

SUMMER
2010

DYSAUTONOMIA news

by Kristen Fouts

Out of Control

When I was first diagnosed with POTS, it wasn't long before I realized that I was no longer in charge. I tried to keep working, but my body simply refused to cooperate. I tried to exercise but could barely stand up. I tried to push myself, but all my old tricks to cope with my poor health didn't work anymore. Suddenly, almost overnight, I felt completely out of control.

The realization that we no longer have the control we are used to is a terrifying reality, regardless of the cause. When that cause comes in the form of physical illness, I think it's even scarier. The mind can run wild with unsavory creativity when the unknown looms large and the future is a giant question mark. When my ability to work, socialize, and even stand was taken away from me, I felt a deep sense of helplessness. Where do I turn? What can I do to make this easier? How can I help myself?

Of course, my doctor recommended the usual (water, salt, Gatorade, compression hose, and medication), but those things didn't give me the control back. I was still left without the ability to predict how I'd feel or the strength to perform the activities I once did effortlessly.

In some sense, a feeling of not being in control is healthy. Watching Kate Gosselin trying to micromanage a household wakes me up to the reality that all control is not good control. Having POTS has taught me that it's ok to have piles that are unsorted. It's ok to have some dust around. It's ok if you can't meet everyone's needs and wants. It's okay to learn to say "no" sometimes.

However, there are aspects of life that require a certain amount of consistency and predictability in order for a person to minimally function. When it comes to dysautonomia, every hour can be like a bad biological surprise party. Will I get dizzy and pass out in the grocery store? Do I have enough strength to go out to dinner? Will I make it through this time outside with my family, or will the heat be too much? These are common and valid concerns for people with our condition, and learning to cope with the varying condition of our bodies from minute to minute is an art.

Coping can take many forms, and each person develops personal ways to adapt or to better predict and avoid their "triggers." I have developed some coping strategies over the years but still struggle with the chronic frustration that chronic illness produces. A few weeks ago, I obtained some help in that area.

During a recent visit to my POTS doctor, I received the advice to read a particular book which is an international best seller. The book was not written for POTS patients, but instead it was written to give cancer patients a better chance at survival. The author is a well-respected physician and researcher who himself has survived a deadly brain cancer and relapse by making subtle changes in his lifestyle. Instead of allowing his cancer diagnosis to make him feel helpless, this researcher found the science to help himself take back some control over his condition. As I read the book, I realized that his simple diet tips alone were worth making to improve my immune system function and to increase my overall health in the long-run. I have been struggling with fatigue and muscle aches for a very long time, and anything that reduces the inflammation in my body is sure to make

in this issue...

"Out of Control"	1, 15
Meet the Member	2-3
Doctor's Corner	4
Research in Review	5-8

DINET is searching for two newsletter columnists. The ideal people will be creative and have good grammar and spelling skills. If interested, please contact staff@dinet.org.

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

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 member...

By Annette McDermott

I want to focus the spotlight on a gentleman dealing with dysautonomia in this edition of Meet the Member. Often, POTS is considered a “woman’s illness” and it’s important that we not forget many men suffer as well. Dinet.org member (and friend) Simmy was kind enough to agree to share his story with us.

Simmy has been married to his wonderful and very supportive wife for nine years and has two amazing daughters, ages 15 and 12, from a previous marriage. He also has two beloved chihuahuas (twin sisters, one with long hair and one with short). Prior to becoming ill, Simmy worked 23 years installing security systems. This was very physical work and required working with heavy equipment in extreme temperatures. His illness prevents him from working currently and he is now awaiting approval for SSDI.

Simmy experienced a very sudden onset of symptoms while vacationing with his family in Florida. The morning after arriving by airplane, he suddenly began experiencing profuse sweating, tachycardia, and a severe headache with dizziness. He immediately went to the emergency room and after several hours and many tests (all performed while he was lying down) it was determined that he had experienced an anxiety attack and that he should follow up with a cardiologist when he returned home. After experiencing another scary attack later that evening, he and his family decided to cut their vacation short and booked a flight for the next afternoon. A couple hours into the flight, Simmy’s severe symptoms began again. He managed to get through the remaining two hours of the flight, but he was so ill that he asked a flight attendant for assistance. A doctor (who happened to be on board) and flight attendants laid him down and gave him oxygen and soon paramedics boarded the plane. His blood pressure and EKG were normal at this point and he was told again that he was having an anxiety attack. Since that day, Simmy’s life has never been the same. Over the next several days, Simmy underwent a multitude of tests. He had x-rays, thyroid tests, an MRI brain scan and tests for pheochromocytoma - all with negative results. He saw an internist, cardiologist, neurologist, endocrinologist and electrophysiologist and left them all baffled as to a diagnosis.

