

WINTER
2010

DYSAUTONOMIA news

BY JULIE GREGORY

NEW YEAR/NEW YOU ACCEPTING YOUR NEW NORMAL

Anyone living with dysautonomia will discover that there is a certain level of “coming to terms” with your previously held ideas of your life. No one plans to spend their days struggling with bizarre, seemingly unrelated health symptoms that change day-to-day and sometimes even hour-to-hour. These symptoms may render some patients temporarily or even permanently homebound. For many, this is the reality of living with an autonomic dysfunction.

Psychologists have come to realize that patients living with chronic illness -and dysautonomia falls in that category- move through stages very similar to those of patients facing a terminal illness. Elizabeth Kubler Ross's groundbreaking book, *On Death and Dying* (1969), reveals the five stages of grieving. Moving from what you thought your life would be to what it is- is a process. The New Year is a perfect time to take stock of where you are along that continuum:

DENIAL STAGE: This is the initial paralysis that occurs upon hearing the bad news. For many with dysautonomia, this stage is usually quite drawn out. Initially when symptoms strike, we assume we will be cured. Ultimately, many of us s-l-o-w-l-y come to realize that a cure may not be possible. We may have to learn to manage and live with our illness. Our lives will NOT be what we imagined. This is understandably a shocking realization.

This stage can become problematic, however, when one stops here. I know someone with dysautonomia who is stuck in the Denial Stage. He's become a reclusive eccentric. He still works, but only in the middle of the night, when he feels best. (Luckily, he's been able to create a career where this is possible.) He rarely wakes before late afternoon. He totally neglects his family. He's seen an electrophysiologist, received a diagnosis, but never fully allowed himself to come to terms with his illness. He tried a medication once, didn't care for how it made him feel, so he pretends he's fine. He doesn't explain his absence at any family/school functions. That's just who he is- a modern day "vampire" living among us, but rarely seen. He works hard to avoid dealing with his reality.

continued on page 3

in this issue...

New Year. New You	1, 3
Meet the Members	2, 4-5
Doctors Corner Q&A	6-8
Research in Review	9-12

*Wishing you a
Happy New Year!*

**Dysautonomia News is a
quarterly publication of the
Dysautonomia Information
Network. Subscribe to
Dysautonomia News at
www.dinet.org/join.php**

Have you ordered a copy of the documentary yet?

Packed with medical interviews, personal testimonies, facts and statistics, this documentary presents an in depth look at a disorder that is often misunderstood by both patients and doctors.

Order Changes: Living with Postural Orthostatic Tachycardia Syndrome for \$12.00 plus \$3.00 shipping today!

<http://dinet.org/Documentary.htm>

Dysautonomia News exists to inform and educate. The content should not be used as a substitute for professional medical advice, diagnosis or treatment. Readers are encouraged to confirm all information with other sources and a physician. Please keep in mind that research is evolving and future discoveries may change or disprove some currently held beliefs.

meet.the.members...

By: Annette McDermott

Shannon Donegan and Autumn Austin are two of the stars of Dinet's recent documentary, "Changes – Living with Postural Orthostatic Tachycardia Syndrome." Now that many of us have seen them in the documentary, we thought it would be nice to learn more about their lives. They graciously agreed to share their stories in this edition of Meet the Member.

Shannon Donegan's Dinet screen name is shannabanana, a nickname some of her friends gave her in high school. She was diagnosed with POTS in October 2005 at the age of 14. Although her symptoms came on suddenly, she recalls being sick a lot more than normal, especially after gym class. One night, she woke up with horrible nausea. She thought it was the stomach flu, but after weeks, it didn't go away. Other symptoms developed such as headaches, dizziness, abdominal pains and weakness. She lost a great deal of weight and had trouble eating. Like many POTS patients, Shannon ended up in the ER a few times and was referred to several doctors. Despite enduring many tests, she didn't get an early diagnosis. Tests came back normal or revealed only minor things, like acid reflux, that couldn't cause her severe symptoms. After being sick for about a month, she started having anxiety attacks from the stress of being ill, and was told by many doctors that the problem was anxiety/depression, even though a 3-hour psychiatric exam was normal. Finally, after a year and a half of debilitating symptoms, Shannon was referred to Dr. King at Children's Hospital of Eastern Ontario. He felt there was an orthostatic intolerance problem and ordered a Tilt Table Test that finally diagnosed her with POTS.

Shannon lives with her mom and dad, her younger brother Adam and their dog Casey. She loved her early teenage years before she got sick. She especially loved 7th and 8th grade and enjoyed going to school and seeing her friends everyday (although she did often get in trouble for talking too much in class!). Her hobbies are photography, media arts, animals, reading, movies and her YouTube channel. Right now, working isn't possible for Shannon. She worked from home this past summer but even that was draining for her. At one point, she had a part time job but she just couldn't be reliable due to her illness. Some days she could work her 3-hour shift (sitting) without a problem but other days within a half hour the room was spinning and she was extremely nauseated.

POTS has completely turned Shannon's life upside-down. One day she was a regular teenager going to school full time

and the next she was bedridden and struggling to do simple tasks like eat and shower. It's hard for her to watch her friends go off to college, going out every weekend while she is stuck inside a body that won't behave. She feels like she's missing the best years of her life. Despite the negative impact dysautonomia has had on her life, Shannon does feel some positive results from her illness. She never takes the "good days" for granted. She knows that no matter how many bad days she has, and no matter how discouraged and depressed those bad days make her, that when a good day comes along, she is completely ecstatic! These good days are what keep her going. Even if all she's able to do is go to the store for 20 minutes, it is the best feeling after being in bed for weeks on end! She says that no matter how sick she's feeling, she holds onto the fact that she will have a good day again in the future. Even if it's next month, it will happen!

