

DYNA

Fainting Robins Newsletter

"The Young and the Dizzy"

"Back To School" - Special Edition

August 2001

"Dysautonomia for Dummies"

By: Dr. Blair Grubb

"All beginnings are hard..."

-The Talmud

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

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

significantly change. The brain uses a similar mechanism to help regulate temperature. Blood vessels tighten to help the body conserve heat and relax to help the body release heat.

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

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

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

Failure of the autonomic nervous system to function appropriately is referred to as a “Dysautonomia.” Other terms are used to describe different forms or subtypes of Dysautonomia. Neurocardiogenic syncope refers to fainting due to a sudden fall in heart rate and blood pressure. The terms Orthostatic intolerance and Postural Orthostatic

Tachycardia Syndrome (POTS) both describe a condition where the heart rate is excessively high in an attempt to compensate for a low blood pressure. Symptoms will often begin after a severe stress (such as a viral infection or the flu). There are many different types of dysautonomia (more than can be described here). Tilt table testing is used to measure the body's responses to upright posture and to help establish a diagnosis by measuring a patient's heart rate and blood pressure responses to the passive stress of gravity.

Some people with Dysautonomias may be only mildly affected with only occasional symptoms, while other can be severely affected with constant severe symptoms. Those with severe forms of dysautonomia can be virtually bedridden. Many young people who develop these problems will slowly get better over time with the right medications and with physical reconditioning. Maintaining a high salt and fluid intake is also important. In some young people symptoms can be so severe that they can have difficulty completing school work, and they may need extra help just to keep up. Young people with very symptomatic Dysautonomias may need to have a home tutor until they are strong enough to return to regular classes. Others may be able to attend school with a limited or part-time schedule. These students may further benefit from tutors. Patients may alternate between good and bad days and on occasion may miss class due to exacerbations of their illness.

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



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

An Ill Child's Lament

I want to dance
but my legs will not hold me
I want to sing
but my voice will not rise
I want to write
but my hand keeps shaking
I want to laugh
but tears cloud my eyes
I want to study
but my mind will not focus
I want to eat
but I feel sick inside
I want to live, like everyone
else does
but that's just a memory
of a long bygone time
I don't want your pity or
expressions of sorrow
I don't need condolence
or lamentations of woe
All I ask is patience
and some understanding
As I slowly rebuild
my old shattered dreams

By: Blair P. Grubb, M.D.
Ohio

"Sickness"

The sight is like a drunken mind,
being role played in a movie.
Dizziness feels like going blind,
not able to walk a distance.
Numbness flows through the
extremities,
of all young parts of my body.
Consciousness is lost to darkness,
leading me to fall into my faint.
Awaken with tingles riding along,
diaphoretic, cold and feeling alone.
Soaking clothes and sheets,
coping with lying in a puddle of
sweat.
Hearing someone trying to comfort
me,
not fully comprehending on what is
said
I think about what all I have,
mainly the ones who try to help and
love.
Long days with mixed episodes,
peaceful nights to sleep it away
Tomorrow comes another day,
wondering the sight of the next
movie played.
Thinking about how normal used to
be.

By: Amanda Washburn, Age 18
Texas

**NOTE TO
TEACHERS AND
SCHOOL OFFICIALS:**

It is our hope that you read this newsletter thoroughly and take into consideration what the DYNA members are trying to express. Some of them have been dramatically impacted by their dysautonomia and have had to make major lifestyle adaptations very suddenly. Since their symptoms are not always “visible” they are often judged wrongly by others. Along with dealing with such traumatic conditions they have the additional burden of learning some extremely hard life lessons at a very vulnerable age. These conditions can be devastating socially for them. They need your understanding and support.

