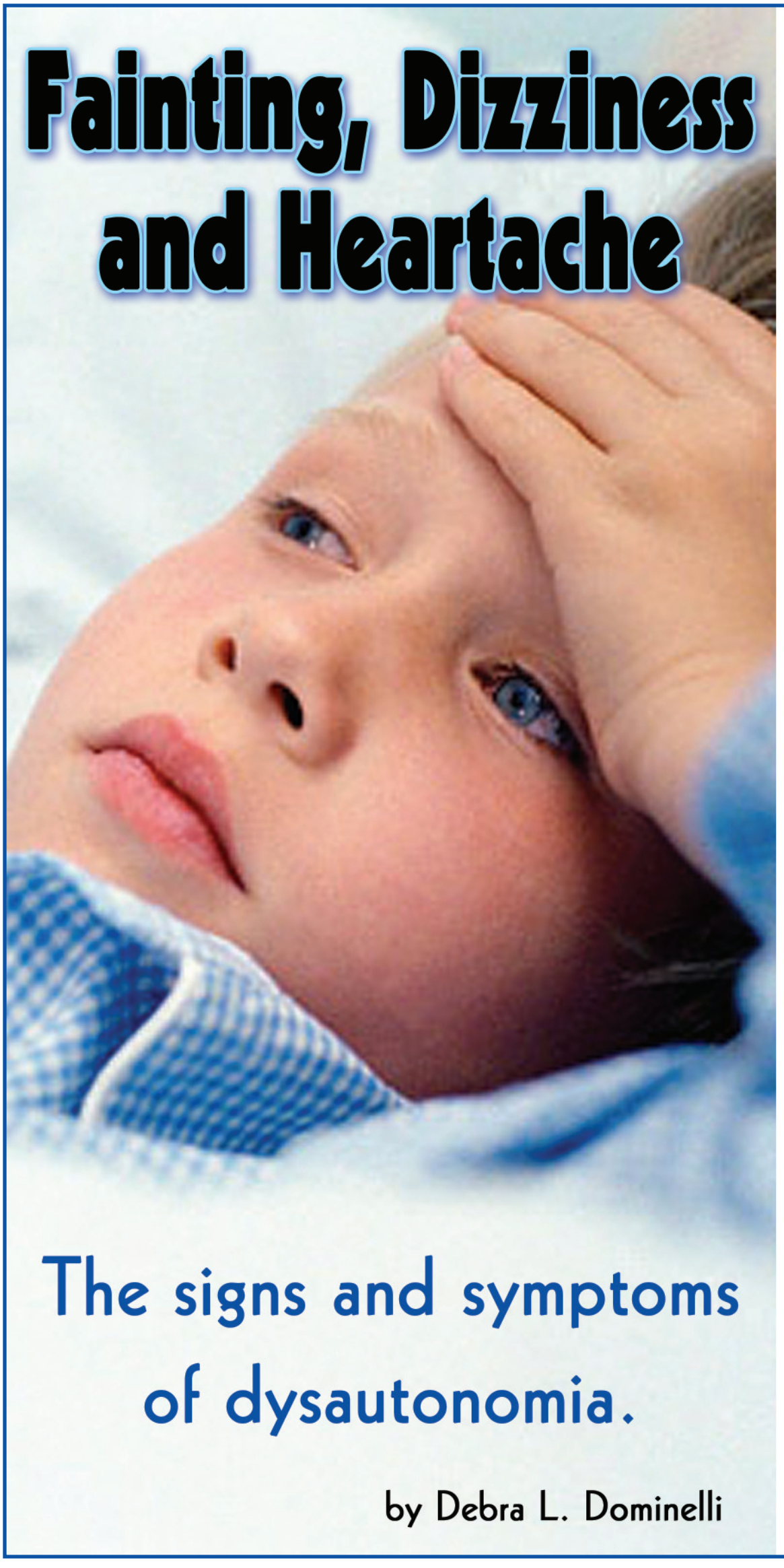
Fainting, Dizziness and Heartache



The signs and symptoms of dysautonomia.

by Debra L. Dominelli

An obscure medical condition, dysautonomia is now being diagnosed more often in children. This is partially due to awareness promoted by a group of extraordinary youth who are afflicted with the condition themselves.

