

DYNA Newsletter

“The Young and the Dizzy”

Summer/Fall

Special Edition

2002



Dysautonomia:

When our Autonomic Nervous System (ANS) malfunctions, it is known as Dysautonomia. The ANS participates in the regulation of all 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. Symptoms may include: Tachycardia, dangerously low blood pressure, excessive fatigue, exercise intolerance, severe dizziness, fainting or near fainting, gastrointestinal problems, seizures, and migraines.

Dysautonomia is a chronic and invisible illness. Children with dysautonomia are often told, “You sure don’t look sick.” Their parents are often told, “She/he sure looks fine to me.” **Well, looks are only skin deep and dysautonomia goes much deeper than the skin!**

People with a chronic illnesses fall into two categories:

- 1) Those with obvious conditions that are visible on the outside and are easy for other’s to recognize.
- 2) Those with invisible conditions who look fine on the outside and are difficult for other’s to recognize.

When you have an invisible illness you often end up explaining your condition to others before they can even begin to understand what you deal with day in and day out. When you have something rare and unusual like Dysautonomia you often end up explaining your condition over and over and over again. Our DYNA members have become good at explaining their conditions and this newsletter is their voice. They ask that their teachers, friends, and school systems educate themselves about dysautonomia so that they can better understand what it's like for them to suffer with it. Ralph Waldo Emerson once said, "*The secret of education is respecting the pupil*". When you're dealing with a dysautonomia student, respect comes through awareness.

Any individual with a chronic illness will greatly benefit from support and education. We held our very first DYNA Social Camp in Maumee, Ohio July 9-12, 2002. Youth with dysautonomia traveled from all across the country to attend. It was an honor to have Dr. Blair Grubb of the Medical College of Ohio speak at our "Goofy Slipper Lecture." His informative session has been video taped and will be made available to DYNA members, physicians, school systems, and all interested parties (email info@dynakids.org for information on ordering). To make this lecture "kid friendly" and casual the kids wore "Goofy Slippers" and they presented Dr. Grubb with his own pair of Giant Monkey Feet Slippers. The event was a tremendous success and the kids truly enjoyed the opportunity to meet in person. For the first time in history children with dysautonomia stood face to face (and when they couldn't stand they laid down). They found out they were not so alone in the world and happy faces and laughter were everywhere! We plan to hold this event annually and will keep you posted via our new web site www.dynakids.org.

The week after the DYNA Social Camp the NDRF held it's 2002 Conference in Washington, DC with the leading experts in autonomic research speaking (Dr. Cecil Coghlan of the University of Alabama, Dr. David Goldstein of NIH, Dr. Blair Grubb of the Medical College of Ohio, Dr. Phillip Low of Mayo Clinic, Dr. Christopher Mathias of St. Mary's – London, Dr. David Robertson of Vanderbilt University, and Dr. Julian Stewart of the Medical College of NY. While the adults with dysautonomia were attending the DC function most of the children were home recovering from their own event the week before.

It's been a busy summer for our DYNA kids! Dealing with their conditions, working hard at reconditioning, following doctors orders, taking on tasks to help within the Youth Network, finishing up their school work from last school year, giving their parents a hard time, and still getting in some quality time on email and IM with each other (as if that was ever in question!).

The great thing in this life is not so much where we are, but in which direction we are moving.

Oliver Wendel Holmes

Debra L. Dominelli
President, DYNA, Inc.



Dysautonomia Pioneers



Time flies and it seems like summer just began and now here we are at the “**Back to School Edition**” of the DYNANewsletter. Quite appropriately, this edition is being released in conjunction with the **brand new DYNA web site www.dynakids.org/**. This is all a part DYNA’s continuing effort to help make school systems, school nurses, administrators, teachers, and students more aware of dysautonomia and how it affects everyone. When we say everyone, we mean just that “EVERYONE”. Brothers, sisters, parents, extended family members, friends, neighbors, and classmates are all impacted when someone close to them is diagnosed with a condition like dysautonomia.

Dysautonomia is tough enough to explain to doctors and medical professionals who never had the opportunity to learn about it. Fortunately, compassionate souls in the medical profession who are willing to learn about dysautonomia usually end up becoming very strong advocates for their patients.

Having symptoms that are invisible on the outside or often appear **after** an activity makes these conditions very hard for others to understand and believe.

