Dysautonomia News  Dysautonomia Information Network  September Newsletter 2016

WHAT'S NEW AT DINET

October is Dysautonomia Awareness Month!  Visit our Facebook page [here](#) for dysautonomia related news, research and stories.

Dinet is Looking for a New President!

- Providing direction and support for promotion and fundraising projects to raise awareness & educate the public about dysautonomia
- Help develop new features, policies and structure to the services that volunteers provide to DINET’s members
- Aid the medical researcher in keeping up with the latest medical advancements
- Lead meetings with the DINET board to provide updates and reports on projects & direction of DINET

For more info, click [here](#).
## DINET
**is looking for a new President!**

### Responsibilities of the President include:
- Providing direction and support for promotion and fundraising projects to raise awareness & educate the public about dysautonomia
- Help develop new features, policies and structure to the services that volunteers provide to DINET’s members
- Aid the medical researcher in keeping up with the latest medical advancements
- Lead monthly meetings with the Board of Directors, providing updates & reports on projects, finance and the general health and direction of DINET

*If interested, please contact: dinetandforuminfo@dinet.org*
What would you do if I told you that I consider Dysautonomia one of my greatest assets? Perhaps your chronic illness could be the key to your next opportunity. Having an incurable health condition gives you a specific set of skills. When you use them to your advantage, amazing things could happen. Here’s a list of some of the skills I’ve acquired from POTS and how I used them to create the greatest opportunity of my life.

**A Thick Skin**

From the interviewer who is skeptical about your ability to perform the job, to the stranger in the grocery store who feels the need to grab something off the shelf for you, we all experience society’s reluctance to believe in our abilities. After countless times of hearing “no,” “you can’t do that” and “are you sure you are capable of that,” you develop a thicker skin. Failing becomes less scary because you know you’ll figure a creative way out of it (more on that later). For me, the constant doubt people have in my abilities as a person with Dysautonomia/a person in a wheelchair, has been perfect preparation for a life in the theatre........an industry known for rejection.

**Attention to Detail**

Dysautonomia can strip away large aspects of your life. Whether you lost your job or the ability to participate in basic life, chronic conditions make you look at the big picture and realize what’s most important to you. As you reevaluate, you become grateful for the little things. Those little things are the minute aspects of your life. Attention to detail is an asset in many career fields. So next time an interviewer asks you what your strengths are, tell them you have an acute sense of detail.

**Creativity**

I firmly believe disability makes you inherently more creative. Every day, we walk (or roll) through a world...
that isn’t tailor made for us. Every day we encounter more problems than the average person. Each time we encounter these problems, we try to find a creative solution to them. When exercises are too vigorous, we get creative and modify them. If chores become too strenuous, we find a way to get them done. We do them while sitting and/or perhaps break up chores into chunks to complete throughout the day or week. We get creative with recipes for our restrictive diets. We find alternate routes when there are too many stairs. When I became fed up with the lack of opportunities I was being offered because of my Dysautonomia, I created my own.

It came to me one night as I lay awake staring at my ceiling; I have a story. I have a beautiful, complicated story. From there, all the frustration over the lack of Dysautonomia awareness poured out of me in the form of a script I feel very passionate about. I wrote a one—woman musical called Dysfunctioning Just Fine. I used the creativity that autonomic dysfunction granted me to create a personal opportunity as well as a chance to spread awareness for our community.

The show started as a way to turn an incredibly negative aspect of my life into something positive. But it’s become much more. It has become one of the ways that I hope to enlighten people about life with Dysautonomia.

So my advice is to go out there and play your crappy hand like a royal flush. Use the unique set of skills that your disability has given you to create an opportunity for yourself. Perhaps you will simultaneously bring awareness to this illness. It could mean volunteering a special skill to DINET or other Dysautonomia foundations, starting a sports team for others with illnesses, or selling your own handmade jewelry to raise money for Dysautonomia. Whatever it is, just go for it. I’ve never felt as immensely proud of something, as I am of Dysfunctioning Just Fine. It’s been a dream of mine to use my art as a platform to spread awareness for people with Dysautonomia and other disabilities. It’s the largest project that I’ve had the pleasure of working on and I created it myself. I assure you, nothing has ever felt as good.

