

“A
Ray
of
Hope”

Dysautonomia Youth Network of America, Inc.

“The Young and the Dizzy” Newsletter

Back to School

2004 Edition

Dysautonomia is a medical term used to describe a group of conditions that are caused by a malfunction of the Autonomic Nervous System (ANS). The ANS is a very involved and complicated system. It regulates all of the unconscious functions of our bodies; our cardiovascular system, gastrointestinal system, and urinary system are just a few. It also regulates body temperature, metabolic processes, and the endocrine system along with many other functions. Orthostatic intolerance is a hallmark of multiple forms of dysautonomia. Each dysautonomia case is unique and symptoms can range from mild to debilitating. Treatment must be individualized and may include pharmacological and non-pharmacological methods. Symptoms may include: Tachycardia, bradycardia, palpitations, chest pain, dangerously low blood pressure, wide swings/sudden drops in blood pressure, excessive fatigue, exercise intolerance, dizziness, fainting/near fainting, gastrointestinal problems, nausea, insomnia, shortness of breath, anxiety, tremulousness, frequent urination, seizures, cognitive impairment, visual blurring or tunneling, and migraines.

For more about dysautonomia see our web site: www.dynakids.org.



PICTURED:

HASAN ABDALLAH, MD, BLAIR P. GRUBB, MD, ROBERT HOELDTKE, MD AND DEBBIE DOMINELLI WITH SOME OF OUR DYNA KIDS AT OUR “GOOFY SLIPPER LECTURE” JULY 13, 2004

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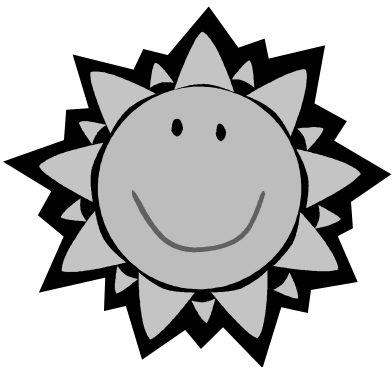
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SPECIAL THANKS TO:

"The Young and the Dizzy" Newsletter
Production Coordinator: Richard C. Dominelli



"Don't wait for a light to appear at the end of the tunnel, stride down there...and light the bloody thing yourself."

Sarah Henderson 1936
Australian Outback Station Manager and Writer

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YOU KNOW YOU HAVE DYSAUTONOMIA WHEN....

When your Mom tells you to drink before you drive.
Mandy, Maryland

When your long term goals include getting out of bed and taking a shower!
Jessica, Michigan

When every time you see your doctor, he asks what color your urine is.
Debbie, Maryland

When you know why your doctor asks what color your urine is!
Melissa, Indiana

You wear sunglasses and shorts in the winter!
Sophie, New Zealand

You have read through all the magazines in the doctors office....twice.
Jennifer, Pennsylvania

When you can spell dysautonomia without having to look it up in the dictionary!
Ashley, Virginia

When you can pronounce dysautonomia!
Kristen, Texas

Your brain fog is so bad that you can't even remember your own symptoms!
Angela, Kentucky

When people who don't know what they are talking about are actually jealous of you for missing school!
Julie, Michigan

When you know where all the bathrooms are.
Lorin, Alabama

When your doctor actually WANTS you to eat beef jerky!
Jonny, California

When you live by the motto, "What goes up must come down."
Richard, Maryland

If you used the phrase, "That is so true" while you read this.
Samantha, Alabama



*"It is never too late
to be
what you
might
have
been."*

Please Note

DYNA strives to bring about awareness on dysautonomia conditions and to provide support for youth diagnosed with dysautonomia.

Our newsletters are mailed to many hospitals, physicians and private individuals across the nation. This newsletter provides a casual forum for medical professionals to offer their expertise and state their professional opinions. It also serves to assist with support and awareness issues concerning our youth members and to provide our members with an opportunity to express themselves.

Specifically, we do not endorse any opinion, fact, research or other information stated in this newsletter and assume no liability or responsibility for its accuracy or efficacy. It is the responsibility of each individual to consult with their own physician for all medical advice.

Debra L. Dominelli, President

Directly Speaking

THE DYSAUTONOMIA WAR

The youth in DYNA know what it is like to be judged and because of this they do not judge other people. However, even in DYNA the kids may wonder...”Why are some people with dysautonomia doing better than me?” or they may ask themselves, “Why do other people not understand what I have or believe me?”

To understand WHY, you need to look back into the medical history of some other conditions. For example, when cancer was first discovered many years ago the medical experts thought it was a brand “new” discovery. Of course, in this modern and advanced medical age we all now know that cancer had been around long before the medical experts ever “discovered” it and gave it a formal name. When they “discovered” cancer, the experts of the past initially thought that there was only one type of cancer, only one cause, and they usually thought it was fatal. As medical science advanced over the years the experts found out that there are many types of cancer, many causes of the various types, and many degrees of each form. For example, you can have a mole or a brain tumor. Usually, it is the brain tumor that is the most serious and most complicated; but sometimes a mole can be life threatening too (as is the case with advanced skin cancer). Also, sometimes a brain tumor can even be cured. It just depends on the variables in each case. There are different degrees of every form of cancer. Each case is individual. Some types can be cured and some can’t. Some cases respond to treatment and some don’t. Early and proper treatment is essential. Everyone understands this about conditions such as cancer. Well, it’s similar with dysautonomia!

It was once said that “Doctors are men who prescribe medicines of which they know little, to cure diseases of which they know less, in human beings of whom they know nothing.” Did you know that initially conditions such as Diabetes, MS, Asthma, and many more – were thought to be psychosomatic? Medical science has evolved over the years but it still has flaws. With time and above all, AWARENESS, the misunderstood conditions of the past became recognized and understood. Someday dysautonomia will be too.



We are at the beginning stages of “discovering” dysautonomia. Typical of **NEW** discoveries there is sometimes great ignorance surrounding them and there are often doubters and non-believers. The most difficult thing to change is a closed mind!

The DYNA kids are the patients making medical history in the dysautonomia field. Medical science is now learning more about the various forms of dysautonomia. Physicians are learning how to better treat it. Dysautonomia has always been around. It is nothing new, but what the experts are starting to learn about it is new. New medicines and new treatments are on the horizon. Knowledgeable doctors are moving forward in this field. History is being made. Many patients are getting diagnosed earlier now and hopefully these patients are getting proper treatment started earlier. These newly diagnosed patients are very, very fortunate that the patients before them fought hard battles and kept fighting for awareness of these conditions. There is still a war going on and there is still a lot to learn. We have a long way to go but we are on the right path now.

Some of our DYNA kids are the “old hero’s” of this dysautonomia war. Some are the new “heroes”. Some of the kids do medically better than others but **ALL** of the DYNA kids are **fighters**. In DYNA we know that if a dysautonomia patient is not doing as well as another dysautonomia patient it is not because they are not fighting but because their case is different. The DYNA kids are fighting their own individual battles but they are all fighting in the same war. And, in case you were wondering, in DYNA we don’t believe in holding “pity parties.” We believe in becoming **BETTER** not **BITTER**. We believe that having an illness does not mean you have a weakness.

Debra L. Dominelli,
President / Executive Director



***All truth passes through three stages.
First, it is ridiculed.
Second, it is violently opposed.
Third, it is accepted as being self-evident.***

Arthur Schopenhauer



Dysautonomia



Professional Contributor

Richard N. Fogoras, MD

A family of misunderstood disorders

In the 19th and early 20th centuries there used to be a condition called neurasthenia. People would find themselves suddenly unable to function, due to a host of inexplicable symptoms, often including fatigue, weakness, strange pains, dizziness and passing out. Doctors would not find anything to explain these symptoms, so they were attributed to a "weak nervous system," or neurasthenia. Women with neurasthenia (for men were not given this diagnosis, by and large) were often confined to their beds, where they would either recover or, eventually, die. And while nobody knew what caused this condition, everyone - doctors and laymen alike - took it seriously.

Most modern doctors hearing about this mysterious condition merely shake their heads in wonder. Few seem to consider the possibility that "neurasthenia" is still with us. Consequently they are less capable of recognizing the manifestations of this condition than were their old-time counterparts, and tend to be far less sympathetic to its victims.

Yesterday's neurasthenia, today's dysautonomia

People who a century ago would have been called "neurasthenics" today are given a host of diagnoses. These include chronic fatigue syndrome (CFS), vasovagal or neurocardiogenic syncope, panic attacks, anxiety, inappropriate sinus tachycardia (IST), irritable bowel syndrome (IBS), postural orthostatic tachycardia syndrome (POTS), or fibromyalgia. Sufferers of all these conditions tend to experience an imbalance, and most often a peculiar volatility, in the autonomic nervous system - an imbalance that we now call dysautonomia.

