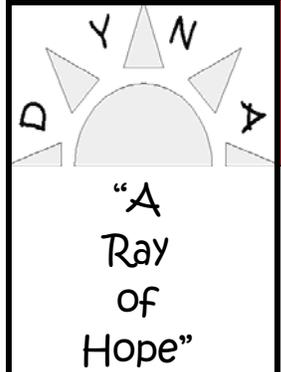


Dysautonomia Youth Network of America, Inc.

“The Young and the Dizzy”

www.dynakids.org

2006



Dysautonomia is a medical term used to describe a group of conditions that are caused by a malfunction of the Autonomic Nervous System (ANS). The ANS is a very involved and complicated system. It regulates all of the unconscious functions of our bodies; our cardiovascular system, gastrointestinal system, and urinary system are just a few. It also regulates body temperature, metabolic processes, and the endocrine system along with many other functions. Orthostatic intolerance is a hallmark of multiple forms of dysautonomia. Each dysautonomia case is unique and symptoms can range from mild to debilitating. Treatment must be individualized to the patient and may include pharmacological and non-pharmacological methods. Symptoms may include: Tachycardia (extremely fast heart rate), bradycardia (slow heart rate), palpitations, chest pain, dangerously low blood pressure, wide swings/sudden drops in blood pressure, excessive fatigue, exercise intolerance, dizziness, fainting/near fainting, gastrointestinal problems, nausea, insomnia, shortness of breath, anxiety, tremulousness, frequent urination, convulsions, cognitive impairment, visual blurring or tunneling, and migraines. See our web site: www.dynakids.org for more information.

2006 DYNA Summer Chill



Pictured: Phillip R. Fischer, MD; Blair P. Grubb, MD; Julian Stewart, MD; David Levy, JD; Barbara Straus, MD; Ken Davis, Ph.D.; Beverly Karabin, CNP, Medical University of Ohio; Dawn Nelson, RN, Mayo Clinic; Jennifer Winter, CPNP, Children's Memorial Chicago; the DYNA members that were able to attend our annual Summer Chill event and DYNA Board Members DeAnn Douglas and Debra Dominelli.

“Goofy Slipper Lecture” on Dysautonomia



Phillip R. Fischer, MD
Mayo Clinic
Rochester, Minnesota



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



Julian Stewart, MD
New York Medical College
Valhalla, New York



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

Board of Directors

Debra L. Dominelli,
President/Executive Director

James Dominelli,
Vice President/Treasurer

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

M. Patricia Chance, CCRC,
Health Trends Research, LLC

Dinah Christopher, MLT, CCRC
Health Trends Research, LLC

DeAnn Douglas, RNC

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

Main Contents

Fainting, Dizziness & Heartache	3
Search For Oneself	6
Passed from Pillar to Post	8
How Do You Know So Many People	9
Dating & Dysautonomia	10
Giving Therapy	12
A Note For The Doctors	12
Driving Miss. Dizzy	13
Summer Chill	16
Can Dizzy Kids Go To College	18
Educational Plans/October Slide	19
Educating The Dysautonomia Student	20
Dealing with Insomnia	22

Medical Advisory Board

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

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

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

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

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

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

Randy Thompson, MD
Center for Patient Care
Pensacola, Florida

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



Debra L. Dominelli in the DYNA office

The "Young and the Dizzy" Newsletter

Editor: Debra L. Dominelli
Assitant Editor: Amanda L. Dominelli
Production: Richard C. Dominelli
Proofreading: Irene Dominelli

*Dedicated to our DYNA Members
who inspire our mission to promote
awareness and support for youth
afflicted with dysautonomia.*

Printed and Mailed by:
Sir Speedy Printing
Terry Fath
Linthium, MD

Fainting, Dizziness, and Heartache An Invisible Condition - Dysautonomia

Debra L. Dominelli, President/Founder
Dysautonomia Youth Network of America, Inc.

An obscure medical condition is now being diagnosed more often in children. This is partially due to awareness promoted by a group of extraordinary youth who are afflicted with the condition themselves.

The Dysautonomia Youth Network of America, Inc. is a pioneering group of young advocates from across the world that are diagnosed with life impacting conditions known as dysautonomia. These children often experience a host of perplexing symptoms including fainting, dizziness, and excessive fatigue. Instead of feeling sorry for themselves, they are taking action by spreading awareness and thus making a difference in the future.

What is dysautonomia?

Dysautonomia is a medical term utilized for a group of complex conditions that are caused by a malfunction of the autonomic nervous system (ANS). The ANS regulates all of the unconscious functions of our bodies, including our cardiovascular system, gastrointestinal system, metabolic system, and endocrine system. A malfunction of the ANS can cause debilitating symptoms and may pose significant challenges for effective medical treatment.

Orthostatic intolerance (the inability to remain standing) is a hallmark of the various forms of dysautonomia. Dysautonomia conditions can range from mild to debilitating and, on rare occasions, can even be life threatening. Each dysautonomia case is unique and treatment must be individualized. Patients should be evaluated by a physician who is well-versed on the recent treatment modalities.

How it is diagnosed?

To diagnose dysautonomia, a tilt-table test is usually performed. This test evaluates how the patient regulates blood pressure in response to simple stresses. Tilt-table testing involves placing the patient on special table with a foot-support. The table is tilted upward while various machines monitor blood pressure, electrical impulses in the heart, and oxygen levels.

The following diagnostic terms may be issued to children with forms of dysautonomia:

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Neurocardiogenic Syncope (NCS)
- Neurally Mediated Hypotension (NMH)
- Vasovagal Syncope
- Post-Viral Dysautonomia
- Familial Dysautonomia
- Non-Familial Dysautonomia
- Generalized Dysautonomia

Who gets dysautonomia?

Researchers have discovered a genetic predisposition toward developing dysautonomia conditions. This means that there is a susceptibility to the conditions that can be triggered under certain situations. A genetic predisposition does not mean that everyone in that family is destined to develop the conditions.



Mandy
Age 16
Maryland
POTS

“The hardest battle you will ever fight will be the battle to be just you.”



Katherine
Age: 12
Wisconsin
POTS



Emily
Age 16
Virginia
POTS

“Children
require
guidance and
sympathy
far more than
instruction.”

Annie Sullivan

Childhood dysautonomia conditions typically (but not always) strike adolescents after the onset of puberty, often after a period of very rapid growth. There is a female to male ratio of 5 to 1. Some of the patients report a sudden development of symptoms after a viral illness, immunization, or trauma. Others may see a more gradual onset. Although very rare, there are children born with tragic non-familial forms of dysautonomia. There is also a distinctive form of dysautonomia called Familial Dysautonomia (FD) that has been identified in individuals of Ashkenazi Jewish extraction.

Impact

The symptoms of dysautonomia conditions are usually “invisible” to the untrained eye. The child can appear to be as healthy as other children. The manifestations are occurring internally, and although the symptoms are quantifiable and verifiable medically they often are not visible on the outside. Symptoms can be unpredictable, may come and go, appear in any combination, and may vary in severity (wax and wane). Often patients will become more symptomatic after a stressor or activity. Patients may find themselves involuntarily limiting their life-style activities in order to compensate for the conditions. Symptoms can sometimes be so severe that some children may require placement in homebound teaching programs for health impaired students; others will be able to attend school, often with modifications in their educational plans. The social isolation experienced by not being able to attend school or community activities is one of the hardest things for these children to deal with.

Since youth with dysautonomia are usually normal in appearance, it can be a hard condition for laypeople to understand. Even the general physician sometimes misses the clues leading to a proper diagnosis. The symptoms are often difficult for the young patient to verbalize and the conditions are not always promptly recognized. Traditionally, cardiologists and cardiac electrophysiologists can efficiently diagnose and treat these children. Sometimes neurologists and other pediatric specialists get involved as well. Families often find themselves desperately traveling great distances to the few pediatric dysautonomia specialists throughout the country for a proper diagnosis and innovative treatment.

The financial burden placed upon these families is often significant. The emotional toll and heartache can be devastating for everyone involved. Such an overwhelming illness has a rippling effect on the entire family. Chronic illness counseling is often recommended to help the patients and their families deal with the impact of the conditions on their lives.