At this point, Simmy was homebound and only able to walk from the couch to the bathroom using a rolling walker his



DINET member and friend, Simmy with his furry friend

wife purchased for him. The only thing that seemed to keep his symptoms at bay was lying down. Early in September 2008, Simmy was researching pheochromocytoma on the Internet and came across a blurb that said, “Symptoms may be confused with those of POTS.” He had no idea what POTS was and searched the Internet for more information. He soon learned that POTS stands for Postural Orthostatic Tachycardia Syndrome. Simmy says, “a supernova-sized light bulb went off over my head when I found that of the 31 symptoms commonly associated with POTS, I suffered from 27 of them.” He purchased a heart rate monitor watch and chest strap to closely monitor his heart rate and quickly realized that just standing up greatly increased it. He decided to make a video of how his heart rate is affected by standing and sitting. The video shows that upon standing, his heart rate spiked to 146 bpm and then plummeted to 67 bpm just by lying down (to see Simmy’s video, go to youtube.com and search simbofats and click on the watch). He knew he was on to something. Was this the diagnosis that had eluded so many doctors? Further research led Simmy to Dr. Nicholas Tullo who, after many more tests and observations, finally diagnosed him on June 9, 2009 with POTS. He has also been diagnosed with Inappropriate Sinus Tachycardia, Paroxysmal Atrial Arrhythmia and possible Orthostatic Hypotension.

POTS has affected every aspect of Simmy's life. He now spends 95% of his time lying down, either in bed or on the couch. He does not feel safe driving anymore, especially after a near blackout recently. He used to have shoulder-length hair but has had to cut it off because it was too hard to take care of. Showering can only be done sitting down and is so exhausting that he does it sparingly (but he promises he is not a stinker!). He says that stairs are murder for him and carrying anything heavy is not an option. He's had to learn to perform common daily activities in a horizontal or squatted position. He is thrilled to have recently purchased a reclining wheelchair and cooling vest that allows him more mobility and provides some relief from symptoms caused by the heat.

Simmy's day begins after he wakes up, takes his morning meds and snoozes for another 30 minutes. After waking up again, he heads to the bathroom to wash as quickly as he can before the dizziness, headache and other symptoms force him to stop. He then either heads back to bed or lies down on the floor until he feels well enough to dress and walk downstairs to the couch. His wife brings him coffee, vitamins and breakfast, then kisses him and the pups and heads to work. The next few hours alternate between Simmy lying on the couch watching TV (he likes CNN, and the Science, Discovery or History channels), going to the bathroom, taking meds, and attempting the elliptical trainer for a minute or two (three if it's a good day). His lunchtime routine consists of quickly grabbing the makings for a sandwich and preparing it while squatting in front of the refrigerator. After taking lunch back to the couch, he has to wait about 15 minutes for the nausea to subside before he can eat. The afternoons follow a similar routine as the mornings - time on the couch with a few trips to the bathroom (have to keep up with the flow of Gatorade!) or the fridge and maybe another try

at the elliptical trainer. Dinner is made by his wife and enjoyed together on the couch while they catch up on the day (and laugh a lot!). When it's time to go upstairs, Simmy's wife prepares the drinks for the night (along with some puppy treats) and takes them upstairs. Simmy then crawls up the stairs and after a few minutes of squatting or lying on the floor at the top, he walks into the bedroom. He has to get undressed lying down. He then takes some more meds, enjoys some more conversation and TV and then it's lights out. It takes him about two or three hours to fall asleep. The routine starts all over again the next day, but Simmy reminds himself that he is fortunate to have a "next day."