As educators you can make a difference in their lives emotionally and academically. If you have a child in your classroom that suffers from dysautonomia you will be getting some life lessons yourself this year. Count yourself lucky! I can honestly tell you that these children are amazing individuals and it is an honor to know each and every one of them. **They are truly special kids – not for their disabilities but for their abilities!**

Debbie Dominelli

**SYMPTOMS OF
DYSAUTONOMIA MAY
INCLUDE:**

Excessive Fatigue
Exercise Intolerance
Recurrent/near syncope (fainting)

Dizziness

Lightheadedness
Vertigo
Nausea
Tachycardia (rapid heartbeat)

Palpations

Visual Disturbances

Tremulousness

Weakness

Chest Discomfort

Shortness of Breath

Mood Swings

Anxiety

Migraines

Gastrointestinal Problems

Noise/light sensitivity

Insomnia

Frequent Urination

Temperature Regulation Problems

Brain fog/forgetfulness

*Adversity has the effect of
eliciting talents which, in
prosperous circumstances,
would have lain dormant.*

Horace

Getting Educated Together

By: Susie Hetrick, Age 16
Ohio

I would like the school systems to have an understanding of what it is like for us kids with dysautonomia. Our lives change almost overnight. Sometimes people can be so mean! I know that schools can't help and/or control some things, but there are many things that they could do to help us dysautonomia kids that they don't do. **The one thing each teacher needs to do is read what it is like for us kids with dysautonomia!** Start by reading this newsletter and then ask the family for more information if you want. **Get educated about dysautonomia so that you can help us get our education!** Take the time to try to understand what we go through. Some suggestions I have for teachers and school staff are:

Don't look the other way when you see one of us coming. **Make us feel like we belong** in school too. We may miss a lot of days – but it's still our school! **Include us** in school activities when possible. If it is something we can't do we will tell you. Part of dealing with our conditions is that we learn to make choices. If you don't include us we always hear about it anyway and that just makes us feel worse. **Please remember us...**send us the school newsletter's etc. when we are stuck home. **Don't forget about us** when it comes time for school pictures and other important rights of childhood. **Call us!** Find creative ways to keep us in touch with our school and to **make us feel like we belong** too.

Don't be afraid of us – that just causes more stress for us. We are learning to handle our conditions and we wouldn't be in school if our doctors thought it was too dangerous.

We usually have a hard time keeping up with everything. Fatigue is big part of our condition. This is not laziness as some people like to think. It is true **medically documented FATIGUE!** What little good hours we have in a day we have to squeeze everything into! It's called our **"Window of Opportunity."** We want to be kids too and have a life outside of our illness and our school work. Usually **our social life is the first thing we loose.** We constantly have to make choices about what we can do. Sometimes our bodies choose for us and we can't do

ANYTHING...but when we do get a choice we may elect to do something social. **Be happy for us when you see us out and about.**

School is very stressful. Transitions are very stressful. **Please understand** the impact stress has on us. Just trying to keep up is stress! A kind word goes a long way.

Don't judge us...believe us. If you read up on our conditions you will see that many of our **symptoms are not "visible"** symptoms. It's hard enough for us to live this way and when you judge us it just makes everything worse.

Sometimes **we need to lay down.** Sitting in a chair in the nurse's office is not lying down. The cots are not comfortable when you are dizzy. We may prefer the floor. If you want to **make us comfortable,** give us a bean bag and a soft, clean blanket in a nice **quiet** place where we don't have to worry about people staring at us.

Sometimes we want to be home. This is not because we are unnaturally attached to our parents or homes. Please don't judge our parents either. Sometimes we have absolutely no choice and we have to stay home. Sometimes we make a choice and elect to be home. **Please don't try to talk us into staying at school if we ask to go home. We know our bodies.** We have worked hard to learn its signals and to learn to make the right choices based on our conditions.

Don't punish us for our limitations! We deserve a bit of credit for how hard we work just to stand up! We may not be able to carry a full work load or do our homework, but our grades should not suffer because of this.

Get this straight...please! We are not faking! If you think that then you obviously did not read up on these conditions!

It isn't easy for us to live this way. We loose our whole existence and we have to learn how to create new lives with our limitations. People gossip and don't understand. We are also terrified that we will not get better and that we will not be able to regain any of our old lives. **Please support us. We can get educated together!**

One Day I Woke Up

One day I woke up
on the wrong side of the bed.
When I tried to stand
I fell - like I was dead!

I was still alive,
but I could no longer "live".
Standing was more
than my body could give.

My world fell apart
I'll never be the same.
It's been a long road back
with lots of heartbreak and pain.

But I'm standing tall again
I took baby steps with pride.
I'm one of the lucky ones
with a good doctor at my side.

Most people have no idea!
Their ignorance is such bliss!
They are lucky without knowing
their autonomic systems exist!

