"A
Ray
of
Hope"

Dysautonomia Youth Network of America, Inc.

"The Young and the Dizzy" Newsletter

Summer Edition 2003

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, palpations, 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, cognative impairment, visual bluring or tunneling, and migraines.
For more about dysautonomia see our web site: www.dynakids.org.

PICTURED: **Blair P. Grubb, MD and some DYNA members at our Summer Chill 2003 "Goofy Slipper Lecture" on Dysautonomia.**

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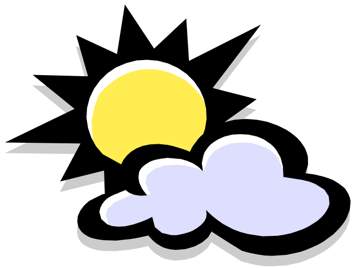

WHAT DYNA MEMBERS SAY

"The degree of mutual understanding and support that can come from shared experiences is incredible. The first time I "met" someone from this network we "talked" online for hours. In many aspects I felt like I had found a long lost sister."

Melissa, 22, MD

"I am grateful that now kids diagnosed with (dysautonomia) have a place to turn to for support. It truly helps to know others who are dealing with the same thing. I will always cherish the friendships I have developed during this phase in my life."

Jenni, 19, OH

"What was really great was when I found kids like me that I could write to and talk to. …Knowing that other kids are out there, just like me, suffering with this and understanding, makes it easier for me to get through another day."

Meg, 12, NY

"When I got my first newsletter and read the story of another girl my age, tears filled my eyes. It sounded so much like what I was going through. I e-mailed her right away and since then I have made countless friends through DYNA."

Katie, 17, TX

"I thought I was the only one with this disability until I became a member of DYNA. Some of the people I know are now my best friends."

Mary, 13, IL

"I have good days and bad days. None of my days are like they used to be before I got sick. Everything I do impacts my POTS. I am not going to let it take away what life I can have though. I am working hard at reconditioning and doing the best I can to still be a kid. It helps to know that I am not alone and it helps to have the friends I have made through DYNA."

Mandy, 12, MD

Directly Speaking

THE BALANCING ACT

For young people impacted with dysautonomia, dealing with their illness, maintaining friendships and "just being an everyday kid" can be a constant and stressful balancing act.

Quite often a dysautonomia patient can only handle a certain amount of activity on a given day. Usually, the activity they do today will impact how they feel tomorrow. Their symptoms are varied and impact every aspect of their lives. For the most part, the only predictable thing about their conditions is that they are totally unpredictable! Most dysautonomia patients never know how they are going to feel on a given day and at a given moment. For many of these patients, how they feel can literally change in a heartbeat. Dysautonomia children must constantly work their childhood around their "good days" and their "bad days" and deal with the on-going stress of their conditions along with the everyday stress of normal childhood. To complicate things even more, when one is dealing with a condition like dysautonomia, even things like the weather are known to impact the symptoms so the balancing act is even more difficult to maintain.

Getting schools, friends, and neighbors etc. to understand such a condition is often very frustrating for everyone involved. These illnesses are not well known and are not visible on the outside. People can't just see heart rate and blood pressure changes by looking at an individual and most of us cannot relate to what it feels like to have such impacting and often disabling symptoms. Communication is essential to bringing about awareness and on-going support for these families. Dysautonomia parents and children will need to become their own advocates.

The changes and adaptations of dealing with any chronic childhood illness can be heartbreaking for everyone involved. Families often must reinvent their lives to accommodate the illness and everyone in the family is impacted. Flexibility is a must. Mistakes are inevitable. A child's chronic illness is a very tragic thing to deal with, but how you deal with it makes all the difference to the child. DYNA strives to become a part of a TEAM that works together to help maintain this delicate balancing act for children with dysautonomia. Together there is always hope.

Debra L. Dominelli.
President / Executive Director

Professional Contributors

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.

Postural Orthostatic Tachycardia Syndrome
A Description for the Young Patient

Professional Contributor

Blair P. Grubb, M.D.
Professor of Medicine and Pediatrics
Director, Cardiac Electrophysiology Services
Division of Cardiology
Medical College of Ohio

All of us tend to take for granted that when we stand up, our blood pressures and heart rates will remain stable so that we can perform whatever activity we desire. However, in dysautonomia patients this automatic regulation of blood pressure and heart rate does not occur.

Normally, when a person stands, gravity will pull a large percentage of their blood (roughly one third) to the lower half of their body. If we as human beings did not make any compensation for this pooling of blood, all of us would pass out whenever we attempted to stand. Most of us do not pass out, however, because as our blood is pulled into the lower half of our bodies, it stretches the blood vessels that are located there and the stretch is automatically calculated and measured by our brains. Our brain then commands three things to happen quickly in order to compensate: 1) It makes our heart beat faster, 2) It makes it beat more forcibly, 3) Most importantly it tells the blood vessels in the lower half of the body to constrict up to three times tighter than they had previously been. This constriction of the blood vessels pushes blood from the lower extremities of the body upward towards the brain. It happens very quickly, thus the average person can jump out of a chair or jump out of bed and not notice any of these automatic changes.

Once a person is standing or sitting, they must constantly maintain this fight against gravity. If this automatic system fails in any way, larger amounts of blood will be pulled into the lower half of the body. The blood that is in the lower half of the body is not available to circulate into the upper half, thus the brain will have ever decreasing amounts of blood and therefore less oxygen to feed it. If a person's blood pressure falls slightly, they will experience general fatigue. If it falls further, they may experience more severe fatigue and feel very lightheaded and dizzy. If it falls further still, they may lose consciousness (faint).

In some individuals, this regulating system (referred to as the autonomic nervous system or ANS) fails to operate appropriately. In some dysautonomia patients, upright posture will be characterized by an abrupt loss of consciousness because their blood pressure and heart rates fall to very low levels. In other people, however, part of the correction mechanism will work well, and parts of it will not. In some individuals their blood vessels do not constrict appropriately and their brain signals their heart to beat faster and harder in an attempt to compensate.
This attempt to compensate is inefficient and utilizes a great deal of energy. The patients often experience excessively high heart rates (tachycardia) and at the same time they would feel

extremely fatigued along with numerous other symptoms. Patients with this type of disorder are referred to as having the Postural Orthostatic Tachycardia Syndrome (POTS). This diagnosis means that their heart rate goes up extremely high when they stand. This increase in heart rate occurs as a compensation for the failure of the blood vessels in the lower half of the body to tighten. Patients suffering from POTS experience excessively high heart rates when they stand. They also suffer extreme fatigue, have exercise intolerance, and their bodies can't perform many of the normal things that other people are able to do. POTS patients tend to display numerous symptoms due to the malfunction of their autonomic nervous system (migraine, gastrointestinal etc).

POTS can appear for a variety of reasons such as following a viral infection, or a severe injury, and often occurs during rapid growth phases of adolescence. Many young people who suffer from these disorders may slowly grow out of them as time goes by. Nearly three quarters of the adolescents who begin to have problems related to the POTS will slowly improve or have their symptoms become more manageable by the time they reach young adulthood (however, a small percentage may continue to have problems and may develop additional symptoms at various stages).