A day in Shannon's life starts when she wakes up around 10:00 a.m. If she wakes up any earlier, she is quite drained. She needs at least nine hours of sleep to function. In the morning, she takes her a.m. medications and normally lies down on the couch with a book or her laptop until it is time for lunch. Although she is not able to do much upright, she will try to do some exercise lying down. If she is feeling well enough, she will walk around the house a bit. In the afternoon, she normally watches movies or TV and will then eat dinner with her family. She tries to sit at the table if she is feeling well enough. After dinner, she usually has a friend over to keep her company. She then takes her evening medications and goes to sleep.

Shannon is inspired by anyone who is dealing with a chronic illness. She believes it is one of the hardest things that humans face. It leaves people feeling out of control and completely helpless at times.

Talking to her friends who also deal with POTS or other chronic conditions has made her realize that being ill truly makes you a stronger person. If she is feeling down about being sick, she talks to others who have been through the same thing. This inspires her to be grateful for what she has. Shannon's favorite quote is, "This too shall pass." She believes anyone with dysautonomia can find comfort in it because just knowing that things WILL get better has always been helpful to her. Another quote she loves is, "Fall seven times, stand up eight!" She laughs when she hears this quote

continued on page 4

ANGER STAGE: This stage usually occurs after the Denial Stage. Patients often release bottled-up emotions as they are struggling to have to deal with a life changing illness on a daily basis. Keep in mind that this is a healthy, normal stage in the grieving process. It's important to safely work through this understandable resentment and fight any cultural taboos against feeling/expressing anger. No one plans to live with dysautonomia. Your life is interrupted. Anger is OK and certainly justifiable. Getting stuck in this mode, however, is not healthy. To patients perennially in this stage, Dr. Kubler Ross was fond of saying: "Learn to get in touch with the silence within yourself and know that everything in this life has a purpose, there are no mistakes, no coincidences, all events are blessings given to us to learn from."

BARGAINING STAGE: This stage usually occurs after the patient has moved through the first two stages. It may be a personal and internal dialogue with one's creator. In our most private moments, we might say, "If you cure me, God, I will give ALL of my money towards finding a cure for dysautonomia." The patient reaches out to the universe for a way out.

DEPRESSION STAGE: Many living with chronic illness are all too familiar with this stage. It is a normal part of grieving our lost lives, but it feels awful. Patients at this stage can only see the losses associated with chronic illness. It is hard to move through your normal routine without feeling very dark and heavy. It is so important to recognize this step for what it is: an important stage towards acceptance. If you are worried you are stuck in this stage, ask yourself if you can still find pleasure in things that once made you happy. If the answer is no, don't hesitate to reach out for help.

Other signs of a more chronic depression include: trouble sleeping, sleeping an extraordinary amount, difficulty eating, or eating too much. Since symptoms of dysautonomia can overlap with those of depression, it is a good idea to seek professional help if you are unsure that you not just experiencing adjustment symptoms. An antidepressant (often temporarily) can help one move beyond this stage AND can often improve symptoms of an autonomic dysfunction.

ACCEPTANCE STAGE: At this point, the patient has typically progressed through the previous stages and begins finding a "new normal". An example can come in the form of a simple lifestyle change. One forum member recently commented, "I notice I feel better if I shower in the evenings before I go to bed. Not having to bathe in the morning gives me more energy to get through my day." These small pragmatic steps are the beginning of truly accepting your new reality.

Once you've begun to accept your illness as your "new normal," you can truly find happiness again. Perhaps you are not living the life you imagined. However, it can be an equally glorious life- a life in which you are grateful for small moments of symptom relief/control and a life where you are empathetic toward others' struggles. Patients at this stage are often described as having a bigger perspective. They've come to terms with their illness, found lifestyle solutions, and moved forward in peace. Dr. Kubler Ross contends that living with any illness could be seen as a gift. "It's only when we truly know and understand that we have a limited time on earth- and that we have no way of knowing when our time is up, we will then begin to live each day to the fullest, as if it was the only one we had."

Do you recognize yourself in any of these stages? Are you worried that you might be stuck in one stage or another? Are you repeatedly cycling between two stages and not moving forward. Recognizing exactly where you are, is the first step towards acceptance. Dr. Kubler Ross noted that patients move through these stages in their own time, not all patients move through every stage, and the stages are not necessarily in order. We all ultimately move towards wholeness, peace, and acceptance when we are ready.

"People are like stained-glass windows," according to Dr. Kubler-Ross. "They sparkle and shine when the sun is out, but when the darkness sets in... their true beauty is revealed only if there is light from within."

As this New Year begins, and you consider resolutions, try this. Instead of planning to lose/gain 5lbs, clean your closets, or wash your windows, how about working on finding your inner light instead? Use your illness as an opportunity to shine your light of greater understanding, acceptance & peace.

**Does your place of business
or family give to charity?
If so, please let them know about the
Dysautonomia Information Network,
WWW.DINET.ORG. DINET is completely
funded by member's donations and
can't exist without them.**

THANK YOU!

**DINET would like to thank the following people for helping
with this newsletter:**

Michelle Sawicki, DINET President & Editor

Judith Pettibone, Copy Editor

Staci Friedman, Designer

Janie Farrens, Writer

Julie Gregory, Writer

Annette McDermott, Writer

Dr. Svetlana Blitshteyn, Contributor

Dr. Julian Stewart, Contributor

Dr. Amer Suleman, Contributor

Dr. Satish R Raj, Contributor

"Firewatcher", Research volunteer

"Yogini", Research volunteer

"Artemis", Research volunteer

"Steph06", Research volunteer

continued from page 2

because it reminds her of actually falling down when she blacks out. She believes that people with dysautonomia can really relate! Shannon continues to educate people about POTS. She invites everyone to check out the YouTube channel she and four other “potsies” have created where weekly videos are posted about POTS and its impact on their lives. The address is: www.youtube.com/5awesomepotsies.

