

# SPRING 2011 DYSAUTONOMIA news

## DINET will disappear without your help. As in disappear. Read on.

**Our wonderful leader, Michelle Sawicki has hit the infamous brick wall of 'too little time'. If you are someone, like many of us, to whom Michelle has made a difference in your life or in the life of someone you love, please read on. And try to help us!**

**Judith Pettibone, copy editor.**

I have a confession to make: Lately, I feel as if I have let down DINET. My time is so limited these days. I work, attend grad school and also breed canaries so that I can pay for grad school. With so little time for my family, my time for DINET is extremely limited. The website has suffered and notes stay in my inbox far longer than they should. It is a rare day that I am able to check in at the forum and see what is going on. Helping the moderators has become rather impossible.

I've searched diligently for a new leader for DINET over the past two years. To no avail. At the end of 2010 I came to a critical point in this organization's history. I decided I could no longer run DINET. Since I had been unable to find a suitable replacement, I felt I had no choice but to dissolve the organization. I planned to keep the website and forum up but my choice was to no longer shoulder all of the responsibilities of running a nonprofit organization.

Over the years well-meaning people have asked me, "Why aren't you holding fundraisers? Why aren't you running races? Why aren't you raising money for

research?" It is inevitable that a few of these questions are posted on our forum every year. Ultimately some members want to know why DINET is not doing more. This translates for me: why am I not doing more.

As the leader of DINET, people have understandably high expectations of me. Truth is, I feel I should be meeting these expectations. When I am unable to do so, I feel I as if I am failing. I feel like the organization I have created is failing. It was ultimately the feeling of failure that led me to contact a Detroit based organization called Community Legal Resources to discuss dissolution at the end of 2010.

Community Legal Resources (CLR) is no stranger to DINET. It was back in 2003 that I met Mitzy Sharp Futro, lawyer and program director of CLR at that time. We began a conversation at a State of Michigan class for nonprofits. I was surprised when I learned Mitzy was in charge of an organization that helped budding 501c3 organizations obtain legal status, and I was even more shocked when she offered to help me. DINET exists today because of Community Legal Resources.

As I write this in early 2011, I can once again say DINET exists today because of Community Legal Resources. While I was sure of my plans to dissolve DINET, current lawyer and program director at CLR, Leor Barak, talked to me about different ways I could try to keep DINET afloat. He said that it is not at all uncommon for nonprofits to take periods of inactivity while the leader is fulfilling other responsibilities. He encouraged me to keep trying to find someone to take over DINET and to not give up. Somehow this very persuasive

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**DINET**  
Dysautonomia Information Network

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man talked me into hanging in there. Because of the conversation I had with him I've decided to keep trying to find another leader for DINET. I've decided to give DINET a fighting chance.

That said, DINET needs a fighter. We need a new, strong leader who can take this organization into the future with hope, dreams and new ideas. A person who has some business background and experience would be best. Comprehensive knowledge of postural orthostatic tachycardia syndrome and some understanding of other forms of orthostatic intolerance are needed. DINET's new leader should be able to read and interpret medical studies. Some experience in website editing would be helpful as well. Most importantly, DINET's new leader needs to be compassionate. People will turn to you for help, and you should be willing to do what you can to help them.

Everyone at DINET is a volunteer, and the new leader will start as a volunteer as well. I had always dreamed that DINET might bring in enough money to actually have paid staff, but that dream never became a reality. If that dream had become a reality, I probably would not be writing this letter today. So my request today is two-fold:

1. I ask everyone reading this letter to stop and ask yourself if you or someone you know could take over DINET. This organization needs a new leader.
2. I ask that everyone reading this stop and ask yourself what you have done to help DINET financially. The bottom line is that we will never be able to fulfill our member's dreams without financial

support. This organization needs paid staff. We need to have people, positions and programs we can all rely on. We need to make sure this organization stays afloat.

I won't be running races or other fundraisers in 2011. I probably won't be on the forum very often. I might not be able to update the website regularly. I definitely will not be quick in answering emails. I ask that you understand, and I ask for your help.

With very best regards and fingers crossed,

*Michelle Sawicki*

P.S. Remember you will not be alone. You will inherit our many fine volunteers and they will gladly reach out and help you make DINET the huge success it can be.



DINET President and Founder,  
Michelle Sawicki

## Pets for POTS Patients

By Kristina Gundersen

**Why not pets?** The research on pet ownership consistently shows a positive relationship between mental and physical health and pet ownership. Even the experts find it difficult to explain scientifically why exactly this phenomenon occurs. I have my own theories about the subject and want to share them with you.

First, pets are intuitive. Although they cannot express their concerns verbally (with the exception of talking parrots, perhaps) they can certainly show how much they care when their owners are not feeling well. It is comforting for pet owners suffering from any type of chronic illness to experience the unconditional love and understanding most pets exhibit. At the end of the day, you can always count on your cat or dog to bring you a smile. They don't judge and they don't care if you're functioning at 100% or at 10%. And perhaps most importantly, they will be happy to have your company and remain faithfully by your side regardless of any physical impairment.