Proper therapy includes making sure the patient gets enough fluid and salt in their diet. In addition, reconditioning and exercise is extremely important. Patients should work towards at least twenty minutes of aerobic exercise three times a week and should also aim to build up the strength in their lower extremities. Different medications are often prescribed and must be individualized toward the patient. For example, drugs that tighten blood vessels could help push blood back towards the brain and reduce some of the symptoms. Not every patient responds the same to the medications and patients will need to communicate closely with their physicians in order to find the right combination and balance of medications for their particular case.

Although POTS can have quite an impact on your life at various stages, with the proper support and with qualified professional medical management, the majority of people who suffer from it do manage to find ways to lead a happy life. Support and awareness from those around you is tremendously beneficial and can make all the difference.

A man was walking on a beach littered with dying starfish washed ashore at high tide.
The man bent down and gathered up starfish after starfish, carrying them back to the ocean.
Someone saw him and scoffed, "There are too many. Do you think you can save them all?
Don't be silly. What you're doing won't make a bit of difference!" The man looked down at
the little starfish struggling in his hand as he gently returned him to the life-giving sea.
"It makes all the difference to this one," he said.

Neurocardiogenic Syncope

Professional Contributor

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Neurocardiogenic Syncope (NCS), Postural Orthostatic Tachycardia Syndrome (POTS), Dysautonomia, and Vasovagal Syncope all can refer to the same phenomenon (dysautonomia). Despite what condition one has been diagnosed with, the cause and treatment are often essentially the same, and for practical purposes not being differentiated in this particular article.

NCS is most commonly discovered in adolescents and in older adults. It is essentially a failure of the brain and the cardiovascular system (blood vessels) to adequately communicate and respond to each other, therefore, it is not really a "heart defect". Because of the way people are made, it is "easiest" for blood to pool in the extremities. It requires "work" (messages sent by the brain, contraction of blood vessels, pumping of the heart) to send blood to the heart and brain. For most people this process of returning the blood to the central part of the body (vital organs and brain) works efficiently and without notice, just like breathing. However, there are a number of forces that can work against this: gravity, too little fluid in the vessels, dilation of the vessels, problems with neurotransmitters (chemicals in the brain that allow nerves to communicate) available to convey messages from the brain, and even changes in barometric pressure. In addition, people who have NCS often diurese (urinate or loose body water) more than they should. This leaves less fluid in the blood vessels.

When this process does not work well symptoms can be experienced such as: dizziness, lightheadedness, fainting, headache, neck/back pain, visual disturbances, difficulty breathing, chest pain, heart racing, sweating, feeling too hot or too cold or rapid swings in body temperature, nausea, abdominal pain, GI problems, muscle aches or pains, fatigue, depression.

Unfortunately, it is not obvious from looking at someone that they have NCS. Because there are so many factors that affect blood return to the central organs, an affected person may be fine one moment and have significant trouble the next. Also if someone has had this condition for a long time, they may not always realize that what their body does is abnormal – sort of like not noticing when your eyesight slowly deteriorates.

Many people who have NCS have been made to feel as if they are "crazy" because a doctor cannot initially find anything to explain a symptom that they are having (i.e. no infection to explain fatigue or nothing wrong with the abdomen to explain severe pain). Many doctors have little knowledge about this condition as it was not well understood until the late 1980's, and at that time, often only the most severe and obvious cases were identified – those in which people passed out frequently. Now we realize that one can have this condition without passing out.

Some people get NCS abruptly in their teenage years and it leaves just as abruptly. Some people have it "'forever" but the symptoms may wax and wane so that they are not always terribly symptomatic and therefore do not always require treatment. For some, NCS is hereditary and for others it is not. Don't be surprised if someone else in your family has some of the same symptoms you do. Not everyone has this condition to the same degree. It can range from very mild to completely incapacitating (bed ridden). There is nothing that anyone did to "cause" this and nothing that could have been done to prevent it. It just is.

There are objective ways to identify NCS besides symptoms: changes in blood pressure and/or pulse between sitting and standing (stress of gravity), and a tilt table test. The tilt table test provides prolonged gravitational stress to the cardiovascular system and eliminates some of the ways that the brain counteracts those stresses. The patient's blood pressure and pulse as well as other indicators and symptoms are monitored during this test.

Treatment consists of understanding the problem, increased salt and fluid intake, prescription medications and self-help measures. Knowing that one has this condition and what makes the symptoms better or worse is the most important step. Physical illness, psychological stress, allergies (histamine causes blood vessels to dilate), dehydration, and barometric pressure changes (including flying or high altitude) make symptoms worse.

Position is important because of gravity. Patients will experience fewer symptoms when sitting or laying down than they will experience when standing. If one is still symptomatic lying down, they should get their legs higher than the heart (prop them up on a pillow or the arm of the couch). Moving muscles helps too, because this squeezes the blood vessels and helps return the blood to the heart and brain. Good cardiovascular health is also important as it can help decrease symptoms. Regular aerobic exercise should be done for 40 minutes at least three times a week, when it can be done without creating symptoms. Patients should take warm or cool baths/showers instead of hot. Heat dilates blood vessels. Dilated blood vessels keep more blood away from the central organs therefore causing more symptoms.

People with NCS need much more fluid and salt every day than "normal" people (who need >64 oz. fluid per day). When feeling symptomatic, even additional fluid and salt is needed. Fluids are important because increased volume in the vessels allows more blood to reach the brain. It is like trying to fill a sink without having a stopper in the drain. It can be done, but it takes <u>A LOT</u> of fluid. Salt helps keep fluid in the blood vessels longer. Caffeine raises the blood pressure so it also helps get the blood back to the brain (caffeine is not tolerated well by all patients). Caffeine is also a diuretic, so it will cause you to lose extra fluids. The use of caffeine should be limited to once in the morning and perhaps when you need to feel better FAST. If the heart and kidneys are normal and healthy, extra salt and caffeine should cause no problems and will often HELP A LOT.

When NCS patients are symptomatic they should sit down and drink 20 ounces of liquid and take some salt. In 15 minutes, although symptoms won't be completely gone, they should feel much better. The sooner symptoms are treated the easier it is to make them go away. The longer they are ignored the harder it is to get rid of them (it will take A LOT more salt, fluids, etc.). The manner in which the extra salt and fluids is gotten into the system is less important than the fact that they do get into the system. One can drink soda, eat potato chips and pretzels or drink water and take salt out of their hands. It's their choice, THEY JUST NEED TO DO IT!

SEVERAL MEDICATIONS CAN BE PRESCRIBED WHICH WILL BE TAILORED TO YOUR SPECIFIC NEED:

FLORINEF

This is an alpha-adrenergic receptor sensation, which means that it helps the blood vessels return the blood to the brain. People who do not have a good intake of potassium may require a supplement while using this drug.

SSRI (Serotonin Reuptake Inhibitor)

This is a group of medications which help the serotonin balance and communication ability in the brain. Serotonin is a neurotransmitter; it controls blood pressure, heart rate, body temperature, menstrual periods, etc. Many people with NCS may not have adequate stores of serotonin. These medications help restore balance. SSRI's include: Zoloft, Prozac, Paxil, Effexor, Celexa and Lexapro. While these medications are often used to treat depression, this is NOT why they are prescribed for NCS patients. These medications are taken once a day, and take 4-6 weeks before one can see their full effect. They are started at low doses and increased as indicated.

