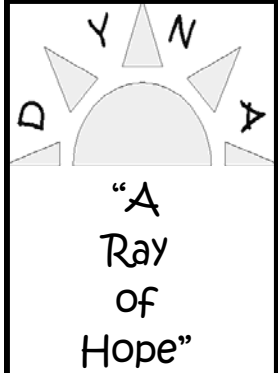


Dysautonomia Youth Network of America, Inc.

“The Young and the Dizzy”

www.dynakids.org

2007



Dysautonomia is a medical term used to describe conditions that are caused by a malfunction or dysregulation 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 (the inability to remain upright) is a hallmark of multiple forms of dysautonomia. Each dysautonomia case is unique and symptoms can range from mild to debilitating. Treatment will vary according to the specific condition and 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, generalized weakness, 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.

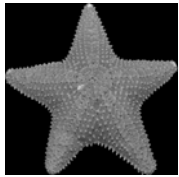
Visit www.dynakids.org for more information.

DYNA Summer Chill



“Having a Healthy Illness”

July 5, 6, 7, 8 2007, Dulles, Virginia



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.

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Main Contents

Being Supportive of a Child with POTS	3
The Pediatrician and POTS	5
Exercise and the POTS Patient	6
Degrees and Dysautonomia	8
Being a Parent to a Child with Dysautonomia	10
Amish Community and POTS	11
Friends & Teenage Dysautonomia Conditions	12
Dear Doctor	15
2007 Summer Chill Pictures	16

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The "Young and the Dizzy" Newsletter

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

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Being Supportive of a Child with POTS

The Gentle Spirits of DYNA

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

If you have not had the privilege of knowing children diagnosed with POTS, you might be surprised at how beautiful these children tend to be (inside and out). Physicians who have treated these patients have noted that the classic patient with POTS often has strikingly large eyes, fine boned features, and long limbs. More often than not, they also have fair skin and hair (no matter what nationality – they tend to be fair compared to others). It is not often that I see a POTS patient that is not a physical beauty! Another noted fact is that these children tend to be highly intelligent and are typically in the top 10% of their class. They are usually high achievers. Once they become ill, the associated brain fog and cognitive issues often require educational accommodations until recovery, but they still tend to excel academically and still aspire to achieve above the norm. This determination to achieve probably works in their favor during their battle for recovery!

I call my DYNA members that are diagnosed with POTS, “*Gentle Spirits.*” Every time I mention this nickname to someone who has associated with these children, I receive absolute agreement. These children are very loving, caring, and compassionate individuals. They are typically devoted friends, humanitarians, animal lovers, and very involved within their communities and educational systems. They truly are “the cream of the crop” of young society.

So, with POTS cases we often have an intelligent, socially involved, high achieving, sensitive, teenage beauty with an invisible, variable, and unpredictable illness. Often their symptoms appear after activities and not during. Is it a wonder that so few people understand the true impact of their medical situation? The children with mild cases look great, appear healthy to the public, and tend to manage their life very well once medically supervised. The more moderate to severe cases also look great, and when able to venture out—they too appear healthy to the public and may even appear to function relatively well to the untrained eye. “*Appear*” is a key word here. What people see in public is often not what the patient gets in private with these conditions. Unfortunately, ill informed individuals sometimes don’t believe the child is sick and they may accuse them of malingering or being lazy. Sometimes jealous peers will gossip about them or accuse them of trying to get special attention.

Below are some tips to help you better understand your POTS friend, classmate or relative. Your support is extremely important to help them cope and deal with this unusual and little known illness. Support is medically recognized as instrumental in the healing process for all those afflicted with a chronic illness.

- BELIEVE, UNDERSTAND. If you don’t understand what is happening, find out before you say anything that could hurt someone.
- Read our web site so that you understand the condition. Really read it – don’t just glance at it. Contact our office if you have questions. All calls remain confidential.
- Help others believe. Eliminate the ignorance and promote awareness.
- Recognize that the patient is experiencing a loss (loss of control over their body, loss of social life, and loss of perception of themselves as having a healthy body). Allow them time to grieve their loss. There are typically stages to dealing with illness and they may need to go through them (denial, anger, bargaining, sadness, and finally acceptance and determination to overcome).
- Be a good listener. Let them know that you care and that you are available if they want to talk. Don’t assume they already know this.
- Keep them company without overwhelming them. Suggestions are: reading books together, watching movies, sharing a favorite TV program together once a week, going out for dessert or pizza occasionally and just “hanging out” together. Remember that sometimes just picking up the phone or dropping by to say that you care truly matters.

continued...

“Kind words can
be short and
easy to speak
but their echoes
are truly
endless.”

Mother Teresa

“The measure of love is compassion; the measure of compassion is kindness.”

