

Youth Network Newsletter

“The Young and the Dizzy”



**Winter/Spring Edition
2002**

DYSAUTONOMIA YOUTH NETWORK OF AMERICA, INC.

“Gut Feelings”

By: Gisela Chelimsky and Thomas Chelimsky, MD

Many children have stomach pains. The organs in the stomach include the liver, which eliminates toxins, the pancreas which makes chemicals to digest proteins and fat, the gallbladder, which makes chemicals to dissolve fat, and the bowel, which moves food along as it is absorbed. All of these processes and organs may become sick and cause very severe pain. Some children with stomach pain may have a serious disease of the bowel such as “Crohn’s disease” and “ulcerative colitis”. In these diseases, there is often blood in the stool, and the person may feel very sick and lose weight. In other cases the symptoms are subtler.

In many children with belly pain, a thorough evaluation shows no serious problem. The pain is nonetheless very real, and may result in absent days from school and restricted social activities. Such children may have a problem called “functional abdominal pain”. In adults, a similar disorder is termed “irritable bowel syndrome” or “spastic colon”. To determine whether a child has functional abdominal pain requires a thorough evaluation by the pediatrician or pediatric gastroenterologist.

What is functional abdominal pain? Doctors define it as abdominal pain without any evidence of a structural cause (an abnormality one can *see* in the microscope), a physiological cause (an abnormality of a chemical one can *measure*) or an anatomical cause (an abnormality one can see with the naked eye). In other words, doctors cannot find anything unusual when they perform standard tests looking at the gut, or measuring what comes out. However, these tests do not tell the whole story. This is because our ability to evaluate one of the vital elements of gut function, its ability to move food along, is very primitive. The gut may look normal, and the stool may seem fine, but the whole process depends critically on moving food from one station in the gut to the next, through

all the loops of small bowel, into the loops of large bowel, and finally out to the rectum. This process, called “motility” is extremely complex and variable.

Because of this complexity, we do not understand the cause of “functional abdominal pain” at this point in time. In fact, studies in the last decade strongly suggest a problem with “motility”, the movement of food through the gut. Motility depends on a function called peristalsis, moving food from one segment to the next. One segment of gut must contract, while the next one relaxes. This pushes food from the contracting segment to the relaxed segment. If, however, the contracting segment tightens against the next segment when it does not relax, or while it is still filled with contents, food will not move. This is thought to result in a painful cramp.

A large set of nerves coordinates this movement of food along the gut. In fact there are more nerves in the gut than in the spinal cord. These are buried in two layers of the bowel wall. They receive information about food texture, food movement, tension of the bowel wall, and many other items. They send this information to other parts of the gut to produce relaxation or contraction of nearby and distant parts (did you notice how you must go to the bathroom shortly after you fill your stomach? This is because these nerves produce a reflex called the “gastro-colic” reflex). They also send information to the brain for sensations like fullness, pain, nausea, etc.... Moving food along this long flexible tube is a very large task in coordination. If food moves too quickly it will not get fully digested, and a lot of water may be excreted with it, resulting in diarrhea. If food moves too slowly, it becomes too bulky to move well, and constipation may ensue. Constipation may be very severe, and be associated with painful cramps.

We do not understand exactly how the movement of food in the gut is coordinated. We do understand that the nerves inside the bowel wall work poorly by themselves. They need input from the rest of the autonomic nervous system. The two branches, sympathetic and parasympathetic, balance one another. When one of them is cut off, such as loss of the sympathetic branch in a patient with paralysis due to a traumatic spinal cord injury, intestinal content movement slows to a crawl, and all types of artificial methods must be used to enhance bowel motility. We believe that the parasympathetic branch enables gut contraction to propel food forward. Working in concert, the sympathetic branch coordinates the way the gut contracts, and has been called the “brake” of the gut. Perhaps, when the sympathetic branch is not working, the gut contracts to move food forward, but there could be no open space (relaxed segment) for the food to move into. This would be like trying to empty a tube of toothpaste into another tube that is already full. If the first tube has feelings, he will have a cramp. Clearly, based on this reasoning, lack of food movement could be due either to inadequate contraction or inadequate relaxation.

Deeper probing has suggested that the problem does in fact lie in these *controlling elements* of the gut. Although we cannot directly study these nerves to the gut, those same types of autonomic nerves also control a host of innumerable bodily functions, including the bladder, the pupil, and blood flow to nearly every organ. In particular, the autonomic system controls some functions that lend themselves more easily to measurement, such as heart rate, blood pressure and sweating. Therefore, it is easier to

study these particular nerves, and then extrapolate this information to the nerves that control gut motility.

Based on this reasoning, we have begun to test the cardiovascular autonomic control in children with functional abdominal pain. The abnormality we find most often is a postural tachycardia syndrome, often abbreviated POTS, and defined by an increase in heart greater than 30 bpm when the person goes from lying to standing, without any blood pressure drop. POTS is probably due to an inability of the veins to tighten normally when the person stands, and blood does not adequately return to the heart. The patients' main complaint is dizziness and fatigue, due to their constant struggle to keep normal blood flow to the brain. On careful questioning, people with this syndrome frequently admit to abdominal pain, nausea and bloating as well as other symptoms of irritable bowel, even though this is not their primary complaint. These symptoms have a marked similarity to some children with “functional abdominal pain”, though in these children, the main complaint is the pain, not the dizziness. So in patients with *mainly abdominal complaints*, dizziness is there when one questions carefully, and in patients with *mainly dizziness*, one can find abdominal symptoms.