But I have an education!
I learned the hard way!
I got lost on life's road
I took the long way!

I took a bumpy path.
It was dark, even by day
I'm not saying I'd take it again
But I did learn on the way.

It was lonely on my path.
I am still kinda sad.
I learned a lot about people
some good - some bad.

But I won't turn bitter!
I refuse to give in!
I'm fighting a battle
that I'm gonna win!

I can't do what I used to.
But I appreciate things more.
I refuse to give up
because health closed a door!

I have learned to pick my battles
I will keep fighting them too.
I am confident in myself
My health war isn't through!

Mostly I've learned that the sun
shines
Even on a cloudy day!
And that I have to find the
sunshine
Sometimes...ray by ray!

By: Amanda Dominelli, Age 11
Maryland



Bermuda High – Good for Dysautonomia !



We contacted Mr. Tom Sater, Meteorologist, of Fox 5 News in Washington, DC to find out if he had any idea why so many DYNA Members say that bad weather and humidity seems to impact their symptoms.

Mr. Sater mentioned some old weather proverbs about air pressure and explained some interesting facts to us.

One weather proverb says:

“Men, when pressure is high – you eat better, sleep better, and work harder!”

This is because when the air pressure is high your blood pumps better and you have more oxygen to your brain.

Another weather proverb says:

“When pressure is low – teachers say that children misbehave more.”

This is because when air pressure is low your blood does not pump as well and you have less oxygen to the brain.

Mr. Sater tells us that animals are very susceptible to pressure changes in the atmosphere (especially cats). He mentioned that Ben Franklin once said *“you can learn more about the weather by watching animals than by reading any weather almanac.”*

When asked if there was an ideal location for DYNA Members to live, Mr. Sater suggested Bermuda because of the famous “Bermuda Highs.” I don’t think he will get any arguments from the DYNA Members with this location! Sounds like a great place for our next conference! If only we could get them to tolerate the plane flight!

Thank you Mr. Sater! We truly appreciate your assistance and we like your suggestions!

Recommended Sites:

DYNA youth recommend the following sites for their teachers and classmates!

Dr. Julian Stewart of 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>

Life

*It's being right,
When your always wrong,
It's wanting to sing,
Without a song*

*It's liking winning,
But accepting losing,
It's staying calm,
When things get confusing*

*It's stayin ahead,
When others fall behind,
It's being able to see,
When others go blind*

*It's standing up,
Whenever you fall,
It's being there for friends,
Whenever they call*

*It's learning to love,
What you've grown to hate,
It's learning what to change,
And what's simply fate*

*It's standing taller,
Than any other,
It's making it through,
By working together.*

By: Jenni Hinman, Age 17
Ohio

Pre-Meds at Hopkins

*Alone again
Same as before, but different
Progressive
It pulls at my heart strings
Literally,
And down my leg
Through my back
Stealing my breath
I stumble down the street
Past a group of nobodies
Around a world of apathetics
They look away, step away
In fear? In ignorance?
Turn away,
Like you do to the starving skeletons in
National Geographic
Pretend they do not exist
The land of the Free
Home of the Brave
There is no room for those who are
different
They say to each other in
Mandarin Chinese
Hoping that she,
That I
will disappear.
A reminder that when they are doctors
Their peers are sick, are people.*

By: Leah Master, Age 20
New York

**“In the end, we will remember not the words of our enemies,
but the silence of our friends.”**

Martin Luther King, Jr.



The Other Strong One



By: Lisa Albrecht, Age 16
Pennsylvania

I have been sick for four years now. In that time my life and the life of my family has changed drastically. Before I got sick we were an active family...always doing things. Now we have had to sacrifice many things due to my health. I was no longer able to attend school or go out with my friends. My parents had the strain of worry on their minds and had to look to each other for the support that they were not getting from family and friends. They had no time off. I was always there and it was hard for them to leave me. And then there was my sister, Kelly.

Kelly was eleven years old, a year younger than me, when everything started. Life for her completely turned around. Instead of doing the usual family activities, she was stuck in the house with the rest of us. She had to learn how to occupy herself or else she'd be stuck doing nothing, like the rest of us.

Kelly gradually, after time, stepped into the role of big sister. This wasn't easy for either of us. Kelly had to grow up quicker than she was ready for and I had to accept the fact that my little sister had to help take care of me. Which wasn't easy because I was supposed to look out and care for her, not the other way around. But over time we both accepted it.