Anonymous

- Empathize rather than pity. Pity is not welcomed by most POTS patients because they find it demoralizing.
- HELP! Realize that it is hard for people to ask for help. No one likes to feel like a burden. Don't ask what you can do – think of what you SHOULD DO – AND JUST DO IT. (People who need help don't always have the energy to ask for it or explain it, they just need someone to do it.)
- Don't disappear because you don't know how to help. Stick around and just be a friend. If you don't know what to do – talk to them and just tell them that you care.
- Recognize that people with POTS need to budget their energy and resources - they must find a balance between accomplishing the things that must be done with the things they would like to do. Sometimes there is not even enough time to accomplish what MUST be done.
- Expect ups and downs. They will have good days and bad days and everything in between. There is little consistency or predictability about POTS.
- Understand that they may need to cancel plans at the last minute and know that it is hard for them to commit to plans.
- Don't give simplistic advice such as, “You need to eat better, take special vitamins, get more sunshine, rest more, etc.” These statements reveal that you don't understand their condition.
- Don't tell them, “You don't look sick.” While you may mean this as a compliment, they may think you doubt that they are really ill. Although they may look the picture of health, POTS is an invisible illness and you cannot see heart rate, blood pressure, migraines, fatigue, dizziness and many of the symptoms.
- Don't put them in a bubble. Emotionally or physically. You cannot protect them from the hardships of life. Just be there to help them through things.
- Avoid KNOWINGLY exposing them to viruses that might set them back medically. Their immune systems are sensitive right now.
- Remember that they need to live as normally as they can. Don't exclude them from invitations because you are afraid they can't make it. Let them decide their own limitations. Communicate with them and be honest if you are holding or attending a function that you suspect they physically can't handle. Be open with them. They may feel left out, but it is better to always be honest.
- RESPECT them.
- Remember they are still the person they were before they got sick and you are still the same person you were. **Don't let illness change that relationship.**



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“Dare to reach out your hand into the darkness, to pull another hand into the light.”

- Norman B. Rice



The Pediatrician and POTS

By Amanda Dominelli

A pediatric patient diagnosed with POTS walks (or staggers and rolls) in for an appointment. She/he is dizzy, nauseous, weak and above all dependent on you, their pediatrician, to provide them with answers. You could probably use a few answers yourself, too! POTS can be an overwhelming condition to deal with – for patients, parents, and doctors alike. A pediatrician who is able to develop an understanding of the special needs of a patient with POTS can be a priceless asset and a true blessing.

As a pediatrician, it is quite possible that you have never encountered a patient with POTS before. A little independent research can go a very long way. DYNA's website is a great place to start: www.dynakids.org. You can also email us at info@dynakids.org or call 301-705-6995 to request medical articles and other beneficial information. Please be sure to request your free copy of our **Awareness Series Brochure: Your Pediatric Patient with Dysautonomia: A Guide to Understanding Autonomic Dysregulation** (provided to physicians for free). A full series of brochures is also available for printing directly from the web site. While research is valuable, it's also important to listen directly to your patient and inquire about their specific needs. Pediatricians should recognize that there are variants in each POTS case and that each patient must be considered on an individual basis.

Below are some basic suggestions to assist you in properly caring for your POTS patient. Please feel free to contact our office if you have questions.

OFFICE VISITS:

- Mornings are hard for these patients and thus afternoon appointments tend to work best.
- It is helpful to take the patient to a quiet, cool room where they can recline while waiting their turn for an appointment. Even your office will suffice if you don't have an available exam room.
- They should avoid exposure to other sick children at this time.
- Allow them to drink water and bring salty snacks to their visit.
- Remember that their brain fog issues may prevent them from properly communicating their symptoms during their appointment and request that they keep a daily symptom log for your review. They can find one at: <http://www.dynakids.org/resources.jsp>
- Sometimes it is beneficial to provide opportunities to speak with the child and parent separately as they both may wish to discuss certain issues in private.
- Inform your staff about the patients specific condition and unique needs so that everyone is on the same page with caring for this patient.

PROPERLY TAKING BLOOD PRESSURE FOR POTS PATIENT:

- Have the patient lie quietly for at least 3-5 minutes and take the supine BP, and record. Taking BP in both arms is recommended for initial reading. After the initial reading always utilize the arm with the lowest BP results (since the goal here is to note the low BP of the patient).
- Have the patient sit upright on the exam table with legs dangling; wait at least 2-3 minutes before taking BP. Record.
- Deflate cuff while patient is sitting.
- Have the patient stand. They may need support; be extremely careful if the patient is dizzy while sitting or says they are dizzy when first standing. If the patient becomes symptomatic (heart racing, lightheaded, dizzy, warm, nauseated etc.) put the patient quickly in the supine position and abort trying to take the blood pressure.
- It is better not to push it if the patient feels poorly while standing. Sometimes numbers mean nothing if your patient ends up on the floor!
- In all positions the arm should be at heart level. Cuff size is important, it must conform to the patient's body habitus. Measure the arm circumference and use the appropriate cuff size.

“One way to get
high blood
pressure is to go
mountain
climbing over
mole hills!”

Earl Wilson

Exercise and the POTS Patient

By Debra L. Dominelli

Many POTS families contact the DYNA office, frustrated with inflexible (and sometimes ill-informed) medical professionals who promote extensive exercise regimens as the answer to their child's recovery. Recently DYNA received a phone call from a very emotionally distraught and heartbroken 12 year old who thought he would never get better because he could not handle the exercise program his physician had presented. The nurse had inaccurately told the child (one that we all know to be a fighter) that "he was just not trying hard enough." Parents and children contact us on a daily basis with similar horror stories. Therefore, the time has come for DYNA to make its position known on this issue. DYNA's position is based on consultation with leading, respected, conservative, experienced medical professionals; extensive long term personal observation; and anecdotal advice from scores of patients and members.