PROAMATINE/METHYLPHENIDATE/ADDERALL

These work by causing vasoconstriction (squeezing of the blood vessels). ProAmatine does not have the stimulatory effect on the brain that Adderall and Methylphenidate do. It is not given in as high a dose as that used for people with Attention Deficit Disorder. Some people with NCS have trouble with memory and concentration - but it is controlled by treating the NCS (salt, fluids, medications). Short acting Methylphenidate, Adderall and ProAmatine have a quick onset of action. This means that they start working within 30 minutes of the time taken and stop working in approximately four hours. There are long acting versions of Methylphenidate and Adderall (but not ProAmatine) that last for 8 to 12 hours.

Biofeedback can also help many with symptom relief.

Ibuprofen has some activity against NCS, for this reason, if you tolerate Ibuprofen, this is a better choice for aches and pains than Tylenol.

Motivation is critical. When one has something important to do, adrenaline can kick in and help control symptoms.

NCS can be controlled. The more quickly one learns to recognize the symptoms and treat them appropriately, the quicker one will feel better (it takes A LOT of salt and fluid). Medication can also be added to control symptoms. It does take time to see the effects of various medications, so patience is needed. Even patients who have good symptom control will have occasional "bad days" when LOTS more salt and fluid are needed. All patients do better with support from family and friends.

Do not protect yourself by a fence,
but rather by your friends.

Czech Proverb

Understanding The Mystery of the POTS Teenager

Professional Contributor

Todd Davis, MD
Children’s Memorial Hospital
Chicago, Il

POTS (Postural Orthostatic Tachycardia Syndrome) is a mysterious illness. It is mystifying not only to the affected teenager and his/her family, but it is often equally, if not more, mystifying to acquaintances, classmates, and teachers.

Teenagers and their parents come to understand that the disease waxes and wanes. They also come to understand the complicated nature of the illness and its many paradoxical features. The many faces and features of the condition are often poorly understood by those who know the teenager with POTS. For example, 40% to 70% of children with POTS at some time or another during the disease have neurocognitive difficulties such as inability to concentrate, difficulty remembering things, and difficulty sequencing things. At the same time they may be physically active, able to walk in a mall or be out shopping with their parents. Such activities are immensely important for the psychosocial well being of the teen. Yet teachers and school administrators are often confused by seeing a teenager who appears to be perfectly well by all appearances, yet is having great difficulty at school or is unable to attend school at all.

In order to minimize conflicts with people outside of the family circle, it is imperative that parents and teenagers with POTS (to whatever extent possible), take on the task of educating others about the illness (including school personnel). For example it is extraordinarily important for a teenager with POTS to maintain as full a social life as possible. If a teenager decides to stay up late at a social activity, that is okay even if it means a small setback for the next day or two.

Most teenagers with POTS will recover. When they recover, the goal is to have them restored to full functioning. To achieve that end, everyone involved with the teen with POTS must exude compassion and understanding, and strive to know as much as they possibly can about the disease and the teen who is struggling to be rid of it.

The afternoon knows what the morning never suspected.

Swedish Proverb

“I Am a Teenage Dysautonomiac”

A special regular feature on a DYNA youth member

Sarah Semmelman, Age 15,
Pennsylvania, Diagnosed with POTS

Going into high school last year, I was full of hope and I thought*, “This is my year. I'm starting high school, and I'm going to have an awesome time!”* Of course, at the time I didn't know what I was about to endure, and how much my life would actually change. In October, I had a sudden onset of POTS. Of course, I didn't realize it was POTS then. I went from doctor to doctor, trying to figure out what was wrong with me. The doctors were not sure either, and I never seemed to get a straight answer from them. All the while, I was missing 3-4 days of school a week, and sometimes I went weeks without being able to go to school at all. I finally found out that I had POTS. I went on homebound teaching in January, and it's made things so much easier for me. Well, most things.

I never realized the people I had been friends with for so many years could turn on me so fast! Being a teenager is hard enough, but to lose your friends due to an illness that you have no control over makes you want to crawl into a hole and never come out again. Friends are supposed to be supportive and help you out. My friends never called to check on me and they never visited me. They gossiped about me behind my back. They thought that I was just making all this up for attention. I never really talk to those friends anymore. I was very hurt when they didn't stick by me. They just went on without me and never looked back. They didn’t even try to understand what my life was like with POTS. They couldn’t see that with a chronic illness like POTS I could have good days and bad days and sometimes even horrible days. They just didn’t “get it” and they never really even tried to.

People with Dysautonomia have so much to offer! Because of what we have had to endure, we can listen better than anyone. We take the time to care about others. We understand what it means to have a problem. We are supportive of our friends. We appreciate our friends and deeply value their friendship. We respect our friends.

Looking back, I'm happy I lost those “friends”. It was bound to happen sometime I guess. It took my illness for me to realize that they weren't the people I thought they were anyway. I'm a lot more careful about trusting people now and I am a lot more selective about my friends. For a while I wouldn't open up to anyone, because I figured they would think I was complaining about being sick. But I am healing now – in more ways then one.

The past few months, I've made some awesome new friends. They come to see me, and sometimes if I feel good enough to go out, we go to the movies and just have fun. I feel like “me” again. My new friends and I talk too, and they even bring my illness up and ask me how I feel. They care, they are supportive, and they try their best to understand.

Having an illness like POTS makes you realize that people are not always what you think they are and you learn what a true friend really is. It hurts when you find these things out. But I am a stronger person now and I am a better friend. I wish people would understand that just because you can't see something, it doesn't mean it isn't there. Because that's Dysautonomia.

My Gift, The Curse

By: Alex Gallina, Age 12
New York, Diagnosed with POTS

I sat up in my bedroom,
as I began to cry.
That is when I realized,
this curse may never die.

Though this may be the case,
and very very true.
I have learned some lessons,
I care to share with you.

I learned what true love is,
from my friends and family that care.
And I appreciate the fact,
that they will always be there.

I also found a strength,
I never knew I had.
That helps me go on,
when I am very sad.

All this comes in a package,
one you must unwrap.
For outside it may look like a curse,
but it's whats inside that will attract.

Everyone needs to learn these lessons,
and I am special indeed.
To be me and someone,
who learned these lessons we all need.

> *The journey of a thousand miles begins with a single step – or just by getting your behind out of bed.*
>
> *Modified Chinese Proverb*

My Thoughts

By: Krystal Linderman, Age 15
Maryland, Diagnosed with POTS

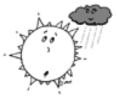
Sometimes I sit up at night
Wondering how tomorrow will be
Wondering if I'll have those symptoms
So many others can't see
They say that I'm faking it
That it can't possibly be real
But that's just because
Its something they can't feel
But then I remember
Not to worry about what they say
And I know that no matter what
I'll be okay.