Kelly also had to give up a lot of things. For one, she wasn't allowed to argue with me. She always had to let me have my way because if I got mad, I got sicker. She had to give up her wants and desires just so that I wouldn't get worse. She has never once complained. I didn't know about this until recently. I always thought that I was just really good at arguing! Guess not! She no longer has to do this because my health has improved some, so I don't always win anymore. You have no idea what a shock it was to lose an argument after winning for years! Now I have to fight to win. Even though I lose sometimes, it's worth it because now I have the strength to fight.

Kelly does many things for me. My favorite is when she puts me to bed when my parents aren't home. She gives me my meds early. Then after I start to fall asleep on the couch, she walks me to bed. She never forgets to wind up the music box before she closes the door. This is something I will miss when one of us moves out. I dread the time when that will come.

My sister means the world to me and I couldn't live without her! She takes care of me, she goes out and does things with me, she loves me and she keeps me company. When she isn't home I always, well almost always, miss her. She is a very strong and special person. To be able to care for another is one of the greatest gifts you could have. I only wish there was something I could do to thank her. There are no words to express the way I love her or how much I need her.

Dizzy Dysautomaniac's School Humor

Those impacted with Dysautonomia often experience dizziness, brain fog, and clumsiness. These symptoms come on very suddenly - which makes for some traumatic moments and even some laughable “dizzy” moments. DYNA members often try to find the humor in the situations they find themselves in. **The following is dedicated to the school personnel and teachers who have been there for us during our rough times!**

School Vocabulary List for Youth Network Members

Absent: The notation usually following your name in class record.

Fire Alarm: How to make a bad day worse!

Nurses Office: Where you spend most of your school time.

Janitor: The person who keeps the floor that you fall on sparkling clean.

Field Trips: Something that means a lot of walking, noise, and confusion that you can never attend.

Hometeahcer: Your best friend.

Giggles

* One DYNA member was recently telling a friend about what a waste of time she found school. Of course, most people who have dysautonomia know all about the impact of gravity and she was no exception. Today she spent the whole science class sitting through a lesson explaining how Sir Issac Newton discovered gravity while sitting on the ground under the shade of an apple tree. She told her friend, “Well, if he had been sitting in Science class somewhere he never would have discovered nothing!”

* Two kids with dysautonomia were talking about their memory problems. “Memory is so important that some people actually get monuments erected for it.” one child said. “How do you figure that?” questioned the other child. “Well, you know they put up monuments in “honor” of people’s memory all the time!”

* A teacher was explaining the word “recuperate” to her class. “When your Dad works hard all day and he is tired and worn out he comes home at night what does he do?” She asked the class. A student replied, “That’s exactly what my Mom wants to know!”

This newsletter sponsored by:



What is A Reflex Anoxic Seizure?

By Trudie Lobban
Founder, RAS Support Group
England

REFLEX ANOXIC SEIZURES (RAS) occurs mainly in young children but can occur at any age. Any unexpected stimuli, such as pain, shock, fright, causes the heart to stop, the eyes to roll up into the head, the complexion to become deathly white, often blue around the mouth and under the eyes, the jaw to clench and the body to stiffen. Sometimes the arms and legs jerk. After what seems like hours but is probably less than 30 seconds, the body relaxes, the heart starts beating and the sufferer is unconscious. One or two minutes later the sufferer may regain consciousness but can remain unconscious for well over an hour. Upon recovery, the sufferer may be very emotional and then fall into a deep sleep for two to three hours and looks very pale. RAS attacks may occur several times per day / week / month. The attacks appear to come in batches.

Other names for Reflex Anoxic Seizures:

Reflex Asystolic Syncope
Neurally Mediated Syncope
Neurocardiogenic Syncope
Pallid Syncope

For additional information:
www.stars.org.uk
Or email trudie@stars.org.uk

Any Youth Network Members
interested in having a pen pal in
England - please contact:
Trudie Lobban

Just Another Name...

You may be wondering about all the names you keep hearing with these disorders! Well, you are not alone! It gets very confusing! Each doctor seems to use different terms for the various forms of Dysautonomia, and even different countries use different terms! On top of that we all use acronyms for each term...no wonder everyone is so confused! To complicate things even more, there is a considerable degree of overlap in these syndromes and the line between them is often blurred.