Shannon’s co-star in DINET’s documentary was Autumn Austin. Autumn’s DINET screen name is Sunnysmile. This name is significant because her mother used to sing, “You are my sunshine,” to her. When Alzheimer’s took away her mother’s ability to speak, she communicated with Autumn through her eyes and her “sunny” smile, which she had up until the last few days of her life. Autumn will always keep these memories close to her heart.

Autumn was diagnosed with Hyperadrenergic POTS with Peripheral Autonomic Neuropathy on January 31st, 2006 and although her severe symptoms began in 2000, she believes she may have had POTS as a child due to frequent syncope episodes. In August 2000, she woke up suddenly one night at 3:45 a.m. with a racing heart, cold sweats and a feeling of doom. Over the next several days, she did not feel like herself and decided to make an appointment with her internist. At her appointment, her heart rate was 167. She also had profuse sweating, shortness of breath, chest pain, dizziness and a feeling of impending doom. Her internist immediately sent her to the ER concerned that she was suffering from a myocardial infarction. She was immediately admitted to the cardiac unit. Her EKGs were abnormal and her resting heart rate was over 150. A cardiologist ran a 24 hour urine test and the results revealed very high levels of catecholamines (over 2000). She was referred to an endocrinologist to rule out a Pheochromocytoma. The results of the MIBG scan were normal and her urine was re-tested and once again showed high catecholamine levels. She went from one doctor to another trying to find a diagnosis. Despite the severity of her symptoms, she was told she had everything from PMS, PMDD, and anxiety disorder, to SVT, Cushing’s, peri-menopause, MVP and cardiac infection. The list went on and on. Her internist was convinced she had supraventricular tachycardia after reviewing the results of a 30-day Holter Monitor and recommended she see a cardiologist for consideration of a cardiac ablation. She decided against this recommendation because she just was not convinced of the diagnosis.

As time went on, her symptoms worsened and new symptoms evolved. Some of these symptoms were terrible fatigue, brain fog, nausea, vomiting, tremors, facial twitching, involuntary movement of muscles, blurred vision with floaters, dizziness while standing, heat intolerance, near syncope, insomnia, frequent urination, and constipation alternating with diarrhea. She would fall asleep at inappropriate times, and she had a difficult time driving without feeling like she was going to

pass out. She was unable to exercise and heat became her worst enemy. Her symptoms usually became worse after showering, eating meals and grocery shopping. Housework and daily living slowly became very difficult. She spent a lot of time in bed praying for an answer. Autumn then decided to get another opinion from a female gynecologist to see if these symptoms were related to early menopause. The doctor noticed that her legs were discolored and mottled. Autumn told her that they always looked like that and were even worse when she would stand. The doctor felt that the profuse sweating and high heart rate were not due to early menopause and asked Autumn’s internist to run a variety of tests. All the tests were normal and she was again left without a diagnosis. Finally, a friend suggested getting another opinion with a cardiac electrophysiologist. After a very thorough evaluation and review of symptoms and the high catecholamine levels, the EP cardiologist suspected that Autumn had POTS and recommended she see Dr. Blair Grubb at the University of Toledo. The Dr. also suggested she check out a website called potsplace.com. Autumn went home and read everything that she could on that website and finally knew that she was headed in the right direction. After a tilt table test and a few other tests, Dr. Grubb confirmed the diagnosis of hyperadrenergic POTS with peripheral neuropathy. Finally after years and years of knowing that there was something terribly wrong, Autumn found herself crying with relief. Her life would be forever changed but at least she knew that she was NOT crazy.

Autumn has been married to her childhood sweetheart for 22 years. She is blessed to have a supportive and helpful husband. They have two sons ages, 9 and 16. Her 16 year old also has POTS and her 19 year old has a primary immune deficiency. Despite living with a chronic condition they both are well-adjusted happy young men and she is very proud of them. Her 19 year old son is currently pre med at the University of Michigan. His health issues have inspired him to go into the medical field and help those who struggle to get good medical care. Her younger son is a high school junior who has ambitions to work in the field of astrophysics. Their newly adopted Siberian Husky has brought much happiness to their lives. This dog acts like a therapy dog, staying by Autumn’s side when she is not feeling well.

Autumn is currently unable to work. Prior to having children she worked as a social worker at an inpatient psychiatric hospital. She then became a stay at home mom until taking a job in 2006 for an elderly woman. Unfortunately, Autumn’s health continued to decline and made it impossible for her to work. She is happy being a ‘stay-at-home’ mom even though she is not able to do all she used to do. She and her family have learned to be creative in living their daily lives as both a family and as individuals. She does have difficult days but has learned to embrace them instead of fighting them mentally. She has found that humor helps her, and on bad

continued on page 5

continued from page 4

days she will watch a funny sitcom or movie, relax, and remind herself that perhaps tomorrow will be a better day. On good days, Autumn loves to cook and bake for her family. She also enjoys gardening but the summer heat is a challenge. She also writes poetry when something inspires her.

Dysautonomia has greatly impacted Autumn's life. She cannot pick up and go as she pleases and sometimes has to miss out on gatherings with family and friends. One of the most difficult and frustrating parts of being ill for Autumn has been trying to explain POTS to family, friends and physicians and dealing with people who often look at her and say "but you look so healthy" when she feels so awful. Although POTS has had a negative impact on her life, her illness has also had a positive effect. Dysautonomia has given her a greater appreciation of life and taught her that the most important things in her life are the people in it and the time shared with them. She has learned that less is more and has also found a deeper sense of spirituality. Autumn's children inspire her. They both have had to deal with daily health problems yet they remain stoic, have ambitions and live life to the fullest. Autumn is also inspired by her mother (who passed away a year ago at the age of 67 due to Alzheimer's and Parkinson's) who had a very difficult life. She used to tell Autumn that she always held her head up high, and she often spoke of "Foot prints in the Sand". She reminded Autumn that God always carries us during our most difficult times in life. Although living with POTS has not been easy for Autumn and her family, they have been able to recreate how they live and it works for them. They value each day. Autumn's favorite childhood memory was going to her family cottage in Indian River, MI during the summer months. She and her family still do this and her sons have been able to enjoy something that she did when she was a young girl.