Though dysautonomia has affected Simmy's life in many negative ways, he is able to identify a few positives as well. He has made many new friends on www.dinet.org and has learned just how precious the one life he has really is. He appreciates the little things more than he ever did and he now has time to watch the science shows on TV he loves so much.

Simmy recalls being a very active child and was always running, jumping, climbing and playing sports. Prior to becoming ill, his hobbies were skydiving, scuba diving and race car driving. Now, his hobbies are watching TV and surfing the Internet and contemplating the universe while occasionally traveling to far away galaxies in his mind.

Stephen Hawking inspires Simmy and his favorite quote is: "*Life happens. Deal with what you have as best you can.*"

Thank you, Simmy, for sharing your story. Your sense of humor and positive outlook has often been an encouragement to me as well as many others on dinet.org. We look forward to learning more from your experiences. Hopefully, someday in the future you'll be well enough to travel and enjoy your hobbies again.

Research Study *Opportunities...*

Researchers at Vanderbilt University Medical Center and Meharry Medical College have developed a new research registry called ResearchMatch. The program connects people who are trying to find research studies with researchers who are looking for people to participate in their studies. If interested, visit www.researchmatch.org. It takes between 5-10 minutes to register and anyone residing in the United States can join.

Angel Flight @ NIH has access to airline tickets for study participants. Patients must have a financial need and be able to travel by commercial airline. Angel Flight @ NIH is sponsored by the Office of Rare Diseases Research (ORDR) and administered by Mercy Medical Airlift (MMA). MMA is a non-profit organization that has served people in situations of compelling human need through charitable air transportation since 1984. MMA uses a variety of resources including volunteer pilot organizations, frequent flyer donation programs, airline contributions, business partners, and personal giving.

www.dinet.org

doctorscorner



Q: I was officially diagnosed with dysautonomia five years ago prior to getting pregnant. About 4 months after having my daughter, I started to have severe bouts of insomnia. This has continued now for almost two years. I have periods of not being able to sleep at all that often last a couple of months, and then feel like I need to sleep all the time before the insomnia starts again. I never had this problem before having my daughter and nothing seems to help. I wanted to know if insomnia is a symptom of dysautonomia, and if so, why is it so hard to sleep?

Sarah from California

A: Sleep disturbance, including insomnia, can be associated with dysautonomia and can often aggravate dysautonomia and other related conditions, such as migraine headache and fibromyalgia. Having a newborn and doing nighttime feedings can certainly lead to sleep disruption, even in healthy people. You can ask your doctor to refer you to a sleep specialist, a doctor who specializes in sleep disorders, for evaluation and management of insomnia.

Dr. Blitshteyn

Q: My 8 year old son developed a severe case of POTS suddenly this year. The cardiologist diagnosed him with a Mast Cell Activation Disorder, which causes his blood vessels to dilate. He is now on Gastrocrom, other mast cell medications including allegra and midodrine. He is much better now, although can only stand for very short periods. My question is this: Can he "grow" out of POTS? Is it possible that he will get better with time?

Thank you so much for your contributions.

Kathy in VA

A: Mast cell problems are a far more specific problem than idiopathic POTS. I cannot give you a good answer to this and I commend your cardiologist for thinking of this. I would contact someone who does allergy/immunology or who specifically studies Mast cell disorders.

Dr. Stewart

Q: My daughter is 15 and was recently diagnosed with a positive tilt table test showing NCS. I've noticed on numerous occasions that she has a 30 point heart rate increase upon standing. Her primary MD feels there is probably a POTS component as well. We are waiting to see an autonomic nervous system specialist for a proper diagnosis and treatment. Recently she developed an erythema to her hands and feet with some swelling and burning pain. Heat and pressure to those areas aggravated her pain. Her skin became calloused over a three day period and her skin began to peel. She had been on a drug trial of cymbalta for six weeks for treatment of her syncope and her episodes have become less debilitating. Could burning, peeling skin be related to her dysautonomia?

Nancy from California

A: I doubt it. Sounds like a contact dermatitis? Also, please note that virtually all fainters have an increase in heart rate way before the faint that usually exceeds 30 bpm. Also many completely healthy young women have similar increases in HR and are completely asymptomatic. POTS is chronic orthostatic intolerance. Fainting is usually acute with normal days most of the time. I am afraid some of my colleagues have propagated the near myth of POTS with syncope. Virtually all of my chronic POTS patients have never fainted in real life although they can be made to on the tilt table.