The autonomic nervous system controls the "unconscious" bodily functions, such as heart rate, digestion, and breathing patterns. The autonomic nervous system consists of two parts: the sympathetic system and the parasympathetic system. The sympathetic system can best be thought of as controlling the "fight or flight" reactions of the body, producing the rapid heart rates, increased breathing, and increased blood flow to the muscles that are necessary when an individual is in danger or under stress. The parasympathetic system controls the "quiet" body functions, for instance, the digestive system. In short, the sympathetic system gets the body ready for action, while the parasympathetic system gets the body ready for rest. And in normal individuals, the parasympathetic and sympathetic components of the autonomic nervous systems are in perfect balance, from moment to moment, depending on the body's instantaneous needs.

In people suffering from dysautonomia, the autonomic nervous system loses that balance, and at various times the parasympathetic or sympathetic systems inappropriately predominate. Symptoms can include frequent, vague but disturbing aches and pains, faintness (or even actual fainting spells), fatigue and inertia, severe anxiety attacks, tachycardia, hypotension, poor exercise tolerance, gastrointestinal symptoms such as irritable bowel syndrome, sweating, dizziness, blurred vision, numbness and tingling, anxiety and (quite understandably), depression.

Sufferers of dysautonomia can experience all these symptoms or just a few of them. They can experience one cluster of symptoms at one time, and another set of symptoms at other times. The symptoms are often fleeting and unpredictable, but on the other hand they can be triggered by specific situations or actions. (Some people have symptoms with exertion, for instance, or when standing up, or after ingesting certain foods). And since people with dysautonomia are usually normal in every other way, when the doctor does a physical exam he or she often finds no abnormalities.

The problem of evaluating dysautonomia

The severity of the symptoms in people with dysautonomia are typically far out of proportion to any objective physical or laboratory findings (especially when the doctors don't know which findings to look for). This lack of objective findings makes life very difficult. In modern medical practice, grounded as it is in the gathering and interpretation of objective data, when patients have the audacity to complain of symptoms without providing the objective medical findings to back them up, they are often written off as being hysterical.

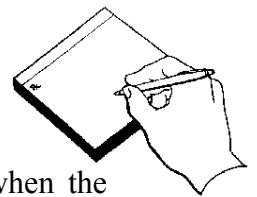
Patients lucky enough to be taken seriously by their family doctors are likely to be referred to a specialist. The type of specialist they are sent to usually depends on the predominant symptom they are experiencing, or on the symptom that most impresses the family doctor. And the diagnosis they are ultimately given depends on their predominant symptoms and which specialist they end up seeing. Thus: Those whose main complaint is easy fatigability are likely to be diagnosed with CFS. Those who pass out are labeled as vasovagal or neurocardiogenic syncope. Those whose resting pulses are noticeably high are said to have IST. If dizziness on standing up is the chief problem, POTS is the diagnosis. Diarrhea or abdominal pain buys you irritable bowel syndrome. Pain elsewhere ends up being fibromyalgia. Whatever the diagnosis, however, a dysfunctional autonomic nervous system almost always plays a major part in causing the symptoms.

And whatever the symptoms and whatever the diagnosis, all these syndromes are real, honest-to-goodness physiologic (as opposed to psychologic) disorders – probably variants of the same general disorder of the autonomic nervous system – and while they can make anybody crazy, they are not caused by craziness.



What causes dysautonomia?

Dysautonomia (and all of the above syndromes) are caused by many different things, and do not have one, single, universal cause. It seems clear that some patients inherit the propensity to develop the dysautonomia syndromes, since variations of dysautonomia often run in families. Viral illnesses can trigger a dysautonomia syndrome. So can exposure to chemicals. (Gulf War Syndrome is, in effect, dysautonomia – low blood pressure, tachycardia, fatigue and other symptoms – that, government denials aside, appears to have been triggered by exposure to toxins). Dysautonomia can result after various types of trauma, especially trauma to the head and chest. (It has been reported to occur after breast implant surgery). Dysautonomias caused by viral infections, toxic exposures, or trauma often have a rather sudden onset. Chronic fatigue syndrome, for instance, most classically begins following a typical viral-like illness (sore throat, fever, muscle aches, etc.), but any of the dysautonomia syndromes can have a similar onset.



What becomes of people with dysautonomia?

Fortunately, the prognosis appears far better than it was in the days when the disorder was called neurasthenia. This is likely because bed rest is no longer considered the treatment of choice. Most victims of dysautonomia eventually find that their symptoms either go away or abate to the point that they are able to lead nearly normal lives. Sometimes, in fact, the probability that things will ultimately improve on their own may be the only thing to keep some of these individuals going.

But whether the symptoms eventually improve or not, many victims of dysautonomia experience symptoms that completely disrupt their lives, and the search for competent medical assistance in rendering their symptoms tolerable is all too often a difficult one.

How is dysautonomia treated?

Unfortunately, just as there is no generally accepted nomenclature for the dysautonomia syndromes, just as there is no generally accepted set of criteria for diagnosing many forms of dysautonomia, just as there is no general agreement on their causes or on the precise mechanism that produces the autonomic imbalance, so there is no generally accepted approach to treatment. Possibly the most important step in treatment is to find a physician who understands the nature of the problem, is sympathetic toward it (i.e., does not consider you merely a crazy person), and who is willing to take the prolonged trial-and-error approach that is often necessary in reducing symptoms to a tolerable level.

In any case, since the underlying cause of dysautonomia is not known, treatment is largely aimed at controlling symptoms, and not at "curing" the problem.



Non-drug therapies

Physical activity:

While most doctors don't realize it, the experiment as to whether restricting physical activity helps dysautonomia was done 100 years ago. The experiment failed. Big time. Thus: maintaining a daily level of physical activity is probably the most important thing people with dysautonomia can do. Some daily level of moderate activity helps to stabilize the autonomic nervous system, and in the long run makes "relapses" of symptoms more rare and of shorter duration. Physical activity may even hasten the day when symptoms go away on their own.

Physical therapy and similar "alternative" treatments such as yoga, tai-chi, massage therapy, and stretching therapy have been reported to help as well.

Dietary supplements:

Any time a medical condition exists that doctors treat poorly, purveyors of dietary supplements have an open field for pushing their products. Not only do patients feel they may have no better alternative, but also the medical profession, embarrassed by its failure to treat effectively, has little grounds for complaint. Consequently, thousands of unsubstantiated claims have been made about the ability of various vitamins, coenzymes and herbal preparations (all the usual suspects - you know the ones) to relieve the symptoms of dysautonomia. As a member of the embarrassed medical establishment, DrRich can only say - it's your money; try not to spend it on anything that will hurt you.



Drug therapies

A host of pharmaceutical agents have been tried in patients with dysautonomia. Those most commonly felt to be useful include:

Tricyclic antidepressants - such as amitriptyline (Elavil), desipramine (Norpramin), and nortriptyline (Pamelor) - have been used, in low dosage, to treat several of the dysautonomia syndromes. Selective serotonin reuptake inhibitors (SSRIs) - such as fluoxetine (Prozac), sertraline (Zoloft), and paroxetine (Paxil) - have also been used to treat these syndromes. When effective, the tricyclics and the SSRIs appear to do more than merely control any depression that might accompany the dysautonomias. There is some evidence that they might help to "re-balance" the autonomic nervous systems in some patients.

Anti-anxiety drugs - such as alprazolam (Xanax) and lorazepam (Ativan) help to control symptoms of anxiety, especially in patients with panic disorder.

Anti-low blood pressure drugs - Fludrocortisone (Florinef) helps prevent the symptoms caused when the blood pressure drops when the patient is upright (a condition called orthostatic hypotension). Orthostatic hypotension is prominent in vasovagal syncope and in POTS.

Non-steroidal anti-inflammatory drugs - Ibuprofen (Motrin, Advil), and naproxen (Naprosen, Aleve) can help control the pains associated with the dysautonomias, especially fibromyalgia.



It is worth mentioning again that there is no tried and true treatment method that always works in treating patients with dysautonomia. A trial and error approach, requiring the patience of both doctor and patient, is almost always necessary. In the meantime, victims of dysautonomia can try to reassure themselves by remembering two facts. First, dysautonomia usually improves as time goes by. Second, the academic medical community (and the pharmaceutical companies) have now accepted the dysautonomia syndromes as real, physiological medical conditions. Consequently, a tremendous amount of research is going on to define the precise causes and mechanisms of these conditions, and to devise treatments that are effective more often and to a greater extent than many of the treatments being used today.