We have suggested that POTS and “functional abdominal pain” could in fact reflect the same underlying problem, with one group of children having predominantly orthostatic problems (dizziness, fainting) and the other mainly gastrointestinal problems. The connection between the two sets of symptoms is still unclear. We have two postulates:

- a) When a child that suffers from POTS is in the upright position, there may be decreased blood flow not only to the brain, but also to the gut, and this could induce pain.
- b) The sympathetic nervous system, one of the 2 branches of the autonomic nervous system, may not be functioning normally in patients with POTS. This may be the reason the veins do not constrict. This same sympathetic nervous system also helps coordinate food progression from the stomach. This would explain why a sympathetic nervous system problem could produce both symptoms of POTS as well as abdominal pain, feeling of fullness after eating, and bloating.

This new understanding has already advanced treatment of functional abdominal pain a little. If one treats abdominal pain with treatment normally used for POTS, such as beta-blockers or fludrocortisone, quite a few patients get better. This is very surprising, since these drugs have no known direct pain relieving effect, and have never been previously reported to work for these gastrointestinal problems. The fact that they do work is exciting, and suggests that we may be on the right track in connecting these two sets of symptoms (POTS and functional abdominal pain). Nonetheless, our understanding of the role of the autonomic nervous system in association with functional gastrointestinal problems is still very small, and much more research is needed. It is not clear why or how these drugs work. It is also not clear why some patients do not respond to them. Other patients seem to benefit from the traditional agents used for irritable bowel

syndrome, which slow down the parasympathetic nervous system. These varied responses to different treatments suggests perhaps that functional abdominal pain may in fact be a large set of similar disorders that really have different basic problems at their core. One could conceive of a bunch of cars that do not start, but some are missing spark plugs, others are missing fuel, and others have a failing distributor cap. They all look the same until you discover the underlying problem.

Up until this point, we have spoken of problems that relate to gut *function*, the motor side of the gastrointestinal tract. Other groups have evidence showing that **gut feeling**, the sensory side of the tract, is abnormal also. If the nerves that normally convey pain become abnormally hypersensitive, one can easily imagine that an event that is not suppose to produce pain does in fact convey pain, and that a mildly painful occurrence becomes excruciating. This is called “visceral hyperalgesia”, and this clearly plays a role in functional abdominal pain as well. Patients with this problem respond well to a class of drug called the “tricyclic antidepressants”. These agents modulate signal processing in the spinal cord. We do not know whether all patients have both function and feeling abnormalities (a likely scenario, since these are closely integrated by the spinal cord), or whether some patients have one type of problem, some have the other, and others have both. We will need to do further investigations.

Our current approach is to utilize the concept of “comprehensive pain management”, through a team of professionals that work with the patient. This means:

- 1) Teach the person coping strategies to live a normal life in spite of pain, and to limit the impact of pain on their activities, through psychological counseling and physical and occupational therapy.
- 2) Condition the person’s body to be in good shape, as this increases endorphin production, and improves response to chronic pain.
- 3) Insure good, solid sleep, and healthy, regular diet, avoiding triggering foods.
- 4) Use whatever works, from the medication perspective; if autonomic testing suggests a “POTS picture” use this type of agent. With visceral hyperalgesia, try a tricyclic antidepressant. We do not use opiates.

Gisela G. Chelimsky, MD
Assistant Professor Pediatric
Gastroenterology & Nutrition
Rainbow Babies & Children’s Hospital,
Assistant Professor of Pediatrics Case
Western Reserve University

Thomas Chelimsky, MD
Department of Neurology
Director, Pain Center
Director, Autonomic Disorders
Case Western Reserve University &
University Hospitals of Cleveland

Dysautonomia

When our Autonomic Nervous System (ANS) malfunctions, it is known as Dysautonomia. The ANS participates in the regulation of our body’s automatic systems, including our cardiovascular, gastrointestinal, and urinary systems. It regulates temperature, metabolic processes and the endocrine systems as well as our

reaction to stress – the “flight or fight” response. Orthostatic intolerance is a hallmark of Dysautonomia.

The Youth Network extends a special Thanks to:

Thomas Chelimsky, MD

and

Gisela Chelimsky, MD

*Case Western Reserve University &
University Hospitals of Cleveland*

David Levy, JD

*Boomerang
Deerfield Beach, FL*

Terry Fath

*Sir Speedy Printing
Hanover, MD*

Angela Dowd,

*AC Dowd Designs
Petaluma, CA*

I have had enough experience to make
this statement.