DYSAUTONOMIA

By: Laura. Kline, Age 14
Pennsylvania, Diagnosed with POTS

D - Dealing
Y - Years
S - Stressful
A - Awareness
U - Understanding
T - Tragic
O - Overwhelming
N - Nuisance
O - Oblivious
M - Mysterious
I - Intolerance
A - Accepting

The Rainy Day



The day is cold, and dark, and dreary;
It rains, and the wind is never weary;
The vine still clings to the moldering wall,
But at every gust the dead leaves fall,
And the day is dark and dreary.

My Life is cold, and dark, and dreary;
It rains, and the wind is never weary;
My thoughts still cling to the
moldering past,
But the hopes of youth fall thick in the blast,
And the days are dark and dreary.

Be still, sad heart! and cease repining;
Behind the clouds is sun still shining;
Thy fate is the common fate of all,
Into each life some rain must fall,
Some days must be dark and dreary.

Longfellow

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

Preventive Technique

Crossing your legs when you have to stand still can help those that feel faint when standing. A great advantage to doing this technique is that it can be accomplished without calling any attention to your self. You can follow these simple steps to stay upright longer:

1. Cross one leg over the other while standing. Make sure that both feet are flat on the floor.

2. Tense your leg muscles. Squeeze your legs firmly together as if holding a $100 bill between your knees on a windy day.

3. Tighten your buttock and abdominal muscles. Breathe normally until your symptoms pass. Hold it for at least 30 seconds.

   If you still feel faint after stopping this maneuver, sit or lie down flat while tensing your legs, buttock, and stomach muscles.

Nothing in the world can take the place of persistence.

Talent will not; nothing is more common than unsuccessful men with talent.

Genius will not; unrewarded genius is almost a proverb.

Education will not; the world is full of educated derelicts.

Persistence and determination alone are omnipotent. The slogan, “Press on,” has solved and always will solve the problems of the human race.

Calvin Coolidge

Some people think only intellect counts: knowing how to solve problems, knowing how to get by, knowing how to identify an advantage and seize it. But the functions of intellect are insufficient without courage, love, friendship, compassion and empathy.

Dean Koontz

CONGRATULATIONS TO OUR HIGH SCHOOL GRADUATES OF 2003!

DYNA
"Ray of Hope Scholarships"

were awarded to:

Lisa Lynn Albrecht, PA

Susanna Kay Hetrick, OH

Christy Ann Lake, OH

Krystal Darlene Linderman, MD

Jessica Lauren Wahl, MI

FOR THEIR OUTSTANDING PERSEVERANCE AND FORTITUDE

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

Terry Fath / Sir Speedy Printing
Hanover, Maryland

Mr. Bob First / Farmer & First, P.C.,
Warren, Rhode Island

Jen, Francis & Al / Lattice Group, Inc.,
Kensington, Maryland

Brent Martin / Full Zoom Productions,
Toledo, Ohio

FORTITUDE:

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

PERSEVERANCE:

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

People are like stained glass windows –
their true beauty can be seen only when
there is light from within.
The darker the night;
the brighter the windows."

Elisabeth Kubler-Ross

Hats off to youth member, Susie Hetrick!

Susie unselfishly donated her hard earned winnings from her local county fair to DYNA!
Way to go Susie!

SINCERE THANKS AND

HEARTFELT APPRECIATION

TO ALL THOSE THAT MADE THE 2003

SUMMER CHILL POSSIBLE!

Special thanks to Lillian Phillips and all the DYNA parents who volunteered their time, energy and expertise to this wonderful event!

TOGETHER WE CAN MAKE A DIFFERENCE!

> *Rest is the basis of all healing.*
>
> *Father Thomas Keating*

The Phone Call

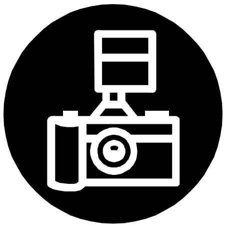
D.L. Chance

How are you doing?
I have been meaning to call.
Life keeps me busy
You know, I'm so popular and all.

I am sorry that you're sick.
You sure look fine to me.
I really don't have the time to listen.
I have places to go and people to see.

Time flies so fast.
I will try to call again someday.
I hope you feel better.
I just don't know what else I can say.

It is sad for me to talk to you.
I wish things were how they used to be.
But I can't sit around and chat right now.
The world still turns for me.



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In honor of all those with dysautonomia
Blair P. Grubb, MD

In honor of Lisa Albrecht
Mr. & Mrs. Joseph M. Roper

In honor of Mary Bibbs
William C. Bannerman Foundation
Mr. & Mrs. David Bibbs
Mrs. Margaret F. Bibbs
Mr. & Mrs. William A. Crane
Mr. & Mrs. Wm. D. Frost
John W. Link
Diane & Bob Johnson
Annette B. Peck
Max Wildman

In honor of Julie Chinitz
Mr. & Mrs. Gil Chinitz
Mr. Matthew Soifer

In honor of Mandy Dominelli
M. P. Chance
Dinah Christopher
Mr. & Mrs. Richard Dominelli

In honor of Melissa Douglas
Mr. & Mrs. Gary Douglas

In honor of Chelsea Drauss
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In honor of Brian Gerdel
Mr. & Mrs. Joseph Anderer
Mr. & Mrs. Richard Collins
Mr. & Mrs. Ronald Gerdel
Mr. & Mrs. Pat Hibson
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In honor of Stephanie Graf
Mr. & Mrs. David W. Graf

In honor of Blair P. Grubb, MD
*Mr. & Mrs. Marshall Granor

In honor of Robert Hoffer
Mr. & Mrs. James Hoffer

In honor of Laura Hornston
Mr. & Mrs. Grant Hornston

In honor of Glenn Johnson
Lt. Col. & Mrs. Larry M. Johnson

In honor of Ashli Jones
G.O. Jones & Associates, Inc.

In honor of Krystal Linderman
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In honor of Leah Master
Master Family

In honor of Brandy McReynolds
Mr. & Mrs. Ted McReynolds

In honor of Andrea Myslenski
Mr. & Mrs. Douglas Myslenski

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Mrs. Betty Phillips
Mr. & Mrs. Larry Phillips
Cindy, Terra, and Devin Phillips
Teresa Smith & Jim, Ashley, Mary, Malorie

In honor of Amanda Shrake
Waters Landing "Thunder" Swim Team

In honor of Nicolai Sand
Mr. & Mrs. Ole Sand

In honor of Jonny Timmsen
Mrs. Susan J. Miller

In honor of Jessica Wahl
Mr. & Mrs. William Wahl

In honor of DYNA High School Graduates:
A loving Grandmother who wishes to remain anonymous

MEMORIAL CONTRIBUTIONS

In Loving Memory of Jim Margolin
The Chinitz Family

In Loving Memory of "Pa" (Tommy Phillips)
Mr. & Mrs. Larry Phillips & Family

In Loving Memory of Marilyn Shuey Yark
Mr. & Mrs. Michael Killam

True Friendship

By: Jennifer Oppenheim

Last year I was getting ready to enter a new school and I was a little scared. Luckily, before school started, I was asked to come in and help the teachers get ready for the school year. I gained a lot more than confidence that day - I gained a great new friend!

I met a girl who has POTS. We started talking and having fun and from that time on we have been good friends. Because of her POTS she can't do many physical things. She is not even able to attend school full time. When she was first diagnosed she couldn't even get out of bed or stand up! She worked very hard to get better. Now she still needs to avoid some things and she still can't stand or walk for a long time. Some days are better for her than other days. Unfortunately, she can't come to school often - so the school system sends a teacher to her.