Who is he: As well as being a supporter and friend to DYNA kids, Dr. Rich is a former professor of medicine, and a longtime practitioner, researcher and author in the fields of cardiology and cardiac electrophysiology.

Experience: Dr. Rich practiced and taught clinical cardiology for 20 years, and during that time served as Director of Cardiac Electrophysiology at the University of Pittsburgh, and then at Allegany General Hospital in Pittsburgh. He has been listed in *Best Doctors in America* for the past 8 years. He has authored numerous scientific articles, book chapters, and books on various aspects of heart rhythm disturbances and is recognized nationally and internationally as an expert in this field. Currently he is working as a consultant and webmaster of YourDoctorintheFamily.com, an on-line guide to understanding and surviving the American health care system.

Education: Dr. Rich received his bachelor's degree from Duke University (1971), and his doctorate in medicine from Ohio State University (1975). He did postgraduate medical training at the University of Pittsburgh and Stanford University, and is board certified in Internal Medicine, Cardiology, and Electrophysiology.

Comment from Dr. Rich: "The best health insurance is a good understanding of your medical conditions and the options available to you."

* To learn more about Dr. Rich please visit the following:

<http://heartdisease.about.com>

<http://syncope.about.com>

www.yourdoctorinthefamily.com

My Fate

*I used to live in normal
Until I got sick and lost my way
Now I live in no mans land
And take my life day by day*

*The only thing that I can count on
Is that I can't predict tomorrow
I take the good days with the bad
And try to push past all the sorrow*

*Doctor listen to me please
Open your heart to my plea
I can do my job and keep fighting
If you can keep searching for a cure for me*

*While other girls my age dream
Of athletic boys and romantic dates
I dream about a much older man
Who's intelligence holds my fate.*

-D.L Chance

Caring for Children with Illness



Professional Contributor

Deborah Christopher Weber, LCPC

When someone we love becomes ill, it elicits a natural protective impulse to do everything we can to make him or her feel better. This impulse may be intensified when the patient turns out to be our child. There are some methods for handling a child's illness which may enhance their chances of recovery or for achieving some normalcy during a very difficult time. Here are ten suggestions for caring for children with chronic illness.

- 1) ***Model optimism.*** There is dramatic evidence which suggests that optimism may play a role in preventing illness, and in shortening those illnesses we do contract. Although feeling optimistic in the face of catastrophic injury or illness may seem incongruent, to surrender to pessimism may guarantee a much more negative outcome. Children tend to be optimists by nature, however, parents who frequently express pessimism or behave in negativistic ways greatly influence their children. Remember that your children are constantly looking to you to learn how to act. This is true even during illness.
- 2) ***Avoid making the child's illness the focal point of the family.*** This may be difficult if both parents are required to expend much of their time and energy in caring for the sick child. The problem in getting used to planning every family decision around a child's illness is that it may engender resentments in other family members. It also may create an expectation that the identified patient in the family will continue to be the primary focus long after the medical crisis is resolved. This frequently leads to a disruption in normal boundaries and familial roles.
- 3) ***Be honest but age appropriate in sharing information with the child about his or her illness.*** Depending on the chronologic age and maturity of the child, you and your doctor may agree to explain in some detail why the youngster is ill. But be careful not to overload the child with so much information that it creates fear. Although "knowledge is power," too much knowledge can be quite anxiety provoking in children. Increasing anxiety may intensify symptoms or prolong episodes.

- 4) **Show non-illness related attention to the child.** Sometimes when children have been diagnosed with serious illness, parents begin to spend much more time interacting with the child in order to administer medication or prescribed treatment, or to provide extra comfort. Unfortunately, there may be little time left for “regular” activities once shared and enjoyed by parent and child. In their effort to treat the illness, occasionally parents inadvertently turn their children into patients first, children second.



- 5) **Continue to discipline as appropriate.** When children are sick, parents tend to let them slide a bit when it comes to behavior. For instance, we rationalize a temper tantrum (or two) by saying, “*She’s not feeling herself today.*” Or if a child begins to refuse to comply with set bedtimes, we may say, “*He’s just feeling insecure right now.*” Those explanations may certainly be true, and some latitude in responding to acting out is appropriate. However, if the child’s behavior begins to deteriorate on a somewhat regular basis, it is important for parents to be consistent with discipline. All children test the waters to see how much they can get away with. Sick children are no exception. When parents are consistent with discipline and love, children receive reassurance that their world is still safe and intact despite their illness.

- 6) **Resist making your sick child a “victim” of his or her disease.** Well-meaning parents sometimes make the mistake of allowing their children to “wallow in misery” until their only identity is that of a sick person. Additionally, when a serious childhood illness is diagnosed, some parents begin to think of themselves as victims. This attitude can quickly infect children. Be careful in speaking to others regarding your child’s illness or progress. Children who overhear comments such as, “*I feel so sorry for him,*” or “*She’s no better and she’s never going to get better,*” may begin to internalize the message that they truly are hopeless victims.

- 7) **Include other children in your child’s life.** Whether siblings or friends, having other children close by who freely interact with your child may help to decrease symptomatology and lighten their mood. Allowing the child to engage in normal activities may help him or her to feel more like a child and less like a patient. It may also give the child a greater sense of belonging to a community of peers, instead of being the youngest member of an exclusive circle which typically only includes the patient and caregivers.

- 8) **Don’t let your fears, worries, or resentments burden the child.** Too often the designated primary provider, the one to whom most of the responsibility for caring for the child falls, begins to view the child as a confidante. Because they are often alone together and bound by something more than just a

parent/child relationship, the parent may begin to share too much of his or her own emotional baggage with the child. Inappropriate sharing of information is a form of role reversal known as parentification of a child. Such a situation will not enhance the child's chances of recovery, and may, in fact, hamper it.

- 9) ***Accept help.*** Better yet – **ask** for it! Being the primary caregiver for a sick or infirmed child is tiring. Parents who believe they must do everything on their own will eventually suffer burnout. When this occurs, mental and physical fatigue, resentment, and ineffective parenting will begin to appear. Enlist the help of family members and trusted friends. Join a support group that provides occasional respite care. If the child is age appropriate, trust him or her to stay alone occasionally. This will help to boost their self-confidence while allowing you some down-time. Both of you will benefit.

- 10) ***Educate yourself regarding your child's illness.*** Becoming knowledgeable about what to expect will help you to face the illness with calm and confidence. This in turn will reduce your anxiety and, by extension, your child's.

Sometimes illness is an inescapable fact of life. How you handle your child's illness will set the stage for them to learn how to effectively handle other setbacks they may face in the future. Parents who show love, acceptance, and consistency toward their children in the face of illness or when all is well will increase their chances of raising happy, well-adjusted individuals. It is the best gift a parent could ever give a child.



Deborah C. Weber, LCPC
Manager, Intensive Outpatient Program
Shore Behavioral Health
Dorchester General Hospital
Cambridge, Maryland

“Wherever there is hope, dreams begin coming true.”

Genienne Bondv

Teaching Children with Dysautonomia

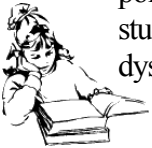
Professional Contributor

Liz Hunsaker, Home Teacher
Charles County Maryland



I have been a home teacher in Maryland for fifteen years, and I have taught students who have been in accidents and who suffer from many types of illnesses. For the past five years I have taught three students with varying degrees of dysautonomia, and I have found them to be among my brightest, most hardworking, and interesting students.

Because of my experience teaching students with dysautonomia, I was asked to write some pointers which may help other teachers who have been lucky enough to be assigned one of these special students. There are certain things of which you should be aware when working with students with dysautonomia.



Since these students experience such a reduced amount of blood flow to the brain they sometimes operate in a foggy state and have difficulty concentrating on what you are teaching them. It is important to learn to recognize the signs of this and not expect as much of the student at this time. You may want to read to them some of their material that doesn't involve as much concentration. Quiz your students orally instead of always requiring a written response or a written test. Don't make them tackle math problems on days when it is difficult for them to think clearly. Adapt your curriculum and your methods of teaching to the changes and phases of their illness. Above all, let your student feel comfortable enough to tell you when he or she can no longer concentrate. Since their appearance isn't always the best predictor of how they are feeling, they are the only ones who truly know if they are up to your challenge.