Uninformed people will often say, “You look fine to me.” or “You don’t look sick.” Many times vague symptoms at adolescence (such as dizziness, fainting, fatigue, and stomach issues) are dismissed as “growing pains”, “adolescent misbehaving”, “acting out” or being “manipulative to gain attention.” However, adolescents impacted with forms of dysautonomia have very legitimate medical conditions and none of those terms apply to their particular symptoms.

How can parents get school systems to accommodate, understand, and support students with dysautonomia? These students have a legitimate medical condition and have the LAW on their side when it comes to educational accommodations. Unfortunately, even with the law on your side you may find that creating an understanding and supportive atmosphere within your school system can be complicated at first. Remember that communication is essential. It is strongly suggested that the families of students with the various forms of dysautonomia attempt to educate their school systems about their particular condition and the impact it has on them. You should provide the proper school personnel with documentation from your physicians and with information from the most recent medical journals, web sites and books. Remember that some uninformed individuals may elect to dismiss information when it doesn’t come from their own (the school’s) resources (school nurse; school counselor etc.). Unfortunately, dysautonomia patients have the additional burden of having an illness that was not well understood or taught until recently and is for the most part unknown. Continuous communication with the proper school personnel is vital.





The fact is that certain illnesses only become better understood with time, research, and with advocates for their recognition. **Our DYNA kids are “dysautonomia pioneers”**. They are going through the hardships and struggles of traveling unknown territory and clearing the path for future children impacted with these conditions. With progress and awareness dysautonomia will become better understood. More research will tie in a better explanation of the medical issues associated with it. In the future, explaining it to the school systems won't be a problem because all the right people will be up-to-date on these conditions.

History demonstrates to us that being a pioneer isn't easy. DYNA parents get upset because they want their child with dysautonomia to have qualified and professional educational instruction and they want the school systems to recognize the educational support issues that their children face. Kids with the illness often get frustrated because they think that no one in their school system understands or believes what they are going through. They often feel tremendously isolated from their peers. The school personnel get frustrated because no one can give them the “straight story” about what they are dealing with. Of course, with dysautonomia there is no “straight story” and each case is individual and needs to be addressed independently. Often there is very little predictability on how a student with dysautonomia will progress and what modifications must be made educationally. Being the first with anything – good or bad – isn't easy.

It would be nice if there were one simple way to resolve the problem, but there isn't. One of the ways that the Youth Network is trying to help is by working in association with both the **American Association for Caregiver Education**, who currently host the DYNA website on their internet server and the **Lattice Group Inc.**, who have donated their time and expertise in designing and maintaining the DYNA website. On the DYNA site you will find; newsletters, updated medical articles, information, helpful hints, youth member's letters, poems, and more. The site is available to schools and administrators who will be able to access it in order to gain the whole picture about the student with dysautonomia. School systems will find that dysautonomia does exist and that world-renowned specialists are diagnosing and treating it. They will understand that real kids are suffering from it. They will find that there are many determined professionals and lay people who care about and support these children and who are determined to help the schools make an informed decision on how to help them obtain a fair and supportive education. They will gain an understanding of the challenges students with dysautonomia face and be better equipped to support them.





Keep in mind that this new site is not where the DYNA kids meet and communicate with each other. That is a private and secure situation under the direct management of Debbie Dominelli, without whose diligent efforts there would be no DYNA. Her unwavering rule is that all kids within DYNA must be protected and their Internet communications safe and secure.

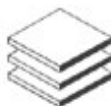
Debbie knows that kids are very capable and she has a deep respect for her DYNA members. DYNA is all about – KIDS. Kids issues, kids problems, kids solutions and “kids for kids” under the proper supervision and guidance from professionals that only have their unique and specific interests in mind. DYNA consults with the kids and asks what they want and determines their specific needs. One of the main issues that the kids currently express is their need to gain understanding and support from their school systems and their extended family and friends. They wish to bring about better awareness of dysautonomia and of the impact that dysautonomia has on them. They want to approach this issue without turning it into a complicated and detailed medical effort, and without resorting to individual “war stories.” DYNA admires them, supports them, and is going to help them.

So...now it is “Back to School” and that means for all of us! Everyday we learn something new about dysautonomia. We “teach” but we are also “taught”. Education is an ongoing process for all of us.