Sometimes I go over to her house to hang out with her and we play games that aren't real active. Its fun to have a friend like her because I learn new things from her all the time! She thinks of things that I never would think of. We play board games and watch TV, sometimes we just talk and have fun. We are just happy to be together.

She has taught me a lot of things. She has taught me that no matter how bad things seem there is always a way to find a bright spot. She has taught me what true friendship really is and that just being with your friend makes everything better. I am thankful that I went to school that day to help out the teachers because I came away with so much more and since then I have learned some valuable lessons. **I gained a good friend and I also became a good friend.**

"Hope" is a thing with feathers

"Hope" is the thing with feathers –
That perches in the soul –
And sings the tune without the words –
And never stops – at all –

And sweetest – in the Gale – is heard –
And sore must be the storm –
That could abash the little Bird
That kept so many warm –

I've heard it in the chillest land –
And on the strangest Sea –
Yet, never, in Extremity,
It asked a crumb – of Me.

Emily Dickinson

SPECIAL THANKS

To
ST. JUDE MEDICAL
AND
MR. MICHAEL LEVISON
FOR HOSTING OUR
"GOOFY SLIPPER LECTURE"

I
must deal with the world
as it is reacting around me
and not as I see or desire
it to be in my plots and dreams. . .

By: Brett Young, Age 16
Pennsylvania, Diagnosed with POTS

ASK THE EXPERTS

The following questions were submitted to our panel of experts.
Please feel free to send your questions to us. All questions will remain anonymous.

Q: My POTS child finds it very hard to shower or take a bath and gets very symptomatic afterwards. Can you explain why this simple act is so impacting on her symptoms?

A: Heat dilates blood vessels and causes a drop in blood pressure that will bring on symptoms for many POTS patients. This includes bath and shower water and hot tubs. POTS patients should not utilize hot tubs or spas. Another factor to consider is that most dysautonomia patients are very sensitive to temperature changes and should avoid overly warm or overly cold conditions (this means both bath water and climates). It is recommended that POTS patients take luke-warm baths and showers. Since often the combination of STANDING and WARM WATER is too much for their systems some patients find that a shower chair benefits them in showers. Many patients say that they find that they usually do better with taking their shower or bath just before bed as opposed to first thing in the morning.

Q: My 15-year-old POTS child won't go shopping with us anymore. We wanted her to go to the mall with us but she completely refused saying she didn't feel "up to it." We even offered to get her a wheelchair so we could go out as a family but she got very upset at the suggestion and was afraid her friends would see her. She says she would rather not go if she is not feeling up to walking herself. What should we do?

A: The truth is that sometimes severely impacted POTS patients do need to utilize wheelchairs when absolutely necessary (events that require lots of walking and long term standing such as getting through airports, traveling through hospital hallways, and sometimes even the necessary shopping ventures they must make). When making a decision on utilizing a wheelchair for a POTS child it is best to talk with your dysautonomia specialist. You must always take into consideration each circumstance. Remember that your child is at an age when perception or how people perceive her, is very important to her. It sounds like in this case; she would rather stay home than have her friends see her sitting in a wheelchair. We are all different in how we handle illness and we need to respect those differences, especially in children. In the long run your daughters determination to avoid the wheelchair may actually benefit her physically. Deconditioing can be a major issue for dysautonomia patients. Let her do her own walking when she feels that she can and wants to do it and trust her to know her own limits. Remember, with POTS, it could also be the fact that the noise, lights, and confusion of the mall are just too much for her delicate system right now. Respect your daughter's wishes and admire her determination. In the end her willingness to rest as needed and to walk when she possibly can may actually be a saving factor in her health.

Q: My POTS child seems to catch every cold or virus. What can I do about this?

A: Individuals with chronic illnesses are more susceptible to germs. Dysautonomia patients often experience dramatic set backs if they catch the flu or another virus. Because of this, many dysautonomia specialists recommend flu shots for their patients. You should speak to your doctor about your particular situation. You should also make sure that you take the time to inform your extended family members, friends, and home/classroom teacher(s) about the impact that catching a virus can play on your child's system. Ask them to stay away when they are sick. A mild cold for a healthy individual may mean a hospitalization for your child and many sleepless nights for everyone involved.

Rekindling the Flame

Professional Contributor

Blair P. Grubb, MD
Professor of Medicine and Pediatrics / Cardiology
The Medical College of Ohio

I really didn’t think she was going to make it. Once a bouncy and perky 7-year-old girl, who loved more than anything to dance, she slowly began to lose her stamina. With each passing day she seemed to grow more and more weak and fatigued. When she suddenly awoke in the night saying she could no longer breathe she was rushed to the local hospital. There she was found to be in florid congestive heart failure with a barely beating heart that virtually filled the whole of her chest. She was transported by helicopter to us in the middle of the night as a potential transplant candidate. She was near dead when she came. However, on arrival we found her to be in a sustained idiopathic ventricular tachycardia that appeared to be coming from the left ventricle, which had dilated her heart to a barley contracting mass of tissue. We stabilized her heart failure, but we could not keep her out of the tachycardia despite our best attempts at drug therapy. This was over a decade ago and radiofrequency ablation had just been introduced and was still considered highly experimental. We offered this to the parents as a way to stop this incessant rhythm that was destroying her heart, and with teary eyes they agreed to let us try. When I spoke to Emily, the little girl, her only question was “Will I be able to dance?’

The next day we took her to the lab and slowly and methodically mapped the tachycardia. Finally, after what seemed to be forever, we found a suitable target site. Holding the catheter tightly, with my own heart pounding in my chest, I ordered the energy turned on. The tachycardia that had nearly taken her life, and had proven so resistant to therapy, disappeared in an instant. For the first time in weeks her heart maintained its normal rhythm. For the briefest of moments, I felt a surge of sheer joy, but then quickly repressed it. “It may come back,” I thought, “she may have complications, the failure may not resolve.” When I spoke to her parents I dampened my words with phrases like “might be gone.” and “we’ll have to see what happens,” always hedging my bets against possible failure. Again for the briefest of moments I saw a flicker of fire within them, but my cautious words quickly extinguished it. The flame of passion was once again put out by my own fear of being burnt by it.

Later that day when the child was awake and back in her room I returned to check on her. Her little eyes were bright and her smile reached from ear to ear. “Am I fixed?” she asked, the words virtually bubbling out of her. The room was filled with family, and I again put on my reserved and cool exterior, remembering all to well the times in the past when things had not gone as expected, and muttered a somewhat restrained, “Yes, I hope so.” Her bright little eyes then seemed to stare into my very soul, and her innocent voice asked, “Then why aren’t you happy?”
I froze, not knowing what to say, for she had touched on the very question that all of us struggling with the strain of the every shifting landscape of modern medicine must come to face: What became of our passion, the flame that once seemed to burn so boringly within us?