You may notice by the article next to this that Trudie Lobban is British and that in England they use the term, Reflex Anoxic Seizure (RAS) to describe episodes of Neurocardiogenic Syncope in young children. You will also notice in the article on the following page, that Trudie's daughter calls her Mom... "Mum". That is the standard English term for Mom. Just think of all the words we Americans use for Mom! Language and terms vary everywhere and the various forms of Dysautonomia have many names too. We don't want to get hung up on the names...we will leave that battle to the doctors!

*A good education is the next
best thing to a pushy mother!*
Charles Schultz, Peanuts

What it's like to have RAS



By: Francesca Lobban
Age: 11
England

My Mum is Trudie Lobban and she runs a support organization where I live in England for Reflex Anoxic Seizure's (RAS). I am really proud of my Mum. I am glad that she is helping lots of people all over the world. I sometimes help her by addressing envelopes and placing stamps etc.. About 2 months ago some TV people came to film my Mum and me and they also filmed another Mum and her doctor. It was quite fun but a bit boring because it took a long time. Charlotte, my sister, stood behind the cameraman and tried to make me laugh! All my friends watched it. When I went to the bus the next day everyone asked "Was that you on TV yesterday?"

I thought it would be good to let you know how it feels to have an RAS episode.

After I have an attack I feel dizzy and drowsy. I feel weary and dead like I can't move without hurting my legs. I often get horrendous pains in my legs – especially at night. Mum sometimes rubs my legs. I lay down and rest on my bed or on the sofa. When I have had an attack everyone seems to be shouting. Everyone is so noisy! Mum says she is not shouting - but her voice seems so loud to me! Afterwards, I also want to just cry and cry and cry...I don't know why. My Mum gives me big hugs and tries to make me laugh and feel better but I don't really feel better. I feel shaky and I just want my Mum. I feel frightened.

*Courage is very important
Like a muscle, it is
strengthened by use!*

Ruth Gorden

Yesterday, I was so tired, but I couldn't sleep because I was afraid. I like it best when my Mum is with me because I know she will save me if she can. I wish the doctors could help make this go away or give me some medicine to help me feel better. I hate it! I don't play hockey at school because I am afraid I will get hit. Yesterday it wasn't a hockey ball that hit me but a tennis ball! Today, all my friends were asking if I was OK. I didn't like it and I just wanted to be left by myself. I hate it when everyone looks at me. I feel stupid. I would love to hear from anyone, anywhere who understands. I'd like to hear how you feel and what you do. Maybe we can help each other.

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 \$18.00
914-273-1014 Ext. 117 or
1-800-877-8761
ISBN#087993413

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

Sick and In School: How to Make the School Year Better

By: Megan E. Gurney
Manassas, VA

Guess what happens in late August/early September? It's back to school time! Ugh. I don't know about you, but when I think about another whole school year I feel overwhelmed and worried.

I am a twenty-one year old college senior who has been suffering from a severe case of Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) for over three years. **Orthostatic intolerance** is one of my more debilitating symptoms.

The following information is based on my own experience and research and is very useful to parents of school age children and those young adults in college who have a medically based disability.

Nothing can compare with the embarrassment and frustration I felt when I lost consciousness in the restroom of my community college or when my very tall classmate carried me out of computer class after I was found lying in the back of the classroom. So, if things like this happen to us, then why do we hold to the same standards as "normal" people? It is surprising how willing the public school systems and universities are to accommodate to students' specific challenges.

The secret of education lies in respecting the pupil.

Ralph Waldo Emerson

On July 26, 1990, the 101st Congress passed the **Americans with Disabilities Act**. This law protects and assists people like us (the dazed and confused?) so that we are able to go to school, work, and public places. **According to Public Law 101-336, the act "prohibits discrimination and ensures equal opportunity for persons with disabilities."** This allows the disabled individual (ie: dysautonomia patients) to accept a job or attend school full-time while the responsibility of accommodations relies on the employer or school. For information: (<http://www.usdoj.gov/crt/ada/pubs/ada.txt>).