David Levy, JD
American Association For Caregiver Education
www.CaregiverED.org

**Thanks to the unselfish efforts of the professionals at the
Lattice Group, Inc.
DYNA now has a website!
We sincerely thank Francis Yoon, Al Yoon, and Jennifer Shepherd for
their generous support and compassion!**



LATTICE GROUP, INC.

Do you Remember Me?

J. Hinman



*Do you remember me?
Because I remember you.*

*I passed you in the halls,
and sat by you in class.
Little did you know the things you said
would shatter me like glass.*

*I was the same as all of you,
I had crushes, A's and B's
but then I became "different"
struggled and dropped to C's and D's.*

*The teachers thought I was faking,
Other students started rumors,
I would have been much worse off,
If it weren't for my sense of humor.*

*In just a few weeks
I became pregnant, on drugs or dead,
and soon enough, with help from others,
It was all in my head.*

*I did nothing to deserve these things,
my body decided long before,
that I would be either at home in bed,
or at school lying on the floor.*

*At first I let you get to me,
and you really got me down,
but I decided long ago,
I will no longer frown.*

*Now I've met wonderful people
with the same ailment as I
and with them and the whole Youth Network
I will surely get by.*

***We worry about what a child will be tomorrow,
yet we forget that he or she is someone
today!***

Stacia Tausher





Working Together for Home Instruction



Home instruction is a partnership in your child's education. The partnership is between your child's school, the home instructor, and the family. According to the law, a child is entitled to home instruction if the family presents a valid medical reason substantiated by a health care professional. This may be due to a temporary or a permanent medical condition. Reasons for home instruction might include: a broken leg, mononucleosis, asthma or another life-threatening illness, or the suspension of a student classified as special needs.

In order for the child to receive the greatest benefit, it is important for all members of the educational team to keep an open line of communication. Each member of this partnership has specific responsibilities to the student.

It is important for families to understand when the home instructor arrives, the student should be prepared to begin his or her schoolwork. An adult must be present in the home. There should be a specific area for the teacher and student to work. A well-lit, cheerful workspace is beneficial for both the student and the instructor. Crying siblings, loud music, and vacuuming under the table where the student is working, is not conducive to home instruction! (It is often helpful to have a sense of humor☺)

All parties should treat home instruction as they would treat the school experience. It is helpful for the student to have basic supplies such as paper, pencils, erasers, scissors, glue, and items that would normally be age-appropriate for classroom use. (Some instructors bring these items with them into the home.)

Arrangements should be made for specific instruction times. If it is necessary for the parent to cancel due to the child's illness, they should attempt to contact the home instructor prior to the instruction session. Home teachers should make every effort to provide the scheduled hours of instruction and should cancel only due to sickness or emergencies. Cancellations due to the child's illness are inconvenient, but this is a job that requires flexibility on the part of the student, the family, and the instructor and school system. Although the instructor should arrive with lesson plans (just as any classroom teacher), the instructor should be realistic in her/his expectations and know that sometimes those plans need to be changed. Often modifications in the workload must be made to accommodate the sick child. An uncomfortable or sick child does not always feel an overwhelming compulsion to work tedious math problems, or read a forty-page assignment. With this in mind, parents should remember that the instructor may have quite a bit of material to cover in about one-fifth the time a classroom teacher would have.

From the onset of home instruction, parents should communicate with the instructor regarding the workload that your individual child can tolerate due to their illness. Regular communication between the parent and the home teacher is essential for success.

Home instructors not a “courier service” for homework to and from the child’s home school and they have a legal responsibility to provide ACADEMIC INSTRUCTION AND LESSONS to their students. Parents must also encourage students to complete homework assignments left by the instructor when possible. Home instructors are usually (but not always) certified teachers. Due to the nature of the job, they are expected to be a “jack of all trades”. Parents should remember that this teacher may work with a kindergarten student’s phonics skills in one home, and then work with a junior high student with algebra and honors science in the next home. An organized instructor will have lesson plans and a specific schedule.