Abraham Lincoln



**SYMPTOMS OF
DYSAUTONOMIA MAY
INCLUDE:**

Orthostatic Hypotension
Tachycardia (fast heart rate)
Palpations
Chest Discomfort
Low Blood Pressure
Recurrent/near syncope (fainting)
Dizziness
Lightheadedness
Gastrointestinal Problems
Excessive Fatigue
Exercise Intolerance
Nausea
Visual Disturbances
Weakness
Shortness of Breath
Mood Swings
Anxiety
Vertigo
Migraines
Tremulousness
Noise/light sensitivity

Sorrow

In this sad world of ours,
sorrow comes to all,
and it often comes with bitter agony.
Perfect relief is not possible,
except with time.
You cannot now believe that you will
ever feel better.
But this is not true.
You are sure to be happy again.
Knowing this,
truly believing it,
will make you less miserable now.

Insomnia
Frequent Urination
Temperature Regulation Problems
“Heads You Win, Tails You Lose”

Brain fog/forgetfulness



By: David Levy, JD

When I was asked to write something on positive thinking for this newsletter, I began to wonder what I would say to kids who have to have such a positive attitude in their day-to-day lives in order to deal with all the stuff that happens to them. They must deal with teachers and administrators that don't understand their conditions; neighbors and family members that don't believe in something that they have never heard about before; and many other people who just don't believe you can be "sick" when you look so good.

Since I am no genius, I decided to go out and see what some other, smarter people had to say about this situation and I came up with the following:

It's how you deal with your health issues that matters. Someone once asked Helen Keller, who was deaf, blind and mute what she thought was the biggest handicap, her reply, "ignorance."

Ignorance is really what we all deal with. When you have POTS or Dysautonomia and people don't *want to understand* – that's ignorance. Rest assured that ignorance happens everywhere in the world and it sure isn't limited to the people that you know or just to conditions like dysautonomia.

Wayne Dyer, the great inspirational speaker put it very well when he said, "The highest form of ignorance is when you reject something that you don't know anything about." Boy is that true! So, realizing that people can be ignorant means we have to learn not to fall victim to their ignorance. That's directly up to you. How you turn "lemons into lemonade" is really how you approach the situation.

Each of you has a health issue, but so do millions of other people. And, while their problems don't make yours any better, it's what *you* do with yours that matters. A great line, paraphrased from Harry Johnson, puts it all in perspective. He said, "The human body has been designed to resist an infinite number of changes and attacks brought about by its environment. The secret ... lies in successful adjustment to... the stresses..." How you adjust is up to you. You can do almost anything you put your mind to.

That great writer, *Anonymous*, really put it right on-the-line when she wrote, "God gave us two ends. One to sit on and one to think with. Success depends on which one you use; heads you win--tails, you lose."

Remember, there are millions of ways to measure success. How you view it and what you think it means is really what is important. It is your inner strength that really matters. One

of the greatest men of all times said it best: "Strength does not come from physical capacity. It comes from an indomitable will." -- *Mahatma Gandhi*

You all have that strength, find it; use it; and be the winners that you are.

Persevere



*Life is tough – especially for you
But you can't give in – you must follow this through
Relish triumph over surrender
Treasure laughter instead of tears
A positive attitude
Will get you through these years.*

*Enjoy your good days – just "keep on keeping on"
Don't stagnate in the darkness – cherish the dawn!
Your life has changed
You will have to change too
How you change
Is up to you.*

*Stand when you fall – crawl if you must
Leave those that "don't get it" - behind in your dust!
When it comes to others -
Don't waste your energy on trying to explain
You have no time for negative people -
Use your strength on those that are a positive gain.*

*Heartbreak and sorrow – you have had many of both
Your spirit sure has had an opportunity for growth!
Leave no room for bitterness
No pity parties here!
Take life a day at a time
You must persevere!*

By:
Debbie Dominelli



What the caterpillar thinks is the end of the world...the butterfly knows is only the beginning.

Anonymous



The Cracked POT

Author Unknown

A water bearer in India had two large pots, each hung on each end of a pole, which he carried across his neck. One of the pots had a crack in it, and while the other pot was perfect and always delivered a full portion of water at the end of the long walk from the stream to the masters house, the cracked pot arrived only half full.

For a full two years this went on daily, with the bearer delivering only one and a half pots full of water in his master's house. Of course, the perfect pot was proud of its accomplishments, perfect to the end for which it was made.

But the poor cracked pot was ashamed of it's own imperfection, and miserable that it was able to accomplish only half of what it had been created to do.

After two years of what it perceived to be a bitter failure, it spoke to the water bearer one day by the stream. "I am ashamed of myself, and I want to apologize to you." "Why?" asked the water bearer. "What are you ashamed of?"

"I have been able, for these past two years, to deliver only half of my load because this crack in my side causes water to leak out all the way back to your master's house. Because of my flaws, you have to do all this work, and you don't get the full value from your efforts, said the cracked pot.

The water bearer felt sorry for the cracked pot, and in his compassion he said, "As we return to the master's house, I want you to notice the beautiful flowers along the path."

Indeed, as they went up the hill, the cracked pot took notice of the sun warming the beautiful flowers on the side of the path, and this cheered it some.

But at the end of the trail, it still felt bad because it had leaked out half of it's load, and so again the pot apologized to the bearer for it's failure.

The bearer said to the pot, "Did you notice that there were flowers only on your side of the path, but not on the other pot's side? That is because I have always known about your 'flaw' and I took advantage of it. I planted flower seeds on your side of the path, and every day while we walk back from the stream you have watered them. For two years I have been able to pick these beautiful flowers to decorate my master's table. Without you being the way you are, he would not have this beauty to grace his home.