Second, pets help their owners establish a regular, healthy routine. Although some pets certainly require more maintenance than others, all pets share the basic requirements of food, water, and a little attention. Having a consistent routine in place is often a healthy way to maintain a sense of normalcy and keep you grounded when your personal health and life may feel out of control. Your pet depends on you to help meet their basic needs. However, do not let that scare you. The right pet can be easy to care for and provide years of meaningful companionship.

Finally, pets can help facilitate a better social life for their owners. Most people take great pride in their animal companions and love talking about it with others. Your cat's funny antics can make a great icebreaker and conversation topic. If you are able, a local dog park might be a great way to meet new friends and get out of the house for a little sunshine and exercise with your own furry friend.

If you are suffering from POTS or dysautonomia and have limited energy or physical abilities, it does not necessarily mean you have to rule out the possibility of becoming a pet owner. You may simply want to opt for one that requires less regular exercise than an active breed of dog. There are many options. A small dog, a cat, a turtle, or even a tank of beautiful tropical fish can all bring great joy and comfort to their owners. Take the time to conduct some research to find out which pet may be right for you.

## A special thanks to our volunteers for making this newsletter possible:

Michelle Sawicki, **DINET President**

Staci Friedman, **Art Director**

Judith Pettibone, **Editor**

Janie, **Physicians's Q&A & Volunteer Coordinator**

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## New Study on POTS

### Dr. Julian Stewart of The Center for Pediatric Hypotension in Hawthorne, New York is conducting a new study on POTS.

#### Local Vasoconstriction and Sympathoexcitation in Postural Tachycardia Syndrome Study

##### What comprises the study population?

We are seeking patients aged 15-29 years old with postural tachycardia syndrome (POTS) who may benefit from an investigation of abnormalities of regulation of blood flow. Many people are unable to remain upright for long because of symptoms such as dizziness, nausea and headache or fainting. This may occur on a day-to-day basis and may severely compromise lifestyle. The most common cause of this condition is the postural tachycardia syndrome (POTS), which is believed to affect at least a million Americans. POTS is defined by an abnormal increase in heart rate ("tachycardia") that occurs when upright (therefore "postural"). POTS has many causes and we are attempting to determine the precise biochemical basis for POTS in patients.

There are currently two sets of experiments: one focusing on skin to look at local vascular regulation by nitric oxide, angiotensin-II and oxidative stress and the other to look at sympathetic activation in POTS and its relation to NO, angiotensin, and oxidative stress. You will need to be over 15 years old (i.e. 15-29 years old) to enroll in the studies.

##### What is the hypothesis and its importance?

A major subset of POTS has increased peripheral resistance and low blood flow (LFP) related to increased angiotensin-II (Ang-II), and decreased nitric oxide (NO). NO deficits are reversed by Ang-II type-1 receptor (AT1R) blockade, ascorbic acid (AA) and tetrahydrobiopterin in skin suggesting the importance of oxidative stress. Preliminary data also suggest that the coupling of sympathetic nerve activity to blood vessel contraction is enhanced via Ang-II and NO. We hypothesize that this is due to activation of reactive oxygen species (ROS) including superoxide, which scavenges NO to generate peroxynitrite, and hydrogen peroxide. Combined measurements in the skin and the systemic circulation will be combined with local measurement of ROS production and sympathetic nerve activity will enable us to determine precisely how the autonomic nervous system is affected by the illness. Methods include cutaneous microdialysis to measure ROS, skin biopsy and blood tests to measure gene expression of nitric oxide synthase and Ang-II receptors, and peroneal microneurography to measure muscle sympathetic nerve activity (MSNA). Combined with ultrasonic femoral artery blood flow this will yield assessment of the interactions of nerves with the blood vessels that they control. If we discover specific biochemical mechanisms of POTS in patients, then we may be able to specifically treat the defect.

##### What are the symptoms of POTS?

The key feature of POTS is symptoms which are most prominent when standing. However, in some, findings are present supine (lying down) but worsened standing. Symptoms of POTS include dizziness in all patients, exercise provoked symptoms

and thus exercise intolerance, excessive fatigue, nausea and abdominal pain, headache, shortness of breath and deep breathing, weakness, shakiness and postural anxiety, pallor, and neurocognitive loss (difficulty thinking). These occur on a day-to-day basis. The symptoms overlap with the case definition of chronic fatigue syndrome (CFS) and POTS is often found in CFS in the young. Fainting is relatively uncommon during daily life.

##### What is the goal of the study?

Our study will determine how often blood flow regulation abnormalities and abnormalities of sympathetic regulation produced by nitric oxide, angiotensin-II, and oxidative stress occur in POTS and the mechanism(s) of POTS in individual patients. Specific causes for POTS may vary from patient to patient. Patients will be compared to healthy control subjects. There is a treatment arm with a medication (losartan) that reduces the binding of angiotensin and increases NO. If we know the specific biochemical mechanism we may be able to offer further specific treatments to specific patients.

