

“A
Ray
of
Hope”

Dysautonomia Youth Network of America, Inc.

“The Young and the Dizzy” Newsletter

2005 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.



2
0
0
5

S
U
M
M
E
R

C
H
I
L
L

MEDICAL ADVISORY BOARD

Hasan Abdallah, MD
Children's Heart Clinic
Manassas, Virginia

Michael W. Consevage, MD, Ph.D.
Moffit Heart and Vascular Group
Wormleysburg, Pennsylvania

Todd Davis, MD
Children's Memorial Hospital
Chicago, Illinois

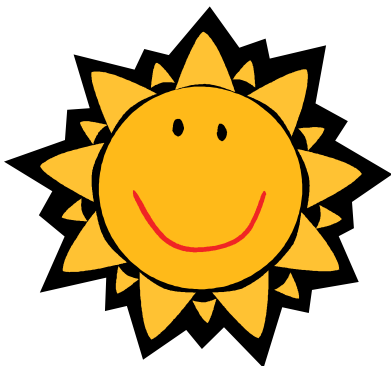
Robert D. Hoeldtke, MD, Ph.D.
West Virginia University
Morgantown, West Virginia

Julian Stewart, MD
Center for Pediatric Hypotension
Valhalla, New York

William A. Suarez, MD
Northwest Ohio Congenital Heart Center,
Toledo, Ohio

Randy Thompson, MD
Center for Patient Care
Pensacola, Florida

Juan Villafane, MD
Children's Heart Specialists
Louisville, Kentucky



"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

BOARD OF DIRECTORS

Debra L. Dominelli
President/Executive Director

James Dominelli
Vice President/Treasurer

Blair P. Grubb, MD
*Professor of Medicine & Pediatrics
Medical College of Ohio*

M. Patricia Chance, CCRC
Health Trends Research, LLC

Dinah Christopher, MLT, CCRC
Health Trends Research, LLC

DeAnn Douglas, RNC

David Levy, JD
*CEO, American Association
Caregiver Education*

SPECIAL THANKS TO:

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

MAIN CONTENTS

Directly Speaking Debra L. Dominelli	2
Dysautonomia Blair P. Grubb, MD	3
Chasing the Moon A Pediatrician's Journey into Autonomics	6
I am a Teenage Dysautonomiac Sophie Hicks	9
Teaching Children with Dysautonomia Liz Hunsaker	13
Communicating With Your Physician	15
Summer Chill Thanks	23

Directly Speaking

The Red Dress on Tuesday

A Word of Caution Regarding Magic Cures and Alternative Treatments



Life with a chronic illness is extremely stressful on all of those involved. Watching children suffer can be heartbreaking for the entire family. Understandably, parents are almost willing to try anything and everything they can in order to find the “magic cure” to “fix” their child. While it is essential that we all maintain hope that someday a cure for dysautonomia will emerge from medical science, we must also be sure to keep everything in perspective in our desperate search to help our children. In addition to seeking professional medical recommendations for treatments, it is important that we exercise great caution in regard to trying unproven alternative therapies without consulting our physicians first.

Every day the DYNA office phone rings with calls from parents of youth with dysautonomia conditions who are desperately searching for answers. Thankfully, due to increased awareness within the medical field, many of these patients are now receiving proper treatment from well-regarded physicians who understand the complexity of dysautonomia. Sometimes the parents ask us if a particular physician is doing enough for their child and if they can trust the treatment recommendations of their physician. The answer is usually, “Yes. Trust your physician and give the treatment time.” We always remind parents to expect to be flexible and to expect to make modifications. Dysautonomia treatments must be fine tuned to each individual patient. Medications and treatments may change through various phases of the illness and you should also expect to make adaptations with the growth of the child. Close communication with the physician is essential to success.

The DYNA phone also sometimes rings with individuals who have heard that somebody found “the magic cure” within a non-conventional alternative treatment. The caller often wants to know if we recommend a particular miracle treatment. Amongst the DYNA volunteers, we call these our “*Red Dress on Tuesday calls.*” *Jane Doe* wore a *Red Dress on Tuesday* (took a nutritional supplement, ate a particular food, etc.) and she felt better, so she thinks that if everyone wears a *Red Dress on Tuesday* – everyone will be cured. Dysautonomia families are often so desperate that they will try anything. So, they sometimes want to know if they should try on a Red Dress like Jane’s. Our answer regarding *Jane Doe’s* alternative treatment is usually, “No *Red Dress on Tuesday* treatment can cure dysautonomia.” It may have helped Jane (or at least she thinks it has helped – especially if she can make money off selling it to you) – but do not expect it to work the same for you and do not expect a complete cure out of it. Most importantly, talk to your doctor before you try that *Red Dress* on as it could negatively interact with established medications and it may impact the results of your physician’s treatment plan.

Alternative therapies have become a multimillion dollar industry within the chronic illness population. Be wary of dramatic claims. Always communicate with your physician prior to starting such therapies. Many desperate patients are paying more in out-of-pocket costs for unproven and controversial treatments than they do for traditional medical care. The use of some of these treatments generate great concern involving the costs, risks vs. benefits, possible suppression of effective conventional therapies and the motivation for profits made off of desperate individuals seeking such magic cures.

We must be constantly aware that there are no quick fixes for dysautonomia. Traditional medical treatment, physician prescribed medications, physical therapy, time, patience and lifestyle modifications will all work in favor of the dysautonomia patient. *Red Dresses* may look good and may even sometimes offer merit within the standard treatment plans. However, wear those *Red Dresses* with great caution and only with the supervision of your physician.

Debra L. Dominelli,
President / Executive Director



Dysautonomia



Professional Contributor

Blair P. Grubb, MD

“All beginnings are hard...”

-The Talmud

All animals must be able to keep their blood pressure and body temperature stable regardless of the position of their bodies or the temperature outside. For animals, this is easier because being on all four legs their brains are closer to their centers of gravity. However, we human beings have a unique challenge, because by walking on two legs our brains are much further away from our centers of gravity, so our systems must work harder than those of other animals.