Dr. Stewart

**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!

Orthostatic Intolerance: Cognition and Hopelessness in Association With Subsyndromal Orthostatic Hypotension.

Czajkowska J, Ozhog S, Smith E, Perlmutter LC. *J Gerontol A Biol Sci Med Sci.* 2010 May 17. [Epub ahead of print]

BACKGROUND: The move from lying to standing is typically associated with a variety of physiological and neurohumoral changes, most especially a slight increase in systolic blood pressure (SBP). Decreased efficacy of the various mechanisms that control orthostatic blood pressure (BP) regulation may result in lightheadedness, dizziness, syncope, and cerebral hypoperfusion. The lack of effective orthostatic BP regulation is a symptom for various problems, including fatigue, depression, anxiety, and reduced attention. **METHODS:** This study examined men and women (N = 74) who were aged 30-75 years and asymptomatic for clinical orthostatic hypotension. **RESULTS:** Relatively poor BP regulation in response to orthostasis was associated with decreased verbal memory, decreased concentration, and higher hopelessness scores. **CONCLUSIONS:** Individuals who exhibited less effective SBP regulation even to a subsyndromal degree in response to an orthostatic challenge may be at increased risk for cognitive and affective problems. The relationship between orthostatic BP regulation is best described as curvilinear. PMID: 20478907

Comorbid health conditions in women with syncope.

Ulas UH, Chelimsky TC, Chelimsky G, Mandawat A, McNeeley K, Alsheklee A. *Clin Auton Res.* 2010 May 11. [Epub ahead of print]

OBJECTIVE: We determine the comorbid conditions associated with syncope in women. In addition, we hypothesize a higher proportion of autonomic comorbid

conditions during the female reproductive age. **METHODS:** We identified a cohort of patients admitted to US hospitals with the principal diagnosis of syncope. We compare patient demographics stratified by gender as well as syncope associated comorbidities. We compared these comorbidities in female of reproductive age (15-45) to men as control. **RESULTS:** From a total sample of 305,932, females constituted 56.7% (n = 173,434). Females were slightly older (mean age 70.9 +/- 17.9 vs. 66.7 +/- 17.3; P < 0.0001); with similar racial distribution (white 57.8 vs. 57.5%), and similar length of hospital stay (mean 2.66 +/- 2.63 vs. 2.68 +/- 2.72 days; P > 0.05). Females had higher proportion of migraine (1.65 vs. 1.29%; odds ratio 'OR' 1.29; 95% confidence interval 'CI' 1.21, 1.36); chronic fatigue syndrome (1.73 vs. 1.3%; OR 1.32; 95% CI 1.25, 1.4); gastroparesis (0.2 vs. 0.12%; OR 1.64; 95% CI 1.35, 1.98); interstitial cystitis (0.07 vs. 0.01%; OR 7.44; 95% CI 4.10, 13.5); and postural tachycardia syndrome (0.49 vs. 0.44%; OR 1.1; 95% CI 1.001, 1.23). Orthostatic hypotension was not different between the groups (P = 0.24). When the sample was stratified by age category, the odds ratio for gastroparesis, orthostatic hypotension, and postural tachycardia syndrome was increased (P < 0.05). **INTERPRETATION:** A higher proportion of autonomic dysfunction was present in women compared to men. In addition, these comorbid autonomic conditions were especially prominent during the female reproductive age. PMID: 20458514

Acute fluid ingestion in the treatment of orthostatic intolerance - important implications for daily practice.