For more information on upcoming performances of Dysfunctioning Just Fine be sure to like Meredith’s Facebook page at: https://www.facebook.com/meredithaleighawells

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A "Go Bag" and Why You Need It

by, Amy Keys

Let’s face it - the one thing we know about any form of dysautonomia, is that it can be extremely unpredictable. I might leave the house feeling great and two hours later be lying on the ground nauseous, dizzy, and in tremors. That’s just life with dysautonomia. While there is no magic cure, there are many items that can help with numerous symptoms. It’s important for you, and for anyone who will be with you, to have everything in one place and know where that one place is. There is also this - as much as I know about my symptoms and my meds, should I be recovering from a faint and a paramedic is in my face, I am lucky to remember my name. Could I possibly remember my meds and their dosage? This is why I suggest a ‘Go Bag’.

Where to Begin:
This bag doesn’t need to be anything fancy or expensive. But having everything together in one place, with a list of important information, is incredibly valuable. I purchased my ‘Go Bag’ from Amazon and it’s the perfect size to fit in my purse and be pulled out in a time of need. I bought an Orca Tactical MOLLE EMT Medical First Aid Pouch, which was around fifteen to twenty dollars. I chose to get mine in red because it seemed were I to tell a friend or a medic to grab my medical bag out of my purse, they would see a red pouch with a cross on it. Then they would assume that it was either my Switzerland bag, or my medical bag. My next step was to use Velcro to attach a laminated Medical Accommodation Card to the front. You can print one for various disorders here: http://www.dysautonomiainternational.org/page.php?ID=164

What to Put in Your Go Bag:
Information is going to be essential for any medical emergency. If you’re unconscious or being

Things to include in your Go Bag:

1. Medication list (including dosages)
2. Allergy list
3. Emergency Contact
4. Medical Power of Attorney or Living Will
5. Doctor’s Name/ Numbers
6. Prescription Emergency Meds (in original bottles)
7. OTC Symptom Reducers (Tums, Salt tabs, etc.)
8. Small Misting Fan
9. Small Snack (granola bar)
10. Oximeter & Vomit Bag
11. Chapstick and/ or Sunscreen
loaded into an ambulance, anyone treating you will want to know what medications you are taking before adding anything more. It’s imperative that you keep this list up to date with correct medications and dosages, as well as any allergies. I also included an emergency contact list with phone numbers on my information sheet. Some people include a living will or medical power of attorney.

I also keep a few of my prescription bottles on hand for really rough times. I recently read a blog from a girl who referred to her Go Bag as her ‘stop bag’. As in - stop throwing up, stop tremoring, or stop pain (well, as much as possible), etc. I keep my ‘stop tremoring’ and my ‘stop throwing up’ medications in my bag. If you plan to keep prescription medications in your bag, make sure they are in the original bottle with your name on them. My years of dispatch remind me of the numerous ‘pill checks’ we had to perform to confirm exactly what the medications were in people’s possession. It’s critical to have the ability to verify that it was in fact prescribed to you, not your neighbor’s sister’s friend who is in town from Alaska. Next, remember the over-the-counter symptom reducers. For me those include Tums (the tiny bottle is so cute, too), Tummy Drops, Ginger Chews, a Larabar or something similar, salt tablets, a portable misting fan, and Chap Stick. I also have my oximeter and a handy dandy hospital vomit bag. Your list may vary, but by all means keep whatever might help you feel better when you’re suddenly feeling really bad. While I was doing my first Tilt Table Test, this conversation took place.

**Nurse:** Amy, how are you feeling?
**Me:** S**T**.

**Nurse:** I can’t write that down.
**Me:** Yes, you can, Ruth, I believe in you.

Put whatever helps you from feeling like ‘S**T**’ in your bag.

A Go Bag can make the difference between a perfectly awful day and one where you can feel some better, a lot better and maybe even pretty darn good. It doesn’t help you to have all the things you need “back home.” Like a Scout – be prepared.
She was 9 years old. And it was only one of the times she had noticed that something was wrong with me.

I was doubled over on the edge of my bed, wracked with tremors, pushing my terrors for the future away from myself. I had been told my neurological condition was progressive. I was living in fear of what was to come.

She came over to me and cradled my head in her arms, shushing me and stroking my hair. “It’s going to be okay... poor Momma,” she murmured. Her arms seemed so strong, yet so frail, wrapped around my head. An image of her tiny hand wrapped around my finger on the day she was born flashed across my mind. I thought about how unfair it was that she should be bringing me comfort. So young, she should be out in the yard doing cartwheels with her friends, selling lemonade or riding her bike. Not picking up on cues invisible to most and cradling her mother’s exhausted head in her arms.

I looked up at her, filled with the wonder of who she is as a person, her capacity to love, to make me feel like her words could be true. I looked at her as the tears filled my vision. And as I said “I’m so sorry, honey.” She shushed into my hair. “It’s okay Momma.”