##### What can your own doctor do?

Your doctor can rule out other illnesses such as infectious and inflammatory conditions which can produce similar symptoms. For example, most blood tests can be performed by your own physician. In addition you may have seen a cardiologist, a neurologist, or an endocrinologist. Tests such as tilt table tests may have been performed which is the standard means to diagnose POTS: POTS may have been diagnosed during a preliminary laboratory session by an excessive increase in heart rate of greater than upright associated with symptoms of orthostatic intolerance. However, the tests we will be performing are not ordinarily available to your doctor. They are, however, all approved ways of measuring how blood vessels work. POTS can be treated by a combination of lifestyle adjustments such as avoidance maneuvers and by medication which your doctor can administer. The tests performed during the study may help us determine what treatment is best for you. We will provide you and your doctor with test results and treatment information

##### How do I know if I'm eligible to be in this study?

All POTS patients are eligible. It can be difficult to distinguish those with different causes of POTS prior to entry into the study. At this time we cannot accurately predict who has which form of circulatory dysfunction, or who has sympathetic activation. Therefore all patients who fulfill the criteria for POTS and are between 15 and 29 years old can enroll.

The diagnosis of POTS may be made by your doctor or your consulting doctors. However, this requires documentation of

a standard tilt test demonstrating the changes in heart rate associated with symptoms of OI that are characteristic of POTS. The diagnosis of POTS may also be made through contact with our center which will include a standard tilt table evaluation. The diagnosis of POTS is prerequisite to the the study proper.

**Exclusion:** Criteria for initial exclusion will include a condition known to be associated with endothelial dysfunction, an active medical condition that may explain the diagnosis, a previous medical condition with undocumented resolution that may explain the diagnosis, past or present major psychiatric disorder, or substance abuse within 2 years before onset of symptoms.

**Inclusion:** Cases will be between the ages of 15 and 29 years old referred for evaluation of orthostatic intolerance with 3 or more of the following symptoms for at least 3 months: dizziness, nausea and vomiting, palpitations, fatigue, headache, exercise intolerance, blurred vision, abnormal sweating, heat. Cases will have the diagnosis of symptomatic postural tachycardia made during a screening tilt table test. Cases will have normal physical examination, and normal electrocardiographic and echocardiographic evaluations. Only those free from heart disease, and from systemic illness will be eligible to participate. This excludes patients with illnesses and disease states known to be associated with endothelial cell dysfunction such as diabetes, renal disease, congestive heart failure, systemic hypertension, acute and chronic inflammatory diseases, neoplasm, immune mediated disease, trauma, morbid obesity and peripheral vascular disease. At the time of testing all patients and control subjects must refrain from vasoactive drugs for two weeks. Please check with us about any medication that you are taking.

#### Who pays for the exams, or testing?

The diagnosis of POTS is a clinical diagnosis that may be made by your doctors or by our center. In either case clinically appropriate fees may be incurred. There is no charge to you for any of the testing directly related to this study. We will pay each participant a daily fee to help defray any expenses in participating in the study.

#### How can I get a questionnaire for this study?

You can click on the Questionnaire icon, and download and print out the application and mail it to us. The mailing address is on the last page of the form. Alternatively you can email the application to courtney\_terilli@nymc.edu or you can also fax us the application at 914-593-8890. Or, you can call us at 914-593-8888, leave your name and address on the voicemail and we'll mail you an application.

#### What happens if I'm eligible to be in the study and decide to participate?

If you would like to take part in these studies, the nurse study coordinator, Courtney Terilli will contact you to go over questionnaire material and discuss arranging for the study. She will review the consent form with you and we will also review the consent and any questions you may have when you arrive for the study. You and your parents (if applicable) should understand the study, and its risks and benefits. You can click on the icon for Consent Form to read about our study.

Testing lasts most of a week and you will also be asked to have a measurement of blood volume. We will make appointments to come to our center for your visits. You'll arrive at 9:30 AM on the day of your appointment. We ask that you not eat or drink anything after 6 AM that morning. Please wear comfortable clothing and

bring along a pair of shorts and a short sleeve shirt. We will meet you at the Bradhurst Building and take you to the laboratory area. Here then you will meet our nurse coordinator Courtney Terilli, and Drs. Julian Stewart and Marvin Meadow who, along with other staff, will review the study with you, and answer any questions you may have. After obtaining your or your parents informed consent you'll answer a few questions, have a brief physical examination, give a urine sample, and be taken to the laboratory area.

You will undergo tests of how the blood vessels function. We will measure blood flow properties of the leg and arm vein using noninvasive techniques while lying flat. You will then have a brief tilt table test for at most 10 minutes so that we can confirm POTS and measure whether there are important fluid shifts when upright. On another day we will measure the impact of gradual tilting on memory.