Symptoms

Symptoms of dysautonomia can include: tachycardia (fast heart rate), bradycardia (slow heart rate), orthostatic hypotension (low blood pressure when upright), orthostatic intolerance (the inability to remain in an upright position), syncope and near syncope (fainting), severe dizziness, excessive fatigue, exercise intolerance, migraines gastrointestinal issues, nausea, insomnia, shortness of breath, thermoregulatory issues, anxiety, tremulousness, frequent urination, cognitive impairment (brain fog), visual blurring or tunneling, seizures

Treatment

Treatment is based on the condition, the sub-type, and the patient specifics and must be individualized. Treatment often includes pharmacological and non-pharmacological methods. Fluid intake of 2 liters a day along with an increased sodium intake is often recommended to help increase the patient’s blood volume. Various medications are commonly utilized and each is fine tuned to the particular patient. Medications will also typically require ongoing adaptations as the patient physiologically develops and changes. The hope is to be able to obtain enough symptom relief to initiate a gentle reconditioning program. Reconditioning is important and must be done slowly and can be an extremely frustrating and arduous process.

Prognosis

There is limited data on the prognosis of children afflicted with these conditions; however, research is being carried out at the nation’s leading medical institutions (Cleveland Clinic, Johns Hopkins, Mayo Clinic, Medical University of Ohio, National Institutes of Health, NY Medical College, Vanderbilt Medical Center and others). It is exciting and revolutionary, and there is tremendous hope on the horizon.



Will
Age 15
North Carolina
Dysautonomia

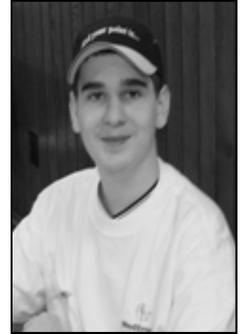
The statistics demonstrate that a good number of these children will improve significantly by the time they reach their early to mid 20's. Patients who do not fully recover will often see an improvement in their symptoms with the proper medical management and upon reaching full growth maturity. Some patients will experience exacerbations of symptoms at various times throughout their lives.

What the public needs to know

Children who have dysautonomia struggle with some of the most basic functions that healthy people take for granted, beginning with getting out of bed in the morning. Each day and each moment brings new and unexpected obstacles, which would often be considered daunting by even the most casual observer. Yet, without exception, these young individuals face each day with a profound courage and incredible strength despite the betrayal of an uncooperative body.

Dysautonomia conditions are widely unknown. Because of this, there exists a shocking ignorance about the life-style impact on these young heroes and their families. What dysautonomia patients need most is support, understanding and encouragement to help them deal with this complex, debilitating, and poorly understood group of disorders.

Tragically, youth with these conditions more often experience a fundamental lack of support and understanding within their local communities. Awareness crusades promoted by the youth themselves are addressing this problem community by community, and DYNA members are making a difference one by one. As said by Sarah Henderson, an Australian Outback Station Manager and Writer, *"Don't wait for a light to appear at the end of the tunnel, stride down there...and light the bloody thing yourself."*



**Brian
Age 18
Florida
POTS**

"Never give in!
Never, never,
never, never,
never. In nothing
great or small,
large or petty -
never give in
except to
convictions of
honor and good
sense."

~Winston Churchill



**The purpose of DYNA is to facilitate change:
change in improving the lives of our DYNA members and their families;
change in the community-at-large,
to foster awareness and a better understanding of dysautonomia conditions;
and change in the future,
to encourage compassionate care, efficient diagnosis, and reliable treatment
of childhood dysautonomia.**

**Together we can create change.
Together we have the power,
Together we have the support,
and Together - we all have a role to play.**

At DYNA, Inc. we value every single donation. Our goal is to have dysautonomia children and patients as a whole reap the largest benefit from each donation through our numerous support, development, and awareness programs. Gifts to DYNA, Inc. will be used wisely and efficiently. An independent financial audit is conducted yearly and you can rest assured that your gift is being utilized to its fullest. Administrative costs and overhead are kept to a minimum and various professionals donate their services to the organization in order to make this possible. DYNA, Inc. is a not-for-profit organization with 501 (c)(3) status, contributions are tax deductible. Please consider making your donation to DYNA today.

Checks should be made payable to: DYNA, Inc.
Mail to: 1301 Greengate Court, Waldorf, MD 20601



**Alice
Age 17,
Virginia,
POTS**

Search for Oneself

Ashli Jones

The impact dysautonomia has on an adolescent's life is obscene. The limitations and challenges they must adjust to are physically and emotionally draining. Their relationships and social life are ruined, and their entire family is changed. Every aspect of an adolescent's life is changed forever, which forces them to search for a new self.

Eventually, as weeks turn into months and months into years, adolescents begin to accept their illness. One step that is important in the acceptance process is for teens to learn about their condition and get in tune with their body. Identifying what triggers specific symptoms and at what time of day they feel the best are extremely important to develop effective coping strategies. Teenagers gain more control over their illness if they are knowledgeable about how their bodies operate.

The next step towards acceptance is for adolescents to put all of the knowledge that they have accumulated about their bodies into action. This is the time when teenagers need to determine their limitations. "It takes courage to admit that we must let go of what we have known," but by doing this teens also free themselves from further pain (Donoghue and Siegel 81). Setting limits is not an easy task, and it takes a lot of trial and error. This process is especially grueling for people like me who enjoyed challenging themselves and trying new things prior to becoming ill. High achievers, "...often pay a high price for overexertion, which often aggravates the condition or illness" (Sveilich). It is especially challenging for teens to set limits because they experience periods of exacerbation and remission. Times of remission often bring false hope because as soon as a teen believes they are getting better, they are crushed again with debilitating symptoms. Then the whole process of setting limits begins again.

The road to acceptance is a bumpy ride. Even after having dysautonomia for two years, DYNA member, Sophie Hicks, still struggles with accepting her illness: "You're forced to grow up so fast, yet you're so dependent on people to care for you and help you. I am beginning to accept what I have now, and with acceptance I feel stronger although it still hurts to watch people live so freely" (Interview). I can sympathize with Sophie, because although I have had dysautonomia for over five years, I still long for the abilities I had in the past. An excerpt from my journal shows what has been most difficult for me: "I think of all the dreams I used to have and how those dreams are drifting further and further away everyday. I try not to dream anymore because it only causes hurt and frustration, but every now and then I find myself going out

at night, gazing at the stars and letting my mind go free into a different world. I can't help but think what I would have been like if I had the ability to pursue my childhood dreams. Instead here I am stuck in a body that I will never be able to pursue all of my dreams in. It is still hard for me to accept that the child who dreamed the biggest dreams may never see them come true."

Eventually, teens begin to adapt to their new life not only physically, but mentally too. Although the hopes and dreams that they had in the past will never completely disappear, "former goals must be replaced with more attainable ones, and new lifestyle rules must be developed and adhered to" (Sveilich). Teens begin to focus on what they really want in life, and that is the first step towards a thriving life with dysautonomia; however, you must begin by first learning to cope.

Thriving with Dysautonomia

"Yesterday is but a dream, and tomorrow is only a vision, but today well lived makes every yesterday a dream of happiness and every tomorrow a vision of hope" (Hearts and Minds).

According to the Merriam Webster Dictionary online, the word thrive is defined as, "to grow vigorously" and the word "cope" is defined as, "to deal with and attempt to overcome problems and difficulties." If a person with dysautonomia wants to live a happy and fulfilling life, they cannot view their illness as something to "deal with". Many people with invisible chronic illnesses such as dysautonomia tend to spend their whole lives "coping" with their condition. To thrive with dysautonomia it is essential to embrace everything the illness has brought to one's life. There are two aspects that are involved in thriving with a chronic illness: choice and time.

The beauty of having the luxury of choice is that it can never be taken away from someone. In every situation a choice can be made. There is no such thing as "having" to do anything, yet the phrase, "I have to" is a popular choice of words. The key to thriving with such a life altering illness like dysautonomia, is to replace the phrase, "I have to" with "I choose to". For someone with dysautonomia, using the phrase, "I choose to" gives them a sense of control of their life that is cursed by uncertainty. A chronically ill person has the power to decide everything in their life, just like everyone else. "You can control yourself in more and more mature ways. You can increase control over your thoughts, disciplining your mind to focus on the present while avoiding the tyranny of 'what ifs' about the future. You can control

ways of relating with others, growing each day more honest with your feelings, more understanding of those around you, more controlled in your demands and complaints. You can develop more positive, realistic attitudes, and you can control negative, self-pitying ones” (Donoghue and Siegel 77).