Only by recognizing those emotional instances that lie hidden in the daily moments of our work do we come to understand the conflict that rages within each of us, our longing for the creative and passionate internal fire with its wondrous warmth and intensity, balanced with our innate fear of being burned by it. Finding this fire is an essential need for preserving a person's soul, for "while we believe we are merely going to work each day to earn a living, the soul is secretly locked in a life or death struggle for its own survival." Yet at the very moment, when the fire begins to glow within us, the fear comes over us. Our memories fill with every complication, bad outcome or lawsuit that we have seen or experienced. The brilliant poet and philosopher David Whyte describes these critical moments as when "the universe turns toward us, realizing we are here and about to make our mark. We hear the wild divine elements in the world hold their breath, waiting for our next move, our next word, but at last the center of real attention, we turn and take a step back…" Whyte goes on to say "That being afraid of the fire and the possibility of being burnt, we freeze everything and everyone around us so that they can neither move nor feel the warmth of their own flames that we reject those wondrous moments that offer the soul a chance for complete fulfillment. It is difficult to experience joy, the risks seem just too great and its occurrence at work may be so powerful that we can experience it as a sense or terror." We somehow prefer to be in a "comfortably numb" state of self-anesthesia with which we are more familiar. Yet there is no choice without consequences, for we simply cannot ignore our soul's fire without damaging ourselves in the process. A vital passion still smolders within us, regardless of if it is acknowledged or not. Failing to allow the fire to come forth, our souls fill with a dense toxic smoke, like a flame starved for oxygen. This poisonous smog is composed of complaint, blame, resentment and self-pity. The longer we ignore it, the more we are overcome with its noxious components. Whyte states that we need only open ourselves for a moment to the fresh air of the world for this smoldering mass to burst into flame with the power to transform the ordinary into the exquisite and wondrous. All this passed through my mind in an eternal instant. I felt myself relax, as if this child had somehow case an immense burden from me. Our attention was then drawn to the flickering television screen perched just above our heads. The children's channel was playing Cinderella, and the story was just at the point where Prince Charming asks the beautiful young lady who has caught his eye to dance. Emily turned to me and asked, "Will I be able to dance?" In answer I bent down and swept the child up into my arms. Then with her suspended in air, we slowly waltzed around the room to the music, as her family clapped, and Emily giggled with delight.

How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving, and tolerant of the weak and the strong -- because someday you will have been all of these.

George Washington Carver

STRENGTHENING EXERCISES

Terry insert exercise page here.

FINDING CREATIVE WAYS TO SUPPORT A SICK FRIEND

By: Brianne Bourassa

When your friend is diagnosed with something like dysautonomia, it can be hard for your friend as well as for you. One of my closest friends was diagnosed with POTS and suddenly all the time we spent together was shortened because she couldn’t do as much anymore. I could not see her as much as I used to. She was unable to go to school, and I wasn’t allowed at her house very often because she wasn’t feeling well. When I could see her, we were both so excited that the next day her symptoms would be even worse. It made me feel bad every time it happened.

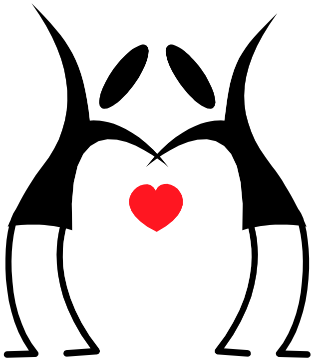
Since we were such good friends, I wanted to do something to support her. I missed seeing her, but I still had to go to school and do regular things myself. At first I called her, but some days she felt so bad that she couldn’t always talk on the phone. So I decided to keep in touch with her through writing, even though she lives in the same neighborhood as I do.

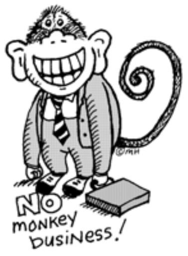
Every day before school I would drop a letter off at her house, just talking about anything I felt like talking to her about. I told her what was happening at school, in my family, with my pet, what was on TV, anything I thought she would find interesting or funny. The letters were short and sweet and sometimes very silly. Pretty soon we made up the “Back and Forth Book”, a spiral notebook that we decorated and passed back and forth to each other every day. Whoever had the book would write the date and a note and drop it off at the other’s house. It first started out as a story, each of us would write a paragraph of the story then pass it to the next to continue it. That way, the story kept changing all the time. After a while, our writing turned out to be just notes to each other.

While my friend was going through her worst time, most of our communication was in writing. I hoped that my notes let her know she had my support and our friendship was still strong. If you have a friend with dysautonomia, always try to be a good friend and let them know they have your support, even if the only way you can be there is through notes.

Don’t walk behind me,
I may not lead.
Don’t walk in front of me,
I may not follow.
Just walk beside me and be my friend.

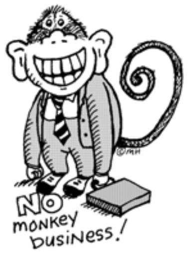
Albert Camus





TIPS FROM THE PRO'S

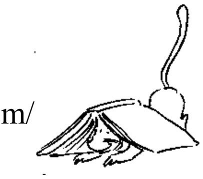
Suggestions for Living with Dysautonomia



- Eat a diet high in salt!
- Carry and drink fluids with you everywhere! EVERYWHERE! ALL THE TIME!
- A salt packet added to 20 ounces of Gatorade, or pop does not change the taste – try it.
- Keep an emergency packet with you (fluid, salt packets, salty snacks, and chocolates).
- Watch how caffeine affects you. It helps some patients and some patients cannot tolerate it well.
- Watch how sugar affects you.
- Plan ahead: if you know something is going to happen that will impact your symptoms (like a storm, standing in line, a big test), load up on your fluids and salt ahead of time and also during the stressor.
- Take frequent breaks.
- Be upright and sitting or standing as much as you can.
- If you get dizzy, squat, lie down or sit in a chair with your feet elevated.
- Avoid standing still for prolonged periods. Curl your toes, cross your legs, and tense your leg muscles when you have to stand for any amount of time.
- Avoid hot water! Take lukewarm or cool showers and baths. If you get dizzy in the shower use a shower chair. Make showers short.
- Avoid heat. When going out in the summer have someone cool down the car prior to your getting into it.
- Avoid extremes in temperature. Even in the winter the cold can be hard on your system. When going out have someone take the chill off the car prior to your getting into it.
- Avoid sitting for long periods at the computer or at your desk. Sit Indian style when possible. Get up and move around regularly.
- Avoid long periods of intense concentration. Concentration lowers blood pressure. Always drink and consume salty snacks while doing school work and taking tests. If possible take frequent breaks.
- Viral illnesses will make you worse. Avoid public places during flu season. Speak to your doctor about getting a flu shot.
- Over the counter cold medications, nose drops, sprays, and eye drops may dangerously elevate your blood pressure. Do not take these without consulting your doctor.
- Persistence and determination will pay off in the end.
- Remember that everyone has different degrees with their various conditions and don't compare yourself to others.
- Keep the faith! Things will improve once your treatment gets started.

Smart Reading

The Fainting Phenomenon: Understanding Why People Faint And What Can Be Done About It
By Blair P. Grubb, MD
Mary Carole McMann, MPH
ISBN#087993413 $18.95
1-800-216-2522
http://blackwellpublishing.com/



Primer on the Autonomic Nervous System
By David Robertson, MD, Phillip A. Low, MD, Ronald J. Polinsky
ISBN#0125897618

Searching the Web

The following sites provide newsletters and information that you might find informative.