When a normal person stands gravity pulls about 1/3 of the body's blood to the lower half of the body. The body must quickly sense and compensate for this or the brain would not receive enough blood (and oxygen) and the person would pass out. The brain determines that this downward displacement of blood has occurred by sensing that there is more stretch on blood vessels in the lower part of the body than in the upper part. The brain then tells the body to do three things quickly: make the heart beat faster, increase the force of the heart's contractions, and tighten up the blood vessels in the lower half of the body to about three times their previous tightness. This process forces blood from the lower half of the body to the upper half so that upon standing the blood pressure does not significantly change. The brain uses a similar mechanism to help regulate temperature. Blood vessels tighten to help the body conserve heat and relax to help the body release heat.

The part of the brain that regulates these functions is called the brain stem or medulla. It also regulates a number of other functions in addition to blood pressure and body temperature. These include contractions of the muscles that move food along your intestines, sweating, urination and pupillary function. This system is called the Autonomic Nervous System, the term is derived from the Greek root meaning “self governing.” The autonomic nervous system is involved in the regulation of virtually every organ of the body.

Normally, the system works quite well, by automatically making changes to keep blood pressure, temperature, and bowel and bladder function stable. However, in some people the system does not work properly and many functions that most people take for granted fail to operate as well as they should. When these individuals are in a standing position their blood pressure falls due to failure of the blood vessels in the lower half of the body to tighten.

These people may often faint or have trouble thinking clearly, in addition to suffering feelings of lightheadedness, dizziness, and fatigue. In some of these individuals the heart rate may go excessively high in an attempt to pull the blood pressure up to more normal levels. This process is quite stressful and is quite energy inefficient, thus producing a sense of extreme fatigue, inability to exercise and feeling that the heart is racing. Some people may also experience bowel problems such as constipation, abdominal cramping, gas, periods of diarrhea and nausea. Additionally, individuals suffering from this condition will also have difficulty regulating body temperature and feel excessively cold or hot. A large number of patients also suffer from migraines, as well as forms of attention deficit disorder. Patients often experience severe unremitting fatigue.

Failure of the autonomic nervous system to function appropriately is referred to as a "Dysautonomia." Other terms are used to describe different forms or subtypes of Dysautonomia. Neurocardiogenic syncope refers to fainting due to a sudden fall in heart rate and blood pressure. The terms Orthostatic intolerance and Postural Orthostatic Tachycardia Syndrome (POTS) both describe a condition where the heart rate is excessively high in an attempt to compensate for a low blood pressure. Symptoms will often begin after a severe stress (such as a viral infection or the flu). There are many different types of dysautonomia (more than can be described here). Tilt table testing is used to measure the body's responses to upright posture and to help establish a diagnosis by measuring a patient's heart rate and blood pressure responses to the passive stress of gravity.

Some people with Dysautonomias may be only mildly affected with only occasional symptoms, while other can be severely affected with constant severe symptoms. Those with severe forms of dysautonomia can be virtually bedridden. Many young people who develop these problems will slowly get better over time with the right medications and with physical reconditioning. Maintaining a high salt and fluid intake is also important. In some young people symptoms

can be so severe that they can have difficulty completing school work, and they may need extra help just to keep up. Young people with very symptomatic Dysautonomias may need to have a home tutor until they are strong enough to return to regular classes. Others may be able to attend school with a limited or part-time schedule. These students may further benefit from tutors. Patients may alternate between good and bad days and on occasion may miss class due to exacerbations of their illness.

What patients need most is understanding and encouragement to deal with this complex and debilitating poorly understood group of disorders. Slowly but surely we are learning how and why these illnesses occur and are developing better and more effective therapies to help patients return to normal productive lives. A cooperative approach that combines the efforts of physicians, the patients, their families and educators is often the most important aspect of successful management of Dysautonomias.

Blair P. Grubb, MD
Professor of Medicine and Pediatrics
Medical University of Ohio

Recommended Resources

DYNA “2005 Goofy Slipper” Lecture Educating the Dysautonomia Student

Blair P. Grubb, MD, Hasan Abdullah, MD,
Price: \$25.00
Produced by: Full Zoom Productions
Toledo, Ohio 419- 531-8362

Order form available on the DYNA web site:
http://www.dynakids.org/social_lecture.jsp
or email us at info@dynakids.org

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

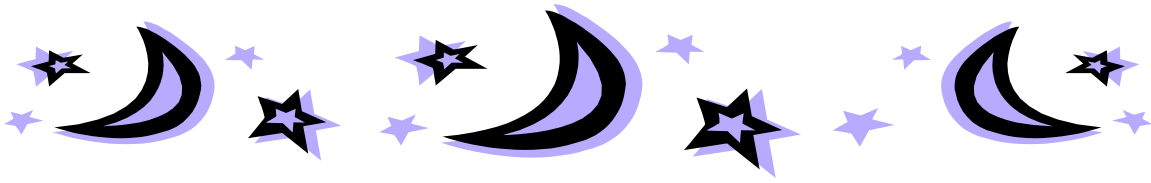
The Fainting Phenomenon: Understanding Why People Faint And What Can Be Done About It

By Blair P. Grubb, MD
Mary Carole McMann, MPH
ISBN#0-87993-491-3
Blackwell Futura Publishing Company, Inc.
www.blackwellfutura.com

Syncope: Mechanisms and Management

By Blair P. Grubb, MD
Brian Olshansky, MD
ISBN#1-40512-207-2
Blackwell Futura Publishing Company, Inc.

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



Chasing the Moon:

A Pediatrician's Journey into Autonomics

Chasing the Moon: A Pediatrician's Journey into Autonomics

I am a pediatrician in practice for the last 20 years, and have encountered all types of patients in different practice settings. And yet, nothing in my experience prepared me for the most challenging patient I had ever attempted to deal with, that is, my daughter.