Each of us has our own unique flaws. We are all CRACKED POTS. Don't' be

ashamed of your flaws. Acknowledge them, and they too can be the cause of beauty.
KNOW THAT IN OUR WEAKNESS WE FIND OUR STRENGTH!



My Eyes



By Amanda Washburn
Age 18, Texas

*If you gave me a coin for all the negative
I'd be rich off all the ugliness
It doesn't stop me from smiling
You have to make up for some of the world
I may not be perfect in some eyes
But I can smile behind my tired eyes
I cannot be weak for I am too strong
There are tears that don't show behind anger
Inside everybody is hiding something
In my writing I express my feelings
My goals have been set
Holding me back is my sickness
Do I stress others or depress myself
I am too proud then to just sit still
My Mom is my closest inspiration
I follow her footsteps and beautiness
If I gave out coins for all my love
The world would be painted true colors!*

I wrote this because there is so many people who are close to me that don't truly understand my condition or the impact it has on my life. So much of living with a chronic illness like dysautonomia is "invisible" to the outside world. It is very hard to go through a sickness like this when it seems like you won't get better and it is frustrating to not have the support of people you thought you could always count on. I have tried to gain something positive out of this experience. My Mom has helped me and believed in me the entire way. I don't know what I would do without her! I have learned that when you have to go through so many obstacles you just can't give up on yourself! I know it is hard for us teens with dysautonomia – but we can make it and gain something positive out of it.



PROVERB

*It is written
in the Talmud
that
when a child
enters this world
his hands are clasped
tightly
into fists
As if to say
“All this will be mine!
I will inherit it!”
but when the old
depart this life
their hands lie open
As if to say
“All this I bequeath you,
for in truth
I have acquired
Nothing”...*

Blair P. Grubb, MD



Sometimes

By Mary Bibbs, 14
Illinois

Sometimes I have bad days
but other times
I have good
Sometimes I go to school
but other times
I wish I could

Sometimes I cry
but other times
I don't
Sometimes I just sit there in
bed
thinking about
how wonderful it would be
to fly.

Sometimes I think
about all the other
people there are in this world
and maybe, just maybe, they
might have something like:

ME!

Sometimes.

The “POTS Light”

By Jenni Hinman, Age 18
Ohio

I was 16 years old when I was diagnosed with POTS. I had just gotten over mononucleosis and my Uncle and Godfather had just passed away. Everything really threw me for a loop!

At first, there were just so many negatives to deal with. I was in the hospital and when the doctors prescribed Zoloft I didn't even care if they called me “depressed” or said I was “having panic attacks.” But, I knew this was not the case. I knew I was really sick and that something major was wrong. I knew that this was not “depression” or an “anxiety disorder.” I knew all this! But after the death of my closest relative and with all the stress the doctors put me through asking me such ugly things like “Do you do drugs?” or “Does your Mom keep alcohol and household cleaning supplies locked up?” I guess I sure started to feel pretty depressed. I wasn't suffering from “depression”...but the attitude of the doctors sure did depress me! I WAS A STRAIGHT “A” HONOR STUDENT – HOW DARE THEY!

It was a very long road but luckily after dealing with the wrong doctors, I found doctors who KNEW what they were talking about, who understood POTS, and who were informed enough to treat POTS properly. Boy was I happy then! They put me on medications too. And, Zoloft was one of the medications. However, Zoloft is not prescribed for POTS because of “depression.” Zoloft is not just used to treat depression – it is also used for many other conditions as well. It helps with serotonin levels and POTS patients need help with that.

After the first change my view, I began to ed, I began to POTS and my



life. My anger turned into strength, and oddly enough sadness began to turn into happiness. Not completely, but it certainly began to change.

Today, I want to focus on the upside of POTS. Yes – you read that correctly – the upside of POTS! You see with the right doctors and medications, I am much more functional, and my POTS is...well – under control more now. I feel that I have had the blessings to be able to see two different sides of life. Fortunate and unfortunate, and sickness and health. And although I, of course, prefer the healthy lifestyle – I would never give away my POTS. I have learned too much from it.

I have learned that God does not give you these things! You know how people like to say, “God never gives you anything you can't handle?” Well, believe me, God did not GIVE me my POTS...but he sure did help me through it.

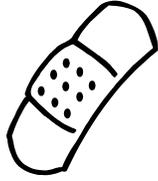
I now know who my true friends are.

And most importantly, I have learned not to judge others.

I could go on and on with what POTS has taught me. I now know what is important in life. I am so much stronger than I was 2 years ago and small predicaments seem like a “piece of cake” to me now.