Why am I telling you all of this? Because I can say with confidence that it is nearly impossible to excel or have any fun in school while struggling with some kind of chronic illness. With this wonderful law, no one can legally deny rights to an equal education just because you are sick! That means that if you have proof that you really want to, say, go to college, you can do it and it might not be so difficult because you aren't trying to keep up at the same pace as those who have nothing wrong with them. Being disabled is not a bad thing, and because of the guys at ADA, we can be sure that someone will help us out. The following is a step-by-step list of ways to tap into the disability resources at your school.

Look up the qualifications for disability with the Social Security Administration. They often deal with Supplementary Security Income and Social Security Disability and these standards can be a good basis for what it might mean to be “disabled.” I’m sure that the SSA has a website and they have resources available at your local office.

Have your doctor write a note, on his/her letterhead, summarizing the diagnosis and the effects it has on the patient. Make sure he/she includes that based on medical observations, *name of patient* cannot perform duties at school at the same pace as the other students.

If you are attending a public school (esp. Jr. or Sr. High) or a university, ask about disability resources and how you can get in touch with the people in charge. At my community college, it was small enough that I just talked to my professors at the beginning of the semester so that they were prepared for my “bad times.” At George Mason University where I currently attend, I established a file with the DRC (Disability Resource Center).

If you are about to begin college, be aware that a disability office should be located somewhere on campus. This place can be your best friend! It provides services such as extended time for assignments, classroom changes, parking/escorting for us fainters, priority registration, and alternative testing times. Do not be afraid to ask for help or feel like you can handle things yourself. One of the responsibilities that Americans have is to uphold the law and this includes the ADA. Disability centers are very confidential and are sensitive to each case individually.

For a good example of university disability resources, **check out this website:**

<http://www.disserv.stu.umn.edu/UDS>

For more detail on the Americans with Disabilities Act, go to their homepage at: <http://www.usdoj.gov/crt/ada/adahom1.htm>

or call the ADA Info. Line toll-free at: 1-800-514-0301

A college degree and a teaching certificate define a person as a teacher, but it takes hard work, dedication, and compassion to be one.

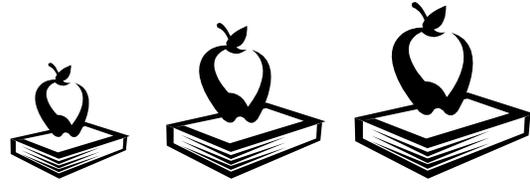
Paul McClure



**DYNA
MEMBERS EXTEND A
SPECIAL THANKS TO
DR. BLAIR GRUBB
AND
MR. DAVID LEVY.
YOUR EFFORTS
TOWARD THE
YOUTH NETWORK ARE
TRULY APPRECIATED!**

Educating Students With Dysautonomia

Barbara Steel
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Working as a teacher and a special education consultant I have found that students with dysautonomia, most of whom have average to ABOVE average IQ, present with challenging and unique needs. The disorder significantly impacts their educational, social, and physical experiences. What makes dysautonomia so difficult is that it lies in the category of **INVISIBLE DISABILITIES**. Those of us who have not experienced this disorder can not truly appreciate what it must feel like. **Imagine having a severe flu constantly. Everyday you feel like you will pass out. You have absolutely no energy (it is even hard to stand up or sit up). Your concentration is severely affected, the room spins, your heart is racing, your senses are dulled – you have trouble receiving and processing information and your vision is blurry.** This may just be part of the symptoms a dysautonomia student could be experiencing. Yet, schools often expect students who have these symptoms to be able to function fully all day – everyday and to be successful! **COULD YOU???**

PHYSICALLY: Symptoms vary from one form of dysautonomia to another, student to student, day to day. Often as the student grows their symptoms change. There is no predictability. The symptoms can be mild - allowing the student to participate in almost all aspects of the school program with a few modifications, or they can be very severe life-threatening symptoms which require major medical modifications to the school experience in order for the student to continue successfully. **Students with dysautonomia are 504 eligible and most are eligible for services under “health impaired” as outlined in the IDEA law.**

EDUCATIONALLY: Educational needs vary from individual to individual. The family, student and medical/treatment team **MUST** be an integral part of the school planning team for the student to be successful. Meeting the educational needs of students with dysautonomia requires **FLEXIBILITY** by school personnel, teaching staff and parents. **SOME BASIC SUGGESTIONS ARE:**

SEATING: Younger students must sit where the teacher can see them at all times. A discreet signal should be used to let the teacher or assigned buddy know that the student is not feeling well and needs assistance. A system should be set up for managing the individual situations that may arise. A seat close to the door may be beneficial due to ventilation and access to the rest room.