Her first symptoms were unrecognizable as anything beyond normal childhood complaints of headache, stomachache, and tiredness. Their frequency made me wonder if they were real or fabricated, and their association with social problems at school made me feel they were due to her sensitive temperament, and her desire to avoid school. And yet, even at this time, certain unusual behaviors like her refusal to put any effort into relay running on a very warm school sports day, should have alerted me to something more going on. Increasing moodiness, development of body image problems and an eating disorder convinced me that they were not organic in origin, and I thought to improve the situation with counseling. Even in the face of a history of fainting in a locker room at Junior High with a loss of urine, my assessment was that she was trying to get out of gym, and I made sure to bring her back to school after changing clothes. Nothing in my medical training had prepared me to diagnose or treat an autonomic disorder or the myriad of symptoms related to it.

Over the next few years, other than difficulty in getting up and inability to eat in the mornings, the onset of migraines, and premenstrual moodiness, my daughter's life seemed quite ordinary, and she enjoyed both academic and musical successes. High school followed suit until a suicide threat alerted us to the fact that in addition to her untreated ADD and eating disorder, she was depressed. Specialists helped in beginning her on medications, but unknown to me at this time, she was beginning to have feelings of dizziness regularly, and occasionally would pass out after speech and debate tournaments. She took great pains to disguise these episodes. Symptoms of tiredness, dizziness and fainting increased especially as a counselor at an overnight camp, where waiting on tables in the heat was required. Despite medication to elevate her blood pressure, given by a specialist, her camp experience had to be cut short due to an exacerbation of the feelings of depression. In retrospect, if one's blood pressure is low enough to feel at best tired all the time, and at worst, fainting, it is not difficult to imagine how depression would almost be inevitable. During that summer our daughter came with us on a trip to Washington, D.C. On one of the warmest days of the summer, she became unresponsive on a subway immediately before our stop. Several family members were

able to pull her off the subway, and lay her on a nearby bench in the station. It took about an hour to get her alert enough to take her blood pressure medicine, and then able to stand up and climb the subway stairs. The rest of the summer was spent on the sofa.

In eleventh grade, all of these problems were foreshadowed by the suicide death of my daughter's best friend. She dropped out of school for a few weeks, and replaced me on a trip to Europe with her father. She had daily calls from her therapist, and was allowed to cry in her counselor's office anytime of day, but despite these measures, depression and migraine frequency increased and were followed by a crescendo in symptoms related to fainting, especially during choir. This was a particular problem during a choir trip to New York City when I was called at 10 PM on a Thursday night to pick her up from New York due to an episode of fainting at the next to the last concert. The director agreed to have her continue touring New York if she would not participate in the last concert, and I would fax an agreement that he would not be held responsible for any injury she might incur with subsequent fainting. This worked except that the director yelled at her on the bus about bringing the choir down, and several of her "friends" stopped talking to her because they were convinced she had fainted on purpose.

That summer was spent completing correspondence courses she needed to make up for courses she failed, and lying on the sofa. A few times I encouraged her to swim. This was the only activity she could sometimes tolerate (probably because the water pressure prevented her blood pressure from plummeting too low.) Once, however, the water pressure did not prevent her gradual loss of blood pressure, and I remember trying to lift a body, which was almost twice my weight, out of the water, and at the same time trying not to cause her embarrassment. Once on a particularly hot day, she walked a short block to the swim club, only to collapse upon entering into the building. Luckily, her method of losing consciousness was slow, so she rarely got hurt, but rather slumped to the floor, often leaning against a wall.

That summer introduced the most symptomatic school year of my daughter's illness, and the most trying for me. She began to faint at school daily, and both of us became a regular fixture at the school office. I tried to discourage calling the paramedics after the first few times, because there was no treatment they could offer her better than time and her blood pressure medicine. I stocked the office with Gatorade, and she frequented the office cot for long periods of time. We were privileged to have a doctor who educated the office staff about her disorder and a very responsive principal, who was willing to go all over the school with a wheelchair to retrieve her. One of the only humorous episodes of that period was watching an office worker running with a saltshaker toward my daughter who had fainted in the school theater. Her doctor had instructed the office that salt and fluids could help her recuperate from episodes of syncope, and the office took it seriously. Her migraines were so severe that only injectable medicine would relieve them and so frequent during this period that she was missing 1-2 days a week because of them. Inevitably, after their occurrence her problems with syncope would last all day instead of just in the A.M. It became more and more difficult to get my daughter up in the A.M. without fainting, and our ritual consisted of a blood pressure pill, 45 minutes before she had to get up and placing her feet higher than her head to prepare her body to

stand up to get her clothes. Some mornings she simply could not get up, or she would, and then I would find her either on the floor or in her bed unconscious. When she did get to school, and I went to work, I lived in fear of the phone. I was trying to take care of patients, but could make no headway helping my own daughter. . Just when I thought of a solution to one problem, another would come up. I felt I would have had as much success chasing the moon as I was having in managing my daughter's illness.

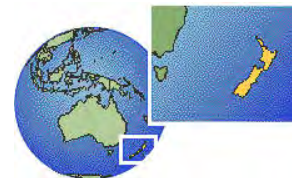
I finally met with the principal to brainstorm ways in which we could help her deal with her illness, and yet get the requirements for graduation. He decided to pull her out of choir, and offer her correspondence courses for the AM classes. I consulted with a migraine specialist who began her on preventative medicine and a syncope specialist who suggested a medicine administered by weekly injections to elevate blood pressure in addition to the medicines she was already on. This medicine required regular blood work to monitor her blood count. Over the next few months we finally achieved results. She could go through the day without fainting and her migraines slowed, then completely stopped. She was able to graduate (she did not faint during graduation,) and begin college. She is currently thriving as a sophomore in College, living at home, and is more like a normal teen, bubbly, rebellious, and making a life for herself.