Students with POTS are often operating on adrenaline to be able to concentrate and get their work completed, and often will "crash" when you leave, so please be considerate if they appear to be getting fatigued. Signs of fatigue that I have noticed are some obvious ones such as frequent yawning, but less noticeable signs may be paleness, shadowed eyes, lack of concentration, and shakiness. Sometimes they won't be able to complete the work that you give them before your next meeting because they used up so much of their energy concentrating and working with you. Concentration lowers their blood pressure, so at times it takes these students a while to feel well enough to complete the work that you have assigned them, so please be understanding about this.

Be aware that students with POTS have good days and bad days. There may also be sudden changes in the way they feel, so they may not always be able to complete a tutorial session with you. Be patient and compassionate. Think how difficult it would be for you to compete tasks and concentrate if your brain was receiving only a portion of the amount of blood flow it needs to think clearly. If you are sensitive to the needs of these often very creative and talented students you will be greatly rewarded. Your job as a home teacher is to enable these students to reach their potential in spite of their limitations, and you will find that they have great potential that they can achieve on their own terms and in their own time.



"I Am a Teenage Dysautonomic"



A special regular feature on a DYNA youth member

Becky King, Age 13
Pennsylvania, Diagnosed with POTS

My name is Becky, I am 13 years old and I live on a farm in Pennsylvania. I am Amish and I do not have the Internet. In spite of not having the Internet, I am still a very active member of DYNA. I belong to the DYNA Postal Outreach Program. This is a special program for kids who don't have the Internet or kids too young or too sick to participate on the Internet.

From what I know I was a healthy normal kid. Of course I got the typical cold and flu every once in a while and the typical childhood illness things. However, in January of 2003, I got a really bad cold (not at all "typical"). I coughed and coughed and couldn't sleep at night. I was very dizzy and had very bad headaches, and to explain it a little easier, I just always felt terrible! Our family doctor thought I had a virus at first. Next they thought it was an inner ear infection. I felt so bad that my family thought maybe something else was going on and they decided to get a second opinion. Next I went through tests and tests and saw doctors and more doctors. I was getting new symptoms about every week and getting worse instead of better. One of our friends knew a doctor personally and they called him. He recommended that we see another doctor and he got us an appointment right away. This new doctor knew about dysautonomia conditions and he diagnosed me with POTS. They tried different kinds of medicines, but nothing seemed to help and I was still not feeling well at all. I felt very, very alone.

A family friend who had the Internet found DYNA for me and I became a member of DYNA and their Postal Outreach Club. Along with support, DYNA provided my family with information on my condition and some up to date medical articles. My family found a specialist (Dr. Hasan Abdullah of the Children's Heart Institute, Virginia) who treats dysautonomia kids and we decided to see if he could help me. He was really nice and he put me on some medicines that seem to be helping a lot more. I am starting to feel better now but I am still very limited. I am very, very lucky because I was diagnosed after being sick for only 3 months and I found a good specialist early in my treatment phase.

DYNA helped me a great deal. Because of DYNA I found a physician who specialized in these conditions and I got the medical treatment I needed. Along with the medical support I also found peer support. The kids in DYNA write me by regular mail since I don't have the Internet and I write them back. I don't feel so alone anymore. I have found a lot of new friends across the world and because of DYNA I have found "A Ray of Hope."

A real friend is one who walks in when the rest of the world walks out.

Walter Winchell, American Journalist

CELEBRATE SUCCESS

PERSEVERANCE:

THE HOLDING TO A COURSE OF ACTION, BELIEF, OR PURPOSE WITHOUT GIVING WAY

FORTITUDE:

STRENGTH OF MIND THAT ALLOWS ONE TO ENDURE PAIN OR ADVERSITY WITH COURAGE.



CONGRATULATIONS TO OUR 2004 COLLEGE GRADUATE:

Leah Masters
who graduated from
Barnard College of Columbia University!

CONGRATULATIONS TO OUR 2004 HIGH SCHOOL GRADUATES

Who received our DYNA
"Ray of Hope Award"

Chelsea Drauss, Michigan
Sophie Hicks, New Zealand
Lauren Howe, Virginia
Jess McDermott, Pennsylvania
Brandy McReynolds, Maryland
Stephanie McGowan, Illinois
Kristin Pare, Wisconsin
Brett Young, Pennsylvania

CONGRATULATIONS TO OUR MIDDLE SCHOOL GRADUATES OF 2004!

Amanda Dominelli, Maryland
Tashina Jordan, Oregon
Jacqueline Mayaisch, South Dakota
Tim Wood, Maryland

2004 WEDDING CONGRATULATIONS FOR:



Kelly Compton & Matthew Bracci
Mandy Melowicz & Matthew Grzyb

"Dreams do come true!"

SPECIAL CONGRATULATIONS TO:

Tom Pugh
Who received the
Eagle of the Cross Award
From Bishop Tobin
of the
Diocese of Youngstown.

Congratulations to:
Susie Hetrick,
Runner-up - Showman of Showman,
Sandusky County Jr.Fair, Ohio

Congratulations to:
Jess McDermott for her
Distinguished Senior Project Award!

Congratulations to:
All DYNA members who made Honor Roll this
year! Too many to list here! Way to go!



ADVICE FOR NEW DYSAUTONOMIA PARENTS FROM DYNA PARENTS:



- Trust your instincts.
- Expect good days and bad days.
- What works today may not work tomorrow.
- It's nothing anyone DID.
- Sometimes all you need is to get through the next five minutes.
- Believe your child.
- You are not alone.
- Pray and never give up.
- Learn to manage the illness and not let the illness manage you.
- Educate yourself.
- Ask for help.
- If their legs work, they should use them.
- Using their legs does not mean they should run marathons! They should take baby steps and build up their strength slowly.
- Expect set backs.
- Be who YOU are, not what the world expects of you.
- Find things for your child to succeed at each day . . . even if it is just getting out of bed . . . and celebrate the success.
- Since you can't do it all, learn to prioritize!
- Spend your energy in productive ways.
- This too shall pass.
- Try to do no harm.
- Be grateful for the small things.
- Keep an optimistic mind-set.
- Encourage strength. No matter what happens. If your child gets better, gets worse, or stays the same, the one thing that your child will need to get through this is inner strength. Encourage it.
- Put the bitterness behind you. It is PAST. Move on.
- Don't dwell.
- Eliminate the negative. Put negative people, negative situations, and the negative energy behind you.
- Instill the positive.
- Find the right doctor.
- Take each day as it comes.
- Remember, illness does not mean weakness.
- No one has a magic pill. No matter how many physicians you see, or how many tests you have – there is not a magic pill in your doctor's pocket waiting just for your child.
- Always have hope.
- Follow your heart.



Glimpse

By Kim Paladino
Age 18, Virginia

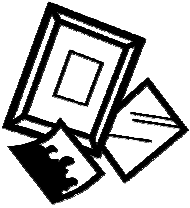
*My body is so tired
But I simply cannot sleep.
All across my hands and feet
The aches and pains they creep.*

*It's nothing new: this stomachache
And as usual I begin to droop.
My head's a pounding migraine too
This illness has thrown me for a loop!*

*I live each day it's just like this
You should try walking in MY shoes
I try my best to fight this thing
I sure have the dysautonomia blues!*

*When I stand up it uses
So much of my energy
The person standing there in front of you
She really isn't the true me!*

*For she, a zombie, stands and stares
Her face as white as snow.
Inside's a different, lively girl
I hope you get to know!*



ALMOST

Mary Bibbs, Age 16, Illinois
Diagnosed with POTS

*almost like picture perfect
looking through another frame
so clear but yet so distant
almost like picture perfect*

*seeing through a different mirror
looks dirty but clean too
almost like picture perfect*

*believing through a familiar screen
so smooth but bumpy at the same time
almost like picture perfect*

Judgment Day

*Gossip...
Chatter...
Petty chit chat...
You sit in church on Sunday
The rest of the week you talk behind my back!*

*Doubters...
Non-believers...
You dare to judge the rest.
You have no idea of what you say-
Your ignorance is truly blessed!*

*I rise above...
I save my energy...
I ignore your yakkity-yak
I turn the other cheek-
You just continue to stab me in the back!*

*High and mighty gossips...
Keep on betraying with your words...
Continue to talk away...
Because sooner or later-
You will face your judgment day!*