Each case of POTS is unique. However, most patients find that balance in all aspects of their recovery works best. That means not too much of any one thing and a little bit of *this* and a little bit of *that* and adapting *this and that* with time! There is no one right answer to the question of what exercise to do and how much. Generally, the well known specialists who have successfully treated many cases of POTS over the long term (and have followed up with their patients on a long term basis as well), will instruct their patients to "listen to their body," pace themselves carefully, and not run any marathons. A regular, slow, and manageable exercise regimen tailored to the individual and the specific case helps avoid the "crash and burn" phenomenon so many POTS patients face. They need modest exercise to avoid deconditioning and to regain their strength, and it is absolutely essential to their recovery, but overexertion can be quite detrimental. You have to find a balance when it comes to exercise and the POTS patient.

Patients who sit in wheelchairs, lay in bed, and recline on couches 24 hours a day will not recover. However, we must also understand that they will not recover by constantly being pushed past their limits. Pushing too hard to obtain the physically impossible too soon stresses their bodies (and can be detrimental to progress) and stresses their emotions (making them constantly feel like failures). Absolute respect for the child's input should be the first consideration of any physician. If the child is emotionally healthy, they are the best judge of their own limitations. They know what their body can or can not handle. We strongly recommend an open discussion between physician and child about their exercise routine without demands, pushing, or coercion. Flexibility in all areas is a must! Plan for success rather than failure – even if it takes extra effort and on-going communication.

We remind all physician's that these children also have social needs that must be met via peer contacts and friendships in order for them to remain emotionally healthy and stable. Their emotional health is every bit as important as their physical health and also plays a key role in their physical health. A healthy child is not a child that is isolated from the population because their exercise routine disables them from functioning in a social manner with their friends or prohibits them from obtaining their education. Families also have a "family life" to meet and other siblings and responsibilities to consider. Often the parents are as exhausted as the children trying to keep up with physician appointments, pharmacy pick ups, physical therapy, school, home instruction, and the requirements of everyday life.

Marriages need extra nurturing during a child's illness and the sibling's emotional health needs to be considered as well. Placing an unreasonable demand for exercise that continually "crashes" the child helps no one and, in fact, harms everyone.

It is in the child's best emotional interest to maintain an on-going education in order to keep pace with their peers. That sometimes means public school homebound instruction on a long term basis (or until the child is well enough to attend school) while balancing the demanding aspects of their illness. In order to keep them socially involved, many schools allow the student to attend for lunch and electives, when possible. Some children only attend after-school clubs. Some parents find it easier to utilize private home-schooling and to interact with their local home-school community for social activities. Children with milder cases are able to attend school more frequently and with better reliability, but moderate to severe cases typically utilize home-based instruction (whether through their school systems or privately).

Consider each child as an individual circumstance. Every situation is as unique as a fingerprint. Therefore, every POTS patient is a one-of-a-kind puzzle that needs to be put together.

continued...

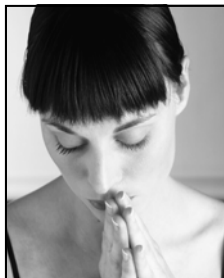
IN CONCLUSION, DYNA'S POSITION ON EXERCISE IS THE FOLLOWING:

- Every child is unique and needs to be accepted and treated that way.
- There is no "One size fits all" solution.
- Exercise is important and reconditioning essential; but how much, what kind, and when is definitely a balancing act that depends on the circumstances of each unique child and each unique medical case.
- Physicians and school officials need to understand that socialization is as important to emotional well-being and health as any medication or program.
- Peer acceptance and interaction is necessary. The child and their parent(s) know best when it comes to obtaining this for their circumstance.
- Each child should be allowed the opportunity to discover what activity levels or lifestyle accommodations work for them in order to maintain that "balance in life."
- The child should be carefully observed so that they don't overdo it, but she/he should not be coddled. If allowed the opportunity, they will eventually learn to pace themselves appropriately.

To get started with reconditioning,
please refer to our web site
Resources Page:

Strengthening Exercises

www.dynakids.org



"There is a necessity for a regulating discipline of exercise that, whilst evoking the human energies, will not suffer them to be wasted."

Thomas de Quincey

When is the next DYNA Summer Chill?

It is in July of course!!!

However, it is a

Private Event

Open to active DYNA Members and their Physicians Only!
If you want to attend, you must be an active member of DYNA prior to our registration deadline.

Helpful Resources

Video

We highly recommend the **DYNA "Goofy Slipper" Lecture Video on Dysautonomia** to all physicians, parents and school Systems interested in learning more about dysautonomia conditions. To order please refer to our web site: www.dynakids.org for an order form.

Book:

The Fainting Phenomenon: Understanding Why People Faint And What Can Be Done About It 2nd Edition

Blair P. Grubb, MD
ISBN: 978-1-4051-4841-2



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See our web site: www.dynakids.org for information.

Degrees and Dysautonomia

The Do's and Don'ts of College

By Diana Singer

While the seemingly endless application process and following college experience can be nothing short of overwhelming, it's also a time of great excitement for a teenager as he or she crosses a bridge into an entirely different world full of opportunities. There are an abundant number of questions and concerns for not only the prospective student, but the entire family as well... and that's for a healthy individual! Add in dysautonomia, and the stress levels grow exponentially.