Z'graggen WJ, Hess CW, Humm AM. *Eur J Neurol.* 2010 Apr 20. [Epub ahead of print]

Background: Rapid water ingestion improves orthostatic intolerance (OI) in multiple system atrophy (MSA) and postural tachycardia syndrome (PoTS). We compared haemodynamic changes after water and clear soup intake, the latter being a common treatment strategy for OI in daily practice. **Methods:** Seven MSA and seven PoTS patients underwent head-up tilt (HUT) without fluid intake and 30 min after drinking 450 ml of water and clear soup, respectively. All patients suffered from moderate to severe OI because of neurogenic orthostatic hypotension (OH) and excessive orthostatic heart rate (HR) increase, respectively. Beat-to-beat cardiovascular indices were measured non-invasively. **Results:** In MSA, HUT had to be terminated prematurely in 2/7 patients after water, but in 6/7 after clear soup. At 3 min of HUT, there was an increase in blood pressure of 15.7(8.2)/8.3(2.3) mmHg after water, but a decrease of 11.6(18.9)/8.1(9.2) mmHg after clear soup (P < 0.05). In PoTS, HUT could always be completed for 10 min, but OI subjectively improved after

both water and clear soup. The attenuation of excessive orthostatic HR increase did not differ significantly after water and clear soup drinking. Conclusions: In MSA, clear soup cannot substitute water for eliciting a pressor effect, but even worsens OI after rapid ingestion. In PoTS, acute water and clear soup intake both result in improvement of OI. These findings cannot solely be explained by difference in osmolarity but may reflect some degree of superimposed postprandial hypotension in widespread autonomic failure in MSA compared to the mild and limited autonomic dysfunction in PoTS.
PMID: 20412295

The clinical relevance of the duration of loss of consciousness provoked by tilt testing.

Zy[ko D, Gajek J, Kozluk E, Agrawal AK, Smereka J, CheciDski I.

Acta Cardiol. 2010 Apr;65(2):203-9.

OBJECTIVE: The authors assessed the relationships between the duration of loss of consciousness (dLOC) during tilt testing-induced syncope (TTS) and demographics, medical history as well as tilt testing results. Previous research focused on the relevance of the type of neurocardiogenic reaction during TTS. The importance of dLOC has not been assessed so far. The study was carried out in 274 patients with suspected neurally mediated syncope and total loss of consciousness during tilt testing. **RESULTS:** The syncope burden, demographics, and data regarding spontaneous syncope or TTS were compared between group 1 with dLOC \geq 47 seconds and group 2 with dLOC $<$ 47 seconds. Medical history revealed that patients in group 1 had more syncopal spells, more frequent syncope-related traumatic injuries, urine incontinence, jerking movements and typical vasovagal history than in group 2. Moreover, group 1 patients had more frequently a cardioinhibitory type of reaction and a shorter active phase duration. In addition, they manifested more frequent accompanying cerebral hypoperfusion signs and reproduction of symptoms during TTS than patients in group 2. **CONCLUSIONS:** The loss of consciousness during tilt testing-induced syncope differs in terms of duration among patients with neurally mediated syncope. The dLOC during TTS is associated with medical history and tilt-testing data which confirm the vasovagal aetiology of spontaneous events. The longer dLOC suggests deeper

cerebral haemodynamic disturbances during either spontaneous or provoked syncope.
PMID: 20458828

Use of Octreotide in the Treatment of Refractory Orthostatic Intolerance.

Kanjwal K, Saeed B, Karabin B, Kanjwal Y, Grubb BP. Am J Ther. 2010 Jun 9. [Epub ahead of print]

There have been reports on the use of octreotide in patients with orthostatic hypotension, postural tachycardia syndrome, and orthostatic syncope. However, there are little if any data on the use of octreotide in patients who have failed multiple other medications. This study was a retrospective chart analysis and was approved by our Institutional Review Board. A total of 12 patients were identified for inclusion in this study. The diagnosis of orthostatic intolerance was based on patient history, physical examination, and response to Head Up Tilt Table testing. These patients had failed multiple medications and were ultimately treated with octreotide. In a retrospective chart review, we collected data, including demographic information, presenting symptoms, laboratory data, tilt-table response, standing heart rate, standing blood pressure before and after treatment (wherever available), and treatment outcomes. Twelve patients aged 33 \pm 18 years, eight (66.7%) females, were found to have symptoms of refractory orthostatic intolerance and failed multiple regimens of medication and were ultimately treated with octreotide administration. Five patients (41.7%) had demonstrated a postural tachycardia syndrome pattern, five (41.7%) a neurocardiogenic, and two (16.6%) a dysautonomic response on a Head Up Tilt Table. Symptoms of syncope and orthostatic palpitations improved in six (50%) of the patients. Standing heart rate was significantly reduced after octreotide administration (80 \pm 8 versus 108 \pm 13; $P <$ 0.05). The standing systolic blood pressure was increased after octreotide administration (107 \pm 26 versus 116 \pm 22). Three patients (25%) reported complete elimination of syncope, whereas another three had reduction in the frequency of their syncope. However, symptoms of fatigue improved only in two (29%) of the seven patients. Octreotide may improve symptoms in some patients with refractory orthostatic intolerance.
PMID: 20535001