-D.L. Chance

**DYNA members are
deeply appreciative
of those that have come to
their rescue.**

**It is with sincere and heart felt
thanks that we commend you
for your compassion!**

*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



The Hand of God

Kellie Beverley, Age 14, Kentucky
Diagnosed with POTS

*I hold in my hand the hand of God,
which I squeeze very tight
and every night he watches me
when the stars are shining bright.
I hold in my hand the hand of God,
which has loving care.
His gentle touch makes me rush to him
when I am in despair.
I hold in my hand the hand of God
and I will not let go.
You can pull on me and tug on me,
but that will only make me grow.
I hold in my hand the hand of God,
which makes me want to cry,
because I know he's there for me
and that is why he died.*

Sometimes

Lauren Gurganus, Age 11, North Carolina
Diagnosed with POTS

*Sometimes it's hard,
sometimes it's tough
feeling dizzy and lightheaded and stuff.
I'm very lucky, I'm fortunate,
some kids are worse than
you can imagine.
Some get sick almost every day,
all they can do is sit and lay.
But I think God has something for us all
Something that makes us feel
strong and tall.
We all have hope and pray that maybe
some day all this will be in the past.
We'll forget our fragileness,
fainting, and falling.
Some day we will be joined together,
comforting each other forever and ever.*

***In Loving Devotion to
Christopher Barrette
11-7-01 - 7-11-04
From his DYNA Friends***

Isaiah 40

*The Lord is the everlasting God,
the Creator of the ends of the earth.
He does not faint or grow weary,
his understanding is unreachable.
He gives power to the faint,
and to him who has no might he
increases strength.
Even youths shall faint and be weary
And young men shall fall exhausted;
but they who wait for the Lord
shall renew strength,
they shall mount up with wings like eagles,
they shall run and not be weary,
they shall walk and not faint.*



We will never forget you.



Judgment

By: Richard Dominelli
Sibling to POTS child

*Do you judge before you listen
or do you have an open mind?
Do you close a door before it's open
Or is it truth you wish to find?*

*Do you judge a book by its cover
or do you read the words inside?
Do you listen to just the lyrics -
or just the music
Or do they both coincide?*

*Do you seek a different life
or do you seek to make a difference?
Do you turn your back to others
or come to their defense?*

*Do you view my words and see
or do you not see my viewpoint?
It's not too late to change your ways
let now be a starting point.*



DYNA

Becky King, Age 13, Pennsylvania
Diagnosed with POTS

*I felt so alone, you stood beside me,
I was sick, you understood
I needed encouragement:
you sent me hope.
I needed friends who understood,
and you sent me many.
The sun has started to shine now,
Even though sometimes
I only see a ray
I've found hope
And that's what counts!*

"Okay"

By: Elizabeth Pugh
Sibling to POTS child



*Their hearts live tales of sorrow
and woe,
Tales of which most will never know.
Every time their heads hit the ground,
Every time their world spins
upside-down,
Someone won't listen,
Someone will just stare,
Someone will not bother to care.*

*But for all those who don't,
And for some reason always won't,
There will be those who dare,
To love ~ not just to stare
To love and to care*

It will be okay.

Someone's in the Kitchen with DYNA!



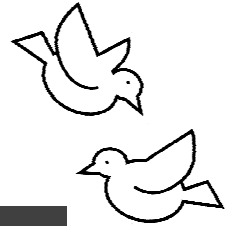
**Order our fundraising cookbook!
\$15.00 (check or money order)
DYNA Cookbook Committee
1301 Greengate Court
Waldorf, MD 20601**

(make checks out to DYNA)

Email us at: DYNACookbook@aol.com
with any cookbook order questions.

**Order forms are on our web site:
www.dynakids.org**

I CHOOSE TO GO GENTLE



Professional Contributor

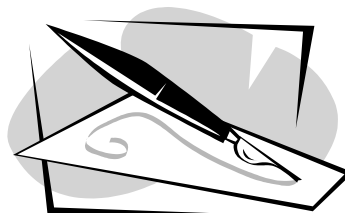
Blair P. Grubb, MD

I was a new attending physician, fresh out of a cardiology fellowship, my first month running the Intensive Care Unit. One of the first patients admitted to me was Jennie, a clear-eyed attractive woman in her late 40s, suffering from severe heart failure, which in turn had caused her kidneys and liver to begin to fail. Hopelessly ill, she had been transferred to our university hospital to see if she would qualify for a heart transplant. Almost immediately after she arrived she suffered a cardiac arrest, and through a superhuman effort we managed to get her back. She required constant attention; I practically lived by her bedside. Twice more she arrested and twice more we snatched her from the jaws of death. A former nurse and school teacher, she was a widow with two grown children. During quiet times she read poetry, the work of Dylan Thomas among her favorites.

After extensive testing the transplant team informed me that she was not a suitable candidate. Too many other organs were involved and she probably would not survive the stress of the surgery. I broke the news to her and her family as gently as possible. "I figured as much," she said. "I know all of you have worked so hard." She reached next to her bed and brought out a small package. "I want you to have this," she said. "The nurses told me that you like pens."

Opening the package, I found a blue lacquer Targa fountain pen. I expressed my heartfelt thanks to them. She then looked straight at me and said, "I ask not to be resuscitated if I arrest again. It has been enough fighting. It is my time, and I choose to go gentle into that dark night..." Her sons nodded their agreement. "Of course," I said, trying to fight back the tears that somehow seemed to come to my eyes. With the very same pen I wrote "Do Not Resuscitate" on her chart. An hour later she was dead.

To this day I use the pen, its presence a reminder of those bonds that link each of us together. That life is both beautiful and mysterious in ways that are sometimes beyond comprehension, and that even in death there can be nobility. There are times when it is better to go gentle into that dark night and quietly bid farewell to the fading light.





A Prayer For the World

*Let the rain come and wash away
the ancient grudges, the bitter hatreds
held and nurtured over generations.
Let the rain wash away the memory
of the hurt, the neglect.
Then let the sun come out and
fill the sky with rainbows.
Let the warmth of the sun heal us
Wherever we are broken.
Let it burn away the fog so that
we can see each other clearly.
So that we can see beyond labels,
beyond accents, gender or skin color.
Let the warmth and brightness
of the sun melt our selfishness.
So that we can share the joys and
feel the sorrows of our neighbors.
And let the light of the sun
be so strong that we will see all
people as our neighbors.
Let the earth, nourished by rain,
bring forth flowers
to surround us with beauty.
And let the mountains teach our hearts
to reach upward to heaven.
Amen.*



It's Not Fair

Samantha Napier, Age 15 South Carolina
Diagnosed with POTS

*It's not fair that life has to be this way
Life gives some people the chance to be
healthy and strong
Healthy and strong is what I'm not
I'm not because life isn't fair.*

*It's not fair that I have to deal with this
Deal with more than normal teens do
Normal teens only worry about
small stuff
Small stuff I used to worry about
but not anymore*

*It's not fair that I want to do so
many things
SO many things I can't do anymore
I can't do them because of this disease
This disease that isn't fair.*

*It's not fair that other people
don't understand
Understand what's wrong with me
What's wrong with me is my disease
My disease that disables me.*

*It's not fair that even though I've
been through this
Been through all these hard times
Hard times that never seem to get easier
And I'm starting to realize...
Hey, life isn't fair.*

THANK YOU FOR SHOWING YOUR SUPPORT

DONATIONS FROM JULY 29, 2003 – JULY 1, 2004



DONATIONS IN HONOR OF PHYSICIANS

In honor of Hasan Abdullah, MD
Mr. & Mrs. Richard Dominelli

In honor of Todd Davis, MD
The Baird Family

In honor of Blair P. Grubb, MD
Marshal Granor
Larry and Janice List

In honor of Peter C. Rowe, MD
Miss. Lauren Howe

MEMORIAL CONTRIBUTIONS

In Memory of Margaret Greaves
Mr. & Mrs. Richard Dominelli

In Memory of Joseph Pastore
Mr. & Mrs. Richard Dominelli

DONATIONS

In honor of Lisa Abrecht
Mr. & Mrs. Bruce Albrecht

In honor of Lorin Arnold
Mr. & Mrs. Charles Arnold

In honor of Katherine Baumann
Mr. & Mrs. Bradford Baumann

In honor of Mary Bibbs
Susanne Abbott
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In honor of Lindz Boehnen
Mr. & Mrs. Daniel Boehnen
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In honor of Mandy Dominelli
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M. Patricia Chance

In honor of Melissa Douglas
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In honor of DYNA Kids
Miss Becky King

In honor of Alex Gallina
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In honor of Brian Gerdel
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In honor of Sal Hughes
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In honor of Glenn Johnson
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In honor of Ashli Jones
G.O. Jones & Associates, Inc.
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In honor of Becky King
Postage Stamps from Francis D'Auria