As a college sophomore, I've made it through that difficult freshman year and can now reflect back on what I'm glad I did, wish I'd known, and a whole host of other issues. Keep in mind that this is how things work at my private school with around 6,500 students – they could be very different at your dream school, so don't assume everything is identical across the country! But regardless of your location, hopefully these Do's and Don'ts will answer some questions and provide insightful advice no matter where you are on the college continuum, from beginning the application process to getting ready to move in!

The Application Process

As you embark on this next stage of your life there are probably a million and one things running around in your mind. In order to stay true to yourself at this time when so many people will try to influence you, make sure you have a set list of priorities, with the top one being your own comfort level and interests - you're the one that's going to be living these years, not your parents, siblings, or best friend! I highly recommend researching colleges early so you get a feel for your possibilities – don't limit yourself by others' expectations and look at a variety of programs according to your interests. Remember there may be times you will need to go to doctor appointments during the week, and there is always the possibility of the unexpected crash. With that said, from personal experience I suggest searching for schools within a one hour radius of your home. I am about 45 minutes away and it is honestly perfect – I still get the feel that I am “away” at college, but my parents are close enough to come get me if needed, and unfortunately that does happen. Also consider the medical support around campus – check into how the student health center works, especially if the school requires you to use their own insurance, and also make sure there is a good hospital close by in case of an emergency.

Once you have narrowed down your list of schools, it is of utmost importance to actually visit the campus on a normal day. Not only will you get a feel for the vibe of the campus and its students, which from personal experience is pretty amazing – I knew within minutes of getting out of the car that my school was “the one,” but it's a first-hand look at many of the things that are important to dysautonomiacs. I highly recommend setting up an appointment with an admissions officer so you can get all your questions answered and also explain your unique situation. Make a good impression while concentrating on what you CAN rather than cannot do – just be realistic. Quite possibly the number one question to ask is about the disability services available – please do not put off talking to those in disability services because you think you can make it without their help. They can help immensely, but not if you don't ask... and accommodations are not retroactive!

Ask about requirements to live on campus, how the roommate situation works (I unfortunately have two of the infamous bad roommate stories and personally prefer living by myself, as many college students simply don't understand all that a chronic illness entails), and how the meal plan works (be cautious of a pre-set amount, often between \$1,000 and \$2,000 a semester, especially if you experience GI symptoms).

“The important thing is the educational experience itself – How to survive it!”

Donald Barthelme

Inquire if the buildings have elevators (some older schools and dorms do not), how far you will have to walk on a daily basis, if there are alternate modes of transportation, if there are strict rules regarding how many absences you can have, what their policy is if you must take off an extended period of time due to your health, and the minimum number of hours (most classes are usually worth three hours of credit) you must take, especially if you need to be a full-time student to stay on your parents' insurance. Receiving these answers will give you a good idea of how feasible it is for you to attend. If it feels like a good fit all around, do not hesitate to apply while keeping in mind the deadlines and possible binding agreements... remember the unpredictability of dysautonomia. Be honest on your application, get it in as soon as possible, and most importantly: don't stress!

The College Experience

At this point you have done your research, applied, received your much-anticipated acceptance letter, and are ready for the college experience! Now is the time to gather all of your information for disability services, including items such as notes from doctors explaining your medical conditions, what medications you are on and their side effects, your handicapped parking request if needed (often freshman parking is practically on a different continent!). Once the people in the disability center receive this information they often have you come in to take a few tests that solely are there to identify how you learn best. Then all of this work comes together and you can meet with the coordinator and arrange your accommodations. These could include extended time for testing, alternate testing locations, absence policies, recorder agreements, alternate housing (be sure to ask about the restroom situation... some dorms have community restrooms where you have to walk quite a distance to get there), and other unique issues. If you are living on campus, which I highly recommend if you are able, move in as soon as possible so you can rest before classes start, meet new people, and find your way around campus.

When arranging your class schedule do not overload yourself – I recommend taking 12 hours (four classes) at least for your first semester as there are a lot of new things to get used to, and time management is an issue for the majority of freshmen! Make sure to allow for adequate rest time and breaks for eating – instead of worrying about the “freshman 15” make sure you're getting enough fluids and salt on a daily basis! It is so important to start the day well with a good breakfast, therefore avoid early morning classes if at all possible, along with back-to-back classes. I recommend developing a plan that lists all the classes you will take for each semester until you graduate so you can space things out but not get behind. Summer classes are wonderful – you can get the same amount of credits in much less time! In every class you will benefit greatly if you get to know your professor. I always introduce myself after the first class and set up a time (often they will do it right then) to discuss my conditions and disability accommodations, and have been thanked repeatedly for taking this initiative.

While your main focus will be on your classes, there is much more to college than simply the academics. The social scene is very prevalent and it is important to have a well-rounded experience. Make friends, join organizations that don't have stringent requirements, and enjoy yourself... but respect your limitations! Drinking any kind of alcohol can be very dangerous to dysautonomiacs for a variety of reasons – don't be pressured by others to do things you are uncomfortable with. Keep up with your meds (you're in charge of them now!) and always allow time for yourself, free from other distractions. Make sure you have time for adequate rest – all-nighters are not easy to recover from! Simply use common sense, and remember – HAVE FUN! College is a one-of-a-kind experience you will never forget!