Later, we talked some more about it. I explained that I wished it were different. I told her how much I wished she didn’t have to see me sick, or worry about me, or feel responsible for helping me. She reached for my hand. “Mom, this is what families do. It’s called loving people,” she said, her quiet voice warm and sure.

This kind of insight is rare in a child. She’s extraordinary, my girl. And she’s right. The time comes in every family when we need to look after each other. It might be an elderly family member or a tiny baby, it might be a sick parent or a child with learning differences, it might be a broken...
heart or a lost dream. Caring for the diverse needs within a family isn’t the sole responsibility of a mother. It is a work of heart from everyone in the family. It’s what families do. Making sense of the challenges we face and delivering the love and care we need. It’s what makes families work.

I have often raged against my diagnosis. Felt like it is a cruel punishment meted out to us alone, among the throngs of well people smiling out from the glossy pages of normal life. Why is it my husband and children that need to suffer through this? Isn’t it enough that I do? Why must it throw their lives into a different trajectory, too? But lately, I’ve been seeing it more often in the light I see shining through situations like that one. I’ve been thinking about her words.

As I watch her grow, I have often thought twice about the hand fate dealt us. It’s true that my diagnosis has brought much suffering. Yet that suffering has brought a perspective that helps each one of us to appreciate the beauty of life so much more. I didn’t choose to get sick. She didn’t choose to have a sick Mom.

But this life; this is the one we got. And it has given us a chance that many other families don’t seem to have. Through all of the moments of need and response, we have learned we can rely on each other. We can rest in each other’s arms. We get it. For every difficulty, there is a flip side benefit. For every compromise, respite. Some of those benefits will be more evident in the long-term. But some, like the strength of connection between us as her arms wrap around my head, are for right now.

I’m grateful for the lessons in love that I get to learn every day. And yes, I am grateful for the space created for that learning by my diagnosis. There are many ways to grow as a person, just as there are many ways shut it down. If there must be sickness, then we are not going to waste any of it ignoring what it has to teach us. It’s just what families do.
When I first embarked upon this project, as my final dissertation, I didn’t know what the study, “Spinal Oscillations and their Effect on Postural Orthostatic Tachycardia” would uncover. I have spent the last 4 years, at the University of Surrey in England, studying Osteopathic Medicine* throughout this time, a large emphasis was put on the effect of Osteopathy on the Autonomic Nervous System (ANS). In fact, there have been studies that look at the effect of osteopathic treatments on the ANS through treatment of the thoracic spine (Henley 2008).

To help you to imagine how the spine links to the ANS the diagram below shows where the autonomic outflow is in relation to the spinal column.

As you can see they are in very close proximity; therefore it is considered that any alteration in spinal position may affect Autonomic function. Because of this close proximity it would be arguably possible to affect the ANS via movement of the spinal column or specific segments. In Hart’s 2013 study there was a statistically significant decrease in the heart rates of participants when they had chiropractic treatment applied to the 4th thoracic vertebrae.

Whedon, et al (2009) suggests that the rationale for the application of oscillations (defined later in article) in osteopathic practice is that it improves neurological function, although a search of the literature shows little evidence to support this. The sympathetic nervous system (SNS) is considered responsible for increases in heart rate, (Klabunde, 2015), it follows that treatment to inhibit the SNS could cause a reduction in resting heart rate.

Harmonic osteopathic techniques are described by Waugh et al (2007) as the application of an oscillatory frequency in a cyclical motion to a patient. The motion and speed of an oscillation varies between

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*Osteopathic Medicine

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each participant depending upon the speed of recoil towards the driving force. There are two main factors that determine the frequency of oscillation. These are the mass of the participant and length of the lever that is applying the treatment, (Waugh 2007). This paper discusses an harmonic approach to osteopathic treatment. It provides quantitative research into the accuracy of two practitioners to “tune in” to a patient’s oscillatory rhythm within the lumbar spine and pelvic complex. The study is limited, as it only compares two practitioners’ application of technique, although 36 participants were recruited and filmed to allow independent data analysis. It demonstrates that the effectiveness of oscillatory techniques can be effected by hip mobility. As force is transmitted through the participants’ pelvis, motion is induced through the sacrum and ilia. This translates through the acetabulum to the hip joints causing them to undertake a pivoting motion. Waugh (2008) demonstrates that any relative restriction would alter the speed of recoil.