A day in Autumn's life starts when she gets up to see her husband off to work and her son off to school. She almost always has to lie back down for a while. She usually will put her make up on while watching morning TV shows in bed. Make up helps to pick her up. Once she gets back up, she starts drinking fluids and tries to figure out what she can eat that has a lot of sodium. Even on good days, she is limited to how much housework she can do but tries to tackle what she can. Reading *The Daily Word* keeps her inspired and she also tries to call a friend or two to stay in touch. She likes to make dinner but has been known to turn to frozen pizza in a pinch. In the evenings, she usually reads a bit while listening to a funny sitcom on TV. Her son's favorite show is *The Simpsons* and she enjoys watching it with him.

Autumn is sincerely thankful for DINET and all the people

who work so hard to keep it going. It has helped her on so many occasions and provided her with a wealth of knowledge. Autumn would like to thank Michelle Sawicki for all her courage, inspiration, dedication and hard work in getting the documentary released. It is her sincere wish that the documentary will reach the eyes of all those who struggle to understand POTS, dispel the myths associated with it and help those in the medical field better understand the disorder.

Although Autumn's health has declined considerably, she is fortunate to have a wonderful team of physicians and wants to offer hope to all those affected by dysautonomia. She is a realist and knows her body functions have deteriorated, yet she tries to have a positive attitude every day. She embraces POTS even though she does not like it. She has accepted that it is part of her now and will be for the remainder of her life.

If a bad day comes along, she allows it. So, she embraces POTS even though she does not like it and has accepted that it is part of her now and will be the remainder of her life. But she believes life is what we make of it and she tries to find happy things to look forward to each day. The book "The Last Lecture" by Randy Plausch, who lost his life to pancreatic cancer, has greatly inspired her. She was inspired by his determination to make the most of what time he had left and that he defied the odds and lived longer and better than the physicians said he would. To Autumn, Randy personified the meaning of the human spirit. She believes we all have the capability to do this and wants us all to live our lives the best we can despite POTS.

Her favorite quote is "Be the change you want to see in the world" by Mahatma Gandhi and her favorite bible verse is, "I can do all things through Christ who strengthens me" – Phillipians, 4:13.

Shannon's and Autumn's performances in the DINET documentary are truly inspiring and will help countless people struggling with dysautonomia.

Thank you both for sharing your personal stories with us!

**There is still time to
cast your vote for
DINET's new logo!**

click here

doctorscorner



Q: Dear Doctors,

My sixteen year old daughter with POTS was diagnosed with Premature Ovarian Failure last fall. Blood tests show she is menopausal (high FSH and low estradiol). Could Premature Ovarian Failure be related to POTS?

Thank you,
Heidi from Michigan

A: Heidi,

There is no evidence to suggest that POTS and Premature Ovarian Failure have any correlation. Nevertheless, it is known that POTS can be affected by hormonal fluctuations, and in some patients, POTS may be secondary to abnormalities in hormonal levels. Alternatively, if premature ovarian failure is caused by some type of autoimmune process, i.e the body attacking the ovaries through formation of the antibodies, it is reasonable to consider that POTS may have been caused by the same autoimmune process. I recommend that you consult an endocrinologist to investigate why premature ovarian failure occurred, which, in turn, may reveal the underlying cause of POTS.

Dr. Svetlana Blitshteyn

Q: Dear Doctors,

I am a 50 year old wife and mother, who has been fighting POTS for many years. I have continued to work with the assistance of FMLA (spell out ... I do not know what this is) through my employer. My blood pressure continues to be more difficult to control due to meds. This causes extreme fatigue as well as brain fog and memory loss. I received over the

last few years, a diagnosis of neuropathy in the lower legs and I believe it is spreading to my arms and face. I have developed severe vertigo and occasionally walk with a cane due to balance issues. My POTS has not responded well to meds, but I can get relief from lying down for short periods several times a day. I continue to take 20 plus pills daily for multiple problems. I have always enjoyed working; however have found it very difficult over the last year to find the energy to go to work and it seems like a massive struggle to get through each day. I have had to result to having my spouse drive me to and from work and rarely go anywhere on my own. Is it possible to receive Disability Insurance due to POTS? How much should I push my body to keep working?

DiAnna from Indiana

A: DiAnna,

There are no easy answers to questions about work, disability and how much one should or is able to push through the symptoms in order to stay employed. I empathize with your struggle and perseverance, but I truly cannot advise on issues that are so personal and subjective in nature. Everyone's ability to cope with a chronic illness is unique, and there are many factors and variables involved in the issues of work and disability. I don't know whether Disability Insurance can be obtained based on POTS alone, but if you have other medical conditions, it could help your case. I am sure an attorney specializing in these matters can provide more information, should you decide to file for disability.

Dr. Svetlana Blitshteyn

Q: Dear Doctors,

In the last month Rhonda has been in the hospital 3 times, CCU unit once. Her blood pressure will be low at 69, and high at 150. She cannot stand for long periods. In the last week she has fallen and even passed out. She has all the signs of dysautonomia. She had a tilt table test done last week. We are waiting for results. We are waiting for an appointment with Dr. Thompson in Pensacola. I've had to take off from work to care for her. She can't stay awake for long periods. I have been noting blood pressure readings. Tonight we did a reading while laying down: 80/49,66 heart rate. Standing up two minutes later: 69/45 heart rate 68. The last 3 times in the hospital they gave her fluids and did various tests that were normal. I took her out for a drive, she slept, and I'm talking deep sleep. We got her home and fed her liquids and she has been sleeping ever since except for the occasional bathroom stops and getting something to drink. Is there anything we can do prior to our appointment with Dr. Thompson? Are there any non-pharmaceutical

measures that can be tried while we are waiting?