Time is a constant in every person’s life, and because it is always there people often take it for granted. Many people treat things in their life like they treat time. A forgotten kiss is okay to a husband because he knows his wife will be there when he returns home for dinner. When a mom misses her son’s first school play she tells herself that everything is okay because there will be a play next year. People often do not realize the importance of life’s little moments. Life’s little moments create memories of happiness and love that last a lifetime.

Teenagers with dysautonomia learn to treasure that they are allotted by their illness, and choose to use that time in a meaningful manner, are embracing a life-altering philosophy that can lead to thriving in our world; it’s a philosophy of life that would benefit everyone.

Conclusion

Everyday I wake up and I think; I think only about today. Many people would say that thinking only about today is not possible because everyone dreams of what they will do in the future and how they will get there, and I completely agree. However, dreaming of the future and how I will get there is why I only think about today. It is unusual for people to think only about the present, and for most it is not necessary to focus their thinking on the present. No one can predict the future, but most people have a general idea of what they are planning to do, how long it will take to reach their dream, and are generally confident that they will follow through with their plans and realize their dream. At the end of their thoughts, no matter how difficult the path to their dream will be, most people know that with hard work and determination they have the ability to succeed. That is why it is necessary for me to think only about today, so that I can be successful today and not worry about tomorrow. If I do not concentrate on the present, I am left thinking about the future, or reminded about shattered dreams of the past.

Dysautonomia can be your beauty or your beast. It can be your curse or your blessing. It can be your heaven or your hell. It can be your angel or your demon. I choose to make dysautonomia my beauty, my blessing, my heaven and my angel. I choose to be happy.

“When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us.”

~Helen Keller

Helpful Resources

We highly recommend the 2006 DYNA “Goofy Slipper” Lecture Video on Dysautonomia to all physicians, parents and school systems interested in learning more about dysautonomia conditions. The video features:
Phillip R. Fischer, MD, Mayo Clinic
Blair P. Grubb, MD, Medical University Toledo
Julian Stewart, MD, NY Medical College
and is not being sold for profit.
To order please send: \$25.00 to
DYNA, Inc. Video, 1301 Greengate Court
Waldorf, MD 20601
An order form is available on or web site
or email us at: info@dynakids.org

Recommended Books:

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

Blair P. Grubb, MD
Mary Carole McMann, MPH
ISBN#0-87993-491-3

Syncope:
Mechanisms and Management

Blair P. Grubb, MD
Brian Olshansky, MD
ISBN#1-40512-207-2

GET INVOLVED IN DYSAUTONOMIA AWARENESS

ORDER DYSAUTONOMIA AWARENESS BRACELETES
See our web site: www.dynakids.org for information.

Ashli Jones is 17, from Oregon and has POTS. She volunteers as the Youth Awareness Co-Coordinator for DYNA. She also volunteers for the Special Olympics. She is enrolled in Oregon State University with plans to study pre-med.





Melissa
Age 18
Kentucky
POTS

“Misfortune shows those who are not really friends.”

Aristotle

Passed From Pillar to Post

Erin Black

What I found hardest about developing NCS was the sudden loss of dignity, and the lack of explanations. Without a warning, I'd black out, and end up helpless on the floor. I found myself passed from pillar to post by the doctors at my local hospital. I found myself scared to lock the bathroom door, in case I should find myself unconscious and unable to get out.

I was formerly an assertive young girl, now growing into a shy and scared adult. I couldn't go out on my own, and even if I did, I ended up like a tired toddler, fearful and desperate for the safety of home. No one knew what was wrong with me – my body was becoming a test laboratory, where nothing was left alone.

Things were bleak – and there were no answers. Luckily for me, I had a period of 'remission', where I could function normally. I started learning to drive. I moved away from my parents, and I began my law degree. I felt blessed that I was so fortunate, and I could leave the grim illness behind.

When it began again, I felt like I had lost everything dear to me. I was finally given a real diagnosis, NCS, but not one that meant anything to me. I was alone, and isolated. I couldn't understand the things that were happening in my body. I turned to the internet for answers, searching and reading everything I could. In the course of that search – I found DYNA.

The first time I logged onto the forum I cried. I couldn't believe there were so many other people who had the same experiences as me. I hadn't thought I was the only one – but seeing the conversations and stories that were told was overwhelming for me. Not only that, but I saw intelligent, confident and pro-active young women and men who were forging ahead with their lives despite all the setbacks they had experienced.

It was the DYNA members who taught me that dignity is something you keep inside for yourself, and no matter what anyone says or does to you, whatever twists and turns your illness takes – once you have that self-belief, no one can take it away from you, however hard they try. Also, when they do try, and you feel like you can't go on – it's the people who understand that are there for you, to set you back on your feet.

I never had that support until I was in DYNA. Thank you, my friends.



Erin Black is 21, from Scotland, and has Neurocardiogenic Syncope. She graduated last year with a degree in Scots Law and is now resident in London, England, where she works in the I.T. industry.



Jennifer
Age 15
Connecticut
POTS

COUPON



This coupon entitles any DYNA Member the privilege of not having to do the dishes!

Standing in place, hands in hot water, full stomachs, bending and lifting can all exacerbate symptoms. Thus, DYNA has established an agreement with our members that if they work hard to maintain quality sleep habits and follow their physicians advice – we will request that their parents excuse them from dish duty!
If they stay up all night, don't drink or don't take their meds – please make them do all the dishes for a week straight!

Note: Due to the suspected complaints our complaint department will be closed after the release of this newsletter.

“How do you know so many other people with dysautonomia?”

Sarina Dane

I remember my doctor asking that question after I had mentioned how some of my DYNA friends reacted to a certain medication. I didn't know how to respond. While DYNA has opened up my world, many doctors and others in my life were skeptical about the idea of me being in a support group. Images of pity parties and wallowing in sickness go through people's minds as soon as I start to talk about the Dysautonomia Youth Network of America. In reality, these perceptions couldn't be further from the truth.

When I first decided to join DYNA over a year ago, I felt lonely, upset, and misunderstood. Of course, I was also worried about the exact same things some of my doctors now warn me about, however the desire to be part of a community where people actually “get it” over-rode all of my concerns. From the day I signed onto the DYNA forum, I knew that I had found something special. Right away my inbox was filled with welcome notes, and IM windows were popping up with friendly “hellos”. I still remember my first contact in DYNA; a girl named Sara, who not only lived nearby, but was *exactly* my age (well, I'm two hours older, obviously making me much more mature!). What struck me was that while a shared illness had brought us together, our conversations focused around the many other interests we had in common. Today, I count Sara as one of my closest friends.

The second person who emailed me lives a little further away. In fact, she lives on an entirely different continent – in New Zealand! I soon learned that this diversity is an integral part of the DYNA experience. I taught Sophie about how my family celebrates Hanukkah, while she told me about the “bach” her family goes to over the holidays. Within weeks, I was talking to people from all around the US and world, developing relationships I never would have had without DYNA. It's not often that a 15 year old from Philadelphia can call girls from Singapore, Scotland, California, North Dakota, and Amish Lancaster as her friends. And that's just from the first page of my address book!

Our geographic differences aside, I started to find out how much I had in common with these other dysautonomia patients. I met people who loved the same things I did – playing soccer, writing for the school newspaper, shopping with friends, and just being a teenager – and who also experienced the same frustration of having to give them up. However, they all took the DYNA motto to heart, “Be Better, Not Bitter”, and taught me how to deal with the enormous loss. Instead of getting depressed and angry, I saw how so many members refocused their angst by offering support to others in the same position. Within the DYNA family, we all share in the success of others,

and encourage those who need a little picking up. The conversations on the forum run the gamut – from the Superbowl, to our pets, to favorite TV shows. Most of the topics are no different than those talked about at any high school lunch table, just in a different format. However, what I have found invaluable is the advice that I get on dealing with everyday situations. Things like dating and applying to college are made that much harder with dysautonomia as a constant consideration, yet I feel more confident after hearing from members who have “been there, done that”. Another important component of the DYNA community is how much *fun* everyone always has. When our social coordinator realized that many of us wouldn't be able to go to homecoming at school, she organized a virtual DYNA homecoming – complete with spirit days and online pep rallies. Another member put together a book club. It's activities like these that give everyone in DYNA something to focus on aside from pills and doctors.

Obviously, DYNA's influence goes well beyond what happens online. The “Summer Chill” (the annual conference held every summer), awareness campaigns, and newsletters all exemplify the type of positivity that runs in DYNA's bones. Phone conversations and sleep-overs were eventually added to the IMs and emails I had with my friends, but the predominant attitude stayed the same: we may have dysautonomia, but dysautonomia doesn't have us.