The home instructor is expected to work with your student’s home school. An open line of communication is very helpful for everyone involved. It is important socially for the student to still be included as a part of their home school and not to be forgotten because they are on homebound instruction. Schools should be sure to include them in yearbook pictures, clubs, newsletters and school assemblies and school awards when possible. It is best to inform homebound students of school activities and let them make the choice to attend or not attend. It’s a good idea to have a teacher at the home school responsible for keeping the home teacher and the student up to date on school activities. No child should feel isolated from their school peers because they are on home instruction. The school should also provide necessary books and supplemental materials to the home instructor and/or the parent. Teamwork is an important aspect of this working relationship. The instructor should communicate with the classroom teacher on a regular basis and the family should be kept up-to-date related to these communications. Without open communications, the job of the home instructor is much more difficult (and sometimes, impossible). If there is a problem, it is important for all parties to discuss the problem: parents, instructor, and classroom teacher or school representative. Depending on the length of time the child will be out of school, an agreement will be made about the grades and progress reports that will be provided. Some classroom teachers prefer to grade the student’s work (along with the work of their classroom peers); others will suggest that the home instructor grade the work. Report cards are usually are mailed from the home school but it is up to the home teacher to verify this is being done.

Home instructors and their students are expected to make the best of difficult situations. Henry Ford said, “*Coming together is a beginning; keeping together is progress; working together is success.*” Remember that you and your child are in an important partnership with the home instructor and the school. It is your responsibility to support the efforts of your child and to continue to advocate for him/her while home instruction occurs. If you have questions, ask them! Communicate with one another and help your child set realistic educational goals.

**Never have ideas about children
and never have ideas for them.**

George Orwell



Cindy Fortlage,
Home Instructor,
Toledo Public Schools,
Toledo, OH



*'We care, we share,
We love to learn'*

Youth Network Guidelines For Educating The Student With Dysautonomia

Educating students with dysautonomia poses unique challenges for the parents, teachers, educational systems, and most importantly the student. The various dysautonomia conditions are very involved and complex. Each child is impacted differently, and each case is unique and needs to be addressed individually. These children's symptoms can vary dramatically daily, hourly, and sometimes minute-by-minute. Some patients with dysautonomia may only be mildly affected with occasional symptoms, while others can be severely affected with constant and severe symptoms. Those with severe forms of dysautonomia can be virtually bedridden. Often symptoms can be so severe that these children can have difficulty completing their schoolwork, and they may require extra help to keep up. Some of these children may have to be placed in a home teaching program with their school systems until they are strong enough to attend regular classes. Others may be able to attend school on a limited or part-time basis and may require a tutor as well. What dysautonomia patients need most is encouragement and understanding to help them deal with these complex and debilitating poorly understood group of disorders. A cooperative approach that combines the efforts of the physicians, the patients, their families and educators is often the most important aspect of successful management of dysautonomia.

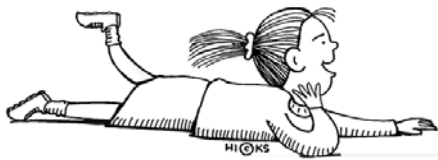
Creating an individual educational plan for these students starts with two things:

- 1) Flexibility
- 2) Creativity

SYMPTOMS OF DYSAUTONOMIA MAY INCLUDE:

Orthostatic Intolerance
Hypotension (low blood pressure)
Tachycardia (rapid heart rate)
Palpations
Chest Discomfort
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
Insomnia
Frequent Urination
Temperature Regulation Problems
Brain fog/forgetfulness



Being unique, there is no one method of dealing with these students that will work for all. However, certain common factors prevail in approaching their education.

- Communication between parents, child, medical and educational authorities is essential. A common, respected understanding for the illness is the only way that a sound foundation can be established.
- Teachers and school staff should demonstrate flexibility in respecting the student's perspective in judging of their own capabilities. Teachers need to weigh their expertise in understanding the actions of "normal" students and then determine the tolerance needed to kids that "look normal" but have a chronic illness that is not well understood.
- Exercise intolerance may require elimination of physical education from the student's individual curriculum. This needs to be reviewed and the student should have an alternative requirement so as not to be "left out."
- Concentration may suffer. Comprehension, deduction, and memory storage and retrieval may be impacted. Curriculum may need to be adapted to meet the student's individual range. This is not too dissimilar to other children with special learning needs.
- Prioritize instruction. This is a function of any quality school system and these needs should be handled by the proper teachers (special ed, etc.)
- The illness produces frequent absences and the system needs to understand this and allow for it in the planning process so not to unfairly prejudice the student.