Charles from Florida

A: Charles,

I would need more information including whether there is a component of autonomic failure (hypotension with standing and no change in heart rate) but most of those folks have supine high BP. Is she totally bedrested? That could contribute. Is her BMI normal? We have had a number of cachectic patients who vary initially from a POTS tachycardia to a persistent bradycardia. Will they be seeing the Mayo Jacksonville doctors in the near future?

Dr. Juilian Stewart

.....

Q: Dear Doctors,

Within a 6-week period of time, my previously-healthy son had two surgeries followed by hospitalization for an ulcer. After this, he began having recurrent problems that were at first diagnosed as dehydration-related and are now, after 5 months, being considered "possible dysautonomia". His symptoms are leg weakness (at times, he is unable to walk at all), blurred/double vision (this comes and goes, according to how stressed he is), anxiety, dizzy spells, nausea/vomiting, and very low stamina. Depression has also become an issue. He had improved enough to try to return to work a couple of weeks ago, and relapsed drastically. He has not undergone a tilt test. Treatment thus far has been provided by his surgeons and a family practice doctor. Have you seen these symptoms?

Lynn from Alabama

A: Lynn,

He is likely profoundly deconditioned and, if it is medically advisable, should start an exercise rehabilitation program

Dr. Juilian Stewart

www.dinet.org

My daughter was diagnosed with POTS when she was five. She has had exercise intolerance since she was three years old. She has progressive symptoms/severity. What are the long term effects of this near constant tachycardia on her heart?

Tammy from Kentucky

A: Tammy,

We do not see tachycardia induced cardiomyopathy (heart muscle damage due to fast heart rate) in POTS patients.

Dr. Amer Suleman

.....

Q: Dear Doctors,

My POTS came on within a 2 month period but became disabling in one day when I had a dizzy spell and have never really recovered. I had a coloric test to test vestibular function where it was found my left ear was 85% weaker. The ENT said that this meant permanent nerve damage. I'm trying to link this to my dysautonomia as they presented at the same time. Can they be linked to one cause like a virus, or could have reduced blood flow to the vestibular nerve due to POTS cause the damage? Is vestibular damage a risk of dysautonomia? My other symptoms are nausea, visible blood pooling, no appetite, feelings of weakness and sleep disturbances.

Ana from Australia

A: Ana,

It is important to remember that POTS is a Syndrome (collection of symptoms and signs) that results from 1 or more disease processes and not a disease process in itself. Therefore, POTS does not "cause" something like dizziness. While the cause of POTS in most patients remains elusive, many patients describe a viral-sounding prodrome. Given the above scenario, it is most likely that whatever caused the POTS also caused the vestibular damage (for example a virus). While many patients describe dizziness, they usually mean lightheadedness and not true vertigo. True vertigo is relatively uncommon in the POTS patients that we see.

Dr. Satish R Raj

Q: Dear Doctors,

I have been recently diagnosed with POTS/dysautonomia in addition to my Narcolepsy. I am currently trying several meds to get things under control. I was wondering if my job could be worsening my symptoms and if I should consider another type of occupation. My job requires long hours on my feet, bending and lifting, and is fast paced. I come home so tired I just want to go to bed. My symptoms seem to be getting worse. I am just ready to feel better and am willing to do whatever I need to do.

April from Alabama

A: April,

Symptoms of fatigue, palpitations, and lightheadedness primarily occur with standing in patients with POTS, so any occupation that requires you to spend extended periods on your feet will make your life very difficult. Walking, bending and lifting are not as bad as just standing, but people with POTS tend to get exhausted after an active day on their feet. There are many treatments for POTS (including lifestyle changes, exercises, and in some patients' medical therapy), so you don't NEED to change your job. But if you can find another vocation that involves mostly sitting, you will likely be able to function better. It's hard to perform at your best when you're not feeling well.

Hope that helps,

Dr. Nicholas G. Tullo

Q: Dear Doctors,

I was diagnosed with dysautonomia a couple of years ago. In doing research on the internet I found that there are many kinds of dysautonomia. My doctor did not mention this – it's just that it is something I was born with. I have many of the symptoms mentioned. I am being treated with Clonazepam and with Ambien because I do not get very much sleep without a sleeping pill. I still do not feel well at all. Should I be concerned that my doctor did not mention the various types of Dysautonomia? Should I pursue a more specific diagnosis?

Carrie from Montana

A: Dear Carrie,

It is true that there are many varieties of dysautonomia. However, it would be extremely unlikely that you were actually born with it. Some varieties of dysautonomia only occur sporadically (like Vasovagal Syncope), some occur alone without any other nervous system involvement, and some

*are associated with other signs and symptoms of degenerative neurological disease. If you would like a more specific diagnosis, you may need to speak with an autonomic specialist. I'm not sure why you are being treated with a tranquilizer like Clonazepam for dysautonomia, unless you also have an anxiety problem as well. There are effective treatments to improve the symptoms of dysautonomia, and I would encourage you to do some more research or perhaps consider seeing a specialist.
Good luck,*

Dr. Nicholas G. Tullo

**Do you
have a
question
for one of
DINET's
medical
advisors?**

**Click [here](#) to ask
your question today!**

RESEARCH IN REVIEW

YOUR SOURCE FOR CURRENT DYSAUTONOMIA RESEARCH!

HOME ORTHOSTATIC TRAINING IN CHRONIC FATIGUE SYNDROME - A RANDOMIZED, PLACEBO-CONTROLLED FEASIBILITY STUDY.

Sutcliffe K, Gray J, Tan MP, Pairman J, Wilton K, Parry SW, Newton JL.

Eur J Clin Invest. 2009 Nov 12.