While my immersion into the DYNA community was a gradual one, I started to find myself feeling less lonely. Not only did I have new friends, but I had gained skills to reconnect with the ones I already had from home. Where I was once diffident when talking about being sick, I started to take an active role in spreading awareness. DYNA has given me the stepping stones to being successful in life, even with the baggage of a chronic illness. I've seen how much older members have accomplished, and know that with them as role models I too can dream big. And when I have one of those days where nothing is going right and I want to give up, there's a wonderful support network to help me snap out of it.

When my doctor asked me how I knew so many other people with dysautonomia, I decided to tell her all about the Dysautonomia Youth Network of America. I was happy to find out that she supported my involvement with the organization. I guess I'm lucky that my DYNA friends have tried to help me better communicate such things. That, and I have a smart doctor.

Written December 2005. Sarina Dane has since accepted the position of DYNA Social Coordinator.

Dating and Dysautonomia: A Tachy Heart Isn't an Empty Heart

Sarina Dane and Diana Singer

Dating as a teenager can be confusing to begin with, but when one of the persons is sick with an illness like dysautonomia, things can get much more complicated. The important point to remember is that having dysautonomia does not mean that a person has to give up having a social life, or a romantic other. It just takes flexibility, understanding, and adaptation to make it work. Every dysautonomia case is unique, and likewise each relationship will be different. Nevertheless, if you want to date someone with dysautonomia, here are some general hints and pointers on how you both can get the most out of it.

1. Learn as much as you can about dysautonomia. Being sick with a chronic illness often consumes a large part of a person's day-to-day life, and if you want to become a part of that life, it's essential that you understand what he or she is dealing with. Not only is it important so that you're able to be a support, but also so you can decide if the relationship is even something on which you are ready and willing to embark. A good place to start is by reading through the DYNA website, as well as visiting the links in the "other sites" section. However, you will get the most valuable information just by asking the person that you like. She probably will be happy to explain what kind of dysautonomia she has, what symptoms she experiences, and how the illness impacts her life. Keep in mind that the physical components of being sick (like fainting and feeling tired) are only one part of the picture; their implications (such as not having the energy to go to school) are equally important to understand.

2. Try to allay her concerns. Many people with dysautonomia are very reluctant to have a boyfriend or girlfriend, simply because they think that it will be unfair to the other individual. However, everyone has some kind of baggage, and dysautonomia just happens to be the hurdle that she's bringing into the relationship. Make it clear that you know she sometimes may be not be up to going out, or that she may have a doctors' appointments at inconvenient times, but that you both can work around these things. It's up to you how involved you want to be with the medical side of things, but what's important is that she knows you'll be there and care about her. By the same token, don't be afraid to express yourself honestly. As long as you are tactful, voicing your own worries and fears about her being sick is fine.

3. Get creative with dates. Typical date activities such as going out to eat or going to a party often just won't work for someone who has an illness like dysautonomia. However, there are so many other ways you can spend

your time together that it doesn't need to be a hindrance at all. If she can't make it to the movie theater, rent some DVDs and have a movie night at home. Spend an afternoon playing video games, or even old-school board games. Order takeout food and have a picnic on the living room floor. There are so many possibilities, and it's up to both of you to come up with fun ideas. If she ever does need to cancel plans, or asks to end a date early, don't take it personally; dysautonomia symptoms are impossible to predict and may come on suddenly.

4. Lighten up. With an illness thrown into the mix, the dynamic of your relationship will be affected, but that doesn't mean that it needs to be the focus of your attention. She's not a porcelain doll and she won't break, so one of the best things you can do is just always try to have a good time. Even if your boyfriend or girlfriend can't participate in all of the "normal" activities you do, it doesn't mean that she doesn't want to hear about them. And what they say is true, laughter really is the best medicine!

5. Know that no means no. Everyone is comfortable with different levels of intimacy, and while it's never okay to pressure your significant other, this holds especially true when the person has health considerations. Like other aspects of a date, she may feel well enough for some things one time, but be too sick on another occasion. Also, never push drugs or alcohol. Substance abuse is not a smart idea to begin with, but it can cause very serious complications for someone who has dysautonomia. No means NO.

Many DYNA members have had very positive dating experiences, despite their health battles. As long as both of you are open minded, you can have a happy and successful relationship, and hopefully will stay a couple for a long time. Not only will you gain a boyfriend or girlfriend, but you will probably also derive a new perspective and insight into life. Good luck!



Diana Singer (left) is 18, diagnosed with POTS. She plans to be a nurse. Sarina Dane (right) is 17, and is diagnosed with POTS/NCS. She will be a high school senior. This photo was taken at the Children's Hospital of Philadelphia when they met in person for the first time.

Lucky Me

~Debra Dominelli

I am the girl you never see
 Invisible typically
 I am a flashing vision now and then
 The long forgotten...sickly friend

I am the homebound student
 Health torments
 The absent kid - the empty seat
 The girl that hides her blue colored feet

I am the heart that beats way too fast
 Lonely outcast
 The ill child that plans to win
 The girl with pale translucent skin

I am out of sight - out of mind
 Medically confined
 The classmate you never got to know
 The dizzy, fainting, blonde weirdo

I am the girl that someday hopes to be
 Symptom free
 Homebound for now I shall be
 Oh lucky, lucky, lucky me.

I Still Believe

~Christy Cole

I still believe that generosity is
 it's own reward
 That kindness will prevail
 That might does not make right
 That a soft answer turns away
 wrath
 I still believe that there's power
 in gentleness
 That there's more to us than
 flesh and bone
 That life will bring more
 happiness
 If lived for peace and not possessions
 I still believe people of
 gentleness and faith
 Can change the world one
 unseen, unsung, unrewarded
 kindness at a time...
 And nothing in this world can
 make me stop.
 Thank you for proving me
 Right.



Jordan
Age 13
California
POTS

When the
 world says,
 "Give up,"
 hope
 whispers,
 "Try it one
 more time!

Author Unknown



Christy Cole, Ohio, (left) is 23 and graduated from Northwood University-Automotive Marketing/Business Management in 2004
Shana Summers, California, (right) is 22 and attends the University of Southern California and plans to attend medical school. Both are diagnosed with POTS. This photo was taken at the Medical University of Ohio, where they met in person. for the first time.

The difference between a helping
 hand and an outstretched palm
 is a twist of the wrist.

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

Farmer & First, PC, Warren, RI
 Lattice Group, Inc., Kensington, MD
 Sir Speedy Printing, Hanover, MD
 VYANET Operating Group, Inc. Eugene, OR



Lynne Abel,
DYNA Postal
Outreach



DeAnn Douglas,
DYNA Parent
Coordinator



Kyli
Age 20
New Jersey
POTS

Giving Therapy

Tara Jones

Although dysautonomia has given me some debilitating symptoms over the years, it has also given me a great deal of empathy. Instead of focusing on my body, I observe friends, family, and even strangers, planning how to create smiles and be there for them in times of need. Making others feel as comfortable and loved as possible is the best therapy that has ever existed! This "Giving Therapy" has allowed me to squeeze the positive out of every situation and has reminded me that even if my body is broken, I can still be an active participant in the world! Be it a homemade card, one of my stuffed animals, a happy mail package, hugs, a cup of tea, an ice pack, or even an email, text message or phone call, making my friends smile is what makes me smile, regardless of my physical condition!

This approach to life does not seem like a job or responsibility; instead, it helps keep dysautonomia tucked away as a *tiny* part of me, while the REAL me, can meet the best friends that the world has to offer - new friends from DYNA, from school, or from the hospital!

If you are asking why I use limited energy focusing on others, you are not alone: I have had many concerned people ask me why I don't just focus on myself or spend my energy to "get better." But, if you realize that "giving therapy" makes me smile, makes me glow with joy even when I'm stuffed with symptoms, then you will realize that it is the most important part of my treatment and healing than any medicine! Moreover, giving my love and laughter to others does more than make me smile about the past and present, but it also prepares me for the future. Instead of running away the next time I am faced with a huge hurdle, I just plow on through because I know that whatever I pick up along the way. I will use to help others down the road!

In my world, I like to think of Dysautonomia as a good thing - it has not just been some monster that inflicts sick days on me; it has given me a new lease on life and a perspective that I would take over anything else in the universe! In fact, my years with a malfunctioning ANS have proved that something I said ages ago really rings true:

"if you live life to love, you'll love to live life"

regardless of *any* hurdles tossed your way! Add "Giving Therapy" to your lives and, instantly - you will discover that spreading your love and sharing your experiences are the best feelings imaginable. No matter how many symptoms are living in your body today, you *can* and *will* impact the world in such a positive way. So, how about giving it a try?