In retrospect, my daughter's illness and treatment were recognized because of my access to specialists who were knowledgeable about these disorders. I was not only unable to recognize the disorder myself, but totally clueless about treatment. Even the connections between the syncope, depression, migraines, and eating disorder came to me only later. In most locations in this country and abroad, the access to experts who can not only diagnose, but also treat autonomic disorders is severely limited. Most physicians are not trained to recognize or deal with them. Only an unusually caring principal would take the time to become educated enough to work with a parent and student in order to deal with a problem so disruptive to the school. In order to increase these patients' access to appropriate health care in this country, we need a far greater effort devoted to research and to educate physicians, especially family doctors and pediatricians about these disorders. We need to develop training programs for specialists who can adequately treat them. We need to create informational materials for schools so they can deal with the acute problems, as well as the larger issue of offering these students programs that will enable them to succeed. No child should have to contend with teachers or students belittling them because of ignorance about autonomic disorders. And lastly, we need to offer education to the public, so parents can recognize these problems, know where to go for help, and serve as advocates for their children in guiding them through a medical system which has been up to this point largely ignorant and apathetic. The field of autonomic disorders is new to medicine, but can be quite incapacitating for patients and families. Not all patients are as fortunate as my daughter in finding appropriate and effective treatment for their disorders, but we need to help as many as we can gain access to specialists, and find peer and parental support with groups like DYNA.

When you are a mother, you are never really alone in your thoughts. A mother always has to think twice, once for herself and once for her child.

~Sophia Loren, Women and Beauty

"I Am a Teenage Dysautonomic"



A special regular feature on a DYNA youth member

Sophie Hicks, Age 17
New Zealand. Diagnosed with POTS

To The Limits Of My Soul and Back Again

Hi, my name is Sophie, I'm 18, and from New Zealand. I was DYNA's first member from overseas. This is my story:

I was always someone who liked to be busy. Drama, theatre, sports, choir, netball, softball, flute and singing lessons, debating, jazz-ballet, theatre productions, volunteer work in the form of netball coaching and umpiring...I did those things regularly, and although life was full to bursting at most times, I loved it. But none of those things could ever prepare me for what I would go through next.

About half way through my fifth form year of school, when I was 15, I started fainting, and having weird pains in my chest. These symptoms didn't bother me much, and I continued with school and everything else. By the end of fifth form though, I was fainting a lot more, and was sent by my doctor to see a cardiologist. I got the usual cardio tests done, Holter monitors, treadmill tests, ultrasounds, the works. Nothing was really wrong, my heart looked fine, although in the tilt table test I had, I passed out in under 5 minutes, an Auckland (New Zealand) record they told me.

So I moved on and was basically told the fainting would go away and that "tall, slim girls at my age did have a tendency to faint," and not to worry about it.

It wasn't that easy. I kept getting worse and worse, and the day after my Birthday, on May the 2nd 2002, I ended up going to hospital by ambulance with bad chest pain. Shortly after that, I took my mid year exams, and had to stop school. I was fainting, feeling dizzy, getting bad joint pain, had constant head and jaw pain, had bad stomach problems (like cramping, and having nausea and diarrhea), and was always tired and had a million other symptoms. The worst symptom at

that stage though was my chest pains. They would be so severe they would put me on the ground and I would just scream. They would last 20 to 40 minutes and after that I would blackout and not come around for 20 minutes. For about 4 months, I had three of these chest pains a day. Truthfully, I'm not sure how I survived that period, both physically and mentally.

I went to cardiologists, neurologists, physiologists, gastroenterologists, endocrinologists, G.P.'s, everything. I had ultrasounds, an MRI, a bone scan, a gastroscopy, esophageal manometry, hospital monitoring, EEG's, ECG's, Video EEG's, and a million other tests. It was always the same, they couldn't find anything structurally wrong, and everything looked to be in working order. I appreciated the honesty of the doctors who told me that they were sorry, but they could not find anything wrong and it was out of their expertise. I did not appreciate some of the other doctor's comments. They said I was crazy, had overbearing parents, and basically hurt me so much. I remember in hospital this doctor telling me that it was all in my head, and I just burst into tears.

It's not fun being undiagnosed. People don't know what you have, so they don't know if they should believe you or not. You feel paranoid, like everyone is against you. You feel really scared, because you have no idea what you have or how to treat it. You have to be subjected to lots of testing and drug trials. And all the while that this is going on your trying to deal with your symptoms and your pain. Invisible illnesses are difficult because you don't know how someone feels, unless they faint or have something you can visibly see.



When you stop doing all the things you used to do as well, it feels like you lose your personality, that you lose who you are. I think this is one of the hardest things I had to deal with. I always thought the things I did defined me. I had no idea who I was when I lost those things. It took me awhile, but I can look back on that period and laugh. The things you do don't define you, it is the person you are. That was a huge turning point for me; it made me feel a lot better emotionally.

To make a long story shorter, in about June of 2003 I was finally diagnosed with dysautonomia. I was so relieved to have a name for what was going on, and that doctors couldn't say I was crazy anymore. I remember searching for more information on dysautonomia and finding the DYNA website. I sat there, reading all these stories from people just like me, and just bawled at the computer screen, knowing I wasn't alone anymore. When I joined



DYNA, it was like a whole new world had opened up. There were all these people who was so lovely, and we could just talk and talk and I would feel like they completely understood me. It didn't matter that I was over the other side of the world from them, they made me feel like they were right next door. I've been with DYNA for over 2 years now, and I am so thankful for all the support I've gotten. I now co-ordinate the DYNA Youth Dysautonomia Awareness Committee too, and that is fantastic.

Before and after I was diagnosed, I went through lots of emotional stages. I was in denial sometimes, other times I would accept my illness, other times I would try and bargain with my body or some other higher force and other times I would just grieve for all the freedom and things I had lost. I would get angry too, and would feel jealous of all my friends at school. I went through a stage where I was really depressed and wondered why I was living. . It is so normal to go through these things though, it is just part of the grief process. Sometimes you think you have gotten through it, and then suddenly you go back into another phase. That's cool though, it's just all part of it, and you have to go with the flow and not fight it.

I'm happy to say my chest pains are a lot better now. Instead of three a day, I get one to two a week. I still faint, get dizzy, have bad headaches, fatigue easily, have the most incredible joint pain, get all sorts of stomach problems, get brain fog, can't regulate my body temperature properly, have vision problems etc, but I have medication and painkillers to somewhat control these things. You can't really compare symptoms with other symptoms; you just deal with them all. I have good days and bad days. Sometimes my body won't let me get out of bed, but other days I can get up, and even go out, which is fantastic.