Abstract: Background Orthostatic (Tilt)-training is an effective treatment for neurally mediated hypotension (NMH). NMH is a frequent finding in chronic fatigue syndrome (CFS). We evaluated home orthostatic training (HOT) in CFS in a randomized placebo-controlled feasibility study. **Methods** Thirty-eight patients with CFS (Fukuda Criteria) were randomly allocated to daily tilt training (n = 19) or sham training (n = 19) for 6 months. Haemodynamic responses to standing were performed in all subjects using continuous technology (Taskforce) at enrolment, week 1, 4 and 24. Symptom response and compliance were assessed using diaries. **Results** Two patients (one from each arm) withdrew from the study. Fourteen patients in each group complied completely or partially, and patients found the training manageable and achievable. Compared to the sham group, blood pressure while standing dropped to 8.0 mmHg less in the HOT group at 4 weeks (95% CI: 1.0 to 15.0, P = 0.03). At 4 weeks, the HOT group had higher total peripheral resistance compared to the sham group; mean difference 70.2, 95% CI: -371.4 to 511.8. Changes were maintained at 6 months. There was no significant difference in fatigue between groups at 4 weeks (mean difference 1.4, 95% CI: -13.5 to 16.2), but there was a trend towards improvement in fatigue at 6 months. Compliers had lower fatigue compared to non-compliers. **Conclusions** A placebo-controlled study of HOT in CFS is feasible. HOT is well tolerated and generally complied with. A likely physiological rationale for HOT in CFS is related to reductions in orthostatic intolerance. An adequately powered study including strategies to enhance compliance is warranted.

PMID: 19912315

PROPRANOLOL DECREASES TACHYCARDIA AND IMPROVES SYMPTOMS IN THE POSTURAL TACHYCARDIA SYNDROME: LESS IS MORE.

Raj SR, Black BK, Biaggioni I, Paranjape SY, Ramirez M, Dupont WD, Robertson D.

Circulation. 2009 Sep 1;120(9):725-34.

BACKGROUND: Postural tachycardia syndrome (POTS) induces disabling chronic orthostatic intolerance with an excessive increase in heart rate on standing. beta-Blockade is an appealing treatment approach, but conflicting preliminary reports are conflicting. We tested the hypothesis that propranolol will attenuate the tachycardia and improve symptom burden in patients with POTS. In protocol 1, a low dose (20 mg) was compared with placebo, and the dose response was assessed in protocol 2. **METHODS AND RESULTS:** In protocol 1, patients with POTS (n=54) underwent acute drug trials of propranolol 20 mg orally and placebo, on separate mornings, in a randomized crossover design. Blood pressure, heart rate, and symptoms were assessed while the patients were seated and after standing for up to 10 minutes before and hourly after the study drug. Supine (P<0.001) and standing (P<0.001) heart rates were significantly lower after propranolol compared with placebo. The symptom burden improvement from baseline to 2 hours was greater with propranolol than placebo (median, -4.5 versus 0 arbitrary units; P=0.044). In protocol 2, 18 patients with POTS underwent similar trials of high-dose (80 mg) versus low-dose (20 mg) propranolol. Although the high dose elicited a greater decrease than the low dose in standing heart rate (P<0.001) and orthostatic tachycardia (P<0.001), the improvement in symptoms at 2 hours was greater with low-dose propranolol (-6 versus -2 arbitrary units; P=0.041). **CONCLUSIONS:** Low-dose oral propranolol significantly attenuated tachycardia and improved symptoms in POTS. Higher-dose propranolol did not further improve, and may worsen, symptoms. PMID: 19687359

OUTCOMES OF PREGNANCY IN PATIENTS WITH PREEXISTING POSTURAL TACHYCARDIA SYNDROME.

Kanjwal K, Karabin B, Kanjwal Y, Grubb BP.

Pacing Clin Electrophysiol. 2009 Aug;32(8):1000-3.

BACKGROUND: Postural orthostatic tachycardia syndrome (POTS) occurs more commonly in women than in men and often affects women of childbearing

age. Many of these women wish to have children, yet there are little reported data on the outcomes of pregnancy in patients with POTS. To date there has been one report of two patients with POTS who successfully completed pregnancy. We report the outcomes of 22 women with preexisting POTS who became pregnant. OBJECTIVE: To assess the outcome of pregnancy in patients with preexisting POTS. METHODS AND RESULTS: Twenty-two patients, age 30 +/- 7 years, with POTS became pregnant. Migraine was the common comorbidity found in 40% of patients. Medications used were beta-blockers (18%), midodrine (31%), selective serotonin reuptake inhibitors (31%), fludrocortisone (13%), combination (40%), and none (18%). During pregnancy, symptoms of POTS remained unchanged in three (13%), improved in 12 (55%), and worsened in seven (31%) patients. One patient who had recurrent episodes of syncope without aura was found to have complete heart block and received a cardiac pacemaker. All patients completed pregnancy successfully. There were no stillbirths. One patient developed hyperemesis. Eighteen patients had vaginal delivery and four patients delivered by cesarian section. No other complications of pregnancy were encountered. Congenital abnormalities were encountered in the form of one atrial septal defect, one ventricular septal defect, and one Down's syndrome. Postpartum symptoms of POTS remained stable in 15 (69%) patients and worsened in seven (31%) patients. CONCLUSION: Based on our observation, patients with POTS can safely complete pregnancy if they desire to do so. POTS should not be considered a contraindication to pregnancy per se. PMID: 19659618

VASOVAGAL SYNCOPE: NEURALLY MEDIATED SYNCOPE

THE INFLUENCE OF A TILT TRAINING PROGRAMME ON THE RENIN-ANGIOTENSIN-ALDOSTERONE SYSTEM ACTIVITY IN PATIENTS WITH VASOVAGAL SYNCOPE.

Gajek J, Zylko D, Krzemińska S, Mazurek W. Acta Cardiol. 2009 Aug;64(4):505-9.