A Note For The Doctors:

Debra L. Dominelli

Children/teens automatically tend to reply: "Fine" when they are asked how they are doing.

In a recent study of DYNA members (including one who was seriously ill in the hospital at the time) their standard reply when their physician asked the age old question, "How are you doing?" was, "Fine."

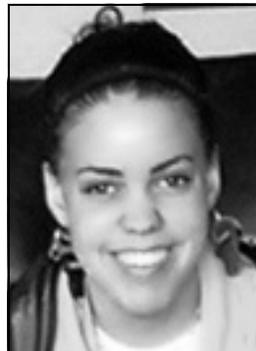
This question has become such a common greeting in today's society that most of us do not even think before we answer it. We are not used to people truly caring how we feel. We just give an automatic reply.

So, the next time you have a young patient in your office and you ask, "How are you doing?" we recommend that you then follow it up with, "So, how are you really doing?" You might be surprised to discover more information that will help you better treat your patient.

And remember, dysautonomia children often suffer from cognitive impairment and may have a difficult time expressing themselves verbally (especially when tired, stressed, or uncomfortable with their surroundings), so you may not get the full details if you don't allow them the opportunity to be comfortable with you. Always make an effort to help them relax and remember to assure them that they can trust you and that you truly do care **HOW THEY ARE REALLY DOING.**

"We may run, walk, stumble, drive, or fly,
but let us never lost sight of the reason
for the journey, or miss a chance to see
a rainbow on the way."

~Gloria Gaither~



Tara Jones is 19, from California and has POTS. She is eagerly awaiting her sophomore year at Stanford University. She enjoys laughing, smiling, and sharing. Her long-term goals include going to law school, working to protect children's rights, and, most importantly, always staying young at heart.



Brianne Bourassa driving her dizzy friend, Mandy

Driving Miss Dizzy

Debra L. Dominelli

For most young people, driving represents independence and freedom. This long-awaited "RITE of passage" of obtaining a driver's license is a special event in the life of any teen. However, the privilege of driving is bestowed upon a citizen by society and is not a RIGHT. The privilege carries obligations which must be carefully considered by parent and hopeful new driver.

Your life, your family's life, your passengers' lives and the lives of everyone with whom you share the road depend on your competence. This RITE of passage is a tremendous RESPONSIBILITY.

Commanding the Road requires:

- A thorough knowledge of rules and regulations - laws of the road.
- Experience driving, technical competence and control of the vehicle.
- The ability to quickly and accurately assess complicated circumstances and react appropriately.
- Mature judgment.
- Concentration.
- Respect for and adherence to rules, common sense and good manners.
- The physical, mental, and emotional ability to accomplish the above

Our nation's laws require that you report any medical condition which might impact your ability to drive safely. That means that dysautonomia patients have some special considerations to take into account when it comes to driving. If you are dizzy, faint, have vision problems, experience convulsions, suffer from brain fog and cognitive issues - you should not be driving. Discuss your situation with your physician and make sure your symptoms are under complete control before you even consider getting behind that wheel. Remember to review your state laws. Ultimately, the laws of your state - not your doctor, parents, or you - decide whether you are granted the privilege to drive.

The Reason For My Purple Backpack

~Kate Traxler

You see her from time to time
 Waiting at the elevator door
 Glaring at the purple bag
 And for a brief moment wonder what for
 Well that girl is me you see
 And I have something that's hard to explain
 It's called Postural Orthostatic Tachycardia Syndrome
 And causes a lot of inner pain
 It takes away my energy
 And causes me to almost faint
 It makes my heart work too hard
 And induces physical restraint
 There are lots of things I cannot do
 Like many things you take for granted
 I can't run or just simply wake up
 I can't take the stairs or dance
 If I stand too long I have to sit
 And the life I knew was stolen from me
 With this handicap I don't know what to do
 Or even who I am anymore
 But one thing I know is true
 I'm still the same as you
 I have drama with friends
 And parents galore
 I have dreams and expectations
 And hope for more
 More to life and that never-ending search to find yourself
 But with POTS that all just takes a back shelf
 So before you snicker and you laugh
 Know it could just as easily be you
 Who has to drag a purple backpack



Kate Traxler is 17, from Illinois and has POTS. She enjoys learning and has interests in history, Manga, writing, and photography. She currently does not know what she wants to major in.

Contributors to DYNA, Inc. (From June 30, 2005—June 15, 2006)

In Honor of Physicians:

Blair P. Grubb, MD

Marshal & Tamar Granor, Larry & Janice List, VYANET Operating Group, Inc. / Tracy & Tammy Jones

In Honor of DYNA, Inc.

Erin Black, Jennifer Dempsey, Blair P. Grubb, MD and Barbara Straus, MD, Boris Kerzner, MD and Mrs. Lucia Kerzner, Megan McLarin, Juliana S. Merhaut, Anonymous

In Honor of Summer Chill 2005:

Gene & Julie Gonzales, Michael & Cheryl Gordon, Anna D. Graham, Carol B. Kaffka, Linda S. Kramer, Pete & Helene Longden, Edna Majors, Dennis & Julie McCrary, Margie Pavone, Larry & Lillian Phillips, Robert & Vicki Romito, Mary Schaffer, James & Merlene Stiles

In Honor of the Following:

Ally Abel

Charles & Lynne Abel, Thomas & Karen Abel

Emily Bartle

Judith A. Bartle

Katherine Baumann

Bradford & Karin Baumann

Katie Bellman

Michael & Sandra Bellman, Sarina Dane

Pacey Berman

Jeffrey H. Berman

Mary Bibbs

Mr. & Mrs. David R. Bibbs, Mr. & Mrs. William Crane, William & Mary Frost, William C. Banner Foundation

Michelle Birney

Robert & Karen Birney

Whitney & Torin Blaker

Ross & Cheryl Blaker

Lindz Boehnen

Daniel & Joan Boehnen

Amanda Boettcher

Karl D. Simoff

Cole Brott

Doris P. Brott

Heather Buck

Brandon Yeager

Patricia Chance

Mr. & Mrs. Blake Buckingham

Christy Cole

Sandy Cole-Cassidy, Donald & Eiko Cook, Brian Stein

Mark Dane

Sergiu & Beth Carniol, Ben & Linda Cooley, Margaret & Ahron Davidi, Roselyn Kraiterman, Betty Leef, Aleda B. Lerner, Elaine Rudnick, Judy and Hy Waxman, Dov & Sandy Weber, Alan & Nancy Weiner, Anonymous

Sarina Dane

Perry Dane & Cynthia Saltzman, Lotti Dane, Dr. Lawrence M. Saltzman & Lisa C. Saltzman, Mina Saltzman

Debbie & Jim Dominelli

Bradford & Karin Baumann, Katie Bellman, Erin Black, Perry Dane & Cynthia Saltzman, Alexa Defiore, Matthew & Amanda Grzyb, Sophie Hicks, Paul Johnson & Nancy McAleer, Stephanie Patterson

Mandy Dominelli

Mary P. Chance, Dinah L. Christopher, Mr. & Mrs. Richard Dominelli, Mr. & Mrs. Bruce Dunn, Mr. Mike Riordan, Brian Stein, Mr. & Mrs. Victor Talbert, Marjorie Transue

Melissa Douglas

Margaret Keifer

Meredith Drude

Fran Drude

Elizabeth England

Scott & Jennifer England

Audrey Geeza

Jane & Jeremy Geeza

Brian Gerdel

Ron & Lin Gerdel, Wachovia Foundation

Annie Giddings

Sarina Dane

Gene, Julie & Jordan Gonzales

Joan L. Giammona

Sophie Hicks

Sarina Dane, John & Marion Hicks, Dave & Sheila Lee & Family

Robert Hoffer

James & Patricia Hoffer

Ashli Jones

Sharon P. Bishop, Charles & Terri Caldwell, Tracy & Tammy Jones, Ruby J. Miller, VYANET Operating Group, Inc.