There are currently two active sets of experiments: one to look strictly at local regulation in the skin and the other to look at sympathoactivation in POTS and its relation to NO and angiotensin. We will test whether antioxidant therapy can reduce overall abnormalities in blood flow and sympathetic activation. We will also sample blood for certain biochemicals, for nitric oxide, and for the expression of gene activity (not measuring DNA) which may be important in POTS. If you are in the "low flow" group of POTS patients we will request that you enroll in a study of the effects of the angiotensin receptor blocker, losartan, on chronic POTS and ask that you return for follow up visits.

In the first set of experiments we use Laser-Doppler flowmetry (LDF) to measure skin blood flow while lying flat. This uses a small beam of reflected light which you cannot feel. LDF will be combined with microdialysis in which we put tiny tubes called microdialysis probes within the skin of the leg using a small needle. There will be five probes placed on the first day of testing and five probes on the second day. This will enable us to measure how much NO, angiotensin, and ROS are being locally produced and will allow us to administer small amounts of chemicals into the skin, testing the ability of the blood vessels to react normally. These are FDA approved. The method only affects the tiny area of skin tested and has no effect on overall circulation. Thus, we can test how blood vessels work without disturbing the natural workings of the heart and circulation. We will stimulate local blood flow by using gentle local heat over a small area of skin. These tests take a number of hours and are more boring than anything else.

Later on and after local anesthesia, we will also obtain two tiny amounts of skin from your leg to look for genetic expression related to nitric oxide and angiotensin. thus, we will have laser blood flow measurements, response to medications and antioxidants, and gene expression from the same organ (skin) at one time.

The second set of experiments investigates more specific regulation of sympathetic outflow from the central nervous system by nitric oxide and angiotensin-II. In these experiments sympathetic nerve activity is measured in a leg nerve using a tiny electrode. We can measure changes in blood flow regulation and autonomic nervous system control during the administration of drugs that can increase or decrease nitric oxide and angiotensin-II in the central nervous system. An ultrasound of the femoral (leg) artery on the opposite side will enable us to tell whether the problems in blood flow regulation arise from the nerve itself or from the conversion of the sympathetic nerve signal into blood vessel contraction.

If you have further questions about the study, please feel free to call: 914-593-8888 for more information or Email at courtney\_terilli@nymc.edu or stewart@nymc.edu

# RESEARCH IN REVIEW

## YOUR SOURCE FOR CURRENT DYSAUTONOMIA RESEARCH!

### PREVALENCE AND COMPLICATIONS OF ORTHOSTATIC DIZZINESS IN THE GENERAL POPULATION.

**Radtke A, Lempert T, von Brevern M, Feldmann M, Lezius F, Neuhauser H.**

**Clin Auton Res. 2011 Jan 30. [Epub ahead of print]**

Although orthostatic dizziness (OD) is a common complaint, its prevalence and medical impact in the general population are unknown. The study aims to assess prevalence, medical sequelae and healthcare and social impact of OD in the general population. Participants of the representative German National Health Interview Survey 2003 (n = 4077, age 18-89 years, response rate 52%) were screened for moderate or severe dizziness or vertigo. As part of a larger study on the epidemiology of dizziness and vertigo, a consecutive subsample of screen-positive participants (n = 825) underwent a structured medical interview for OD based on the criteria: (1) non-vestibular dizziness (i.e. diffuse non-rotational dizziness, light headedness, feeling of impending faint), (2) provocation by sudden postural change (i.e. standing up from supine or sitting), (3) duration of seconds to several minutes, (4) absence of vestibular vertigo according to a validated neurotologic interview. The 12-month prevalence of OD was 10.9% (women 13.1%, men 8.2%), lifetime prevalence was 12.5% (women 15.0%, men 9.6%). OD accounted for 42% of all participants with dizziness/vertigo and for 55% of non-vestibular dizziness diagnoses. The prevalence of OD was highest in young people, although the proportion with severe OD steadily increased with age. OD led to syncope in 19%, falls in 17% and traumatic injury in 5% of affected subjects. Almost half of the individuals with OD (45%) had consulted a physician and 4% had been treated in hospital. OD is a frequent cause of non-vestibular dizziness for which patients often seek medical advice. It carries a considerable risk of syncope, falls and traumatic injury. PMID: 21279415

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### POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME FOLLOWING LYME DISEASE.