POTS Place: An excellent resource for information on POTS and dysautonomia. http://potsplace.com/

STARS: British organization that works together with individuals, families and medical professionals to offer support and information on syncopes and reflex anoxic seizures (often referred to in US as reflex or vasalvagal syncope). http://stars.org.uk/

We strongly encourage Internet Safety for all children:

Web Wise Kids
http://www.webwisekids.com

Recommended Viewing

Dr. Blair Grubb's "Goofy Slipper Lecture" on Dysautonomia
Email: info@dynakids.org
Price: $25.00
Produced by Full Zoom Productions
Toledo, Ohio 419- 531-8362
Contact the DYNA office for ordering information (301-705-6995).

Doctor's Web Sites

Abdullah, Hasan, MD / Children's Heart Institute http://childrenheartinstitute.org/

Stewart, Julian, MD / The Center for Pediatric Hypotension www.syncope.org

Neuroscience for Kids
http://faculty.washington.edu/chudler/neurok.html

Suggested Support Reading

THE ART OF GETTING WELL
A Five Step Plan for Maximizing Health When You Have a Chronic Illness
David Spero, R.N.

WE ARE NOT ALONE
Learning to Live with a Chronic Illness
Sefra Kobrin Pitzele

SICK AND TIRED OF FEELING SICK AND TIRED "Living with a Chronic Illness" Paul J. Donoghue, Ph.D.Mary E. Siegel, Ph.D.

FAMILY SUPPORT ISSUES

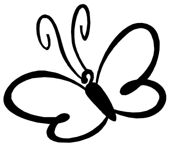
Some forms of dysautonomia cause symptoms that may keep a child at home more often and may make it impossible for them to attend school and social functions with any regularity. When this happens, the child often becomes extremely isolated from their friends and peers. It is very important to the well-being of the child that every possible effort is made by parents, teachers, and friends to keep the sick child "connected" with the outside world.

It is frightening how little support some families dealing with children with chronic illnesses actually have. Unfortunately, in this fast paced world it is often very easy to be overlooked. People seem to assume everyone else is helping. Sometimes families may have to come right out and ASK FOR HELP! Finding support will take a concentrated effort on your part and some people may even let you down, but ask ANYWAY! **SUPPORT MAKES ALL THE DIFFERENCE and your child deserves it!**

The importance of family, social and community support for individuals dealing with chronic health issues has been documented in numerous studies. **Individuals with support respond better to treatments and deal better overall with their conditions.**

Parents may have to resort to finding creative ways to help keep their sick child "connected." Remember, the benefits of having support can help in every aspect of the illness!

ASK! INFORM! EDUCATE! REACH OUT! It's often the little things that matter the most for your child.



Acceptance

By: Regina Hill

Acceptance means that you
can find the serenity within
to let go of the past
with its mistakes and regrets,
and move into the future
with a new perspective,
appreciating the opportunity
to take a second chance. Acceptance means
you'll find
security again
when difficult times come
into your life,
and comfort to relieve any pain.
You'll find new dreams, fresh hopes,
and forgiveness of the heart.

Acceptance does not mean
that you will always be perfect.
It simply means that
you'll always overcome imperfection.

Acceptance is the road to peace -
letting go of the worst,
holding on to the best,
and finding the hope inside
that continues throughout life.

Acceptance
is the heart's best defense,
love's greatest asset,
and the easiest way
to keep on believing
in yourself and others.

SUMMER CHILL SUPPORTERS

AmeriHost Inn & Suites
Maumee, Ohio

Applebee's Restaurant
Maumee, Ohio

Bob Evans Restaurant
Maumee, Ohio

Carrabba's Restaurant
Maumee, Ohio

HomeTown Buffet

Country Buffet
Waldorf, Maryland

Full Zoom Productions
Toledo, Ohio

LATTICE GROUP, INC.

Lattice Group, Inc.
Kensington, Maryland

Max & Erma's Restaurant
Maumee, Ohio

When you're here you're family.

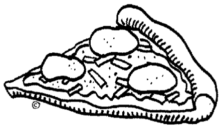
Olive Garden
Maumee, Ohio

OUTBACK STEAKHOUSE®
NO RULES. JUST RIGHT.®

Outback Restaurant
Maumee, Ohio

"Parties On The Go"
McCalla, Alabama

St. Jude Medical
Toledo, Ohio



Wal-Mart Distribution Center
Woodland, Pennsylvania

******* Special Thanks to Blair P. Grubb, MD *******
and the Cardiology Department Staff
at The Medical College of Ohio
for supporting our kids!

Join DYNA and become a member of our Computer Connections Club!

We put young people with dysautonomia in touch with each other.
We also publish informative and heart warming newsletters addressing
the issues that impact our members. 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 country.
We charge no membership fee.

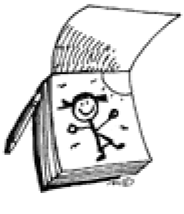
To Join DYNA:

Email us at: info@dynakids.org
(as with any email…if you don't hear back – try again)

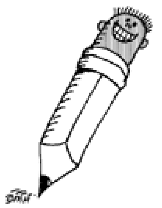
Any physicians who would like to participate in a future newsletter may contact us.
We sincerely welcome your input.

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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The "Young and the Dizzy" Newsletter
is a combined volunteer effort
of our adult staff and our youth members.
Many individuals volunteer their time and
expertise to make this
newsletter possible.

**We sincerely thank Blair P. Grubb, MD,
Kathryn Boehm, MD, and Todd Davis, MD
for contributing professional
articles to this
particular issue.**

We also thank: Teresa Betts, Debra Dominelli, and
Richard Dominelli for their hard work and
dedication toward this newsletter.

We depend on the kindness of others
in order to continue providing this newsletter.

Donations are deeply appreciated and will go far to
help with our mailing expenses.

Remember?

*By: Corey Corder, Age 20
Ohio, Diagnosed with NCS*

*Never forgotten
Never lost
You're gone now
It's no ones fault
Not misplaced
Not halfed
Just where you belong
In the past
Don't be sad
Don't be angry
I still remember
How you changed me*

Even though you may want to move forward in your life, you may have one foot on the breaks. In order to be free, we must learn to let go. Release the hurt. Release the fear. Refuse to entertain your old pain. The energy it takes to hang onto the past is holding you back from a new life. What is it you would let go of today?

Mary Manin Morrissey

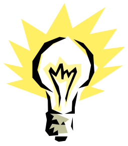
DYNA Members Report

Our Most Disabling Symptoms:

**1) Sheer Exhaustion/Fatigue
2) Migraines
2) Dizziness**

Our Top 3 Most Helpful Medications:

**1) ProAmatine
2) SSIR's
3) Florinef**



***Light travels faster than sound.
That is why some people appear bright until
you hear them speak!***

What DYNA Kids Want YOU to Know:

"Dysautonomia intrudes into every aspect of normal life, it can be severe and disabling and people have to learn to trust our words when you can't see our symptoms."

Laura, 18, IL

"Wearing myself out and trying to live a normal life just makes me worse."