Shauna Jones

Richard & Charlene Jones

Tara Jones

Melissa Yates

Chloe Kingsley-Burt

Karen Kingsley

Karen Kramer

Jack & Linda Kramer

Caitlin Logan

Sarina Dane, Joseph Logan

Amy Longden

John, Susan & Caitlin DiMaina

Jennifer Meineke

Richard & Susan Meineke

Julie Merhaut

James & Deborah Merhaut, Christine Shehadi, Anonymous

Andrea Myslenski

GlaxoSmithKline Foundation, Chad & Tania Gordon, Mr. & Mrs. Douglas Myslenski

Joy Newman

Joann Newman

Juliana Nitis

Gregory & Caren Nitis

Nicole Pavone

Margaret Pavone

Samantha PhillipsGeraldine Brady, Roger Brown,
Lisa Glanton, Ronny & Sherry
Majors**Carolyn Quain**

John & Megan Quain

MacKenzie RoachGreg Amante, Ruth Ann Berkholz,
Arthur H. & L. Bonnie Berko, Julie
Bier, Bill Roach Productions,
Jackson & Ellen Blom, Audrey &
Edward Coe, Dennis D. Corcoran,
Steve & Carolyn Cyphers, Joel &
Joyce Despain, Mary Dorrance,
Richard & Sally Fish, Anthony &
Jane Florkowski, Jerry & Donna
Gagner, Andrew P. Garcia, Beth
Grubba, Justine Gubar, Home
Consulting Company, Dan &
Jennifer Kocse, Andrea A. Kremer
& John M. Steinberg, Janet H.
Lindquist, Katie Linendoll, Max &
Rachel Nichols, Patricia O'Brien,
Nancy Bloom Roach, Alisia G.
Salters, Daniel & Angelina Smith,
Jeff Spencer, Mona Vandenberg,
Jean Vandenberg-Burke, Mark H.
Walker, William & Joy Weinbaum,
Marc Weiner, Jenifer Winiger**Kasey Romito**

Robert & Vicki Romito

Meghan Rooney

Michael & Pamela Rooney

Sandra H. Rubin

Lisa Rubinsky

Heather Savelle

Donna Savelle

Lindsay Schardt

David & Barbara Schardt

Diana SingerKenneth & H. Eleanor Ruch,
Richard & Wanda Singer
Anonymous**Shannon Stec**

Linda Stec

Kristin Swan

Eugene & MaryBeth Pichette

Jessica TaylorMelissa Clement, Jack & Susan
Taylor**Ross Tetzloff**

Mr. & Mrs. Jay Tetzloff

Sarah Thomas

Sarah M. Thomas

Johnny Timmsen

Mr. & Mrs. Erick Timmsen

Loren Vidnovic

Nick & Janet Vidnovic

Caroline & Kate Winter

Robert & Barbara Winter

Melissa Yates

Cathy Yates

**In Loving Memory of:****Madeline Gohn**Hanover Chapter 378,
Order of Eastern Star**Nathan & Norma Klein**Lillian Ansel, Stephanie & Bonnie
Beall, Gilda & Hy Berstein,
Goldie R. Bloom, Mr. & Mrs. Irving
T. Boker, Mr. & Mrs. Albert A.
Bordow, Sydelle Brenner, Edward
& Florence Brown, Zelda Bulman,
The Mah Jong Girls, Elwood Cahill,
Mary Ellen Cain, Barbara Carleton,
Leonard & Hilda Cohen, Norma
Ebert, Their Friends at F/V
Diversified, LLC, Bonnie & Stanley
Favin, George & Nancy Ferenchak,
Frantzen Voelker Investments,
LLC, Blossom K. Friedman,
Penelope T. Garcia, Dorothy R.
Glaser. Global Express Financial
Services, Jerome Goldberg, Claire
P. Goldman, Sylvia Golnick, Jerry &
Shirley Gordon, Thomas & Ellinor
Hatton, Irving & Frances Herbst,
Stan & Sara Hinden, Rita &
Kenneth Honenbrink & Family, Jay
& Louise Howell, Irene Klein,
Norma Klein, Irene S. Klein, Sylvia
T. Kramer, Mr. & Mrs. AlvinKramer, Arnell Kudysh, Irvin &
Eleanor Levine, Suzanne Lifschitz,
Shirley Light, Mary K. Longden,
Margaret Longden, Edward &
Marilda Longden, Pete & Helene
Longden, Sylvia Love, John & Maude
Martyn, Dr. & Mrs. Michael Jerrold,
Howard & Heidi Mitnick, Judi and
Allen Moien, Elaine Molnick, Debra
Nelson, Edythe Oppenheim, William,
Angelina Penn & Family, Sid & Sally
Plitman, Sidney & Neva Plitman,
Esther Plitman, Evelyn Polisher,
Louis J. Richman, Phillip R. Rolnick,
Milton Rosenthal, Arthur & Thelma
Rubinstein, Faye Z. Selfon, Esther S.
Sherman, Bea Weinstein, Mark &
Mindi Weisenbloom, Edward & Diana
Whelan, May Zarin, Fannye and
Donald Zlotnick**Harlan Laney**

Frances Laney, Kristin Swan

Anna Wells

Anna D. Graham

**A VERY SPECIAL
THANKS
TO:**Mrs. Margaret Keifer
For her continued support of
DYNA, Inc.»» *Thank You* ««**To all those who donated to DYNA in 2005:
We couldn't have done it without you!**We have been able to assist young people
impacted with dysautonomia conditions
from points across the globe.
The thanks go to you!

DYNA SUMMER CHILL 2006

Dulles, Virginia

July 6, 7, 8

OUR SPEAKERS:

Phillip Fischer, MD
Mayo Clinic
Rochester, MN

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

Julian Stewart, MD
New York Medical College
Valhalla, NY

“From Strength to Strength”



Professional Participants:

Ken Davis, Ph.D.
Toledo, Ohio

Beverly Karabin, CNP
Med. Univ. Ohio

David Levy, JD
Boca Raton, Florida

Barbara Straus, MD
Toledo, Ohio

Dawn Nelson, RN
Mayo Clinic, Minnesota

Jennifer Winter, CPNP
Children’s — Chicago



BUSINESS SPONSORS:

Embassy Suites-North
Dulles, VA

Heath Trends Research
Baltimore, MD

Old Dominion Brewery
Sterling, VA

Pitter Pat Dog Sitting
Ashburn, VA

Project Linus
Charles County, MD

Reston Limousine
Reston, VA

Riordan’s Restaurant
Annapolis, MD

Sir Speedy Printing
Linthium, MD

Wegman’s
Sterling, VA





Can Dizzy Kids Go to College?

Mandy L. Grzyb and Debra Dominelli

By the time you are making this important decision you should have already obtained the necessary tools for managing your illness and balancing your lifestyle. You've figured out how to cope with your condition, how to handle your own medications and medical needs, how to not give into peer pressure, and how to maximize your learning potential. Many dysautonomia patients find college easier to maintain than High School. With proper communication, the professors tend to be very understanding about a chronic illness and your schedule can usually be arranged to meet your specific needs. You can sleep late if necessary! College is not out of the question for you, after-all, you managed to graduate High School with your illness – so you have already experienced success! You have learned unique life skills and been exposed to situations that will actually put you ahead of many other college students.

Starting college is one of the most exciting times in life. It is both the culmination of all your hard work through high school, and it is the beginning of a new path towards achievement and adulthood. Dysautonomia can present an extra challenge, but if you are prepared and organized it doesn't have to hinder your college experience. College is an incredible gift! Never again will you be exposed to so many different kinds of people and such a vast opportunity to explore, grow and learn. Take full advantage of your four (or more) years there by maintaining a good balance between your health, your academics, and your social life. Below you will find some hints that might help make your time in college one of the most memorable and positive experiences you'll have :