**Kanjwal K, Karabin B, Kanjwal Y, Grubb BP. Cardiol J. 2011;18(1):63-6.**

Background: A subgroup of patients suffering from Lyme disease (LD) may initially respond to antibiotics only to later develop a syndrome of fatigue, joint pain and cognitive dysfunction referred to as 'post treatment LD syndrome'. We report on a series of patients who developed autonomic dysfunction in the form of postural orthostatic tachycardia syndrome (POTS). Methods: All of the patients in this report had suffered from LD in the past and were successfully treated with antibiotics. All patients were apparently well, until years later when they presented with fatigue, cognitive dysfunction and orthostatic intolerance. These patients were diagnosed with POTS on the basis of clinical features and results of the tilt table (HUTT) testing. Results: Five patients (all women), aged 22-44 years, were identified for inclusion in this study. These patients developed symptoms of fatigue, cognitive dysfunction, orthostatic palpitations and either near syncope or frank syncope. The debilitating nature of these symptoms had resulted in loss of the employment or inability to attend school. Three patients were also suffering from migraine, two from anxiety and depression and one from hypertension. All patients demonstrated a good response to the employed treatment. Four of the five were able to engage in their activities of daily living and either resumed employment or returned to school. Conclusions: In an appropriate clinical setting, evaluation for POTS in patients suffering from post LD syndrome may lead to early recognition and treatment, with subsequent improvement in symptoms of orthostatic intolerance. (Cardiol J 2011; 18, 1: 63-66). PMID: 21305487

### NEUROCARDIOGENIC SYNCOPE COEXISTING WITH POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME IN PATIENTS SUFFERING FROM ORTHOSTATIC INTOLERANCE: A COMBINED FORM OF AUTONOMIC DYSFUNCTION.

**Kanjwal K, Sheikh M, Karabin B, Kanjwal Y, Grubb BP. Pacing Clin Electrophysiol. 2011 Jan 5. doi: 10.1111/j.1540-8159.2010.02994.x. [Epub ahead of print]**

Introduction: There is anecdotal evidence that one or more forms of orthostatic intolerance (OI) subgroups may coexist in the same patients. However, there is a paucity of published data on the clinical features and management of patients who suffer from coexisting features of postural tachycardia syndrome (POTS) and neurocardiogenic syncope (NCS). We herein present our experience of 18 patients who we found displayed evidence of coexisting NCS and POTS. Methods: We reviewed charts of 300 POTS patients seen at the University of Toledo Syncope and Autonomic Disorders Center from 2003 to 2010 and found 18 patients eligible for inclusion in this study. Patients

were included in this study if they reported clinical symptoms consistent with both POTS and NCS and then demonstrated a typical POTS pattern (a rise in heart rate without change in blood pressure [BP]) on head up tilt table (HUTT) within the first 10 minutes of upright posture followed by a neurocardiogenic pattern (a sudden fall in heart rate and/or fall in blood pressure) reproducing symptoms that were similar to the patients' spontaneous episodes. Results: We found 18 patients, mean age (30 ± 12), with 15 (84%) women and three (16%) men, who met the inclusion criterion for this study. Each of these 18 patients demonstrated a typical POTS pattern within the first 10 minutes on initial physical exam and on a HUTT. Continued tilting beyond 10 minutes resulted in a sudden decline in heart rate (which in some patients manifested as an asystole that lasted anywhere between 10 and 32 seconds [mean of 18 seconds]) and/or a fall in BP in each of these patients demonstrating a pattern consistent with neurocardiogenic subtype of OI. The mean time to the NCS pattern of a fall in BP and heart was 15 minutes with a range of 13-20 minutes. This group of patients was highly symptomatic and reported frequent clinical symptoms that were suggestive of OI. Recurrent presyncope, syncope, orthostatic palpitations, exercise intolerance, and fatigue were the principal symptoms reported. Conclusion: NCS may coexist with POTS in a subgroup of patients suffering from OI. (PACE 2010; 1-6).©2010, The Authors. Journal compilation ©2010 Wiley Periodicals, Inc. PMID: 21208233

#### **ORTHOSTATIC HEART RATE RESPONSES AFTER PROLONGED SPACE FLIGHTS.**

**Tank J, Baevsky RM, Funtova II, Diedrich A, Slepchenkova IN, Jordan J.**

**Clin Auton Res. 2010 Dec 25. [Epub ahead of print]**

Orthostatic tachycardia (POTS) can occur after space flights. We determined orthostatic heart rate responses in 18 cosmonauts before and 3-5 days after long-term space missions. Cosmonauts undergoing a cardiovascular training program in space experienced only moderate POTS after their return to earth. Cardiovascular countermeasures may have attenuated POTS. Another possible interpretation is that cardiovascular deconditioning is not sufficient to elicit full blown POTS in the absence of additional genetic or environmental factors. PMID: 21188460

#### **EFFECTS OF EXERCISE TRAINING ON ARTERIAL-CARDIAC BAROREFLEX FUNCTION IN POTS.**

**Galbreath MM, Shibata S, Vangundy TB, Okazaki K, Fu Q, Levine BD.**

**Clin Auton Res. 2010 Nov 20. [Epub ahead of print]**

**PURPOSE:** Postural orthostatic tachycardia syndrome (POTS) is characterized by excessive tachycardia in the upright position. To test the hypothesis that patients with POTS have impaired arterial-cardiac baroreflex function, while exercise training normalizes the baroreflex function in these patients.