Being a Parent to a Child With Dysautonomia

By Anne Parkinson

In 2005, when my daughter was diagnosed with dysautonomia, I never could have imagined the impact her condition could have not only on her life, but my life, too. To say that the past two years have been difficult would be an understatement, but, when I consider the situation we are in today, I feel that life is pretty good. My daughter is still sick, but, unlike the mothers of other teenagers, I do not worry about my daughter going out to parties and getting drunk, or making bad decisions. We are close and we trust each other. We're friends as well as family. She and I have a wonderful relationship that is enhanced with every problem that we have to face, and I must admit that we have faced plenty of problems; but we face them together. Of course, she has friends her own age, too, although in finding her truest friends she went through much heartache.

My positive attitude to my daughter's illness was not spontaneous; it took many months for me to see that dysautonomia does not have to destroy everything; in fact, the illness can build strong characters and even stronger relationships.

After her diagnosis both she and I were devastated; as a parent you like to imagine that nothing as horrible as a chronic health problem can affect your child. Yet we both realized that she had lived with many of the symptoms of dysautonomia her entire life, so, we thought that, if they did not worsen, then we could cope very well.

Unfortunately, her symptoms did worsen. I watched as each day she struggled with pain and fatigue. I saw her trying desperately to keep up with school work despite visual disturbances and constant migraines. Each week, it seemed, she would develop a new and bizarre symptom that even her dysautonomia doctors were unable to treat successfully. She tried to keep up some type of social life through taking part in plays at school and the occasional visit to a friend's house, but soon even this became too much for her. She spent weeks at home lying in bed or on the sofa. I could not believe that there was so little medical knowledge about her condition.

Every morning I would research dysautonomia, and every morning as I sat on my daughter's bed trying to wake her, I would tell her the very little that I had discovered. Then, one morning, I did have something of worth to tell her; I had found DYNA. I telephoned Debbie, and my daughter submitted her application to DYNA and joined the dysautonomia Youth Network of America family. Almost immediately my daughter's mood changed from feeling lost and scared to being optimistic and hopeful about her future. She told me that other people her age had the same bizarre symptoms that she had. The knowledge that her DYNA family was there for her, and that she was part of a group of people who would always understand, seemed to empower her, and I noticed she became more comfortable explaining her health condition. Since my daughter joined DYNA, I have joined the Parents' Forum and have received the same level of support; I know there are friends there that I can turn to.

Life still throws at us more than we feel we can handle, but I have learned that there are other kids struggling just like my daughter, and other parents facing similar problems to that which I face because of dysautonomia. But I have also learned that there are parents who have daily worries not only concerning the health of their children, but their safety, too, as their teenagers go from party to party. I feel lucky that my daughter has come to see me as a friend and not as a threat to her personal happiness. She turns to me for advice, and confides in me, and I, in turn, often seek her advice and I confide in her. I know that she is in pain and I would do anything to take that away from her, but there are days when I have to realize that for all dysautonomia has taken away from my daughter, it has given us a relationship that we both value above all else.

“A mothers love for her child is like nothing else in the world. It knows no law, no pity, it dares all things and crushes down remorselessly all that stands in it's path.”

Agatha Christie

Amish Community and POTS

By Alice Butler

On the Dysautonomia Youth Network of America website home page is the statement “Based in the US, but open to the WORLD!” It’s true; we have members from all over the 48 contiguous states, and from Alaska, too. We have members in Great Britain, Australia, Singapore, New Zealand, and inquiries from all over the world (including China). Many DYNA members are active on the member-only private Internet forum; however, there are some who are not able to participate in this service because of their religion and societal values—DYNA’s Amish members.

Becky K., one of several DYNA’s Amish members, became very sick when she was in sixth grade. For many weeks she was bed bound, missing out on her education and social involvement. Her doctors were confused by her symptoms that started after a cold-like virus, thankfully a local doctor knew enough about Dysautonomia to recognize her symptoms and diagnose her with POTS.

As soon as the diagnosis had been given, Becky’s community rallied round her, supporting her and caring about her. One non-Amish friend who had Internet access, started investigating Becky’s illness. Soon she stumbled across the DYNA website, and Becky’s mother telephoned Debbie Dominelli, President of DYNA. “DYNA has been wonderful,” Mrs. K recalls. After listening to Becky’s story, Debbie agreed that it sounded like viral-onset POTS, but she wanted Becky to consult with a medical professional familiar with treating it. She helped the family obtain an appointment with a specialist who confirmed Becky’s diagnosis. The doctor suggested medications for Becky, which have helped immensely. Debbie assisted the family through understanding the illness and they soon became close friends. After a few years, Becky has weaned off all her medications and is now almost as healthy as she was pre-POTS. Her family is still very close with DYNA and still communicate regularly.

Not all patients will improve so drastically with medication or medical treatment, but for Becky, the improvement in her health was enough for her to become active in a community Youth Group and recapture some of the social interaction that she missed so much through her illness.

Because of DYNA, Becky, and other sick Amish youth are not completely isolated. Members like Becky are placed in DYNA’s Postal Outreach Program and receive regular communications from DYNA members. Some Amish members even keep in touch with their DYNA friends by cell phone, and of course DYNA’s newsletters provide opportunities not only for the Amish members to catch up on the latest Dysautonomia news, but also allow for spreading awareness. Becky’s mother explains that she gives copies of the newsletters to doctors who treat the Amish community. She has also helped other Amish children get connected to DYNA and find proper medical care by spreading awareness at Amish Markets. “We spread awareness mostly by word of mouth,” Becky’s mother says. She tells friends and family all about Becky’s illness and DYNA because of the help they received when Becky was at her worst. “The Amish community has always been accepting of Becky’s illness; they could see how ill she was when she could do little more than lie on the couch all day.” DYNA provided us with the information we needed to properly treat Becky and to spread awareness to others.