- Pick the right college. Do your research. If you can't walk a large campus, pick a small campus. If you need air-conditioning, make sure you select a school that has air conditioned dorms. If you don't do well in the mountains or in humid heat, avoid schools in those geographic areas. If you plan to commute, make sure the drive is reasonable. Use common sense in selecting your college. Visit the campus several times and consider requesting to stay overnight in a dorm prior to making your decision.
- Contact your college disability office as soon as possible and inquire about special accommodations. Communication about your condition is essential. Your dean or advisor can help you plan and balance your four years by optimally distributing courses that are demanding. Educate the school about dysautonomia so they can best serve your needs.
- As you go through the college process, remember that your initial decisions are not set in stone. If a roommate doesn't work out, the situation can always be changed. If you choose the wrong class, you will be able to drop it. If the school is not the one for you, you can always change schools. After everything you have already been through, none of these situations is the end of the world.
- Pace yourself. Always listen to your body first when creating your social schedule. You may miss one or two events, but you will gain a lot more if you rest now to avoid a major crash later. There will always be another party, game, or movie – so pace yourself. Always carry lots of water or sports drinks, try to plan your class schedule so that you can have time to rest, and don't worry if you have to take the minimum number of credits to be full-time (if that's what you're doing). For instance, taking nine credits instead of twelve will not only allow you to meet your body's needs, it will allow you time for extra-curricular activities, and make it easier for you to maintain a good Grade Point Average. So go easy on your body – college is not a competition, it's a time for you to allow yourself to reach your fullest potential!
- Be Organized. Keep a personal organizer and use it all the time!! Make sure it has space for writing under each day of each week. Write down all of your appointments, assignments, meetings, and even social events – even remind yourself to drink, have snacks, and eat lunch and dinner. Allow yourself time to go to class and do homework, but also schedule personal time. Take advantage of every day before an assignment is due, this will stop you from wondering how you are supposed to do all that work without giving up friends, eating, and sleeping. Have two weeks to write a paper? Start it the day it's assigned and work on it for an hour or so each day, instead of doing it all at once. Have to read 200 pages in eight days? Read 25 pages for each of those eight days and it will be done easily. Do the same thing for studying, break up your notebook or textbook pages and learn a part each day. You will get good grades and you will have time for other things besides studying, which will lead to a lot less stress and better health. Stock your dorm room with all the necessary items (water, water, water, medications, sanitary products, quick snacks, microwaveable meals for the times when you don't feel up to going out etc.). Think ahead and be prepared.
- Be true to yourself and others will respect you for it. Don't drink or do drugs, these things will compromise your health and, therefore, ruin your college experience. You've been through enough in your life and you deserve to have the best college time possible, so you owe it to yourself to make the right decisions and avoid the things that will hurt you. Also think before you act – ask yourself if what you are about to do

continued

Is worth it: Will one night of getting smashed be worth missing the entire Spring Fling weekend because you're crashing? Of course not! Stand your ground when you feel pressured into doing things that make you uncomfortable, and you will soon find yourself surrounded by a group of friends who respect you and like you for who you really are, not what you pretend to be. And, remember that No means No. Don't jeopardize your health or college life by contracting an STD or getting pregnant and don't risk an emotional scar that will change you forever. Be safe. Talk to your parents, physician, or counselor about your sexual choices and birth control before you leave home. Listen to that little voice inside your head that tells you when you should get out of a bad situation. You did not get this far by being a follower – lead by example!

- If you become overwhelmed, reach out immediately to your parents or a professional. Don't risk a set back. Assistance is a phone call away. And, always remember that your DYNA family will be here for you to support you no matter what and at anytime!



Educational Plans: How to Avoid the October Slide

Debra L. Dominelli

Many children with dysautonomia face what is often referred to as the "October Slide" each fall. The back-to-school season is one of the most difficult times of the year for these children. Dysautonomia children are often very sensitive to barometric changes, allergies, and environmental stressors. The change in the seasons poses an additional burden on their already struggling systems. This additional strain on their bodies combined with the sudden exposure to the school environment, germs, schedule and lifestyle changes, class work and homework stress, the physical burden of new activities that require more upright posture, and even the strain of the new social excitement have been known to cause many medical set backs and hospitalizations each fall.

With communication, planning, life-style management adaptations, understanding from the school systems, and a little common sense from everyone - much of this problem can be avoided or significantly reduced. We urge all DYNA members to work very closely with their physicians and school systems to establish educational plans for their particular situations.

Parents of children attending school should request a 504 Plan through the school guidance counselor and make sure that all staff interacting with the student is included in the process. It is important to create a plan that includes easy to understand information about the medical condition, various symptoms of that particular student, specific triggers, daily medications, physical limitations, expectations, and an emergency plan of action. Be sure to develop instructions on what the school should do and whom they should call in the event of an emergency. Include how to handle the student during unexpected situations such as fire drills, lock downs, and even bomb threats (be sure to avoid prolonged standing in heat, and prepare the student for the flashing lights and noise of the school fire alarms etc.). Prepare ahead for the likelihood of frequent absences and establish an educational plan that works to accommodate the ongoing and varied struggles of the conditions and also helps to keep the student connected with their school peers. These students are living a balancing act and educational efforts must be a full collaboration of all parties involved. Communication, flexibility, respect, and understanding are essential elements to success. Include the student in the planning process when possible and remember to allow time in the child's life for socialization (which is a requirement for an emotionally healthy teen.)

We encourage school systems and families to purchase a copy of our most recent Summer Chill video lecture series on dysautonomia conditions. Email us at: info@dynakids.org.



Gwendolyn
Age 18
Pennsylvania
Dysautonomia

"Always listen to the experts. They'll tell you what can't be done and why. Then do it!"

Robert Heinlein



Mandy
Age 31
Connecticut
POTS

EDUCATING THE DYSAUTONOMIA STUDENT

Debra L. Dominelli

Dysautonomia students are entitled to special educational services under the Individuals with Disabilities Education Act (IDEA) and/or educational accommodations under Section 504 of the Rehabilitation Act. IDEA mandates a free and appropriate public education for all children with disabilities. Being entitled to such accommodations is one thing; being provided them appropriately is another. Each dysautonomia case is unique and each situation is individual. Thus it is essential that the school systems, physicians and the families communicate and work closely in order to provide the dysautonomia student with their specific needs.

For these students, educational decisions vary significantly depending on each medical case and degree of illness, each family situation, each school system etc. Families must make educational decisions on what works best for their particular child in their particular situation.

Various types of instruction are available to dysautonomia patients including:

- ~Full Homebound Instruction provided by the county for health impaired students.
- ~Partial School Days and Partial Homebound Instruction.
- ~Full School Days with various educational accommodations.
- ~Home Schooling by parents or via private instruction.

Public School Students:

If you are a dysautonomia student chances are that you are feeling rather poorly and probably don't have a lot of energy to spend on maintaining relationships with school teachers, administrators and even friends. If you are homebound/partially homebound and can try to save little pieces of energy on a regular basis to stay in touch, you will find it will help you feel connected. If you haven't already done so, provide your school agents with some material explaining your health circumstance and its implications on your life (this newsletter can be a good place to start and please review our web site as well). Ask your school to work with you in establishing your educational plan and explain that this is all new to you too. Everyone will have to allow for flexibility within your plan and continued adjustments will need to be made. Many schools have not dealt with this medical circumstance before - and you cannot assume that your school knows what you need. Communicate with your physicians about your capabilities for your educational plan, request the necessary documentation, and set up a meeting with your school system so everyone is on the same base. We recommend that you specifically request a Medical 504 Educational Plan through your Guidance office. Along with making arrangements for your education, make sure that your system, administrators, and instructors understand how hard it is for you to reserve time for social interaction and keep up with your schoolwork at the same time. Explain your condition. Educate the system about dysautonomia. Ask them to take any extra steps to provide you with school happening updates whenever possible. Communication is absolutely essential! Ask for what you need and understand that your medical situation may have many ups and downs and your condition can sometimes be unpredictable. Maintain flexibility and maintain communications with your school counselor and physician.

School Administrators and Instructors:

Children with Dysautonomia need extra help not just with their studies. To provide them with as whole a school experience as possible, please take extra steps to keep the homebound and partially homebound students informed about school happenings, activities and events. Simple things like newsletters, picture and year book notices, and announcements are important to pass on to the home on a regular, timely basis. Advances in technology have made it simple to 'show' what is happening at school. We suggest that a school based counselor, teacher or staff member be assigned the specific responsibility of keeping these students connected. It is also very beneficial to assign a buddy or another student to help keep the student connected. Consider how these students may feel disconnected and isolated. Recognize that they are still enrolled in the school and thus still a part of the student body! Take the initiative to be creative, compassionate, and proactive. Make the effort! Take a quick picture of the new paint job in the cafeteria or the new computer section in the library. Give out the students email address to classmates (with permission), invite the student in for a class or two around the holidays, beginning or end of the year or just when you are doing a fun activity that they could be included in. Help keep them connected! Invite them to the class parties (even if they can't attend - it means something for them to be invited). Other students can e-mail observations from science experiments in the lab or weekly updates on the school happenings. The year-book committee can send

continued

pictures from the last pep rally. The Spanish Club can send recipes from their recent Spanish cooking venture. The Language Arts class can keep a weekly diary of the personalities within the class and social happenings within the school or put to use their letter writing skills by sending weekly letters. A simple spiral notebook can suddenly become a "Back and Forth Book" that students write in and send to the homebound student for replies! Other teachers and students can even be included in the process and send well wishes too! Practice those community service endorsements that you give to the student body and encourage everyone in the building to reach out to their own schoolmate in need! There are many, many daily instances that the home based student can be included in and made to feel a part of things and small efforts can make a big difference. Physicians have even noted that patients that feel loved and valued thrive better and recover sooner! Take the initiative to make an impact in this individual's life and well being. Up-front and open communications, supportive efforts and understanding are keys to a successful home-bound school experience. Compassion is the key to making a difference in someone's life.