I am currently studying early childhood education through online university. My dream is to be a primary school teacher or a speech therapist, maybe both. I have set up a support website for people with illnesses and disabilities and their families and friends, and I am amazed every day at the people I hear from. They are so inspiring. I still love drama, and you better believe I will get back on that stage. I love hanging out with my boyfriend and good friends, swimming when I'm able to, taking photos, making jewelry and crafting, and doing a bunch of other things.

Having dysautonomia has pushed me to the very limits of my soul, and while I would love to be well again, I don't think I would change

my experience for anything. I live each day as it comes and find something to smile and laugh about everyday. I have met some of the most amazing people in DYNA, and found some of my best friends there too. I have grown so much, and discovered strength I never knew I had. I have found who are my real friends, and who aren't. I appreciate everything so much more than I ever did, and what I appreciate the most is my wonderful family. I am so amazingly blessed to have them, and they make me feel like the luckiest girl in the world.

I have learned from experience that the greater part of our happiness or misery depends on our dispositions and not on our circumstances.

~Martha Washington

SUPPORT DYNA KIDS!

**GET INVOLVED IN
DYSAUTONOMIA AWARENESS**

**ORDER DYNA
AWARENESS PRODUCTS:**

- **BRACELETES**
- **BUSINESS CARDS**
- **POST CARDS**

VISIT:

www.dynakids.org

for ordering information or email us
at: info@dynakids.org



***A Very Special Thanks
to an anonymous donor***

for the extremely kind donation
that was made
in honor of
Debbie Dominelli & DYNA.

This donation was placed toward the
2005 Summer Chill and various operating
expenses. We could not have done it
without you!

Thank You!

Teaching Children with Dysautonomia



Professional Contributor

Liz Hunsaker, Home Teacher
Charles County Maryland

I have been a home teacher for chronically ill students in Maryland for the past fifteen years. Even though I feel that I am an experienced teacher of homebound students, I feel that I have learned a lot from the time I have spent with two students with POTS that I have been privileged to teach for the past five years.

Educating a child with a chronic condition such as POTS, which is not well known and not often visibly apparent to those on the outside requires a lot of understanding and communication, flexibility and patience. POTS children typically have limited energy and difficulty in walking, standing or sitting for long periods of time. They experience brain fog, and although they are very bright, they have difficulty concentrating for long periods of time.

Through my experiences as a home teacher I have learned that each child with a chronic illness is unique and has their own limitations and capabilities. Children with POTS in particular have symptoms that can be unpredictable and fluctuating, so as their teacher you must be flexible and ready to adapt yourself to their feelings and symptoms.

The following are some suggestions that I would like to give to other educators of home bound POTS students:

- Make sure that a 504 plan for the student (or IEP if that is what your school system recommends) is established. Make sure the plan is flexible and adaptable.
- Open and supportive communication is essential in order to fully understand your particular student's health issues and energy levels.
- Do not overextend your student. Remember that sitting and doing lessons may be very draining a POTS student, so you may try short lesson sessions. Watch for signs of fatigue (yawning and color changes).
- Remember that your student has good and bad days, and may not always be able to complete the work that you assign. Often he or she may only have a small window of opportunity even on good day.
- Remember also that the student's condition is invisible. Trust the student if he or she tells you that he has had enough and needs to take a break or stop for the day.
- Concentrate your lesson on the essentials, and don't waste precious time and energy on nonessential work.

- Barometric changes often impact these students. Winter can especially be hard on these children, and they should not be exposed to colds and flu's. You should cancel lessons if you are sick and may expose your student to germs.
- Your student is heat intolerant and needs a well air conditioned room.
- Allow your student to drink fluids and snack during your lessons, since it is helpful in maintaining their energy level.
- If necessary allow your POTS student to elevate their feet or lie down during lessons.
- If it is difficult to meet with your student because of fluctuations in his or her illness, find creative ways to work with him or her (such a telephone sessions).
- If possible, and acceptable to the family, extend lessons through the summer months to keep the student on track.
- Remember that maintaining a social life, and pursuing hobbies and interests are essential to a fuller life for these students. Be understanding if your student feels drained after a social event or physical activity. Help the student find the right balance and work with the family for the best interest of the child.
- Recognize that the family is under ongoing stress, and do try to be compassionate and supportive.
- Above all do not judge.

Through my experiences with students with POTS I have discovered that they are exceptional and creative students, and it has truly been enjoyable to teach them. The home teacher can play such a tremendous role in the lives of these often very isolated children. If you are a flexible, compassionate, and creative teacher you can make such a difference in the lives of these special children, and you may find your own life brightened and enlightened at the same time.



“What lies behind us and what lies before us are small matters compared to what lies within us.”

~Ralph Waldo Emerson

Communicating With Your Physician



Regular communications with our dysautonomia physician is critical to your child's well-being and care. Part of regular communication occurs at your child's doctors appointments. Sometimes you will also need to call the doctor for quick feed-back. Sometimes 'faxing' the doctor can be a helpful tool for maintaining communication and contact.

- Faxing the doctor can be useful when you have a question that does not require the doctor's immediate attention or in the circumstance when leaving a message with the receptionist is not optimal. Think of the fax as a way to be certain that your words are used to convey the essential message of your child's situation to the doctor without a clerk 'translating' your words.
- Faxing the doctor is also useful when your child's circumstances are status quo and don't require immediate assistance from the doctor. Doctors often like communication via fax as they don't get tied up on long telephone conversations and they have all the necessary information in writing to review and place in your child's file.
- Remember, doctors are also happy to know when your child is doing well and when the recommended treatment is producing positive results. A fax update can simply be good news, perhaps in circumstances when you haven't needed to speak with the doctor in a while and just want to bring them up to par on the situation.

Faxes are meant to efficiently and economically relay your information to the doctor. Time is valuable to all of us. If you respect the physician's time, you are more likely to receive reciprocation. A fax should be neat, short, and to-the-point. It doesn't need to be typed. Although a fax is a quick communication, it's always wise to remember the 'magic words' of please and thank you. Polite communications always work to your advantage.