For those of you still dealing with very symptomatic POTS, please know that there is a light at the end of the tunnel and the **“POTS light” is bright, warm and much more long lived than the “POTS illness” is.** Keep in mind that I am not saying that I

am all
accom
medic



I still have to make
ly condition, take my
w all the rules and I

still have bad days. But I c
day and I am tremendously
was. And, **I sure am a be**



y

Dysautonomia, the Invisible

By Becky A. McGowan, RN

If you're getting this newsletter by mail, you probably already know about dysautonomias. All of our stories are unique. However, mine has a little twist to it. I am an Emergency Department Nurse. I go to work every night and I help save lives. I see everything from tiny cuts to major trauma and cardiac arrests. As a nurse, I calm the fears of a child whose Mother brought them in for a cough. I give pain medication to the man who fell off a ladder at work and broke his ankle. I hang an insulin drip and monitor the blood sugar of the diabetic whose condition is out of control. I comfort the family of a person who was injured or killed in a car wreck. I show compassion to my patients and their families. Some of the patients problems are solved in the emergency department, others will need more care. Patients often tell me, "Oh, you just can't imagine what it's like." Oh, can't I? Are you so sure?

How is it possible that I can go to work every night and help all of these people, yet I can't keep my own child upright? I'm helping everyone else, who's helping me? Why is it that no one understands what I'm telling them about my child? I listen to my patients. Aren't you listening to me? I'm telling you what I see as a mother and a nurse. The doctors at work listen to me and believe me. Why don't you? What is so hard about it? Listen to me and understand what I'm telling you, not what you think I'm telling you! LISTEN!

It's very frustrating. Even after the "official" diagnosis of POTS, the frustration goes on. I've learned to accept it and deal with it. But that doesn't make it any easier when my child is having a "POTS Day." No one knows what it's like to have a child with dysautonomia until they have to deal with it. These are normal children with medical conditions.

Dysautonomia symptoms are INVISIBLE. You can't see them or touch them. Unfortunately, most people have great difficulty understanding things they can't see or touch. **I have a very easy way of explaining it: Take the Autonomic Nervous System and screw it all up. It's that simple, yet totally devastating.**

I have found three wonderful and compassionate doctors who assist us. I appreciate them very much. They are: Dr. Todd Davis and Dr. Christopher Johnsrude at Children's Memorial Hospital in Chicago, IL. and Dr. Blair Grubb at the Medical College of Ohio, in Toledo, Ohio.

*God grant me the Serenity to accept the things that I cannot change.
The Courage to change the things that I can.*

And the Wisdom to know the difference.



Positivity

By Jessica Wahl, 16
Michigan

When suffering doesn't seem to have an end, positivity is the answer! Fight till the end. When your feeling scared and lonely, and need someone there, just know in your heart, there are people who care.

(Michael Cuccione 1985-2001)

A young man who was fighting the same battle we all seem to be fighting spoke these words. Like him we fight to stay positive through our tough battles and to stay healthy. I have NCS, and ever since I became sick at age 5, I have always just wanted to be a NORMAL kid. I remember some days when I would have a medical test in the morning, and go to a baseball game or play rehearsal right after. I have always tried to be normal, sometimes pushing myself to the limit. I believe that the main thing to strive for is to stay positive. Your mind is very powerful, and if you keep telling yourself you will get better - you will! There is no point in sitting around feeling sorry for yourself. I always think in my head... "There is a reason God made me this way, so I know things will get better." Just remember...to keep

your head up and smile and above all stay positive!



Someday

By Katie Blaicher, 16
Texas

*Some people do not believe me
They think this disorder is a fake
I don't know why they would think this
If I had a choice, it would be an easy
choice to make!*

*I would choose to be well again
To sing, to laugh,
to dance.
To not feel tired for a day
I think we would all like that chance!*

*But for now I just like to feel that I am
special in some way
That I have this for a reason
Which will be revealed to me someday.*

***The best thing about
the future is that it
comes only one day at
a time!***

Abraham Lincoln

You have a diagnosis now and you also have a struggle ahead of you. Don't let Dysautonomia control you – you try to control it! Don't let people tell you that Dysautonomia is impossible or that it is a losing battle! Fight it! YOU CAN WIN!



Living with Dysautonomia

By Linda Smith
NDRF Executive Director

Living with Dysautonomia can be tough at any age, but it can be especially hard when you are young. A message I wish to relay to our Youth Network Members, as a life-long sufferer of Dysautonomia myself, is that Dysautonomia does not have to destroy your life! There are things that we can do to improve our “Quality of Life”. ATTITUDE is the most important weapon we have.

Dysautonomia will change the way you live, but it does not need to STOP you from living! Believe it or not you can have a full and rewarding life with Dysautonomia. You may have many challenges and you may have to make lifestyle accommodations for your condition. It will be the ATTITUDE that you develop that will determine *how* full and *how* rewarding.

You may have heard about a man by the name of Lance Armstrong who was diagnosed with an advanced form of cancer and was only given months to live. Lance Armstrong beat his illness! With extensive chemotherapy, surgeries, and a whole lot of ATTITUDE and positive thinking he overcame the odds! In 1999 Lance Armstrong won the Tour de France, becoming the second American ever to win the Tour. He is a winner. He proved that you can preserve and triumph over extreme adversity! You have the same power within you! Find it and develop it!

Some tips to help you are below:

If you take medication take it as prescribed by your doctor! Don't skip your medications and always continue taking them until your doctor tells you differently.

When possible plan activities with family and friends – don't stay isolated.

Eat small frequent meals. (5-6 a day)

Drink a lot of water. Avoid soda and juices.

Spend your life focusing on what you CAN do instead of what you can't do.