BREAKS: Sitting for 15 minutes or longer is a problem for many individuals with dysautonomia. Breaks so the students can walk to get blood circulating, get a drink to rehydrate, and a snack (if medically indicated) will help with concentration and classroom performance.

MODIFICATIONS TO SUPPORT LEARNING: Students who have problems as listed above and other problems associated with dysautonomia that affect learning and completing of assignments will require modifications in their program. Longer time or exceptions may be needed to do school work and homework assignments. Shortened assignments are more beneficial than long ones. **Fatigue does not encourage learning!**

When several teachers teach a student they should try to coordinate assignments so they are manageable for the student and often only assignments that are critical for reinforcing learning should be assigned.

MODIFICATIONS FOR TESTING:

Testing modifications must be made on an individual basis. When testing needs to be done, it should be done when the student feels well and in short periods of time over several days with frequent breaks so that the students true abilities are tested not the physical symptoms associated with the dysautonomia (in some forms of dysautonomia lack of attention can be due to lack of blood flow and decreased blood pressure). Fluid intake while testing can help tremendously with concentration.

ENVIRONMENTAL CONCERNS:

Controlled room/environmental temperature is critical for students with dysautonomia. Temperatures too high or too low often cause significant medical symptoms in individuals with dysautonomia as their bodies can not regulate temperature well. Ventilation is also important. Often smells and lights can trigger problems for the dysautonomia student.

PHYSICAL EDUCATION: Participation in physical education may need to be limited or eliminated.

FIELD TRIPS: Will have to be individually addressed.

PHYSICAL COMPLAINTS: Develop a plan with the family, doctors, and student. Never assume it is “behavioral” just because the symptoms may not be visible.

SOCIAL / EMOTIONAL: As with all students requiring modifications in the school program and environment, dysautonomia severely impacts the student’s participation in the school setting. May of these students are absent from school frequently and for extended periods of time

which severely impacts them socially. Dysautonomia students have voiced feeling isolated and “like an outsider.” Even those who were once very involved in their school’s social functions feel isolated. The toll is not only physical but has been described as being socially unbearable. Even the student who is able to attend school may often not feel well enough or have the energy to participate socially. As a teacher you can help facilitate the continued social contacts.

Take time to talk to the student about what is happening to them (physically, classroom assignment wise, socially, etc.).

Help their classmates understand what is happening to the student with dysautonomia (with permission). Ask the student how they would like to handle this and if they would like to participate in explaining their condition.

Make sure the student feels welcomed and a part of the class, especially after multiple or extended absences.

Keep in touch with the student and family by phone. If possible visit the student if they are out for an extended period of time.

Have others in the class help by phoning, visiting, and passing on classroom information and news to the student.

Fortunately, some of these students will out grow their dysautonomia or it will lessen with time. Others will always have it or it may worsen. Research is currently progressing with these devastating disorders and hopefully over time better treatment options and a cure will be found.

Please feel free to contact DYNA for additional information and or suggestions to help you create a positive learning environment for these students.

DYNA puts youth with dysautonomia in touch with each other via the Internet. 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 DYNA
email:
info@dynakids.org**

If you are a youth impacted with Dysautonomia and you do not have the Internet you may write DYNA and we will put you in touch with another member via regular mail.

Any physicians who would like to participate in a future newsletter may contact us. We welcome your input. We would also appreciate it if physicians register to be included on our mailing list.

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

***Our greatest glory is not in never falling –
but in rising every time we fall!***

Confucius

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Donation Information

DYNA is a non-profit organization dedicated to serving individuals impacted with dysautonomia. Contributions can be made to:

DYNA

1301 Greengate Court, Waldorf, MD 20601

No contribution is too small and every donation is deeply appreciated.

Any schools/organizations wishing to hold a fund-raiser in honor of a **DYNA member** impacted with dysautonomia will be provided with educational information on Neuroscience and the Autonomic Nervous System. Please feel free to email us at info@dynakids.org

Please accept my donation to DYNA **Make checks payable to DYNA**

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DYNA 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

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