It's always good policy to keep copies of your written communications with your physician. After you have sent the fax, it's a good idea to make sure it was received in the physician's office. You can call the office, checking to see that it was received. For your records, write down the name (and time) of the person who received the fax and follow through with that individual to make sure the doctor receives it. Keep a copy for your file, and you will have a 'journal' of your written communications with the doctor. You may want to also keep a copy for your general practitioner or pediatrician as well.

DYNA has organized a standardized format for physician communication faxes for your convenience. The fax form is attached in this newsletter for you to make copies of and utilize. Please refer to our web site: www.dynakids.org for additional information and to view sample fax wording recommendations (see the What is Dysautonomia page).

"I'm a great believer that any tool that enhances communication has profound effects in terms of how people can learn from each other, and how they can achieve the kind of freedom that they're interested in."

Bill Gates



PHYSICIAN COMMUNICATIONS FAX

“A Ray of Hope”

Additional Fax Forms available on: www.dynakids.org

FAX TO:

DATE:

FROM:

SUBJECT:

COURSE OF ACTION:

COMMENTS:



Where Have You Gone?

~Kris Brott

You were the one who never stopped,
Playing ball from dawn to dark.

Never one to second-guess,
You went ahead before the rest.

You were the one who was so cool,
You were the one who ruled the school.

But then this came,
There was a change.

The ball stopped bouncing,
Your shadow gone.

Your confidence faded,
Your laughter small.

Can't be the same,
even with old friends.
Will this darkness ever end?

Who you were, it was so strong,
I know you won't be gone for long.

Look deep inside and you will find,
The strength you need to once again shine.

*If a friend is in trouble, don't annoy him by
asking him if there's anything you can do.
Think of something appropriate and do it.*

~E.W. Howe

I Think to Myself

~Heather Savelle

I think to myself, 'I could have been an actress.' Then I realize I don't actually think that any more. When I was little I went to an acting camp and loved it. But now I think of acting and I think 'I could never stand that long or wake up that early'. I could never remember all those lines or look that pretty. I know acting is not my dream. Then I think about it, what if it was? What if my brain has convinced me otherwise because I simply can't do it? I watch TV and I see someone running, standing up so quickly and dashing out the door. I can't do that. I sit up slow and wander to the kitchen or the bathroom. The only thing I dash is salt on my food. I don't know what my dreams are, there is a cloud lingering in the way. I can't see past it, I can't see around it. I feel no breeze, nothing promising to dissolve the cloud. Eventually it must rain harder, it will pour, and my world will be flooded. I have faith, when I look up I will see all the colors of my life painted in a rainbow across the sky. It will be there and I will be waiting. I have faith that I won't drown before the sun comes, before the colors show their beautiful faces. I'm waiting for that wondrous day when I can say "I know how bad it was then, but look how *good* it is now"

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



Glass Pain

~Sophie Hicks

*I do
I try and rearrange the fragments
into a whole glass pane
Pushing prodding poking
Always having some stick out
That cut me
That make me feel pain
That make me cry and cry*

*I still do though
I push them in
I will them in
I drain my body to get them in
It makes me feel so alone
sometimes
And it hurts so much*

*I still do though
I rearrange them
Change them
Reshape them
Mold them.
They stick out
The effort makes me fall to the floor
I still do though*

*Sometimes I throw it,
shattering them again
Making them break into a million
pieces
I get so angry with myself
When I do it.
But then I see the light reflect broken
rainbows off the fragments
And I pick myself up again
And keep on rearranging
In hope that one day I will see it
complete.*

POTS
spelled backwards
spells:



Sara E.

***A VERY SPECIAL THANKS
TO:
Mrs. Margaret Keifer
for her continued support.***

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.

THANK YOU FOR SHOWING YOUR SUPPORT

DONATIONS FROM JULY 2, 2004 - JUNE 30, 2005

In Honor of Physicians:

Hasan Abdallah, MD
Children's Heart Clinic
Mr. & Mrs. Bradford Baumann

Blair P. Grubb, MD
Karen Krusich
Marshal & Tamar Granor

In Honor of DYNA:

Blair P. Grubb, MD
Barbara Straus, MD
Esther S. Miller
Becky King

In Honor of the following:

Abel, Ally
Mr. & Mrs. Charles Abel

Baumann, Katherine
Mr. & Mrs. Bradford Baumann

Beal, Josh
Laura & Eric Beal

Bellman, Katie
Mr. & Mrs. Mike Bellman

Bennett, Christine
Mr. & Mrs. Thomas Bennett

Beverly, Kellie
Bredlow-Utesch Helping Hand
Fund

Bibbs, Mary
William C. Bannerman
Foundation
Mr. & Mrs. William D. Frost

Blaicher, Katie
Elaine M. Blaicher

Blaker, Whitney
Ross & Cheryl Blaker

Boehnen, Lindsey
Mr. & Mrs. Dan Boehnen

Brott, Cole
Mr. & Mrs. Spencer Brott

Dane, Sarina
Perry Dane

Davis, Angela
Kenneth & Wanda Lewis

Drauss, Chelsea
Sandra Drauss

Dominelli, Mandy
Antoine Doumit, DMD
Julie G. Reybold, PC
Mike Ausley
JoAnne Kohut
Dinah Christopher
Mary P. Chance
Mr. & Mrs. Adrian Appleyard

Dominelli, Debbie & DYNA
An anonymous donor

Douglas, DeAnn
Deborah J. Watts

Douglas, Melissa
Mr. & Mrs. Gary Douglas
Mrs. Margaret Keifer

Elliott, Katherine
Ronda Hipwell

Gallina, Alex
Mr. & Mrs. Michael Gallina
Theresa M. Chabot

Gerdel, Brian
Mr. & Mrs. Ron Gerdel

Gonzales, Gene & Julie
Joan L. Giammona

Gordon, Daniel
Michael & Cheryl Gordon

Graff, Stephanie
Mr. & Mrs. Ervin Oberschmidt

Hetrick, Susie
Betty Koppus

Hetrick, Marvin
Anita Manzeck
Don & Linda Woodmansee & Fmy.
Kent & Kathy Anderson & Family

Hicks, Sophie
Mr. & Mrs. John Hicks

Hoffer, Robert
Mr. & Mrs. James Hoffer

Husbey, Megan
Jon & Deb Huseby

Jones, Ashli
VYANET Operating Group, Inc.