**METHODS:** Seventeen POTS patients aged 27 ± 9 (mean ± SD) years underwent an exercise training program for 3 months. Arterial-cardiac baroreflex function was assessed by spectral and transfer function analysis of beat-to-beat R-R interval (RRI) and systolic blood pressure (SBP) variability in the supine position and at 60° upright tilt during spontaneous breathing before and after training. Data were compared with 17 healthy sedentary controls.

**RESULTS:** Even though upright heart rate (HR) was greater in patients than controls, indexes of RRI variability did not differ between groups. Transfer function gain (SBP to RRI), used as an index of arterial-cardiac baroreflex sensitivity was similar between patients and controls in both low- (LF, P = 0.470) and high-frequency (HF, P = 0.663) ranges. Short-term exercise training decreased upright HR and increased RRI variability in POTS patients. LF baroreflex gain increased significantly in the supine position and during upright tilt [analysis of variance (ANOVA), P = 0.04 for training], while HF gain increased modestly after training (ANOVA, P = 0.105 for training) in these patients; however, the baroreflex gains remained within the normal ranges when compared with healthy controls.

**CONCLUSIONS:** These data suggest that patients with POTS have normal arterial-cardiac baroreflex function in both supine and upright postures. Short-term exercise training increases the baroreflex sensitivity in these patients, associated with a decrease in upright heart rate. PMID: 21103906

#### **THE ROLE OF THE CARDIOLOGIST IN THE EVALUATION OF DYSAUTONOMIA.**

**Boris JR. Cardiol Young. 2010 Dec;20(S3):135-139.**

Dysfunction of the autonomic nervous system, or dysautonomia, is an uncommon disease. Postural orthostatic tachycardia syndrome is one of the several types of dysautonomia. Postural orthostatic tachycardia syndrome, also known as chronic orthostatic intolerance, is the most common but least severe of the dysautonomic disorders; it will serve as the model for evaluation and management of the other dysautonomias. Overall, these patients can have variable dysfunction of the autonomic nervous system that is more severe than that observed in typical neurocardiogenic syncope. Frequently, providers are not familiar with either the evaluation or the management of this syndrome, or are just not interested in doing so. This article attempts to describe strategies for evaluation and management of postural orthostatic tachycardia syndrome. The diagnosis of postural orthostatic tachycardia syndrome is made by the finding of orthostatic intolerance associated with a pulse greater than 120 beats per minute in the first 10 minutes of upright position or an elevation in pulse greater than 30 beats per minute in the first 10 minutes of upright position. Overall, these patients can have variable dysfunction of the autonomic nervous system that is more severe than that seen in typical neurocardiogenic syncope. A wide variety of associated symptoms may exist and these symptoms can have tremendous impact on the lives of the patients and their families. Management of these patients can be difficult as well as rewarding. It is helpful to perform an extensive education up front with these patients and their families. Interventions for patients with postural orthostatic tachycardia syndrome typically fall into two broad categories: non-pharmacological and pharmacological. Non-pharmacological therapies are varied, but are based primarily on ensuring adequate status of intravascular fluid. Polypharmacy may be required to control symptoms associated with postural orthostatic tachycardia syndrome. On account of the severity of their symptoms, these patients frequently have difficulty in completing their school assignments. The physician may need to help support the attempts of the family to work with the school to help the patient stay in school. As postural orthostatic tachycardia syndrome is underdiagnosed and poorly understood, it is a disease that provides an excellent opportunity to perform research. The most important studies would be those that aim to elucidate an aetiology and a pathophysiology of postural orthostatic tachycardia syndrome. In the final analysis, the role of the cardiologist in the evaluation and management of a patient with dysautonomia is to help a patient with severe disability to feel as if they are normal, or much closer to it. PMID: 21087570

### **POTS: An Overview**

**Click [here](#)**

#### **A SIMPLE MIRACLE OF WATER.**

**Korsós A, Rudas L, Zöllei E. Orv Hetil. 2010 Nov 1;151(46):1904-1907.**

Chronic orthostasis intolerance or postural tachycardia syndrome (POTS) is a common problem, which is related to the more severe forms of autonomic neuropathy. Upright posture regularly elicits uncomfortable symptoms in these patients, which impairs their quality of life. We present a typical case, where orthostatic hemodynamic response was significantly improved by ingestion of 500 ml tap water. This simple measure could be a potent, long-term therapeutic tool. Orv. Hetil., 2010, 46, 1904-1907. PMID: 21044941

#### **CARDIOVASCULAR AUTONOMIC RESPONSIVENESS IN POSTMENOPAUSAL WOMEN WITH AND WITHOUT HOT FLUSHES.**

**Hautamäki H, Piirilä P, Haapalahti P, Tuomikoski P, Sovijärvi AR, Ylikorkala O, Mikkola TS. Maturitas. 2011 Feb 8. [Epub ahead of print]**

**OBJECTIVES:** During menopausal transition autonomic balance is known to shift towards sympathetic dominance, but the role of vasomotor hot flushes in this phenomenon is not understood. We compared cardiovascular autonomic responsiveness between women with and without hot flushes. **STUDY**

**DESIGN AND MAIN OUTCOME MEASURES:** One hundred fifty recently postmenopausal healthy women with varying degree of hot flushes (none, mild, moderate, severe) underwent comprehensive cardiovascular autonomic nervous testing (controlled and deep breathing, active orthostatic test, Valsalva manoeuvre and handgrip test) assessing both sympathetic and parasympathetic activity. The responses of heart rate, heart rate variability and blood pressure in these tests were evaluated.