The Dysautonomia Information Network (DINET) is a 501(c)(3) non-profit organization run completely by volunteers. No donation is too small and every one is greatly needed and appreciated.

Gastric Electrical Activity Becomes Abnormal in the Upright Position in Patients With Postural Tachycardia Syndrome.

Safder S, Chelimsky TC, O'riordan MA, Chelimsky G.

J Pediatr Gastroenterol Nutr. 2010 May 12. [Epub ahead of print]

OBJECTIVES: Some patients with functional abdominal pain report worsening of symptoms in the upright position. Many of these have a postural tachycardia syndrome (POTS). We investigated whether the electrical activity of the stomach changes during the upright portion of a tilt table test in patients with and without POTS. **PATIENTS AND METHODS:** All of the children undergoing autonomic testing were offered enrollment in this institutional review board-approved prospective study between October 2007 and January 2009. Electrogastrography was recorded 10 minutes in the supine position and during the entire upright portion of tilt. Children were divided into 2 groups: POTS and No-POTS. Findings were correlated with this grouping using Fisher exact test and either Student t test or Wilcoxon rank sum test as appropriate. **RESULTS:** Forty-nine patients participated (35 girls), with a mean age of 14.7 + 3.5 years, 25 with POTS and 24 without. The POTS and No-POTS groups did not differ in baseline normal gastric activity. The change from supine to standing showed a significant difference in the electrogastrographic tracing between the POTS and No-POTS groups ($P < 0.04-0.09$), best seen in channels 1 and 4. In particular, gastric activity became more abnormal in the upright position in the POTS group, whereas the opposite occurred in the No-POTS group. **CONCLUSIONS:** The electrical activity of the stomach changes during the upright position in children with POTS, but not in children without this diagnosis. These changes could relate to their report of worsening pain in the upright position. PMID: 20479685

Comparative clinical profile of postural orthostatic tachycardia patients with and without joint hypermobility syndrome.

Kanjwal K, Saeed B, Karabin B, Kanjwal Y, Grubb BP. Indian Pacing Electrophysiol J. 2010 Apr 1;10(4):173-8.

BACKGROUND: Autonomic dysfunction is common in patients with the joint hypermobility syndrome (JHS). However, there is a paucity of reported data on clinical features of Postural orthostatic tachycardia syndrome

(POTS) in patients suffering from JHS. **METHODS:** This retrospective study was approved by our local Institutional Review Board (IRB). Over a period of 10 years, 26 patients of POTS were identified for inclusion in this study. All these patients had features of Joint Hypermobility Syndrome (by Brighton criterion). A comparison group of 39 patients with other forms of POTS were also followed in the autonomic clinic during the same time. We present a descriptive report on the comparative clinical profile of the clinical features of Postural Orthostatic Tachycardia patients with and without Joint Hypermobility syndrome. The data is presented as a mean+/-SD and percentages wherever applicable. **RESULTS:** Out of 65 patients, 26 patients (all females, 20 Caucasians) had POTS and JHS. The mean age at presentation of POTS was 24+/-13 (range 10-53 years) vs 41+/-12 (range 19-65 years), $P=0.0001$, Migraine was a common co morbidity 73 vs 29% $p=0.001$. In two patients POTS was precipitated by pregnancy, and in three by surgery, urinary tract infection and a viral syndrome respectively. The common clinical features were fatigue (58%), orthostatic palpitations (54%), presyncope (58%), and syncope (62%). **CONCLUSIONS:** Patients with POTS and JHS appear to become symptomatic at an earlier age compared to POTS patients without JHS. In addition patients with JHS had a greater incidence of migraine and syncope than their non JHS counterparts. PMID: 20376184

Postural tachycardia syndrome complicating pregnancy.