The Dysautonomia Youth Network of America, Inc. is a pioneering group of young advocates from across the world that are diagnosed with life-impacting conditions known as dysautonomia. These children often experience a host of perplexing symptoms including fainting, dizziness and excessive fatigue. Instead of feeling sorry for themselves, they are taking action by spreading awareness and thus impacting the future.

What is dysautonomia?

Dysautonomia is a medical term utilized for a group of 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, including 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 standing) is a hallmark of the various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating and, on rare occasions, can even be life threatening. Each dysautonomia case is unique and treatment must be individualized. Patients should be evaluated by a physician who is well-versed on the recent treatment methods.

How is it diagnosed?

To diagnose dysautonomia, a tilt-table test is usually performed. This test evaluates how the patient regulates blood pressure in response to simple stresses. Tilt-table testing involves placing the patient on a special table with a foot-support. The table is tilted upward while various machines monitor blood pressure, electrical impulses in the heart and oxygen levels.

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
•Familial Dysautonomia
•Non-Familial Dysautonomia
•Generalized Dysautonomia

Who gets dysautonomia?

Researchers have discovered a genetic predisposition toward developing dysautonomia conditions. A genetic predisposition does not mean that everyone in that family is destined to develop the conditions.

Childhood dysautonomia conditions typically (but not always) strike adolescents after the onset of puberty, often after a period of very rapid growth. There is a female to male ratio of five to one. Some of the patients report a sudden development of symptoms after a viral illness, immunization or trauma. Others may see a more gradual onset. Although very rare, children may be born with serious non-familial forms of dysautonomia. There is also a distinctive form of dysautonomia called Familial Dysautonomia (FD) that has been identified in individuals of Ashkenazi Jewish descent.

Symptoms:

-tachycardia (fast heart rate)
-bradycardia (slow heart rate)
-orthostatic hypotension (low blood pressure when upright)
-orthostatic intolerance (the inability to remain in an upright position)
-syncope and near syncope (fainting)
-severe dizziness
-excessive fatigue
-exercise intolerance

-migraines
-gastrointestinal issues
-nausea
-insomnia
-shortness of breath
-thermoregulatory issues
-anxiety
-tremulousness
-frequent urination
-cognitive impairment (brain fog)
-visual blurring or tunneling
-seizures

Impact:

The symptoms of dysautonomia conditions are usually "invisible" to the untrained eye. The child can appear to be as healthy as other children. The manifestations occur internally, and although the symptoms are quantifiable and verifiable medically, they often are not visible on the outside. Symptoms can be unpredictable, may come and go, appear in any combination and may vary in severity (wax and wane).

Often patients become more symptomatic after a stressor or activity. Patients may find themselves involuntarily limiting their lifestyle activities in order to compensate for their conditions. Symptoms can sometimes 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 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 these children to deal with.

Since youth with dysautonomia are usually normal in appearance, it can be a hard condition for people to understand. Even general physicians sometimes miss the clues leading to a proper diagnosis. Families often find themselves desperately traveling great distances to the few pediatric dysautonomia specialists throughout the country for a proper diagnosis and innovative treatment.

The financial burden placed upon these families is often significant. Chronic illness counseling is at times recommended to help the patients and their families deal with the impact of the conditions on their lives.

Treatment:

Treatment is based on the condition, the sub-type and the patient specifics. Treatment often includes pharmacological and non-pharmacological methods. Fluid intake of two liters a day, along with an increased sodium intake 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.

Prognosis:

There is limited data on the prognosis of children afflicted with these conditions; however, research is being carried out at the nation's leading medical institutions. The statistics demonstrate that a good number of afflicted children will improve significantly by the time they reach their early to mid 20s. Patients who do not fully recover will often see an improvement in their symptoms with proper medical management and upon reaching full growth maturity. Some patients will experience exacerbations of symptoms at various times throughout their lives.

What the public needs to know:

Children who have dysautonomia struggle with some of the most basic functions that healthy people take for granted, beginning with getting out of bed in the morning. Each day and each moment brings new and unexpected obstacles. Yet, young individuals with dysautonomia face each day with profound courage and incredible strength, despite the betrayal of an uncooperative body.

Dysautonomia conditions are widely unknown. Because of this, there exists a shocking ignorance about the lifestyle impact on these young people and their families. What dysautonomia patients need most is support, understanding and encouragement to help them deal with this complex, debilitating and poorly understood group of disorders.

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Contact www.dynakids.org for additional information on dysautonomia and the youth impacted with it.