Even with the overwhelming support of the Amish community, DYNA’s Amish members still enjoy the chance to meet with their DYNA community. They attend the Summer Chill and get to know the people who have been there for them through the good days and the bad, and give back some of the support that they have received.

The bond created between DYNA members and the Amish community is a strong one. DYNA is based in the US, but opens its doors to all youth suffering from Dysautonomia conditions whether they are in Australia, England, or here in America’s Amish communities.

“I am only one,
but
I am one.
I cannot do
everything, but I
can do
something.
And I will not let
what I cannot do
interfere with
what I can do.”

Edward Everett Hale

Friends & Teenage Dysautonomia Conditions

By Alice Butler

Earlier this year I was asked to do an assembly for my school about my experience of living with an invisible illness. I agreed without hesitation, but, as I sat that thinking about how I would approach it, I realized that even a year ago I wouldn't have felt comfortable standing in front of an audience of over three hundred students and teachers and exposing to them such a large part of my life. Now, though, I was ready. It was my senior year, I had a few close friends I could trust, and some wonderful teachers who had shown themselves to be trustworthy and as much friends as they were teachers. I realized that these few people would listen to what I was saying, but that the other two hundred and fifty would probably switch off and study the patterns on the ceiling or count the number of seats in the auditorium, so I decided that in order to make sure everyone would listen, I had to be positive and try, somehow, to bring some humor into my presentation.

My assembly lasted over twenty minutes, but the effects have lasted for weeks, even months. Everyone listened. I saw their eyes fixed on the screen on which my PowerPoint presentation was projected. I saw them put their books and phones on the floor and actually sit back and imagine what it was like to live with Dysautonomia. They laughed as the slide with the picture of me contorted and licking my elbow filled the screen (I am quite flexible due to joint hypermobility syndrome which is associated with my dysautonomia), and I saw some juniors and seniors surreptitiously attempt to do the same. Yet, as I became more serious and focused on losing friendships because of illness, not being included or even remembered by friends, and the necessity to treat people with an invisible illness just as one would treat someone who had a visible ailment (a broken leg perhaps), the audience seemed to reflect on how society treats those who are sick.

As the final slide faded, many students, with whom I had never before spoken, rushed down the steps of the auditorium to hug me and tell me how sorry they were that they had never known. Other friends came to me and stood looking a little sheepish.

To me, perhaps the most important aspect of my presentation was to portray the feelings of loneliness and sadness as supposed friends abandon their sick classmate. I had suffered this since my diagnosis, and in some ways this was the most painful part of being sick. I could have coped with many of my other symptoms had I had my companions there beside me. I remember telling a group of my friends just what was wrong with me; some of them patted my shoulder, others hugged me, but one girl said "Oh, what a shame. Do you know I've lost my pencil? How can I take a test without a pencil?" And it was then I realized that my friends truly weren't the reliable, loyal people I had thought they were.

During long absences from school I rarely received phone calls from schoolmates. I had messages of support and good wishes for a speedy recovery from most of my teachers, but friends carried on with their lives and left me behind. It wouldn't be true to say that in coping with this I didn't become upset. In fact there were evenings when my mother would speak to another parent and tell me that my friends had been close to my house but hadn't come to visit, and I would cry. I felt as if I had not only lost friends, but I had lost confidence in myself; was I such a poor judge of character as to have thought that these people cared about me? Had I done something to offend these people? Was it all my fault?

In truth though, it is nobody's fault. It is an unfortunate coincidence that Dysautonomia conditions often rear their ugly heads during teenage years, and that during this time new feelings of freedom and individualism and the long-awaited independence and responsibility are finally experienced. Teenagers hurtle from school to sports, play practice to parties, and somewhere in there have to learn how to balance all the new-found liberty. If, in the midst of all this, they learn that a friend is sick, they can't cope and as much as they once cared about this person, they now see them as weaker and unable to join in all that they once could. Some don't like to ask how their friend is doing because emotionally they cannot handle the unfortunate truth that their once healthy friend is now stuck in bed. Others wrongly believe that their ill friend has abandoned them and think that maybe none of 'invisible illness story' is true. And others still can be jealous of the fact that being ill means that school is no longer a priority. None of these views are acceptable reasons to neglect a friend in need, but sadly, many teenagers take these reasons and do ignore such a friend, and simply continue with their lives. They don't have time in their busy schedule to write a note or card, or even make a five minute phone call that would brighten not only the day, but possibly the week of their comrade.

On partially returning to school after a long absence, I was greeted by incredulous faces that were explained as tales emerged that revealed that some teachers had said I wouldn't be returning to school. Some had said I may return but just in case perhaps my position on the Prefect Board (similar to a student council that deals with social, leadership, volunteer, and Honor Code issues) could be reallocated, and one had even told students that I had Bird-Flu! I was incredibly hurt by all these stories that were founded on pure speculation and I was angry to think that they could have found out the truth had they just called me or my parents and asked how I was doing but that they didn't care enough to bother.