My study was ‘repeated measures’ which means that each participant acted as their own control to decrease variability between the healthy participants and those with Autonomic Dysfunction. Each group of participants received one placebo treatment (which involved light touch and no treatment) and two actual treatments which comprised of spinal oscillations for a short 5 minute period. Blood pressure reading for all participants were taken as well as Electrocardiograms at 8 minute intervals throughout the sessions. Although the study was small the findings were statistically significant, showing that patients with Autonomic Dysfunction (primarily postural tachycardia) experienced a prolonged reduction in their heart rate. In fact by session three, after two oscillatory treatments there was a mean heart rate reduction in patients with Autonomic Dysfunction of 9 bpm. Longer studies would be required to establish whether this change can be improved upon and maintained but this study enables patients to make an informed decision as to whether they wish to try reducing symptoms through spinal oscillations.

**This article briefly summaries the findings of multiple long pieces of research, should you wish to have an electronic copy of my dissertation and full list of references please email me at: abi.shrapnell@gmail.com. All data is as far as I am aware correct at the time of publication – June 2016.

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*References


**Additional references available with full dissertation.
Meet the Member: Mary's Story

by, Chelsea Goldstein

Dear Readers,

I owe you a proper “thank you.” When I write this column, I know it will be shared with each of you. Through the writing of it, I gain invaluable insight, and perspective from and connection to the Dysautonomia community. Through your honesty about your experiences, and your willingness to share them, we build a stronger, more effective web of support/resources for all Dysautonomia sufferers. I feel, in return, I owe you thoughtful pieces that, hopefully, do justice to the amazing stories you share. Sometimes, that means I need to share too, which I did a few issues ago by telling my own story. This time, I am honored to share the story of my dear friend, Mary.

Mary and I have grown incredibly close over the past two years. Initially, we bonded over our shared POTS-induced struggles and those often wacky side effects. We regularly meet for coffee and a little food for the soul (Mary is currently rolling her eyes at my loaded word choice). Our meetings follow a familiar format. We begin by insisting we will only chat for an hour, then we will get some work done—we have yet to achieve this. We recount our most recent POTSy episodes—candid discussions about our less-than-normal bodily functions and our complete lack of control over them. We may exchange a few coping tips, laugh at our bizarre circumstances and usually encourage each other to eat something salty.

Having Mary as a friend, someone who truly understands my life shaped by chronic illness, is an absolute gift. I realized, however, that I often fail to remember that Mary’s experiences, while similar to mine, are distinctly her own. I think I know how her body feels, so I don’t stop to ask about the nuances of her journey—instead I assume them. Thus, I asked her, a bit sheepishly, to share her story with you, dear readers. Not surprisingly, through this interview process, Mary imparted her particular brand of wisdom. She approaches her illness with a matter-of-
What have I learned about Mary that I did not know previously? This woman is a warrior, and she seeks no praise for it.

Over the past year; however, I am in complete awe of Mary’s turn around. I asked her what triggered the change. She responded that ultimately, only she could control the way she reacts to the circumstances in her life, in spite of illness or any other happenstance. Whether she resolves to go over, under, around or through her particular health challenges, she has a choice as to how to react to these sometimes uncontrollable episodes. This regularly empowers Mary to see the humor in POTS episodes, instead of succumbing to being overwhelmed.

A particularly favorite story, that embodies Mary’s enviable humor and resilience, occurred on the first day of a new semester. Mary had just finished giving a strict lecture to her undergraduate class on the importance of punctuality and work ethic when she nearly collapsed at the front of the lecture hall. She sat at her desk and rested her head. Students grew alarmed and asked Mary what to do. In her Dysautonomia induced fatigue all she could feebly tell them -- “Get me Cheetos!” The students, while perplexed, ran to the vending machine to retrieve the salty snack along with a bottle of water. Mary kicked off her heals, elevated her feet, munched on some Cheetos and continued teaching. She could have ended class early in embarrassment, fatigue or frustration, but instead she made a choice—a choice to continue on with a literal dose of healthy unprofessionalism.

Today, Mary says that the good days out number the bad, but it hasn’t always been that way. She suffered through a period of nine months, in which her new reality—time away from school and several chronic, debilitating health conditions—understandably, brought on a bought of depression and anxiety. Managing her health was a part-time job, and she had an almost complete PhD dissertation looming over her head. Then, there was the impending need for gainful employment. She didn’t discuss her health issues with colleagues or academic peers, in fear that it might inhibit her success.
Medical Q & A
Answers to Your Questions by DINET's Medical Advisors

#1: I recently had a tilt table test done and while I experienced pre-syncpe symptoms, they went away before anything major happened. So they gave me a nitroglycerin tab and that's when I passed out. My question is, how can the test be considered positive with the nitroglycerin? Doesn't it have that effect on everyone?
- Rebecca B.