Powless CA, Harms RW, Watson WJ. J Matern Fetal Neonatal Med. 2010 Feb 5. [Epub ahead of print]

Objective. To review clinical experience at our institution on postural tachycardia syndrome (POTS) complicating pregnancy. **Methods.** In a retrospective review, we identified nine pregnancies in seven patients with POTS syndrome at our institution. **Results.** Patients who did not require treatment for POTS before conception were less likely to have an exacerbation of symptoms or need reintroduction of treatment. Exacerbations of POTS during pregnancy are variable. Of our patients with exacerbations of symptoms, increases in the existing pharmacologic treatments, such as increasing beta-blocker dosage, was effective in palliation of symptoms. There were seven vaginal deliveries. Two patients delivered without neuraxial anesthesia; the other five deliveries were done using epidural anesthesia without associated complications. POTS does not seem to contribute to pregnancy-related complications. Importantly, there were no adverse

intrapartum events attributable to POTS. Conclusions. Pregnant women with POTS may undergo safe regional anesthesia and vaginal delivery. This contradicts earlier reports in the literature recommending cesarean delivery. PMID: 20136369

DINET is searching for two newsletter columnists. The ideal people will be creative, have good grammar and spelling skills.

If interested, please contact: staff@dinet.org.



A SPECIAL THANKS TO OUR VOLUNTEERS FOR MAKING THIS NEWSLETTER POSSIBLE:

Michelle Sawicki, DINET President & Editor
Staci Friedman, Art Director
Janie Farrens, Writer
Kristen Fouts, 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 1, “OUT OF CONTROL”)

me a healthier, happier person.

As I've started instituting some of these changes, it hasn't been without difficulty. My sudden switch of fiber intake alone was not at all pleasing to my GI system, so I've adapted a more gradual approach - such as substituting healthier side dishes of fruits and vegetables and skipping dessert.

Highlight diet-tips from the book include a diet rich in olive oil, garlic, ginger, omega-3 fatty acids (such as in salmon and tuna), broccoli, green tea, organic berries (raspberries, blueberries, strawberries), tomatoes, and turmeric (found in curry). These foods, among others, have powerful antioxidant effects that can improve health and fight disease.

Another important aspect the book addresses is the avoidance of refined sugar. This is the part that I found most difficult to institute in my own life since I rely on sugar and desserts as “comfort” for my emotions. However, substituting dark chocolate for my usual dessert has proved to be just as satisfying (well, ok, almost) and much healthier than my usual treats of cupcakes, ice cream, and cookies.

Reading this book and making better lifestyle choices has given me a sense of empowerment. Accompanying these changes with gentle yoga has also improved my mood. I don't abide by this new program perfectly. I may go several days and eat more sugar than I should. I may miss days of yoga if I have a flare in my symptoms (or the air conditioner breaks, yikes!). The unpredictability of a life with POTS will always exist, but my ability to cope has now improved.

These changes, combined with my faith in God and prayers for help to endure, have been very beneficial. Instead of letting my dysautonomia victimize me, I now feel more in control because of making better small choices daily. I can't control what happens to my body, but I'm learning that I can control how I respond.

Dietary advice is from “Anti Cancer: A New Way of Life” by David Servan-Schreiber, MD, PhD. Please consult your physician before making any significant dietary changes. And be sure to watch out for the natural caffeine in green tea!

Dr. Julian Stewart and his colleagues at Center for Hypotension of New York Medical College were successful in renewing their POTS grant, which seeks subjects 15-29 years old. Current studies being run at Center for Hypotension include the following:

- Local Vasoconstriction/Sympathoexcitation in Postural Tachycardia Syndrome (July 2010 -2014, Patient Enrollment Opens September 1, 2010)
- Vascular Dysfunction in Chronic Fatigue Syndrome (April 2008-April 2012)
- Hyperpnea in Postural Tachycardia Syndrome.
- Irritable Bowel Syndrome (IBS) and Autonomic Dysfunction
- Microvascular Function in Metabolic Syndrome in Adolescents

Visit <http://www.nymc.edu/fhp/centers/syncope/> to learn more about these studies.