When I realized that, even though I was back at school, I was continually missed out when plans were being made for parties and trips out to lunch, I decided that my friends weren't the people I had originally thought they were. At lunchtime I would see these 'friends' drive away laughing and joking to go and get food at a local restaurant, and I would feel quite alone. I would wish that I had friends such as those from DYNA at my school. More than anything I wanted friends who understand and see past my illness and saw me. I was furious that people could manage to see past the cast that covered one student's leg and see that he was unchanged despite his injury, but that they couldn't see past my illness and see the old me that was still there. Alone, I would search for somewhere quiet I could sit without the smells of the lunch-room making me feel nauseous and worsening my headache. Sometimes I would sit in a teacher's classroom and chat about school and college, and other times I would wander the school looking for place to eat lunch and relax and be myself. It was in this search that I stumbled on a group of wonderful people in the grade below me. They ate lunch in a classroom and chatted about life and laughed and joked. They welcomed me immediately and even once they knew I was sick they didn't see me as a sick student always to be avoided, but as a regular kid. They didn't care about my being sick; they liked me for who I am. We spent lunches together, and sat together in assembly, we talked after school and it was this group of friends who wrote to me when I had another absence from school. It was this group who didn't change their attitude towards me after my assembly presentation because they had nothing to change.

I am pleased that I explained to my school about Dysautonomia, and I am thrilled at the prospect that my explanation of having an invisible illness may help a student or faculty member in the future. I believe that my old friends reconsidered their past attitudes towards me and have become more understanding. My true friends are those I found when feeling lost and alone. In order to find them I had to search and I had to be myself. I experienced sadness and despair before I found them, but once I had found them I never felt alone. They are my truest high school friends and I will miss them dearly when I graduate. These are the few friends whom I knew would listen to my presentation even if it was brutally honest and without humor, because these are true friends. True friends are hard to find, and they can appear in the strangest places, but keep searching because there are people out there who are prepared to listen and understand, and treat you as the person you are and not the illness you have.

A real friend is
one who walks
in when the rest
of the world
walks out.

Walter Winchell



**Special Thanks
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“Throughout the centuries
there were men who took first
steps, down new roads,
armed with
nothing but their own vision”

Ayn Rand



Due to privacy concerns expressed by contributors, DYNA Inc. will no longer publish a list of general financial donors in our newsletter. All contributors will have received a thank you note / receipt and all individuals that donations were made in honor of have been notified.

We deeply thank our financial supporters and truly feel blessed to have you.

**You have made a difference in the world
and a difference in the life of a child.**

**“Unless someone like you cares a whole awful lot,
nothing is going to get better. It’s not!”**

Dr. Seuss



**CONGRATULATIONS TO DYNA, INC. AS RECIPIENT OF:
HUMANITARIAN AWARD OF THE YEAR!
Loudoun Convention and Visitors Association**



**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

Dear Doctor

By Sarina Dane

When people get sick with dysautonomia, so many aspects of their lives depend on successful partnerships. Partnerships with parents, schools, friends, and perhaps most importantly, doctors. In maintaining a successful relationship with doctors, much of the weight falls on us patients. Any member of the DYNA community can emphasize the importance of complying with treatment, preparing for doctor's appointments, and trying to communicate as effectively as possible. Nevertheless, physicians share some responsibility in making sure that this collaboration works well. We understand that medicine is an imperfect and ever-evolving science, so we do not expect magic-wand answers. However, most of us do hope for caring and understanding doctors who try to maximize the quality of our lives as much as possible under frustrating circumstances. In this effort, the key is communication and respect.

Whenever a doctor sits across from me in an icy examination room, I often feel like I stop being Sarina, and become "pt s.d. DOB 4/4/1989, MRN XXXXXXX". I am defined by my blood pressure, pulse, and saturation, and the most interesting things about me can all be found in lab and other test results. So many fellow DYNA members I have spoken to have expressed their wish that the doctors they spend so much time with would help facilitate their growth as a person, rather than simply label their medical problems with a "goodbye and don't let the door hit you on the way out" attitude. It is actually shocking how much of a significant difference a short amount of small talk can make. I don't mean the few trite questions physicians rattle off out of courtesy before trying to decipher whether or not their patients are psychomaniacal, puppy-killing stoners. Believe me, we can tell. This involves pushing your schedule back just a teensy bit more (which is probably already running late) and actually talking to your patient. To me. To us. The sick part of me is truly just one small aspect of who I am, even though it may not always feel that way while lying in an uncomfortable hospital bed. But all of those other things – it is because of them that I so badly want to feel better. This is also not taking a psycho-social history (which I'm sure is very important too), but rather possessing a real interest, and being able to see your patient as a 1,000-piece puzzle whose illness makes up only the periphery.

The only way to connect with any patient – particularly a teenager – is for him or her to trust you. We want to feel that what we tell you will be taken seriously and that you will always give us complete and truthful information. Let us know if we will need to switch to a new (i.e., adult) doctor at some point. Keep us updated on any dysautonomia research you have read. If you don't know an answer, tell us. That small amount of humility can go a long way in our confidence in you as a doctor. Issues of confidentiality can be complicated. Many specialists are involved in a patient's care and parents have changing levels of involvement. Being conscientious of how your dysautonomia patients want their parents involved (or not involved) in their medical treatment will often help cement their trust in you. We don't want you to be our friend in the same way a peer would be, but I am always more willing to have a candid and open conversation with a doctor who treats me with respect and as an equal.