OBJECTIVE: We assessed the influence of short-term and long-term tilt training on the activity of the renin-angiotensin-aldosterone system (RAAS) in vasovagal patients. METHODS AND RESULTS: Thirty-nine patients (28 F, 11 M) aged 39.7 +/- 11.2 years with a history of vasovagal syncope and a positive head-up tilt test (HUT) were studied. Blood samples for plasma renin activity (PRA) and aldosterone (ALDO) concentration were drawn at the baseline, immediately after HUT and 10 min after HUT, during the diagnostic, the negative short-term (2-5

days) follow-up HUT and long-term (1-3 months) follow-up HUT. Tilt training was started after diagnostic HUT. In diagnostic HUT, PRA increased significantly immediately after HUT comparing to the baseline, during recovery the values did not change. ALDO concentration increased after HUT comparing to baseline and further increased during recovery. After short-term tilt training, PRA and ALDO concentrations did not significantly change compared to their corresponding values in diagnostic HUT. After long-term tilt training, PRA did not significantly change compared to the values in the diagnostic and short-term follow-up HUT. ALDO concentration also did not change significantly at the baseline and immediately after HUT, and 10 min after HUT ALDO concentration was significantly lower than after diagnostic HUT. CONCLUSIONS: Tilt training changes the response of RAAS to the prolonged orthostasis in vasovagal patients. The coupling between PRA and ALDO after diagnostic HUT has been found to be altered and the physiological relationship was restored after long-term tilt training. The beneficial effect of tilt training depends partially on changed RAAS activation. PMID: 19725444

HOME ORTHOSTATIC TRAINING IN VASOVAGAL SYNCOPE MODIFIES AUTONOMIC TONE: RESULTS OF A RANDOMIZED, PLACEBO-CONTROLLED PILOT STUDY.

Tan MP, Newton JL, Chadwick TJ, Gray JC, Nath S, Parry SW.

Europace. 2009 Nov 17.

Aims To detect possible autonomic changes due to home orthostatic training (HOT) and to assess the feasibility of a larger, placebo-controlled study of HOT in vasovagal syncope (VVS). Methods and results Twenty-two consecutive patients, aged 18-85, diagnosed with VVS following a positive head-up tilt-table test were randomized to 40 min of HOT (n = 12) or 10 min of sham training (n = 10) daily for 6 months. Baroreflex sensitivity (BRS) and heart rate variability (HRV) were measured at weeks 0, 1, 4, and 24. Symptom response was assessed by event diaries. Home orthostatic training resulted in increases in up and down slope BRS at week 4 (e(log difference) = 1.59, 95% CI = 0.84-3.03 and 1.79, 95% CI = 1.00-3.22) and week 24 (e(log difference) = 1.75, 95% CI = 1.01-3.06 and 1.53, 95% CI = 0.66-2.68) compared with placebo. Relative improvements in low- and high-frequency HRV were also observed in the HOT group compared with placebo at week 4 (e(log difference) = 3.22, 95% CI = 1.06-9.86 and 3.19, 95% CI = 1.03-10.59) and week 24 (e(log difference) = 2.11, 95% CI = 0.72-6.17 and 2.13, 95% CI = 0.52-8.79). Fifty percentage of HOT subjects

and 20% of control subjects were syncope-free at 6 months. Conclusion This was the first placebo-controlled study in orthostatic training which has demonstrated that such a study is indeed feasible. An enhancement in overall autonomic tone is observed with HOT in tandem with a non-significant trend in symptom improvement. A larger, adequately powered, randomized controlled trial of tilt-training is now needed.

PMID: 19919966

DRIVING RESTRICTIONS IN PATIENTS FOLLOWING SYNCOPE IS DIFFICULT FOR PHYSICIANS.

Auton Neurosci. 2009 Dec 3;151(2):71-3. Epub 2009 Oct 21.

Raj SR. Comment on: Circulation. 2009 Sep 15;120(11):928-34.

Syncope occurring while driving has obvious implications for personal and public safety. In this report, the authors aimed to define the clinical characteristics, causes, and prognosis of syncope while driving. Using a case-control design, they studied consecutive patients evaluated for syncope from 1996 through 1998 at the Mayo Clinic in Rochester, Minnesota. Of 3877 patients identified, 381 (9.8%) had syncope while driving (driving group). Compared with the 3496 patients (90.2%) who did not have syncope while driving, the driving group was younger ($P<0.01$) and had higher percentages of male patients ($P<0.001$) and patients with a history of any cardiovascular disease ($P<0.01$) and stroke ($P<0.02$). Syncope while driving was commonly caused by neurally mediated syncope (37.3%) and cardiac arrhythmias (11.8%). Long-term survival in the driving group was comparable to that of an age- and sex-matched cohort from the Minnesota population. Among the driving group, syncope recurred in 72 patients, 35 of whom (48.6%) had recurrence >6 months after the initial evaluation. Recurrences during driving happened in 10 patients in the driving group, 7 of which (70%) were >12 months after the initial evaluation. Overall, neurally mediated syncope was the most common type of syncope while driving. Their findings about the late recurrences of syncope (often >6 months of follow-up) and the overall low incidence of recurrent syncope while driving, may inform future recommendations on driving for these patients.

PMID: 19850538

SYNCOPE WHILE DRIVING: CLINICAL CHARACTERISTICS, CAUSES, AND PROGNOSIS.

Sorajja D, Nesbitt GC, Hodge DO, Low PA, Hammill SC, Gersh BJ, Shen WK.

Circulation. 2009 Sep 15;120(11):928-34. Epub 2009 Aug 31.

Comment in: Auton Neurosci. 2009 Dec 3;151(2):71. Circulation. 2009 Sep 15;120(11):921-3.