Exercise! When your doctor gives you permission - start an exercise program. This helps your muscles get strong. Try exercising lying down; you won't feel as many symptoms. Always talk with your doctor BEFORE starting any exercise program.

Laugh! Research shows that laughter and a positive attitude can be healing. Loma Linda University reports that thirty minutes after 20 medical students laughed through a video of a well-known comedian, their disease-fighting white blood cells increased by 25%! Laughter is great medicine!

Avoid anger and stress. Anger and stress causes the flight-or-flight response, which leads to release of negative chemicals in our systems.

Develop the right attitude!

“Attitude defies limitation and exceeds expectation.”

Source Unknown

Anything is Possible

By Heather Thomas, Age 18
Alabama

Having dysautonomia was like having an armed robber holding me hostage!

Dysautonomia slowly crept in and took away my life in a matter of hours. Dysautonomia took nearly everything away from me. The first thing it took was school. I couldn't go to school anymore and I had to have a homebound teacher. Since I couldn't go to school anymore, I couldn't cheer anymore. Cheerleading was a big part of my life for three years; I was devastated when I had to quit. The next thing dysautonomia robbed me of was my friends. After a while, they quit calling and checking on me. They began to go on with their lives without me. Dysautonomia confined me to a bed and tortured me with every breath I took, because I wasn't "normal". However, dysautonomia unwittingly forgot to take one thing, my **hope**. Insignificant as hope may seem, with hope, I survived.

Every time I realized my life was gone, I hoped. Hope was my weapon. The sicker I would get, the more carefree days I would hope for. When Friday night football games would come and I couldn't cheer, I would hope for a day when I could run and jump again. When my friends began their Senior Year and I wasn't at school, I hoped for the day that I could attend school again. Friends would go out on weekends without me, and that just made me hope even more for the day to come when I could stay out all night with them.

The only thing I had left was hope and with hope I survived my dysautonomia. After nearly 4 years of feeling dead, I am alive again. I attend college! My friends and I do something every weekend now! And all the memories that dysautonomia took when it came into my life, are now being replaced with memories I will cherish forever. Because of my hope, that I feel that God blessed me with, I got better! **Dysautonomia thought it was going to win, but I had the strongest weapon of all – HOPE! No matter how bad dysautonomia makes things, with hope anything is possible!**

“A strong positive attitude will create more miracles than any wonder drug.”

Patricia Neal



Lessons

By Susie Hetrick, 16
Ohio

I have had many life lessons since I got sick. I am talking about true life lessons – life changing lessons. The biggest lesson I have learned is about true friendship. Having an unusual chronic condition like dysautonomia can really help you tell who your true friend is and who is just your fair-weather friend.

Many fair-weather friends would classify themselves as a true friend. They come around once in a while. They may even be nice enough to send you a card or two. But as time goes on and you stay sick they tend to disappear. Sometimes they resurface now and then. But, they don't really know what it means to be a true friend. I sure know what it means...true friends are around in times of need and not just when it's convenient for them and they don't ditch you when they have something better to do! They stick by you! I know because I really appreciate my true friends!

Sometimes the kids at school say things like “She’s just faking it” or (and this one I really love) “She just likes being home all the time.” They have absolutely no idea! Let me set this straight for all us kids with dysautonomia: We hate being stuck in all the time! We are not faking it! And, believe it or not, we don't like missing school so much! When we miss school we miss seeing our friends too!

What's really pathetic is when you know other people are talking about you behind your back. You can't really do anything about it and you just have to learn to live with it. It isn't easy. The other kids go on with their lives and don't even understand what it is like to have the torture of dysautonomia. For the most part, they don't even bother to try to understand or to care about what you have to deal with. I don't mind explaining my condition because I understand it is unusual, but what I truly hate is “defending” my symptoms to people who have no compassion and are just going to gossip behind my back about it later.

A true friend will stick by you no matter what. They will give you a shoulder to cry on (and with dysautonomia - sometimes even a shoulder to lean on). They believe you without you having to “explain” your condition to them. Best of all – they come over and brighten up those ugly four walls you're stuck in all the time. Sometimes a visit or even a car ride is enough to help me feel better about my situation. Sometimes a good friend can be very good medicine!

I have found out who my true friends are and I have also made many true friends through the NDRF Youth Network. It is nice to know that I am not alone in the world and that there are other

people who really do understand. My best friends are my parents, my brother, and my animals. They are always there for me. I can count on them and trust them. I can be myself around them. They help me to realize that things will get better – that things HAVE to get better. They stick by me. Always.



Dysautonomia Quiz



Do you remember what you read from recent newsletters?

1. What's another word that means to pass out or faint? _____
2. It's important to increase your _____ and _____ intake.
3. What does NDRF stand for _____
4. What does ANS stand for _____
5. Who sponsors the Youth Network Newsletter? _____
6. Which doctor wrote the first newsletter main article? _____
7. A type of severe headache, associated with dysautonomia: _____
8. What does NCS stand for _____
9. You should always take your _____ as directed.
10. Fluttering in your chest is called: _____
11. _____ causes 1/3 of the blood to pool in your lower body.
12. Another word for being excessively tired _____
13. It's very important to _____ regularly to recondition your body.
14. The doctor who wrote the second newsletter main article? _____
15. Term that means unable to sleep _____
16. POTS stands for _____
17. The _____ pressure often impacts the symptoms of dysautonomia.
18. Rapid heart rate is also called _____
19. _____ (part of brain) regulates blood pressure and body temperature.
20. NEVER give up _____.