Jazwiak, Abbey & Anna
Mr. & Mrs. James Jazwiak

King, Becky
Mr. & Mrs. Raymond King
Greater Waldorf Jaycees, Inc.

Kingsley-Burt, Chloe
Karen Kingsley & Charles Burt

Krusich, Leah
Stephen C. & Karen B. Krusich

Logan, Caitlin
Joseph & Deborah

Longden, Amy
Peter & Helene Longden

Malecki, Melody
David & Nancy Melecki

Merhaut, Julie
Matthew J. Merhaut

McCrary, Meghan
Mr. & Mrs. Dennis P. McCrary

Myslenski, Andrea
Mr. & Mrs. Douglas Myslenski
Chad & Tania Gordon

Napier, Nick
Napier, Samantha
Mr. & Mrs. Sam Napier

Nitis, Juliana
Gregory & Caren Nitis

O'Donnell, Kathleen
Beth O'Donnell

Romito, Kasey
Mr. & Mrs. Robert Romito

Parvone, Nichole
Margaret Parvone

Peckham, Elizabeth
Mr. & Mrs. Steven L. Peckham

Phillips, Samantha
Mr. & Mrs. Larry Phillips
Tommie & Dwayne Glanton
LYNX Support Specialist, Inc.
Lisa Glanton
Roger Brown

Smith, Kendra
Ronald & Grace Smith

Savelle, Heather
Donna Savelle

Simmons, Alexa
Scott & Angela Simmons

Singer, Diana
Richard & Wanda Singer

Stiles, Jay
Kevin, Teresa, Alyssa, Katie,
Schroeder

Sutton, Lily
CJ Jensen
Old Bay Steamer, Inc.

Schardt, Lindsey
Mr. & Mrs. David Schardt
Linda McCarthy

Shrake, Amanda
Carol Zuber
Joanne Miller
Paul & Jimmie Barefoot
Richard & Dorothy Krabbe
Debra Malloy
Dorothy J. Berlin
Robert & Maura Kelly

Swan, Kristin
Steve & Karen Swan Family
Betsy & Geno Pichette Family
Harlon & Fran Laney

Taylor, Jessica
Mr. & Mrs. James Taylor
Bob & Marie Taylor
Robert M. Taylor

Thomas, Heather
Cathy Thomas

Vidnovic, Loren
Nick & Janet Vidnovic

Winter, Caroline & Katherine
Mr. & Mrs. Robert J. Winter, Jr.
Alan & Sally Winter

Wood, Tim
Edward & Alice Wood

In Memory of:

Isabelle Harelik
Mel & Karol Chinitz

In Honor of Anniversaries:

Chinitz, Ben & Lillian 64th
Anniversary
Chinitz Mel & Karol Chinitz

Meadow, Isa & Steve
50th Anniversary
Mel & Karol Chinitz

Rubin. Sandra - Bat Mitzvah

Ricki & Steuart Schuster
Mark & Pam Carmain
Pamela Royal
Donna & Rusty Hinds
Bob & Peggy Gordon
David & Shelly Edelstein
Kay Krebs
Sadie Schneider
Josef & Gloria Brown
Neil Beckerman
Cathi Miller
Alan & Harriet Schwartz
Greg and Ann Gallagher
Tina & Neal Kurzner
Lauren & Jeff Friedman
Carolyn & Arthur Rubin
Sherry, Ken, & Gillian Levy
Christine Schmitz
Stephanie & Brad Klein
Forrest & Robin Bugge
Lawrence & Susan Kellner
Rose & Alan Taper
Phil Berman, MD & Elly Berman
Bobby & Sondee Hatcher
Jan & David Feinstein
Debbie & Howe Stein
Julie Tipps
Mr. & Mrs. Marvin Kay
Janice Rubin & Charles Wise
Ira & Karl Krause
Michael & Davi Hopkovitz
Helene, Dror, & Jonathan Zadok
John & Michelle Beerbower
Richard & Shirley Landers
Alac & Dana Rubin
Andrea "Obbie" Kay
Wendy, Rob, Gabby,
Samantha, Jessica, Michael &
Marcus

***Multiple Donations are
listed in order of date received.**

**DONATIONS LISTED IN THIS
EDITION ARE FROM
JULY 2, 2004 - JUNE 30, 2005**

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 must 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 provide a **Postal Outreach Program** for children without the Internet. The highlight of the year is our Summer Chill which is a causal and private social event for our members in July.

DYNA believes in empowering our youth by providing them with the necessary tools to become active participates 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

1301 Greengate Court
Waldorf, MD 20601

My name: _____

My address: _____

Telephone: _____

E-mail: _____

Check any that apply:

* 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: _____

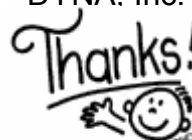
Address: _____

Please notify the above individual of my donation:

_____yes _____no

Please donate by check payable to:

DYNA, Inc.



Join DYNA

DYNA believes in empowering youth with dysautonomia conditions!

DYNA youth are active advocates for individuals with dysautonomia conditions world wide.

DYNA puts young people with dysautonomia in touch with each other.

DYNA works very hard to support youth with dysautonomia and to bring about awareness of these conditions.



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.

Mailing Address:



DYNA

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



All articles original to this newsletter may be reproduced without prior permission only if proper credit is given to contributor of the article(s) as well as to the
Dysautonomia Youth Network of America, Inc.