In honor of Laura Kline
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In honor of Melody Malecki
Mr. & Mrs. David F. Malecki

In honor of Richard Manzeck
Don and Linda Woodmansee

In honor of Amanda L. Melowicz
The Guests at her Bridal Shower

In honor of Jenny Miller
Mr. & Mrs. James E. Miller

In honor of Nick and Samantha Napier
Mr. & Mrs. Sam Napier

In honor of Samantha Phillips
Jackie & Marsha Finch
Ms. Lisa Glanton
Mr. & Mrs. Owen B. Majors
Mr. & Mrs. Ronny Majors

In honor of Julie Powalie
Mr. & Mrs. Tom Powalie

In honor of Heather Savelle
Ms. Donna Savelle

In honor of Lindsay Schardt
Mr. & Mrs. David M. Schardt

In honor of Heather Thomas
Party Supplies for Summer Chill 2004

In honor of Jonny Timmsen
Office supplies from Mrs. Sue Miller
Mr. & Mrs. Eric Timmsen

In honor of Loren Vidnovic
Mr. & Mrs. Nick Vidnovic, II

In honor of Caroline Winter
Alan, Sally and Samantha Haines
Mr. & Mrs. Robert J. Winter

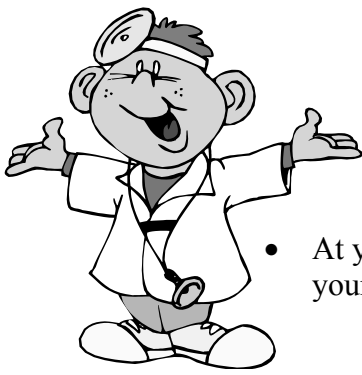
NOTE

The above list reflects donations made prior to July 1, 2004. All donations received after that date will be listed in our next edition.



*You can not judge a person on the
life they have been given
but on the life they have
made for themselves.*

Mandy Dominelli
DYNA Member, Age 13



Communicating With Your Physician

- At your initial appointment and at follow-up appointments always confirm with your physician how they want you to communicate with them.
 - Ask them in what situations they want you to call?
 - What is the process and is there a specific person they want you to go through?
 - What times and what number should you call?
- Respect traditional guidelines.
 - Only call when it is necessary - you will get a lot more respect from your physician and his staff. Don't call for minor things.
 - Remember, your physician cannot walk you through your illness. Individuals with a chronic illness must learn to manage some aspects of dealing with the illness independently.
 - Prior to placing a call to your physician, make a written list of the reasons why you had to call.
 - When you do reach your physician don't take up valuable time with non-essential talk. Keep to the issues clear, short and focused.
 - Always thank your physician for calling you back.
 - Always, remember to thank the staff as well – they got you through.
- If you run into communication issues with your physician it is best to talk to them in a calm and hospitable manner. Talk to them about the issues and attempt to work together.



Communicating With Your Patients

- At our initial appointment and at follow-up appointments always confirm with us how you want us to communicate with you. It helps tremendously if you have your office phone call policy in writing to give to your patients.
 - Provide us the proper numbers to call.
 - Explain to us what circumstances you want us to call.
 - Assign us a specific person in your office for us to communicate with.
- Respect traditional guidelines.
 - We are often overwhelmed when we call. Have your staff be compassionate and supportive.
 - When we leave a message, please have your staff give us some idea of when we should expect to hear back from you. We are usually so desperate to hear back from you, that we do not take other calls while we are waiting. Days go by that we live waiting for that phone to ring with you on the other end! It never fails that when you do finally call we are out getting mail from our mailbox or taking a shower or something! Having an idea of when to expect to hear back from you helps us and lessens our stress.
- Talk to us if you run into communication issues with us. We want to work together. Please be specific about your concerns.



WORKING WITH YOUR SCHOOL



Once you receive your diagnosis you will need to consider communication options with your school. You will be placed in the position of explaining an illness that you yourself still don't quite understand at a time when you are very overwhelmed. Because there are different conditions and different degrees of impact with each dysautonomia case it is impossible for us to address each situation here. Here are some of our suggestions:

- Put any negative experiences that may have occurred within your school prior to your diagnosis completely behind you.
- Initiate communication. Start with your guidance counselor. Have your parents schedule a meeting with your guidance counselor and explain your particular situation. Give them our web site and office phone number.
- If after this meeting, you feel the school guidance counselor is not your best resource, follow the chain of command within your school system. If necessary, go outside of your particular school and contact the main office of your county Department of Education and ask for help. Keep searching until you find the right individual to help you (i.e.: Human Resources, 504 Coordinator, etc.)
- Develop an educational plan that meets your current needs. You probably need to request a meeting to arrange for a 504 Plan or an IEP (depending on your particular needs and school system). These plans help accommodate your condition within your educational program. It is often essential to have these accommodations in order to receive a fair and appropriate education while dealing with a medical condition.
- Your physician may have suggested that you receive homebound instruction. Most school systems have a specific department that handles homebound instruction. Connect with the proper individual in this department.
- Do not worry about tomorrow's needs – start your school plan with today's needs.
- In your plan, allow the flexibility to make future adaptations in order to meet your changing needs, expect changes and anticipate ups and downs.
- If you do require home instruction it is often a good idea to request to meet with the home teacher prior to starting instruction. Your home teacher should be made fully aware of your condition and should be provided with all possible resources. We strongly recommend that all home teachers watch the video from our “Goofy Slipper Lecture” so they have a better understanding of these conditions.
- Communicate, communicate, and communicate. Be open minded, flexible, and patient.

I face disbelief, contradiction and confusion each day as I learn more about my wife's dysautonomia condition. As parents of children with similar complex health issues, you may struggle trying to learn, find resources, and help your school recognize and understand what they have never experienced. Teachers will need your help, patience, and information regarding your child's health condition. Don't give up. The quality of the partnership relationship between you, your child and your school will be a key ingredient in developing an effective educational plan for your child. Know your school...know your resources...know your child...and expect your school to work with you each step of the way.



~Steve Krusich, Superintendent of Lenawee Intermediate School District, Adrian, Michigan

Recommended Resources

The Fainting Phenomenon: Understanding Why People Faint And What Can Be Done About It

By Blair P. Grubb, MD

Mary Carole McMann, MPH

ISBN#0-87993-491-3

Blackwell Futura Publishing Company,
Inc.

www.blackwellfutura.com

*Excellent resource for families
and physicians of individuals
with POTS, NCS and all dysautonomia
conditions.



Taking Charge Overcoming the Challenges of Long-Term Illness

By Irene Pollin, M.S.W. and

Susan K. Golant

ISBN#0-8129-2258-1

www.sistertosister.org

*Excellent resource for all individuals
and families dealing with an illness.

DYNA "2004 Goofy Slipper"

Lecture on Dysautonomia

Hasan Abdullah, MD, Blair P. Grubb,

MD, Robert Hoeldtke, MD

Price: \$25.00

Produced by Full Zoom Productions

Toledo, Ohio 419- 531-8362

Order form available on the DYNA web

site or email us at info@dynakids.org

Available in DVD or VHS

*Excellent for families, schools, and
physicians wanting to better understand
children and adults impacted with POTS,
NCS, and all dysautonomia conditions.

**WE WISH TO THANK THE
FOLLOWING BUSINESSES FOR
THEIR SPECIAL TALENTS
AND KIND HEARTS:**

Farmer & First, PC, Warren, RI
Full Zoom Productions, Toledo, Ohio
Lattice Group, Inc., Kensington, MD
Sir Speedy Printing, Hanover, MD

***A VERY SPECIAL THANKS
TO:***

***Mrs. Margaret Keifer
for her kind heart and
compassionate soul.***



*If someone listens, or stretches out a
hand or whispers a word of
encouragement, or attempts to
understand a lonely person,
extraordinary things
begin to happen.*

Loretta Firzaris 1920

***A Very Special Thanks to the
William C. Bannerman
Foundation
for helping make dreams
come true.***

Debra L. Dominelli wishes to thank
the following kind hearts for the
private contribution collected in her
honor by Jenni Hinman. These funds
were placed directly in the DYNA
account and utilized completely for
DYNA expenses.