**RESULTS:** Responses in heart rate showed differences between the study groups only in the Valsalva manoeuvre where the tachycardia ratio in all symptomatic women was lower (p=0.041) than in women without hot flushes. Neither change in the heart rate variability analyses nor the blood pressure responses were affected by hot flush status. However, there was a non-significantly higher maximum systolic (140 (112-182)mmHg vs. 135 (102-208)mmHg) and diastolic blood pressure (94 (72-112)mmHg vs. 90 (66-122)mmHg) following the handgrip test in women without hot flushes vs. all the symptomatic women.

**CONCLUSIONS:** Menopausal hot flushes seem to be associated with a possibly increased sympathetic preponderance without an effect on parasympathetic activity in cardiovascular autonomic responses. This may imply a potentially negative impact on cardiovascular health in women experiencing hot flushes. Copyright © 2011.

## **Meet the Member**

Please tell us your story. It is amazing how one person's story can inspire or educate.

Kristina, our "Meet The Member" volunteer is interested in hearing from you! We all are.

If you would be interested in being interviewed by Kristina, email her at [kmgundersen@gmail.com](mailto:kmgundersen@gmail.com)

## doctorscorner



Q: There is some medical evidence that vaccines can disrupt the normal functioning of the autonomic nervous system in healthy adults. Should those of us with dysfunctional autonomic responses avoid vaccines, like the seasonal influenza vaccine? Are there precautions that we can take to avoid a post vaccination "crash" or worsening of our symptoms?

Thank you,

Jennifer in Georgia

A: We recommend to our patients to get seasonal vaccines (like the flu vaccine). I suspect that patients with POTS or orthostatic hypotension will feel much, much worse if they were to actually contract the flu.

I think that the vaccine might cause a bit of an inflammatory response that is not well tolerated. One suggestion might be to be more aggressive about rehydration PRIOR to the vaccination with either increased dietary salt & water or IV saline.

This is based on opinion alone, and not on any real data

Satish R Raj, MD, MSCI  
Vanderbilt University

Q: I have had only 3 syncopal episodes in my life occurring in the past 7 years and all of them while flying as a passenger on a commercial plane. I fly about 10 times a year, so most of the time I am fine. I have been tentatively diagnosed with NCS and yesterday I submitted to a TTT. I was doing wonderfully until the cardiologist administered the nitroglycerin tablet. Shortly thereafter I felt exactly as I did when I blacked out on the commercial flights. They immediately lowered the table and administered atropine but I still lost consciousness. My heart stopped and I flat-lined for 20 seconds before they resuscitated me. They are recommending a pacemaker. I am a 40 year-old-male and an otherwise very healthy and very active person.

Are pacemakers an effective treatment for NCS?

Thanks in advance for your input.

Adam in Illinois

A: Tilt Table Testing is designed to reproduce a particular cause of fainting referred to as "vasovagal" or "reflex" syncope. Another term used is neurocardiogenic syncope. In this condition, certain circumstances may trigger an abnormal response from the part of the brain (the brainstem) that controls heart rate and blood pressure. Those circumstances may involve certain stresses such as emotional stress or physical pain. Other factors that may contribute include abnormal pooling of blood into the lower part of the body that may occur with prolonged standing or sitting in one place for long periods of time (such as a long airplane flight). These factors result in an abnormal reflex whereby the brainstem sends out signals that cause a sudden inappropriate drop in blood pressure and/or sudden slowing of the heart. The slowing of the heart or "cardioinhibitory" component of a vasovagal faint can be impressive in perhaps 5-10% of patients, such that the heart can stop for 10-20 seconds or even longer. Pacemakers provide an electrical signal that keeps the

heart beating at a certain minimal rate, thus preventing the heart from stopping. The idea of implanting a pacemaker to treat syncope has been considered an option in some patients with predominantly cardioinhibitory syncope for decades.

Earlier studies in using pacemakers for the treatment of all patients with syncope were somewhat encouraging, as there seemed to be a reduction in the risk of subsequent events. There were studies that suggested a pacemaker could prevent complete loss of consciousness, though people might still get lightheaded (from the drop in blood pressure that could still occur). However, later studies have established that much of the benefit initially seen from pacemakers may actually have been due to a significant "placebo" effect. That is, just doing pacemaker surgery (even though the pacemaker was secretly not turned on) seemed to help many people. The use of pacemakers in patients with syncope decreased some 10 years ago for that reason. More recent studies suggest, however, that people who have documented severe slowing by either a spontaneous recording or perhaps on a Tilt Test may still benefit from a pacemaker. Currently there is a prospective study (ISSUE 3) being done to answer that question.