- Coordination between teachers is essential to avoid overloading the student. Some students may have a low tolerance of laboratory smells and substances.
- In other cases noise and light sensitivity may pose a challenge.
- Bathroom privileges may need to be modified.
- If available, an extra set of books should be provided to keep at home.
- A companion may be needed to help with book bags etc.
- Classroom temperatures may dramatically impact the child. While the overall needs of the class are primary, recognition that a warm environment can compromise these students is needed.
- Remaining upright may present gravity intolerance, therefore fire drills, outside assemblies and other such events may need special accommodations so that the student is not standing out in the heat for long periods.
- Fluids are essential and should be allowed at all reasonable times.
- Salty snacks may be necessary.
- "Brain fog" and forgetfulness are an often-occurring problem with these children and may present a problem and a frustration for the student.
- Tests and exams present practical problems. Flexibility and tolerance in being creative to allow fairness to the class and the dysautonomia student is a hallmark. Special concessions may need to be made, but should not be viewed as "favoritism".
- Keeping the student in contact with his/her school peers can be a tremendous help emotionally. It is hard for other uninformed students to understand what the dysautonomia child is dealing with.
- Rumors often surface among the other students regarding a student's condition. Generally, it is best to be open and to communicate/educate classmates about dysautonomia and about the impact this condition has on the student.
- Children have a great capacity for understanding when treated like adults and dealt with in a mature manner. This is especially important for a child that "appears" to be healthy, but has a chronic illness. Ostracism can happen quickly if the school officials are skeptical.
- Since many doctors are first starting to understand dysautonomia; it would be unfair to saddle the school nurse with being the interpreter of this condition. An open mind and a respect for the literature setting forth the problem is important. This illness was not taught about in medical school or nursing school.



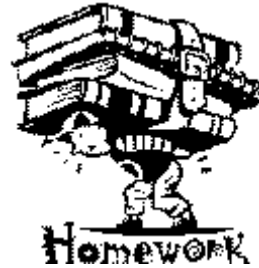
Always remember that children with Dysautonomia are truly special kids - not for their disabilities, but for their abilities!

Where did You go?

By M. Gurney,

You were the one who was Me.
And I was You.
We were inseparable.
Accidents happened, things altered.
You and Me?
We didn't even recognize each other.

You were the one who was Me.
And suddenly You weren't Me anymore,
And I was not You.
Now I am Me and You are gone.
I and Me?
We are the only ones left.



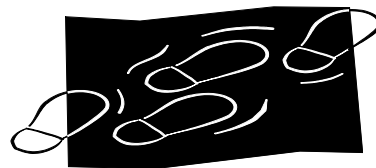
Starting Point

By R. Dominelli

*I lay down and I look around me,
and I look in me,
Twisted and deformed by a world in
which I have no control
I am no longer who I was, nor who I had
wished to become.*

*And as I walk the road of life
I look back at the silhouette of the boy
that is me -
Fading in the distance
and finally disappearing over the
horizon like so many sunsets that set us
apart*

*And yet I still move forward,
Hoping someday to return to the point
from which I started, and find myself
once again.*

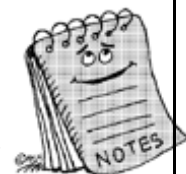




**I have a friend with dysautonomia.
What do I need to know?
How can I help them?**

If you have a friend with Dysautonomia, asking these questions is the first thing you can do to help them. Dysautonomia is what the medical profession calls a *chronic invisible condition*. Chronic means it's long term. Invisible means that you can't actually see what is going on inside of your friend's body and that the symptoms your friend experiences are mostly invisible to other people. Your friend can't put a bandage on it and show people what's wrong. You can't see dizziness, gastrointestinal problems, insomnia, migraines, brain fog, fatigue, exercise intolerance, blood pressure and heart rate changes and many of the other symptoms that make having dysautonomia so difficult for your friend. You may be able to see that your friend is very pale, you may notice that they have blood pooling in their legs and feet, you may even notice that their heart is beating way too fast, and obviously you will notice if they actually faint, but for the most part you won't see the symptoms your friend is dealing with. However, the symptoms are very real, your friend has no control over them, and they do happen (often after activity). Your friend needs your support now more than ever. You can learn about dysautonomia by reading our web-site (www.ndrfyn.aacekids.org/) and you can learn about what your friend deals with by reading our newsletters. Remember, just like any other illness, dysautonomia has various degrees and everyone is impacted differently. There are also different types of conditions under the term of dysautonomia. Your friend's case is unique and individual and everyone with dysautonomia has their own assortment of symptoms and various systems impacted.