**The kids in the Youth Network already know all of these answers.
They live with this every day. How well did you do with it?**

Answers:

(1) syncope, 2) fluid & salt, 3) National Dysautonomia Research Foundation, 4) autonomic nervous system, 5) Mr. David Levy/Boomerang, 6) Dr. Julian Stewart, 7) migraine, 8) neurocardiogenic syncope, 9) medications, 10) palpitations, 11) gravity, 12) fatigue, 13) exercise, 14) Dr. Blair Grubb, 15) insomnia, 16) postural orthostatic tachycardia syndrome, 17) air/barometric pressure, 18) tachycardia, 19) brain stem/medulla, 20) hope

Payment

By Leah Master, New York

*“Do you nap?” I ask
Wondering how she gets through the day
“No,” she says, “I am 20, not 80!”
She forgets my life, I think
She does not remember that I,
A twenty-year-old, her friend
Cannot work two jobs and go to school.
Even as we leave the movie theater that
night
I am tired, my eyes lose their focus.
She runs to her car- “Let’s go out,” she
says
I thought we just did.
My day had been filled with the
supermarket
And now this, dinner and a movie
Tomorrow I would sleep
Happy that I had gone out, had worn my
best jeans.*

*My weekends offer many opportunities
Sleep, if I can.
Work, when I must.
Fun takes its toll, but I cannot resist
For I am still young and do not want to
give up
To relinquish those pleasures,
Few as they are, short as they must be.
A boyfriend or a friend
The movies or a club
Choices to be made.
I decide while completing my homework
That relaxation is essential,*

*Even as I realize its complexity.

My stretchy black pants a uniform of
Fridays,
A passport to multiple freedoms.
I dance in the group
Standing with friends, laughing as the
room spins
The beat makes me move, makes me
joyful
And few understand why I sit
Why my silver medical alert bracelet
flashes the lights into their eyes.*

*Those nights I feel ‘normal.’
I am in college, young still, but not the
same
My friends ask me out again for
Saturday
Not seeing how I strain to walk.
They do not witness my collapse
Since I hide my suffering during these
times,
Opting to lie alone in my bed after the
merriment.
I lie there the next day
And the one after that
Paying with a currency of pain
In a marketplace of illness
I seem to be the only customer.
I let my books stay on the shelf
As my work takes second stage this
weekend.*

*I cannot get up. I cannot think.
Still, I smile remembering nights like
these
Few and far between.
I smile in my stupor
Content with a small taste of living my
age.*



A Smile That Never Fades



By Amanda Dominelli, 11
Maryland

I was pretty young when I was diagnosed with POTS, a chronic illness. At times I couldn't stand, my legs wouldn't hold me. I couldn't run or play with my friends. I couldn't go to school either. POTS took away a lot from me. What hurt the most was the fact that I practically lost my right to be a kid, and to run and play with my friends all day long. But that was over two years ago, and I have to admit that I have learned much from my experience. But still...I lost my right as a kid.

Luckily, I have discovered something that had been hiding inside of me for a long time. My love for horses. I started to read about these majestic animals, and soon my bookshelf was covered with books about them. But I wanted more than to just dream...I wanted to ride. And now I do! I have been riding since this fall and I had thought that my love for horses would die down, but it is stronger than ever. I have my lessons every week here in Maryland at a beautiful place called Fairweather Farm. Riding is really good for me too because it has made my legs much stronger. I ride the funniest pony named Frosty. Frosty has a mind of his own and is determined and I like him.

When I am around horses all my problems are forgotten. I'm no longer a kid that's not a kid anymore...I am a rider! And the horses don't mind my silly mistakes...or the fact that I might not be able to ride them as long as they'd like, none of this matters to them, none of it! To them I am NORMAL. When I am on a horse, my mind is no longer focused on the fact that I am not like everyone else. My mind is focused on riding, and on the fact that after a long wait and a lot of hard work I am finally where I want to be.

My mother admits, sometimes she is afraid of the horses, but I'm not. I'm always confident around them. They sense that. Never have I been nervous on or near a horse. Not even when I was in a Horse Show that Fairweather Farm had. Not even when Frosty and I had just horribly messed up doing a figure eight. I was surprised at that. Normally, if I had done something like that on my own, my stomach would be exploding with butterflies! But when I am on a horse the only butterflies are the ones on the flowers we are riding past.

My love for horses has not subsided, and I don't think it ever will. But my confidence on them was tested that day. The night before my show, my pet bird died and I was so sad that I wasn't sure if I was going to compete. But then I heard the old phrase in my mind, "*You've got to get back on the horse.*" I knew what I had to do! During the show I forgot about all my problems and I was one with the horse. We were happy and it didn't matter at all to me if we won a blue ribbon. It just mattered to be happy! We did win a blue ribbon though and a third and a fourth place one too! When I am on a horse my smile never fades, and it never will...I am a kid again and I am normal!