The Bibbs Family
Ms. Stephanie Graf
Ms. Ashley Grantham
The Gurganus Family
The Hetrick Family
Ms. Melissa Mambort
The Myslanski Family
Ms. Kim Paladino
The Phillips Family
The Smith Family
The Vargas Family



***"The heart of the giver makes the
gift dear and precious."***

Martin Luther 1483-1546

Reaching for the STARS to Help Kids in the UK with RAS



It's known by many different names in different part of the world, but in the UK, Neurocardiogenic Syncope (NCS) in children is more often called Reflex Anoxic Seizure (RAS). RAS is a type of arrhythmia or heart rhythm disorder. A sudden shock or pain can make the heart and breathing stop in a mini cardiac arrest, the patient shows seizure-like symptoms, blacks-out and loses consciousness.

Things are changing, but it's still likely that if your child is suffering from these frightening episodes, you may well be told by uninformed doctors that they are breath-holding spells, or perhaps suffering from epilepsy. They may have been prescribed anti-epileptic drugs or you may have even been told that your child is just having temper tantrums and should be ignored.

Now, thanks to the American based non-profit organization DYNA (Dysautonomia Youth Network of America, Inc.), and the UK charity STARS (Syncope Trust & Reflex Anoxic Seizures), the message is getting across that RAS or NCS and other related conditions are conditions that need to be diagnosed in children and treated appropriately.

While most people reading this newsletter already know the history of the American based organization, DYNA (www.dynakids.org), you may not be as familiar with the history of UK based, STARS. STARS' Chief Executive, Trudie Lobban, started what was then a small support group in the UK, eleven years ago, from her kitchen table. Over the years, STARS has taken more than ten thousand calls, and its website has seen a dramatic increase in hits in the last year alone.

The charity has even managed to help change UK government policy by convincing the Health Department that arrhythmias should be included in the 'heart bible' policy document. Trudie came up with the idea of a UK 'Arrhythmia Awareness Week' to try to highlight the problems of poor levels of diagnosis and treatment and to effect change and, together with several partner charities; she managed to do just that.

Trudie's own daughter has suffered with RAS since she was a toddler. Like Debra Dominelli, President of DYNA, Trudie is driven to help others with her daughter's condition. She's an incredibly dedicated volunteer who has now started a second charity, Arrhythmia Alliance. This means a lot to people like Catherine Reid, mother of five year old Joel in Northern Ireland. He has suffered with RAS since he was a baby and is now being treated. "Can you imagine looking at your child who appears dead in your arms?" asks Catherine. She had just taken baby Joel out of the bath and the shock of the cooler air had brought on an attack. He has suffered RAS attacks during immunizations, birthday parties and simply while playing. At one stage, he had up to three RAS attacks a day. Tests to record the episodes revealed that his heart stops beating for 12 seconds, which Catherine says seems a lifetime when you are holding him. Joel's RAS has led to other complications such as being excluded from activities with his friends and being injured during the episodes. "STARS became my lifeline, providing me with the knowledge that we were not alone. Trudie offered vital support, advice and encouragement. To help STARS, I became a first regional volunteer in N.Ireland." said Catherine. She was repeatedly told by doctors that Joel would 'grow out of it', but as each milestone passed when she expected him to be free of seizures, they continued to occur. Joel is an active and adventurous four year old who loves rugby and other sports and wants to start to join in playing them. His parents are now facing the challenge of striking a balance between keeping him safe and allowing him space to grow up.

STARS has helped thousands of families like Catherine's both in the UK and internationally. STARS and DYNA are two individual organizations from two different countries who are working for the same cause and they both want what is best for children impacted with these conditions. If you think STARS can help you, you can get in touch at <http://www.stars.org.uk> or email Trudie@stars.org.uk. Tell Trudie that her friends at DYNA sent you! Together we can make a difference.

*"My will shall shape the future. Whether I fail or succeed shall be no man's doing but my own.
I am the force. I can clear any obstacle before me or I can be lost in the maze.
My choice, my responsibility. Win or lose, only I hold the key to my destiny."*

Elaine Maxwell
American Writer



LOSING YOUR BALANCE BEING YOUNG AND HAVING A MEDICAL CONDITION



Debra L. Dominelli
Reviewed by Juan Villafane, MD

Living with a medical condition (chronic or temporary) can be stressful and challenging for anyone but is especially hard for adolescents and young adults. It takes time to adapt to having a medical condition and to find ways to live your life in spite of it. It is especially hard to adapt when you are young because everyone else seems to know what is best for you and you often feel that you have no control over your own life. You probably feel that you have lost your balance in more ways than one!

Over time most young people adapt and come to terms with their medical condition and most of them end up becoming awesome adults. Playing an active and positive role in your care and in your future will help you to progress forward and enable you to be better prepared to face the obstacles that await you.

Everyone has different reactions to being diagnosed with an illness. Obviously, at first some people feel very vulnerable, confused, and worried about their health and their future. Some people feel let down by their bodies. Some people may feel that they were cheated and they may feel angry at the world. All these feelings are a part of the coping process. We are all individuals and we all have our own responses.

After being diagnosed with an illness, most people decide to learn more about their condition. Knowledge tends to be power! The more you feel you know and understand about your particular situation the more you feel you have some control over it and the less frightening it is. DYNA believes in involving our youth members and in encouraging them to become advocates for their conditions. We also encourage them to still find ways to be kids.

It is easy for a health condition to become the main focus of a person's life. While it is important to understand your illness, receive support, and be involved in organizations like DYNA, it is also important for you to still be a kid. Remember, having a medical condition is only a part of your life and the condition is not "who you are" but "just something you have."

Adapting to living with a medical condition takes time, patience, support, creativity and flexibility. Young people who deal with such challenges tend to find an inner resilience they never would have known about otherwise. Youth living with such conditions often discover that by playing an active role in their future and by dealing with the obstacles they must face they usually grow to have tremendous perseverance and inner strength. Stand tall and be proud. The future is yours.

*We can be sure that the greatest hope for maintaining equilibrium
in the face of any situation rests within ourselves.*

Francis J. Braceland

Join DYNA

DYNA believes in empowering youth with dysautonomia conditions!
Our youth are active advocates for individuals with
dysautonomia conditions world wide.
DYNA puts young people with dysautonomia in touch with each other.
We work very hard to support youth with dysautonomia
and to bring about awareness of these conditions.
Our newsletters are mailed to most major hospitals
and many physicians across the world.



To Join DYNA:

Click on: JOIN DYNA
on our web-site and follow directions.
Or email us at: info@dynakids.org
(as with any email...if you don't hear back – try again)



www.dynakids.org

Any physicians who would like to participate in a future newsletter may
contact us. We sincerely welcome your input.

Any individual or organization that would like to be included on our
newsletter mailing list is welcome to contact us.

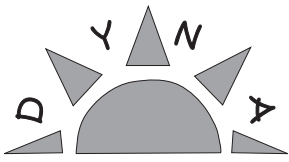
Mailing Address:



DYNA
c/o Debra L. Dominelli, President
1301 Greengate Court
Waldorf, MD 20601
301-705-6995



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well as to the
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Procedure for Taking Standing Blood Pressure For Postural Orthostatic Tachycardia Syndrome







For most accurate results:

- Lie down for several minutes prior to taking standing blood pressure.
- Measure blood pressure at 1-minute intervals for 3-5 minutes.

Have your physician review your chart and look for these signs for POTS:

- Decrease in BP upon standing (up to 20/10 mmHg)
- Heart rate increase at least 30 bpm with standing.

IMPORTANT: In mild cases of POTS it is necessary to stand for longer periods of time. Patients may need to stand for an hour, but we recognize that is impractical for most physicians. It is important to recognize that for mild cases the heart rate changes may be more pronounced in the morning than later in the day. Early morning testing is recommended.

Laying		15 min.	BP _____ / _____ HR _____ / _____	Associated Symptoms (dizzy, headache, near fainting, nausea, ect..)	
Standing readings taken at 1-minute intervals for 3-5 minutes		1 min.	BP _____ / _____ HR _____ / _____		
		2 min.	BP _____ / _____ HR _____ / _____		
		3 min.	BP _____ / _____ HR _____ / _____		
		4 min.	BP _____ / _____ HR _____ / _____		
		5 min.	BP _____ / _____ HR _____ / _____		

TIMING OF WHEN MEDICATION WAS TAKEN AND DOSAGE TAKEN PERTAINING TO THIS BP/HR READING
(circle one and record any notes)

* Reading was taken before taking medications.

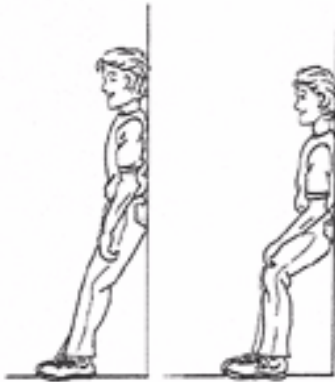
* Reading was taken _____ hours after taking ProAmatine.