It gets very hard to deal with dysautonomia day in and day out, especially for a child or a teenager. Your friend will have good days and bad days. It's very common for people with chronic conditions to have periods where they do well and periods where they are not doing as well. On their good days they just want to get on with life. They will have to make modifications to their activities and do things like taking their medicine, drinking a



lot of water, eating salty snacks, and paying close attention to their body signals – but they still want to be the person they were before they got their condition. Don't treat them any differently but be sensitive to what they are dealing with. Help them resume their lives by supporting them in every way you can. Remember, they may not be able to walk the mall with you like they used to, but you can still invite them for a soda at the food court. Don't forget about them! It's a good idea to talk to them and tell them you want to help and that you will stick by them through thick and thin. Find out from them what it's like to have dysautonomia and specifically ask them how you can help.

Usually, one of the hardest things for adolescents with chronic cases of dysautonomia to deal with is the social isolation they experience. If they are unable to attend school they are suddenly not included in activities. They tend to feel very left out and abandoned. Although it may sound like fun to stay home from school...it sure isn't day in and day out! You would get very tired of it too and you would miss your friends and classmates. You would miss being active and you would miss being social and you would get really tired of not feeling good. It is actually very, very hard to deal with on a constant basis.

Remember to CALL YOUR FRIEND whenever you can. E-mail them quick "Thinking of You" notes. Keep in touch with them and keep them in touch with what's going on at school etc. At first doing this may seem easy for you, but as time goes on it won't be as easy because you may get sidetracked with your own busy social life. Talk to your parents about it and they will help you and they may have some suggestions. Also, talk to the teachers at your school and give them our web site to check out. Suggest that they send notes home to your friend to help them realize they are still a part of your school even if they can't attend. Include them in school activities and tell them about things they may be able to attend and keep them as socially involved as possible.

It isn't pleasant to be a kid with an unusual chronic invisible condition like dysautonomia but with a good friend by their side it will be much easier!

Sometimes the heart sees what is invisible to the eye.

H. Jackson Brown, Jr.

Debra L. Dominelli, President

To the following individuals
who made donations to the
Youth Network:



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

In honor of Mary Bibbs
Mr. & Mrs. David Bibbs
William C. Bannerman Foundation
Margaret Bibbs / Barbara Holmes

In honor of Julie Chinitz
Mr. & Mrs. Gilbert Chinitz

In honor of Amanda Dominelli
Mr. & Mrs. Richard Dominelli
MP Chance

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

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

In honor of Blair Grubb, MD
Mr. & Mrs. Marshal Granor

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

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

In honor of Samantha Phillips
Mr. & Mrs. Burl Majors
Mr. & Mrs. Larry Phillips
Mr. & Mrs. Jackie Finch

In honor of Sarah Pietras
Mr. & Mrs. John Pietras

In honor of Megan Robinson
Mr. & Mrs. Tom Robinson

In honor of Kenneth Sawicki
Mr. & Mrs. Kenneth J. Sawicki, Sr.

In honor of Roland Vargas
Mr. & Mrs. Richard Vargas

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

General Contributions:

Mr. & Mrs. Tom Brosius

Memorial Donations:

In loving memory of Carmen Deane
our "Granny Dean."

1902-2002

Mr. & Mrs. Richard Dominelli

*Every child's life is a piece of paper on
which every passerby leaves a mark.*

Ancient Chinese Proverb

Many thanks to:
Michael A. Sullivan,
*Assistant Prosecuting Attorney,
Director, Internet Crimes Against
Children Task Force, Cuyahoga
County, Cleveland Ohio
for helping us learn about Internet
Safety!
We appreciate you!*



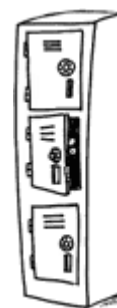
Climb into my Shoes

By: A. Myslenski

The word “visible” is often defined as being able to see or notice something. There are many medical conditions that are “visible”. Chicken pox is one example of a visible condition. There are also many medical conditions that are not visible. Dysautonomia is one of the conditions that is not visible. Dysautonomia is a dysfunction of the autonomic nervous system. People with dysautonomia have many invisible symptoms because the autonomic nervous system controls every “automatic” function in our bodies. Most people with dysautonomia have heart rate and blood pressure regulation problems along with other impacting symptoms.