You should get more than one opinion before agreeing to a pacemaker for this problem, given your young age. One has to consider whether you could use simple physical maneuvers such as the "leg crossing and tensing" maneuver to avoid syncope under these occasional airborne circumstances. Of course, there are other lifestyle changes you could make that might help avoid syncope, such as drinking large volumes of fluid, certain types of exercise, and avoiding situations where the blood can get trapped in your legs (i.e. get up every 30-60 minutes and exercise/stretch your legs to keep the blood return to your heart adequate). The final decision for treatment of your fainting condition should be made with your safety in mind, as the biggest risk is that you could become injured due to a faint. A pacemaker might reduce your chances of fainting in the future. If you have plenty of warning,

however, a pacemaker might not be absolutely necessary at this point. Certainly, the results of ISSUE 3 will go a long way towards helping doctors to understand the true benefit of a pacemaker under these circumstances. Hope that helps!

Nicholas G. Tullo, MD, FACC  
New Jersey Center for Fainting

Q: I was diagnosed with POTS seven years ago. I have been told that I really need a colonoscopy. I am actually afraid because of my medical problems. I have POTS, a gastric bypass and adrenal fatigue. I have an extremely sensitive system.

Are there precautions that POTS patients should take before taking the colonoscopy prep?

Thank you for your help,

Cathy from Texas

A: I recommend discussing your concerns with the gastroenterologist who will be performing the colonoscopy. Typically, a colonoscopy should not cause any problems for patients with POTS. If you have severe symptoms of POTS, you may want to discuss an option of having the colonoscopy done at a hospital, where you can be more closely monitored, rather than at an outpatient clinic. Having IV fluids before the procedure may help with hydration and minimizing vital signs variations during colonoscopy.

Svetlana Blitshteyn, MD  
State University of New York at Buffalo  
School of Medicine and Biomedical  
Sciences

**Do you have  
a question for  
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medical advisors?**

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## Orthostatic Intolerance Study Needs Volunteers

We are seeking fainters (persons who faint) ages 15-29 years of age to participate in a New York Medical College IRB-approved, funded research protocol. The purpose of these investigations is to determine the effects on your body of increasing blood volume either by giving intravenous saline (salt water balanced to be like the body's fluid through a needle in your vein) or by giving an oral rehydration solution (ORS) that is rapidly absorbed from your digestive system.

Some people who faint can have symptoms such as dizziness and mental confusion when they remain upright. This is called Orthostatic Intolerance, or OI. When upright, some people with OI may also develop high heart rates along with these symptoms. When this occurs, it is called the postural tachycardia syndrome (POTS). Some individuals with POTS have been shown to have reduced blood volume. We believe that IV fluids and ORS can increase the blood volume to a similar extent and may reduce symptoms associated with OI and POTS.

This study is designed to take place over 3 days and will last 6-7 hours each day. You will be hooked up to various monitoring devices. We will use a combination of upright positioning on a tilt table with lower body negative pressure (LBNP) to test you for your threshold for OI. On a second day, IV saline will be given through a catheter (soft tube) that will be placed in an arm vein at the beginning of the day and you will undergo tilt- LBNP testing again. On a third day you will receive an oral rehydration solution and have tilt-LBNP repeated a third time.

You will be reimbursed \$150 per day for this testing, which may take place over several days.

Further details of the research and representative consent forms can be found on our web-site, [syncope.org](http://syncope.org)

### If interested, please reply to:

Courtney Terilli, Research Coordinator  
The Center for Hypotension  
Department of Pediatrics  
19 Bradhurst Avenue, Suite 1600 South  
Hawthorne, New York 10532  
[courtney\\_terilli@nymc.edu](mailto:courtney_terilli@nymc.edu); Telephone 914-593-8888

Q: Most research papers say teens who develop POTS and OI usually outgrow it by their early twenties. I have been severely disabled with POTS since I was 13. I am now 25 and have only minimally improved. Is hope lost that I could outgrow it?

Savannah from Pennsylvania

*A: I do not have a lot of experience outside of the 20's but I had recoverees some 10 years after onset.*

**Julian M. Stewart, MD, PhD**  
New York Medical College

Q: POTS patients often have reduced renin/aldosterone along with low blood volume. If increased dietary salt suppresses aldosterone, is it still a good idea to increase our salt intake? Wouldn't that make our hypovolemic issues worse by further lowering our aldosterone levels?

Jennifer from Georgia

*A: Contrary to the usual response to low blood volume, renin is not increased although angiotensin-II is as a result of a defect in the ACE-II enzyme. Aldosterone is also paradoxically low.*

*I don't think salt matters here but I do not have those data. Some forthcoming work from Vanderbilt should address that issue. As I recall these same patients excreted excessive salt.*

**Julian M. Stewart, MD, PhD**  
New York Medical College

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