Dizzy Tip:
Ice water lowers your IQ!

According to the researchers at the University of Bristol in England, drinking ice-cold water can temporarily lower your brain power by as much as 15%! The reason they give is that blood is diverted from your brain to your stomach to warm the water! They recommend that if you need to concentrate - you consider sipping room temperature beverages instead.

BrainPop.com

Is a fantastic educational site for learning about the Science, Health and everything! Check it out!

www.BrainPop.com

Sincere appreciation to the following individuals for their kind donations to the Youth Network:

In honor of Amanda Dominelli.

Patricia Chance

Richard & Irene Dominelli

Recommended Sites:

Julian Stewart, MD / The Center for Pediatric Hypotension in NY has a wonderful site that explains our conditions:

www.syncope.org

The **Neuroscience for Kids** site is highly informative and educational about the brain and the autonomic nervous system:

<http://faculty.washington.edu/chudler/neurok.html>

In honor of Mary Bibbs:

Dal & Mary Frost

Recommended Reading:

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

By Blair P. Grubb, MD
Mary Carole McMann, MPH
Futura Press
ISBN#087993413
Order through NDRF \$17.95
651-267-0525

**Primer on the Autonomic Nervous
System**

Edited by David Robertson, MD, Phillip
A. Low, MD, Ronald J. Polinsky
Academic Press \$53.00
1-800-321-5068
ISBN#0125897618

The Youth Network puts youth with Dysautonomia in touch with each other. We also publish informative and heart warming newsletters addressing the issues that impact our youth members. Our newsletters are mailed to major medical facilities and many physicians across the country. Our goal is to increase awareness of these conditions and to provide support to our Youth Network Members.

To Join

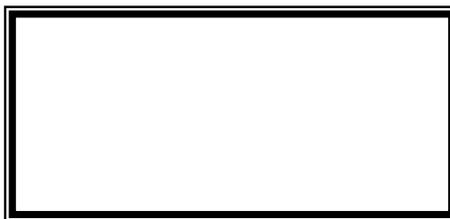
E-Mail: info@dynakids.org

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

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

Mailing Addresses:

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



This newsletter sponsored by:



What is the Youth Network?

Children impacted with various dysautonomia conditions often experience tremendous and sudden isolation from their peers due to the impact of their symptoms. They often have to make drastic life style changes in the prime of their adolescence. It is obviously very stressful, traumatic, and life impacting for the entire family. The Youth Network dedicated to serving these children. We started the Youth Network in April 2001. Our first priority was to give these children hope for their future. Through the Youth Network we strive to help them learn to deal with their conditions in a positive and productive manner. We also wish to heighten awareness of these conditions within the pediatric medical community in order that these children get diagnosed earlier and obtain proper medical treatment.

Mission Statement

The Youth Network was established to assist children who suffer from the various forms of dysautonomia. The mission of the Youth Network is:

- To give those impacted with dysautonomia hope for the future.
- To provide a focused outreach program / support network for young people who are afflicted with dysautonomia.
- To heighten awareness of these conditions and their treatments within the pediatric and adolescent medical community.

- To provide information on dysautonomia through a newsletter and Internet site

How can I help?

Funds are desperately needed. Your donation will go far to help the NDRF Youth Network provide these children with the necessary support network.

How do I donate?

Mail it to: DYNA
c/o Debra Dominelli
1301 Greengate Court
Waldorf, MD 20601

My name is: _____

My address: _____

Telephone: _____

E-Mail _____

Check MasterCard Visa
(Make checks payable to Youth Network)

Name on card: _____

Card Number: _____

Exp. Date: _____

Signature: _____

E

My donation is made in honor of:

Please notify the above individual of my
support: ____yes ____no

Address:



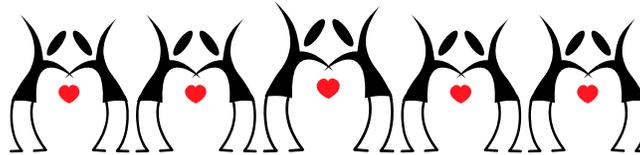
IMPORTANT INFORMATION



The Youth Network will be holding it's first Youth Network Social Camp in July 2002!

We are in the planning process now. Please contact us for more information.

Donations to help cover the expenses of the social will be graciously accepted and deeply appreciated. Please fill out the donation form and specify "Youth Social" on your check if you are interested in helping us bring about this wonderful opportunity.



Youth Network

Debra L. Dominelli, Youth Network Founder / Director
Becky A. McGowan, Youth Network Coordinator

Newsletter Assistant Youth Editors: Richard Dominelli, Jenni Hinman
Internet Youth Hospitality Coordinator: Jennifer Kless
Internet Youth Social Coordinator: Susie Hetrick

Youth Awareness Chairperson: Stephanie McGowan
Youth Awareness Coordinators: Lysie Buteyn, Jennifer Kless, Laura Kline,

Laura Krenak, Jessica Wahl, Amanda Washburn, Kim Wing

There is nothing like a dream to create a future.

Victor Hugo

The Youth Network Members are deeply appreciative of the doctors, nurses, teachers and other professionals who 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

DYNA Youth Network
c/o D. Dominelli
1301 Greengate Court
Waldorf, MD 20601