BACKGROUND: The risk of syncope occurring while driving has obvious implications for personal and public safety. We aimed to define the clinical characteristics, causes, and prognosis of syncope while driving. METHODS AND RESULTS: In this case-control study of consecutive patients evaluated for syncope from 1996 through 1998 at an academic medical center, we documented causes, clinical characteristics, and recurrence of syncope while driving. Of 3877 patients identified, 381 (9.8%) had syncope while driving (driving group). Compared with the 3496 patients (90.2%) who did not have syncope while driving, the driving group was younger ($P=0.01$) and had higher percentages of male patients ($P<0.001$) and patients with a history of any cardiovascular disease ($P=0.01$) and stroke ($P=0.02$). Syncope while driving was commonly caused by neurally mediated syncope (37.3%) and cardiac arrhythmias (11.8%). Long-term survival in the driving group was comparable to that of an age- and sex-matched cohort from the Minnesota population ($P=0.15$). Among the driving group, syncope recurred in 72 patients, 35 of whom (48.6%) had recurrence >6 months after the initial evaluation. Recurrences during driving happened in 10 patients in the driving group, 7 of which (70%) were >12 months after the initial evaluation. CONCLUSIONS: In our study, neurally mediated syncope was the most common type of syncope while driving. The causes of syncope, the late recurrences of syncope (during >6 months of follow-up), and the overall low incidence of recurrent syncope while driving provide useful information to supplement current recommendations on driving for these patients.

PMID: 19720940

TINNITUS AS A WARNING FOR PREVENTING VASOVAGAL SYNCOPE.

Antonio Pirodda, Cristina Brandolini *, Maria Chiara Raimondi, Gian Gaetano Ferri, Claudio Borghi.

Medical Hypotheses 73 (2009) 370–371.

It has been widely outlined by our group the possibility that a sufferance of the inner ear can take place as a consequence of hemodynamic imbalance which could affect young and healthy people and recognize a merely functional origin. As reported in previous papers, an altered reaction of the autonomic nervous

system could actually jeopardize the labyrinthine perfusion even in absence of other damages. From this standpoint, the hypothesis that a hyperactivity of the vagal response to an acute sympathetic drive may result in an inner ear sufferance deserves to be explored. A mechanism which appears to fit to this model is represented by the Bezold-Jarisch reflex (BJR), which is considered to be responsible for vasovagal syncope and is characterized by a dynamic reasonably compatible with our findings. According to these premises, especially considering that the inner ear has a less active protective mechanism against ischemia as compared to brain, in predisposed subjects tinnitus, when considered as an initial symptom of inner ear hypoperfusion, can represent a warning able to prevent the lack of consciousness related to the syncope.
PMID: 19447564

DYSAUTONOMIA:

PSYCHOLOGICAL ADJUSTMENT AND AUTONOMIC DISTURBANCES IN INFLAMMATORY BOWEL DISEASES AND IRRITABLE BOWEL SYNDROME.

Pellissier S, Dantzer C, Canini F, Mathieu N, Bonaz B.

Psychoneuroendocrinology. 2009 Nov 10.

Psychological factors and the autonomic nervous system (ANS) are implicated in the pathogenesis of inflammatory bowel diseases (IBD) and irritable bowel syndrome (IBS). This study aimed to assess, firstly the way IBS and IBD patients cope with their pathology according to their affective adjustment and secondly the possible links between these affective adjustments and ANS reactivity. Patients with Crohn's disease (CD; n=26), ulcerative colitis (UC; n=22), or IBS (n=27) were recruited and compared to 21 healthy subjects based on psychological variables (trait- and state anxiety, depressive symptomatology, negative mood, perceived stress, coping, health locus of control) and sympatho-vagal balance through heart-rate variability monitored at rest. A principal component analysis, performed on all affective variables, isolated a leading factor labelled as "affective adjustment". In each disease, patients were distributed into positive and negative affective adjustment. In all the diseases, a positive affect was associated with problem-focused coping, and a negative affect with emotion-focused coping and external health locus of control. Results show that the sympatho-vagal balance varied according to the disease. In CD presenting positive affectivity, an adapted high sympathetic activity was observed. In UC, a parasympathetic blunt was observed in the presence

of negative affectivity and an equilibrated sympatho-vagal balance in the presence of positive affectivity. In contrast, in IBS, an important dysautonomia (with high sympathetic and low parasympathetic tone) was constantly observed whatever the affective adjustment. In conclusion, this study suggests that the equilibrium of the ANS is differentially adapted according to the disease. This equilibrium is conjugated with positive affective and cognitive adjustment in IBD (CD and UC) but not in IBS.
PMID: 19910123

THE SERUM OF DYSAUTONOMIA PATIENTS ENHANCES PROLIFERATION AND SIGNALING IN SCHWANN CELLS.

Lambrecht RH, Pollard KA, Alshekhlee A, Chelimsky TC, Berti-Mattera LN.

Neurosci Lett. 2009 Oct 30.

Disorders of the autonomic nervous system, or dysautonomias, affect a large segment of the population, especially women, and represent a diagnostic challenge. Identification of biomarkers for autonomic disorders, and the subsequent development of screening methods, would benefit diagnosis and symptom management. We studied the effect of sera from fifteen well-characterized dysautonomia patients (mean age 49+/-16 years, 10 females, 5 males) and ten control subjects (mean age 31+/-14 years, 5 females, 5 males) on the proliferation of cultured Schwann cells and activity of mitogen-activated protein kinases (MAPKs) in these cells. We correlated characteristics of patients with the effects on cell proliferation and signaling. Overall, we observed a significant increase in proliferation when Schwann cells were incubated with sera from female dysautonomia patients when compared to control subjects and male patients. Interestingly, removal of IgGs significantly reduced the proliferative effect of patient sera. We also observed significant activation of p38 MAPK following incubation with both male and female patient sera. These results suggest that patient sera contain factors that contribute to aberrant Schwann cell proliferation and signaling and may ultimately lead to autonomic nerve dysfunction. Our observations represent a promising first step in the identification of dysautonomia biomarkers.
PMID: 19879922

**A SPECIAL THANKS TO OUR
RESEARCH VOLUNTEERS:
"FIREWATCHER", "YOGINI",
"ARTEMIS" AND "STEPH06"**