DYNA SUMMER CHILL 2005

Dulles, Virginia
July 7, 8, 9



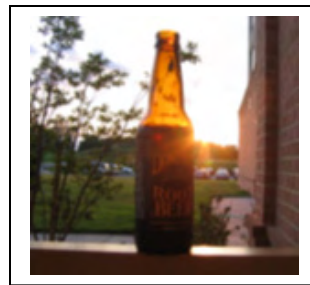
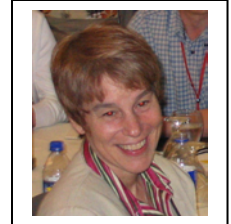
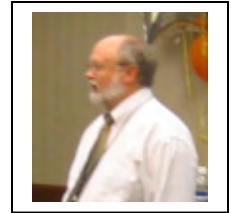
SPECIAL THANKS TO:

OUR SPEAKERS:

Blair P. Grubb, MD
Medical University of Ohio
Toledo, Ohio

Hasan Abdallah, MD
Children's Heart Clinic
Sterling, Virginia

Ken Davis, Ph.D.
Toledo, Ohio



LOCAL SPONSORS:

Mr. & Mrs. Bill Christopher

Dollar Rental Car
Mr. John Schwartz
Dulles, Virginia

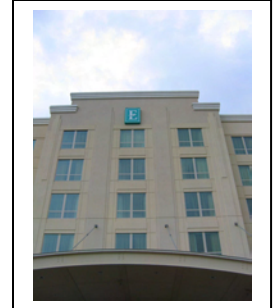
Embassy Suites - North
Dulles, Virginia

Loudoun County Convention
& Visitors Association
Mrs. Michelle Adle
Leesburg, Virginia

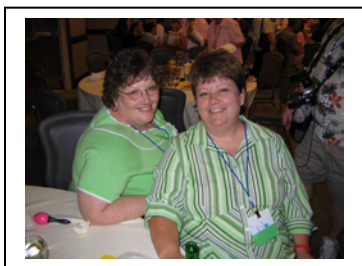
Old Dominion Brewing Company
Mr. John Solomon
Ashburn, Virginia

Reston Limousine
Sterling, Virginia

Wegmans Food Market, Inc.
Sterling, Virginia



Tax deductible donations to help make the
DYNA Summer Chill event possible
are graciously accepted.
Checks should be made out to:
DYNA, Inc.
1301 Greengate Court, Waldorf, MD 20601



The Future

~Katie Blaicher

*What was - is only a memory to me,
Distant, yet all too clear.
Now I am burying that memory
Of what I once knew,
For time has caused change,
And it is no longer the same.*

*What shall be- remains a mystery to me,
Waiting to be revealed.
Like a flower bud in the evening,
Anticipating morning when it will bloom;
I am looking to the future,
Waiting for it to unfold before me.*

*A Special Thanks
to the
William C. Bannerman
Foundation*

*NORMAL is nothing more than a cycle
in a washing machine.*

~Whoopi Goldberg

SPREADING AWARENESS

See RESOURCES page at www.dynakids.org for links.

Loudoun County Times-Mirror

Article:

http://www.zwire.com/site/tab1.cfm?newsid=14887046&BRD=2553&PAG=461&dept_id=506037&rft=6

Monroe News - Article:

http://www.monroenews.com/articles/2005/06/21/your_health/health01.txt



Changes

~Isabel

*My life has changed.
My body will not allow me to run and play anymore.
I can no longer dance.
I cannot walk far.
Some days I can't even stand.
Most night's sleep evades me.
I toss, I turn
Isolated and alone.
My childhood was lost in this horrible illness.*

*At first I was very scared.
I didn't know what was wrong with my body.
It was terrifying.
Finally, I found a doctor who knew.
He has helped me find my way
I now know about heart rates and blood pressures.
I now know about medications and life-style modifications
I now KNOW what truly matters in life.*

*Because of dysautonomia my life has forever changed.
The pain of my illness has been tremendous
But the pain of your rejection has been worse
You were not there for me.
I understand that you were blind at first – you did not know
But what is your excuse now?
Where are you now?*

HINT FOR OUR PEDIATRICIANS AND OUR FAMILY PRACTICE PHYSICIANS

Avoid keeping dysautonomia patients waiting in your waiting room. Being upright, the exposure to germs, the noise etc. all place a toll on their systems. Establish an office procedure that always takes these patients back to an empty exam room or other suitable location where they will have the privacy to lie down or sit in a quiet area while waiting their turn to be seen. Make a note stating this policy on their chart so all staff members automatically know.

IT REALLY HELPS!

DYNA Dysautonomia Awareness Bracelet Order Form

- * Each bracelet is \$4.00 (which includes postage and handling). Please pay by check or money order made out to DYNA, Inc. 1301 Greengate Court, Waldorf, MD 20601.
- * Adult size is around 7 inches in circumference
- * Youth size is around 6 inches in circumference.
- * Orders do not get recorded as donations. These are priced to promote awareness not to raise funds. Donations must be sent in separately.

PLEASE PRINT CLEARLY

Name: _____

Address: _____

Phone Number: _____

Email Address: _____

Number of Adult Bracelets Ordered: _____

Number of Youth Bracelets Ordered: _____

Total Number of Bracelets Ordered: _____ x \$4.00 =

Total Amount Enclosed: \$ _____

Please feel free to print the below information and distribute.

“A Ray of Hope” Dysautonomia Awareness

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 that regulates all of the unconscious functions of our bodies. This includes our cardiovascular system, gastrointestinal system, urinary system, and endocrine system along with many other functions such as metabolic processes, temperature regulation, respiration, etc. Orthostatic intolerance (the inability to remain upright) is a hallmark of multiple forms of dysautonomia. Each dysautonomia case is unique. Symptoms range from mild to debilitating, and on rare occasions can be life threatening. 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.

Please visit our web site at www.dynakids.org to learn more about dysautonomia.

DYNA Inc. 1301 Greengate Court, Waldorf, MD 20601 301-705-6995 info@dynakids.org

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

"A Ray of Hope"
www.dynakids.org

MAIL TO:



A large empty rectangular box intended for a mailing address.

*I have learned from experience that the greater part of our happiness or misery
depends on our dispositions and not on our circumstances.*

~Martha Washington