Most schools and educational systems are not familiar with dysautonomia and do not understand this serious chronic disorder. Often students with the various forms of dysautonomia must have a modified course load due to the impact of their conditions. Many must also have home teaching provided by their school systems. Luckily, there are special laws that make it mandatory for school systems to accommodate these students. Dysautonomia students suffer tremendously impacting “invisible” symptoms and they are legally entitled to modifications. Section 504 of the Rehabilitation Act was the first federal Civil Rights Law to protect the right of people with disabilities such as dysautonomia. Section 504 prohibits discrimination in the education of students with disabilities. Schools must comply with this law. Some dysautonomia students will need a 504 Plan. Often their parents must request that these arrangements be made.

Unfortunately, dysautonomia students sometimes face uninformed teachers who do not want to modify their course load and are not willing to support them. School systems and teachers must educate themselves in order to provide a dysautonomia child with a fair education. As a student with dysautonomia, just writing this paper has worn me out. Most kids with dysautonomia will tell you the same thing. We only have so much energy to spare and it is very hard (impossible even) to function with a regular school work load. In the book, To Kill a Mockingbird, Atticus Finch said, **“You never really understand someone until you climb into his shoes and walk around in them.”** No one really can understand what it’s like for a person with dysautonomia unless they suffer from it themselves.



Teachers can play a very positive or a very negative role in the life of a child with dysautonomia. If they want to play a positive role all they need to do is learn about these conditions so they can help the student impacted obtain a fair education. Dysautonomia students deserve respect and they don’t want you to feel sorry for them! They just want an education like everyone else but they will need modifications to help them obtain it on an even playing field. We students with dysautonomia have learned to deal with our conditions and now it’s the schools turn! Always remember that students with omia are special kids – not for their disabilities but for their abilities!



My Thoughts

By: K. Linderman,

*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.*

Body vs. Mind

By: M. Mambort,

*It shouldn't be so difficult
To write a paper
Or two
Or three
But it is
The mind is willing but the body is weak
My hands shake and my eyes try to bring
the words into focus
The body achieves what the mind
believes
I used to think that was true
And I wish I still could
But my body seems set on proving
otherwise.*



Moments

By: Blair P. Grubb, MD

*In the end
It is the moments
We remember.
The smell of roses
The feel of sun on skin
A kiss in the woods
A tender caress.
Only the moments
Of pain and pleasure
Joy and sorrow
That play themselves
Over and over
In an endless sequence
Of remembrance.
These are what
We cling to
Those moments that form
The history
Of our souls...*



What is DYNA?

Young people 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. DYNA is a non-profit organization dedicated to serving these individuals. We started the Youth Network in April 2001. Our first priority was to give young adults 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 young adults get diagnosed earlier and obtain proper medical treatment.

Mission Statement

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

- To give the young adults impacted with dysautonomia hope for the future.
- To provide a youth focused outreach program / support network for the youth who are afflicted with dysautonomia.
- To heighten awareness of these conditions and their treatments within the pediatric 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 Youth Network provide these children with the necessary support network.



E

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

Name on card: _____

Card Number: _____

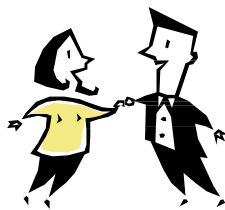
Exp. Date: _____

Signature: _____

My donation is made in honor of:

Address:

Please notify the above individual of my support: yes no



**A HUGE THANK YOU
TO THE FOLLOWING ORGANIZATIONS
WHO HELPED MAKE THE 2002
YOUTH NETWORK SOCIAL A SUCCESS!**



Toledo, Ohio



NO RULES. JUST RIGHT.®

Maumee, Ohio



Dr. Blair Grubb
Medical College of Ohio



Waldorf, MD
Maumee, Ohio

Sir Speedy Printing
Hanover, Maryland

Applebee's
Maumee, Ohio

Wal-Mart Distribution Center
Woodland, Pennsylvania

Cera Products
Laurel, Maryland



Big Boy Restaurant
Maumee, Ohio

Mortons Salt Company
Chicago, IL

Red Lobster Restaurant
Maumee, Ohio

Danish Pastry Shop,
Fremont, OH

Hops Restaurant
Maumee, Ohio

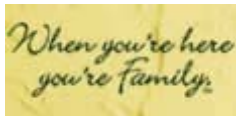
Ideal Bakery
Gibsonburg, OH

Max & Erma's Restaurant,
Maumee, Ohio

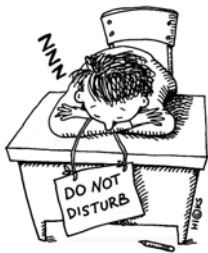
Papa John's Pizza
Maumee, Ohio



Olive Garden
Maumee, Ohio



Maumee, Ohio



Understanding Section 504



Section 504 of the Rehabilitation Act has been a federal law since 1973. For many years the main thrust has been in the area of employment for individuals with disabilities. Within the last decade, the Office of Civil Rights has been charged with the enforcement of Section 504. The Office has become pro-active in the field of education of individuals with disabilities. Advocacy organizations and the legal system have increasingly focused on Section 504's requirement to insure the education system provides a full range of special accommodations and services necessary for students with special needs to participate in and benefit from public education programs and activities. (CASE, Student Access/Section 504 1999 Edition.)

Section 504/Americans with Disabilities Act prohibits discrimination against persons with disabilities, including both students and staff members, by school districts receiving federal financial assistance. This includes all programs or activities of the school district receiving federal funds. Included in the US Department of Education regulations for Section 504 is the requirement that students with disabilities be provided with a free, appropriate education. These regulations require identification, evaluation, provision of appropriate services, and procedural safeguards **in every public school in the United States**. However, many schools remain unclear in their understanding of this powerful law and are limited in their capacity to fully implement its requirement. (CASE, Student Access/Section 504 1999 Edition)

It has been my experience that many public school personnel do not fully understand what a 504 plan is. A 504 plan differs from a special education plan. A student with a specific disability that qualifies them for an Individualized Education Plan (IEP) has impairment that adversely affects educational performance. A student with a 504 plan displays an impairment (physical or mental) that substantially limits one or more major life activities (i.e. learning, employment, breathing, walking, speaking, etc.) The Individual with Disabilities Act defines as eligible, only students who have certain specified types of disabilities and who, because of one of those conditions, needs special education (specially designed instruction). Section 504, on the other hand, protects all impairment that substantially limits one or more major life activities (including learning). Section 504 covers all students who meet this definition, even if they do not need to be in a special education program.



Any parent with a question/concern about a 504 plan should contact the building principal. In some cases the principal may not be familiar with the process and shy away from your request. Don't be discouraged. Continue your pursuit. Ask questions and seek support from those knowledgeable in the field. Request a copy of parent rights from the special education office. Historically, those rights will have parent information regarding advocacy groups.

Michele Ferree, MS Ed.
Special Education Facilitator
NAFC School Corp.

From some of the DYNA Kids about the Summer Social



"Hearing Dr. Grubb speak was wonderful and now I think my Aunt understands."

Susie, Ohio

"It was nice to finally meet people who knew exactly how I felt."

Samantha, Alabama

"It was great to finally meet people face to face that I had talked to on-line and become friends with."

Melissa, Indiana

"Everyone was amazing as can be!"

Jessica, Michigan

"It was a lot of fun meeting everyone and finding out I was not so alone."

Mandy, Maryland

"They were some of the best days I have ever had since I got dysautonomia! I met another boy there who was like me and we had a lot in common."

Nick, South Carolina



"The social was better than I could imagine because it provided support for both me and my family and I realized how much we needed that."

Julie, Michigan

"I can't believe I finally met people face to face who know exactly what I am going through. It's nice to have met people after all this time."

Andrea, Illinois

"It was great to have all of us together. Finally we could all hangout with people who could laugh and not freak out if anyone got symptomatic."

Stephanie, Illinois

"It was a long drive from Texas but well worth it for the family I found."

Katie, Texas

"When we first started the Youth Network in 1999 we talked to Debbie about putting together a camp and she said 'someday.' I appreciate all the work she did to make things come together for us kids. I think we all feel like we have sisters now that we have all met face to face, and it's just been great. Welcome to my family everyone!"

Jenni, Ohio





DYNA puts young adults 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 DYNA Members.



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



This newsletter was created specifically to help children who have dysautonomia. We depend on the kindness of other's to continue providing this service.

*Assistant Youth Newsletter Editors:
Jenni Hinman
Richard Dominelli*

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

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

TO:



Visit us on the web at:
www.dynakids.org