If a genuine miracle treatment became available for my illness, I would take it from the meanest doctor around if that would help. But in the real world, the difference between a mediocre physician and a truly great one often depends not on medical outcome, but on how much the doctor truly cares about how his or her patients are feeling. That kind of compassion is what makes us walk out of your office smiling, and is the main key to making the doctor-patient partnership effective. One of my doctors recently asked me which aspect of being sick was harder to deal with; the "feeling sick" part, or the "having to miss out on things" part. For me, the answer is definitely the latter. Knowing that my doctor understands that I am a person, not a diagnosis code, is what keeps me fighting on my end of the partnership. My DYNA friends and I frequently comment on how unbelievably grateful we are for our doctors, and realize that we cause you more headaches and paperwork than a sweet card at holiday-time can give thanks for. But we do appreciate you, and of course, we do want to thank you.

"Patients serve as unique scientific resource. They report what is wrong and we have to make sense of what they teach. They tell us the truth, so we have to avoid dismissiveness as a defense against our own ignorance."

*David S. Goldstein, MD, PhD
National Institutes of Health*

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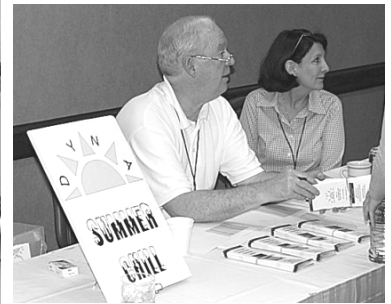
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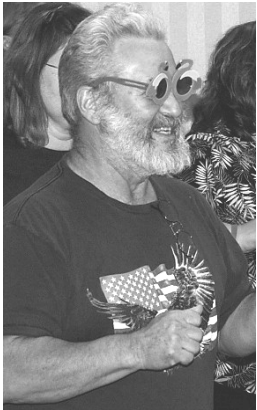
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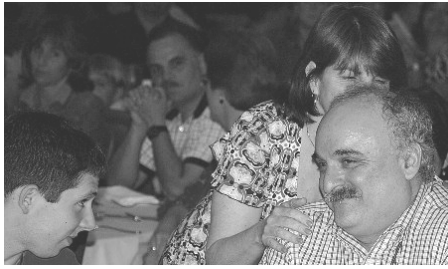
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Thanks to the volunteers and
the many special people who
made this event possible!

DYNA SUMMER CHILL 2007







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 often experience isolation from their peers due to the impact of their conditions. 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 members are overcoming adversity and making a difference in the future together.

DYNA provides its members with a world-wide outreach network. We are focused on providing support to youth afflicted with the childhood dysautonomia conditions and on promoting awareness of these conditions. We also work closely to support the outstanding specialists who treat these children. DYNA connects physicians, patients, and educational facilities and promotes the advancement of treatment options and research. Through organizational programs DYNA also provides current, up to date and reliable, physician-endorsed medical information, physician and patient conferences, and potential fellowship opportunities.

Membership to DYNA is free and is open to individuals under the age of 25. Members must be diagnosed with a form of youth onset dysautonomia. Members are life-time members and are not removed as they age.

While most DYNA members reside in the USA, our member base is international, with young people from New Zealand, Australia, England, Canada, Scotland, Mexico and Singapore. DYNA receives inquiries for information and support worldwide.

DYNA Is:

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

Donate to DYNA

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

My name is: _____

My address: _____

Telephone: _____

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Please donate by check payable to:
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**You may also donate via our web site utilizing:
Justgive.org**

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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 and no amount is too small to make a difference in the life of a child.

*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

CALL IT WHAT YOU WANT WE JUST WANT TO HELP THE CHILDREN!

Are you confused by the medical terminology you have been hearing lately? You are not alone! There is an on-going debate within the medical community as to the specific terminology to utilize for conditions involving **dysregulation of the autonomic nervous system**. These debates sometimes happen with other medical conditions, and are not unique to dysautonomia conditions. Our organization uses the term **dysautonomia**, but your physician may not. The umbrella term utilized for these conditions is not what is important to DYNA, and thus we elect to move forward without entering into the name debate. Call it what you want—we just want to help the children.

The following diagnostic terms may be issued to children with dysregulation of the autonomic nervous system or dysautonomia.

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Neurocardiogenic Syncope (NCS)
- Neurally Mediated Hypotension (NMH)
- Vasovagal Syncope
- Post-Viral Dysautonomia
- Non-Familial Dysautonomia
- Generalized Dysautonomia
- Familial Dysautonomia (FD is a very distinctive form of dysautonomia that has been identified in individuals of Ashkenazi Jewish extraction. These amazing children have their own organization that takes very good care of them.)
- **You may even have heard other terms!**

ANNOUNCING!

DYNA Awareness Series Library of Informational Brochures:

**Available online for printing or ordering!
www.dynakids.org**

- [Your Pediatric Patient is Diagnosed with Dysautonomia: A Guide to Understanding Autonomic Dysregulation](#)
- [Your Child is Diagnosed with Dysautonomia: A Resource for Family and Extended Family](#)
- [Your Friend or Classmate is Diagnosed with Dysautonomia: A Guide to Understanding](#)
- [Educating the Dysautonomia Student: An Introduction for Teachers and Other School Personnel](#)
- [You have Been Diagnosed with a Dysautonomia Condition](#)

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
We have patients who need you!

DYNA

“A Ray Of Hope”

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