Amer Suleman MD, FSCAI FHRS
Adjunct Professor, UT Dallas
The Heartbeat Clinic

“Thanks Rebecca my answer is below:
1. Nitroglycerin can cause vasodilation and drop in blood pressure that can in turn cause cerebral hypoperfusion (lack of blood supply to brain) that would cause a linear decline in blood pressure and a linear increase in heart rate
2. It can also trigger vasodepressor and cardioinhibitory responses resulting in sudden decrease in heart rate (as opposed to increase in heart rate as in condition #1) usually accompanied by nausea.
3. Giving nitroglycerin increases the sensitivity and decreases specificity of tilt table test.
4. It also helps us determine whether the index symptom is related with cerebral hypoperfusion so for example if your symptom was vertigo and it is reproduced by drop in blood pressure then probably it is related with cerebral hypoperfusion.
5. Body’s hemodynamics response to Nitroglycerin also tells us about compensatory mechanism. In your particular case if it was situation #2 then it is not normal. Hope it answers your question”
I was wondering if Dysautonomia (POTS) puts a person more at risk of getting Rhabdomyolysis (A breakdown of muscle tissue that releases a damaging protein into the blood.) or Exertional Rhabdomyolysis (exercise induced rhabdo)? One article stated that women are less likely to develop Exertional Rhabdomyolysis due to a difference in body temperature. The article states "Women seem curiously protected from exertional heat stroke despite their increasing participation in sports and occupations that require a degree of physical fitness. Exertional Rhabdomyolysis is also rare in women. It appears that the body temperature at which thermoregulatory reflexes are activated is lower in women than in men. Thus women appear to store less heat than men for a given workload." Since Dysautonomia causes issues with body temperature does that put us at a higher risk of developing Rhabdo?
- Gwen R.

"I have not seen rhabdomyolysis in our POTS patients, and I have not heard other physicians discussing this problem. so, overall, I would not expect that they are associated. Having said that, there are many reasons for rhabdomyolysis in addition to overheating, including mitochondrial problems or enzyme deficiencies, so it is possible that someone with POTS could also get rhabdomyolysis. In terms of heat causing rhabdomyolysis, I believe that this occurs in the setting of severe heat stroke. While POTS patients do complain of temperature dysregulation, I have not typically seen the internal temperature get into severe fever range."

Satish R Raj MD, MSCI, FPCPC | Associate Professor of Cardiac Sciences | Libin Cardiovascular Institute of Alberta | University of Calgary

I have a friend who is pregnant and having severe orthostatic hypotension. Do you have any information on treatment for pregnant or breastfeeding women? Is there any specific advice for treating POTS or other dysautonomia during pregnancy?
- Kathleen G.

"Generally, several medications can be started or continued during pregnancy, if necessary, for orthostatic hypotension or POTS, which include Florinef and beta blockers. Non-pharmacologic measures should be implemented first, with compression stockings, increased salt and fluid intake, and IV saline where appropriate. If the patient is nearing the end of pregnancy, partial bed rest may be necessary, but full bed rest is not recommended as management of POTS."

Svetlana Blitshteyn, MD | Director and Founder of Dysautonomia Clinic
“POTS commonly occurs after mononucleosis or another viral, bacterial or tick-borne infection. Possible mechanism of POTS after an infection includes immune-mediated or autoimmune process. If your question is about a persistent EBV infection that is shown via EBV serology and positive EBV PCR, you should see an infectious disease specialist. About 50% of population have serologic evidence of past infection (i.e. they had acute infection in the past, but are no longer having the actual virus present in the blood), but there have been no causation found between past infection with EBV and dysautonomia or multiple sclerosis. All available treatment options for POTS should be tried in patients who developed POTS after mono or another infection.”

“Trauma, such as surgery or concussion, are known triggers of POTS and other autonomic disorders. One possible theory is that, for example in concussion, sympathetic overactivity results from the injury to the brain. In the case of neck surgery or neck trauma, it’s possible that stretching or another type of injury to the vagus nerve or cervical sympathetic ganglia could be a factor. There is no specific therapy to correct these possibilities, but treatment options that exist for POTS should be implemented. It’s important to note that currently, there is no scientific evidence that any surgery - neck or other types - can manage, treat or cure POTS.”
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.