<p>“Throughout the centuries there were men who took first steps, down new roads, armed with nothing but their own vision”</p> <p style="text-align: right;"><small>Ayn Rand</small></p>		<p style="text-align: center;">Special Thanks To The William C. Bannerman Foundation</p>
--	---	---

	<p style="text-align: center;">A Very Special Thanks to an Anonymous Donor!</p> <p style="text-align: center;">For the extremely kind donation once again this year. We put it to good use!</p>
<p>Dysautonomia Awareness Bracelets worn by two youth attending the DYNA Summer Chill</p>	

	<p style="text-align: center;"><u>HOW FAR WILL YOU TRAVEL TO MEET YOUR DYNA FRIENDS?</u></p> <p style="text-align: center;">DYNA Youth Members Erin and Louise traveled across the Ocean!</p> <p>Left: Erin Black, from Scotland & currently residing in England with her “adopted” United States Mom, Debbie Dominelli Right: Louise Mulvihill and her Mom, Christine from Ireland.</p>	
---	---	---

DEALING WITH INSOMNIA

Debra L. Dominelli

Insomnia is a common symptom for dysautonomia patients. There are physiological reasons for this symptom and thus it is often extremely hard to overcome and must be addressed firmly and taken seriously. Your physician will provide you with some medical recommendations (which may or may not include medications) but it is also essential that you take a strict approach to resolving this problem. Ultimately, this is a symptom which you will have to have the determination to resolve. You need to recognize that until your insomnia is under control it is unlikely that your dysautonomia will improve. It is not going to be easy to resolve this very overwhelming and uncompromising symptom. On your part, it takes strict willpower, conviction, determination, routine, inner-strength, and above all; honesty with yourself, your parents, and your physician.

You will need to directly address any routines or behaviors that may complicate your insomnia, and stop them. Admit to your 2 AM computer addiction. Even if you are communicating with DYNA friends on-line you will need to turn off that computer at a time which you, your parents, and your physician all agree to. While we all understand your desire to connect with your friends when you can't sleep – staying on the computer all night is not only harming you but is also harming them. You are enablers! Stay firm in your conviction to overcome and be uncompromising in your behavior and you will not only be helping yourself but you will be helping your fellow DYNA insomniacs! It may even be necessary for you to turn over your lap top to your parents at a set time each night.

Consider Relaxation Therapy. This type of therapy aims to reduce stress and body tension. As a result, your mind is able to stop "racing," the muscles can relax, and restful sleep can occur.

Sleep Restriction. Some individuals suffering from insomnia spend too much time in bed trying to fall asleep. They may be helped by a sleep restriction program under the guidance of their doctor. The goal is to sleep continuously and get out of bed at the desired wake time. This treatment involves, for example, going to bed later or getting up earlier and slowly increasing the amount of time in bed until the person is able to sleep normally throughout the night.

Reconditioning. This means using your bed only at bedtime when sleepy. Avoid other activities in your bed, such as using the computer, reading or watching TV. Over time, your body will relate bed and bedtime with sleep.

- Try to go to sleep at the same time each night and get up at the same time each morning. Do not take naps after 3 p.m. Get into a pattern and stick with it. Do not compromise it once you get onto a schedule.
- Avoid caffeine, nicotine, and alcohol.
- Keep your bedroom dark, quiet, and cool. If light is a problem, try a sleeping mask. If noise is a problem, try earplugs, a fan, or a "white noise" machine to cover up the sounds.
- Follow a routine to help relax and wind down before sleep, such as reading a book, listening to music, or taking a bath.
- If you can't fall asleep within 20 minutes or don't feel drowsy, go read in a recliner or do something that is not too active or stimulating until you feel sleepy. Avoid stimulation, bright lights and computer screens during this time. Then try going back to bed.

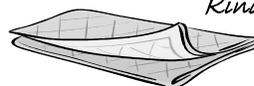
Most importantly be honest with your physician, parents and yourself about your habits and address those that contribute to this symptom.

The miracle is not to fly
in the air, or to walk on the
water; but to walk
on the earth.

~Chinese Proverb



Thank you to Charles County, Maryland Project Linus!
Your kindness toward our DYNA members is truly valued
and deeply appreciated. You have touched our hearts.



Kind Hearts Make a Difference!

Thank you!

DYNA is HOPE

DYNA is a 501 (c) (3) non-profit organization dedicated to serving young people diagnosed with various dysautonomia conditions. These young individuals may experience isolation from their peers due to the impact of their conditions. They are often forced to make dramatic lifestyle adaptations in the prime of their youth. DYNA empowers our members by providing them with the necessary tools to become active participants in their own future. We are a dynamic group of positively-focused individuals. Our youth members are overcoming adversity and making a difference in the future together. They believe in becoming "better" not "bitter" through their hardships.

DYNA Is:

Accurate Information
Community Activities
Informative Professional Website
Dysautonomia Awareness Campaign
Medical Advisory Board
Networking with Leading Physicians
Enlightening Newsletter
Supportive Literature
Physician Endorsed
Private Member Convention
Private, Secure Internet Club
Postal Outreach Program
Professional Educational Advisory Board
Social Programs

Priorities of DYNA

- To give young people with dysautonomia hope for their future.
- To provide a positive support network to young people who have dysautonomia.
- To help young people with dysautonomia adapt to the stress, trauma, and life style changes that they often experience due to their conditions.
- To help young people with dysautonomia manage the isolation and loneliness that they often experience due to their conditions.
- To help young people with dysautonomia learn to deal with their conditions in a positive and productive manner.
- To provide information on dysautonomia and the educational rights of students with dysautonomia to parents so that they can become their child's advocate.
- To heighten awareness of dysautonomia within the Pediatric and Adolescent medical communities so that others can get diagnosed earlier and obtain proper medical treatment.

How You Can Help:

Your tax-deductible donation will enable DYNA to provide children and young adults who have dysautonomia with the necessary support and outreach. Every donation is graciously appreciated.

*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

Donate to DYNA

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

My name is: _____

My address: _____

Telephone: _____

E-mail: _____

Amount Donated: \$ _____

My donation is made in honor of:

Name: _____

Address: _____

Telephone: _____

E-mail: _____



Please donate by check payable to:
DYNA, Inc.

Calling All Doctors

If you are accepting new patients and wish to be added to our Physician Listing, please have your staff contact us at :

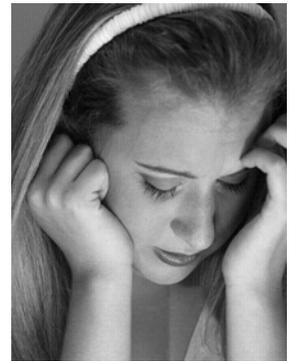
301-705-6995

or refer to our web site:

www.dynakids.org

for directions.

We have patients who need you!



Have you heard of these conditions?

Postural Orthostatic Tachycardia Syndrome (POTS)

Neurocardiogenic Syncope (NCS)

Neurally Mediated Hypotension (NMH)

Vasovagal Syncope

Post-Viral Dysautonomia

Non-Familial Dysautonomia

Generalized Dysautonomia

Then you should know about DYNA!



YOUNG PEOPLE UP TO AGE 25
DIAGNOSED WITH A FORM OF DYSAUTONOMIA
GET CONNECTED TO OTHERS!

Join DYNA:

Go to:

www.dynakids.org

Click on:

JOIN DYNA and follow the directions.

DYNA

"A Ray Of Hope"

1301 Greengate Court
Waldorf, Maryland 20601

Phone: 301-705-6995

Email: info@dynakids.org

Website: www.dynakids.org

All articles original to this newsletter may be reproduced in full-text version only.
Complete and proper credit must be given to the contributor of the article(s) as well as to the
Dysautonomia Youth Network of America, Inc.

No editing or adaptations are permitted in reproduction.

Contact our office at: info@dynakids.org for permission.

Contact us for permission.