* Reading was taken _____ hours after Florinef.

* Reading was taken _____ hours after I felt dizzy, fainting etc.

MEDICATION NOTES: _____

Strengthening Exercises



Holding Up the Wall

- Stand with your back against a wall so that your feet are hip width apart and about 18 inches from the wall.
- Slowly slide down the wall until you are in a half “chair position.”
- Hold this position for 45 seconds.
- Do one repetition of this exercise, 3 times a day.



Holding Down the Chair

- Hold onto a chair for support.
- Stand with your right leg crossed in front of your left leg.
- Squeeze your legs together and hold for 45 seconds.
- Do one repetition of this exercise, 3 times a day.



Standing on Your Toes

- Hold onto the back of a chair for support.
- Stand with your feet 12 inches apart.
- Slowly rise up onto your toes as high as you can.
- Hold this position for 5-10 seconds.
- Put your feet back flat on the floor.
- Repeat this cycle 4 times, 3 times a day.

DYNA recommends that you check with your physician before starting any exercise program.

www.DYNAkids.org

The DYNA "Summer Chill"

is a casual and relaxing opportunity for our DYNA youth (and their families) to meet, socialize, and learn about the various dysautonomia conditions. Below are pictures from our 2004 Summer Chill.



Meeting of the Minds:

Clockwise from left:
Barbara Straus, MD,
Hasan Abdullah, MD,
Blair P. Grubb, MD and
Robert Hoeldtke, MD

"Goofy Slipper Lecture"



"Rainbow Seeds Activity"

Thanks

DYNA SUMMER CHILL 2004

Toledo, Ohio
July 12, 13, 14

Thanks

A VERY SPECIAL THANKS FOR OUR T-SHIRTS AND FOR THE SUPPORT TO MAKE OUR 2004 SUMMER CHILL A SUCCESS:



Medtronic, Inc., Minneapolis, Minnesota: www.medtronic.com

Thanks especially to **Mr. Ross Meisner!**

A SPECIAL THANKS FOR THE PIZZA FOR OUR "GOOFY SLIPPER" LECTURE TO:

St. Jude's Medical, Toledo, Ohio: www.sjm.com

Thanks especially to **Mr. Michael Levison!**



SPECIAL THANKS FOR THE MARKETING MATERIAL

Shire Pharmaceuticals, Craig Lewis, ProAmatine Product Manager

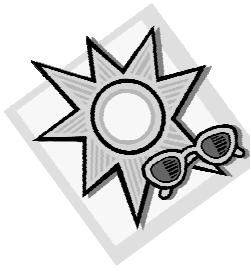
HUGS AND KISSES TO THE PARENTS AND CHILDREN WHOSE TIME AND EFFORT MADE HOLDING THIS EVENT POSSIBLE!

LOVING THANKS TO THE FOLLOWING PHYSICIANS FOR THEIR SUPPORT OF OUR SUMMER CHILL 2004:

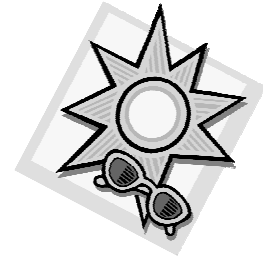


- **Hasan Abdallah, MD:** Children's Heart Clinic, Manassas, VA
- **Blair P. Grubb, MD:** Medical College of Ohio, Toledo, OH
- **Robert Hoeldtke, MD:** West Virginia University, Morgantown, WV

ANY PHYSICIAN WHO WOULD LIKE TO PARTICIPATE IN THIS WONDERFUL EVENT SHOULD CONTACT OUR MAIN OFFICE.



SUMMER CHILL SUPPORTERS!



SPECIAL THANKS FOR THE SUPPORT FROM THE FOLLOWING:

Amerihost Inn & Suites, Maumee, Ohio,
Brandywine Country Club, Maumee, Ohio,
Carrabba's Restaurant, Maumee, Ohio
Cookies by Design, Sylvania, Ohio
Cracker Barrel Restaurant, Maumee, Ohio
Denny's Restaurant, Fremont, Ohio
Food Lion, Charlotte Hall, Maryland

Full Zoom Productions, Toledo, Ohio www.fullzoom.com

Greater Toledo Convention and Visitors Bureau: www.dotoledo.org

Happy Feet Slippers, Goshen, KY: www.buyhappyfeet.com

Ideal Bakery, Gibsonburg, Ohio

In Boutique Beauty Shop Customers, Fremont, Ohio

Maumee State Parks, Oregon, Ohio

Metroparks, Toledo Area www.metroparkstoledo.com

Monclova Township Fire Department, Toledo, Ohio

Max & Erma's Restaurant, Maumee, Ohio

Medical College of Ohio, Toledo, Ohio

Ms. Rose's Dinner Theater, Perrysburg, Ohio

Outback Restaurant, Toledo, Ohio

Papa John's Pizza, Sylvania, Ohio

Parties on the Move, McCalla, Alabama

Sam's Club, Holland, Ohio

St. Vincent's Hospital, Life Flight, Toledo, Ohio

Sir Speedy Printing, Hanover, Maryland

Toledo Zoo, Toledo Ohio



NOTE

In order to protect the privacy of our DYNA Members, the location and details of the DYNA Summer Chill are not released to the public. This private event is only open to registered members of DYNA and their physicians. Any physicians interested in attending the Summer Chill should contact our main office directly for information.

TAX DEDUCTABLE DONATIONS
TO HELP MAKE THIS WONDERFUL
EVENT POSSIBLE NEXT YEAR
MAY BE SENT
TO OUR MAIN OFFICE:

Make checks payable to: DYNA
Mail to: 1301 Greengate Court
Waldorf, MD 20601
301-705-6995

What is DYNA?

Young people diagnosed with various dysautonomia conditions may experience isolation from their peers due to the impact of their symptoms. They often make dramatic lifestyle changes in the prime of their adolescence. The Dysautonomia Youth Network of America, (DYNA) is a 501(c)(3) non-profit organization dedicated to serving these individuals.

DYNA provides its youth members with a world-wide support network that is focused on becoming *better* not *bitter*. We strive to heighten awareness of dysautonomia conditions within the Pediatric and the Adolescent medical communities. We also aim to provide information that will allow our members to access the best available educational resources. We publish a heart-warming and informative newsletter that is mailed to many physicians, hospitals, schools and private individuals world-wide.

One of the favorite support programs for DYNA youth members is the **Computer Connections Club**. This club puts our youth members in touch with each other over the Internet (in a secure and private manner). We also provide a **Postal Outreach Program** for children without the Internet.

DYNA believes in empowering our youth by providing them with the necessary tools to become active participants in their own care. Our organization places a strong emphasis on community involvement and support for our children. **Dysautonomia children may be sick but they are not weak!**

How can I help?

Your tax-deductible donation will enable DYNA to provide children and young adults who have dysautonomia with the necessary support and outreach.

Donation and/or information

Mail to: DYNA

Debra Dominelli, President
1301 Greengate Court
Waldorf, MD 20601

My name: _____

My address: _____

Telephone: _____

E-mail: _____

Check any that apply:

* Please include me on your newsletter mailing list: _____

* I wish to join DYNA _____

* I am a youth/parent of a youth with dysautonomia. Please contact me _____

* I wish to make a donation to DYNA.
Amount Donated: \$ _____

My donation is made in honor of:

Name: _____

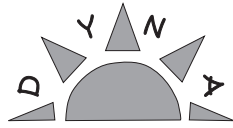
Address: _____

Please notify the above individual of my donation:

_____yes _____no

Please donate by check payable to:
DYNA, Inc.

Thanks!

Dysautonomia Youth Network
of America, Inc
1301 Greengate Court
Waldorf, MD 20601

"A Ray of Hope"

MAIL TO:



"The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, sensitivity and an understanding of life that fills them with compassions, gentleness, and a deep loving concern. Beautiful people do not just happen."

-Elisabeth Kubler-Ross

Do you wish to remain on our mailing list?

You must re-register with us.

Go to www.dynakids.org and click on
JOIN DYNA.

Sign up for our mailing list on our
Registration Form Membership Options.

Support our youth! Order our cookbook:
"Someone's in the Kitchen with DYNA"
Go to our web site for ordering information
or contact us at our main office.

Youth with dysautonomia - Become Better NOT Bitter!

JOIN DYNA! www.dynakids.org

*DYNA kids work hard to promote awareness of dysautonomia conditions
and to make a difference in the future. Join us!*