Kim, 18, FL

"Looking good and being good in spirits does not mean that I am feeling good and not being able to do certain things DOES NOT mean that I don't want to do them."

Melissa, 23, MD

"I can feel different from one day to the next so please bear with me."

Kelly, 26, MI

"I am still going to do what I want to do in life, even though I may have to do it a different way than everyone else."

Melissa, 15, IN

"Just because you can't see something, doesn't mean it isn't there."

Sarah, 15, PA

"My symptoms are real even though I don't look sick on the outside."

Lauren, 9, NC

"I know that I look like every other teenager on the outside, but inside my body struggles to complete the smallest of tasks."

Heather, 19, AL

"I am still ME, only with a few new quirks."

Sarah, 20, OH

"I now know the true meaning of friendship."

Mandy 12, MD

A Special DYNA Youth Project !

Someone's in the kitchen with DYNA!

DYNA Kids
are working very hard on a cookbook!
They plan to sell this book to
obtain funds for our
"DYNA Summer Chill"
and other organizational expenses.

They are looking for favorite family recipes from interested doctors, nurses, teachers, family members, and friends.

Please email your favorite family recipe to: Susie Hetrick, Youth Cookbook Coordinator or Dinah Christopher, DYNA Board Member at info@dynakids.org

Our deadline for submission of recipes is September 1, 2003

Updates and order forms will be posted on our web site. You may also call our main office for details.

301-705-6997

What does “brain fog” feel like?

“**X -** this is me… **X -** this is a SOLID BRICK WALL… **X -** these are my thoughts.”

Mandy, MD

"Sometimes when I have brain fog, I know who I am and where I am, but I feel like I am somewhere else. It's a weird feeling."

Laura, PA

“When I have brain fog is like my brain is on the other side of the house and I can't find it. Or like my brain has been run over by a semi.”

Susie, OH

“My brain fog is a problem with my focus. I look at someone and the whole background is a blur.”

Lori, MA

“For me a brain fog is like I know what I am thinking of, but it keeps eluding me. It gets really frustrating because just hours earlier I knew what it was, but now I don’t.”

Suzanne, KY

“It's like I will be saying something and then all my thoughts will vanish and my mind is empty...completely. When I try to remember what I was saying or thinking about all I *can* think about is that I cannot remember what I was saying or thinking about…It's a vicious cycle.”

Kim, FL

“Hmmm…what about brain fogs?” (this person forgot to sign her name – which is typical with brain fogged people)

Kaley, SC

“To me brain fog is like having a head stuffed with cotton balls. I'm not myself-I feel like I have no control…”

Sarah, PA

“You feel like there is a blanket over your head and if someone would take it off you could see and think clearly.”

Brian, FL

“When people talk, I am vaguely aware of voices, but can't understand them. I can smile and look like I understand, but really I'm trying to figure out what they are saying.”

Julie, MI

"Brain fog is a hazy day in your brain."

Jen, PA

Sincere appreciation to the William C. Bannerman Foundation

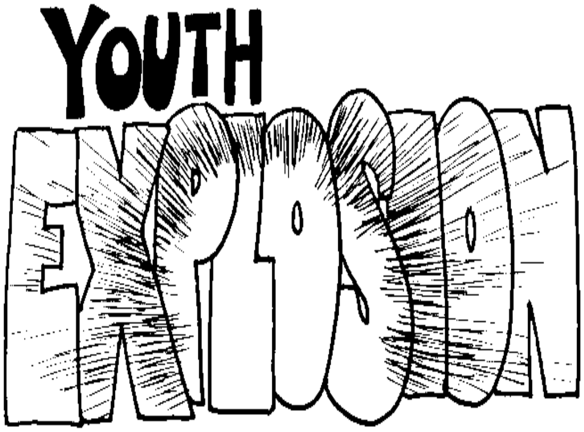
“Wherever there is hope
dreams begin coming true.”

Genienne Bondy

Our youth take a very active role in our organization. We are very proud to announce that the following individuals have been selected to serve DYNA in a volunteer capacity (please see our web-site for additional information):

(Listing in alphabetical order)

Lisa Albrecht
Mary Bibbs
Julie Chinitz
Richard Dominelli
Melissa Douglas
Alex Gallina
Susie Hetrick
Jennifer Kless
Laura Kline
Melissa Mambort
Jessica McDermott
Brandy McReynolds
Kimberly Rowker
Amanda Washburn



The DYNA
"Summer Chill"
2004
will be held
July 12, 13, 14!

Our "Goofy Slipper Lecture"
on dysautonomia
is growing!

Contact our main
office for more information.

E-mail:
info@dynakids.org

301-705-6995

Letter to DYNA

My, name is Sophie. I am 17 and from New Zealand and I have lived with my illness for about 2 years now. I suffer from fainting, numbness, Tachycardia, joint pain, itchiness, tingling, sore throat, headaches, and terrible, terrible chest pain that knocks me unconscious. I have just been diagnosed with POTS. I would like to thank you for your web site, it has changed my life. I cried, and cried, and cried when I read the stories of other people just like me. It always seemed like I was the only one. Mentally, I feel so much better knowing that there are other kids just like me going through this. Physically, I am obviously wasted but your site has given me hope for a better life one day. I have not been to school for years, and I am mostly homebound and I feel terrible all the time. I am so thankful for DYNA. I wanted to join your network but I realize it's only an American thing. But, thank you anyway for your site and for your hard work. I will always be grateful.

Sophie, Auckland, New Zealand

ANNOUNCEMENT

**DYNA IS BASED IN AMERICA
BUT OPEN TO THE WORLD!**

**SOPHIE IS NOW A MEMBER OF OUR
DYNA FAMILY!**

EXTRA SPECIAL THANKS
to the
Bank of Southern Maryland
for donating a copier to
our DYNA office!
We greatly appreciate your
kindness!

What is DYNA?

Young people diagnosed with various dysautonomia conditions may experience sudden isolation from their peers due to the impact of their symptoms. They must 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 nationwide support network that is focused on positive peer support. 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 nationwide.

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).

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.

We charge no membership fees.

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 Registration:

Mail to: DYNA
Debra Dominelli, President
1301 Greengate Court
Waldorf, MD 20601

My name: ____________________________________

My address: ____________________________________

____

Telephone: ____________________________________

E-mail: ____________________________________

<u>Check any that apply:</u>

* Please include me on your newsletter mailing list: ____________

* I am a youth/parent of a youth with dysautonomia. Please contact me as I wish to join your Computer Connections Club ____________

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

<u>My donation is made in honor of:</u>

Name: ______________________________

Address: ______________________________

____

Please notify the above individual of my donation:

____yes _____no

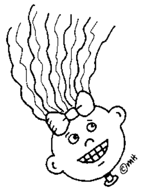
Please donate by check payable to:
DYNA, Inc.

Donation not required for membership.

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

"A Ray of Hope"

Mail TO:



Learn about us at: www.dynakids.org

We are very proud to announce that DYNA *(formerly the NDRF Youth Network) is now an independent non-profit organization operating specifically for young people impacted with the various forms of dysautonomia!*

DOCTORS PLEASE TELL YOUR PATIENTS ABOUT US!
It truly helps to know you are not alone in dealing with these illnesses!