FALL EDITION

# DYSAUTONOMIA NEWS

THE SEASONS OF DYSAUTONOMIA

ADAPTING TO LIFE WITH DYSAUTONOMIA

MEET THE MEMBER
RACHEL'S STORY

PARENTING CORNER
HOW DO YOU SPELL LOVE?

MEDICAL Q & A

DINET

# THE SEASONS OF DYSAUTONOMIA

**by, Jaclyn Daffern**

I've always enjoyed October days. What's not to love? I love visiting the pumpkin patch with the kids and winding through the corn mazes. I love cozying up in a sweater and drinking lattes while I watch the trees come alive with beautiful fall colors. My journey with Dysautonomia started on one such day, just one year ago.

I feel fortunate to have received my diagnosis of Postural Orthostatic Tachycardia Syndrome (by Tilt Table Test) relatively quickly compared to so many who struggle for years waiting for a diagnosis. The cause of my illness is still undetermined but in going through the process of being diagnosed, I realized I'd been struggling with this illness far longer than I originally thought. Being busy with work and family, I had chalked up so many of my symptoms to a list of common illnesses, in many cases declining to take medicines that were offered because of the lack of a concrete diagnosis.

What was especially intriguing to me was how I felt in the fall. As noted in my medical records, I saw an influx of symptoms ranging from headache to fatigue and many in between. Last fall, I experienced a flare up of symptoms resulting in a crash which left me bedbound for a while. I added a new diagnosis of Raynaud's phenomenon when winter came knocking last year. I've been in the emergency room twice so far this October, and it's not even November at the time of this writing.

Late one night, shortly after my diagnosis last year, I read a cardiology article that mentioned the so-called "October slide". The article stated that patients may be more symptomatic at this time of year. I was at a loss. The article gave no other information explaining why this may occur. This was a pivotal point for me. At that time, I was housebound with the exception of doctor's visits and car rides. I thought, "this could be seasonal, it could change!"
What I found was that in the warmer weather and with lifestyle changes, I am overall less symptomatic. I am nowhere near my old self or symptom-free, but I am able to leave the house and work again.

However, the seasons do come around again and so far this fall I've seen a flurry of symptoms that have made me take a few steps/ jumps back. I've asked several folks on support sites how they feel during the fall and I was surprised and comforted, in a sense, that many experienced the same influx of symptoms. Many can even give a specific date of onset of symptoms. My date is October 5th. I

see this date as a reflection point of where I've come from and where I hope to go. I'm so glad to be on the journey with my dependable DINET folks. Thanks for being there no matter what the season!

## My Unofficial Tips for Autumn

1. Rest, reflect and research. You've got the time and baby, it's cold outside.

2. Layer like an onion. Peel off your layers as needed in your different environments. At work sometimes, I could use flip flops despite the arctic temp outside.

3. Learn to knit. Keep your hands busy and moving. Circulation is key. This will also help with #4.

4. Wear accessories! Hats, scarves and gloves. I'm particularly fond of fingerless gloves with optional buttoned mitt flap.

5. Not too hot, not too cold. That's the rule for hand washing, showers and dish washing to name a few.

6. Room temperature drinks with no caffeine. That was a hard one for me. I'm fond of ice and coffee.

7. A trusty blanket. One that can go anywhere with you. In my case, it's my pink one along with the help of my Springer Spaniel. My "compression pup", as he enjoys laying on my legs and feet.

8. A car ride to see the fall colors. My favorite times last year were being chauffeured by my family in a pre-warmed car with a drive through the coffee shop... See #6 (no caffeine) steamers are divine. Fresh air. Change of scenery.

9. Cozies. See #3. Mug cozies are divine for hot and cold things as well as mitts to keep your temperature as stable as possible when handling hot/cold items.

10. A positive attitude coupled with gratitude. A newfound appreciation of the things you can still do and enjoy this fall despite the difficult days/weeks/months ahead, even if these things are modified or different than tradition. It still does the heart good.

# ADAPTING TO LIFE WITH DYSAUTONOMIA

**by, Becia McClaskey**

I openly admit, I am not that great at accepting changes in my life. I fight them all to the death, refusing to give up on my comfortable way of completing tasks because "that's all I've ever known." If you asked any of my friends and family about how well I handle changes, I'm pretty sure they would say, "Becia doesn't change". Becia would rather suffer and do without sometimes, than change. But sometimes change can be the greatest creator and eye-opener in life and, in mine, there has certainly been no shortage.

It was a few months after I received my diagnosis of Postural Orthostatic Tachycardia Syndrome, (POTS), that my campaign for change needed to begin. For me it started with a wheelchair and a ramp. The combination of symptoms I was experiencing and the large amounts of medications my doctors kept giving me caused me to have difficulty walking and even standing. I sustained a pretty severe hip sprain (the first of many), and being upright for long just wasn't (and still isn't) very possible. Out of concern for my safety, my cardiologist suggested I start using a wheelchair. I remember leaving that doctor's appointment upset, not ready for such a drastic change in my life. Even when my friend, who drove me, tried to reassure me, telling me that this would give me some freedom, a safety net so to speak; that this would give me a chance to get out of the house in a safer manner, to possibly live a better life, I didn't believe it. I was upset at this change.

It took a very long time for me to warm up to the wheelchair. I hated it. Then I realized that I hated even more how everyone walked on eggshells around me, never too far behind or ahead because they never knew when my body would say "ENOUGH!" I realized that the wheelchair did let me move around a bit better. It allowed me to get away from situations that triggered symptoms. It provided a safety net for me in case I passed out. It allowed me to go to the store with less physical stress, giving me a bit of independence. If it wasn't for that wheelchair, I honestly think I would have lost count of the injuries I may have sustained from passing out. Without the wheelchair, I would have been homebound/bedbound when my body and mind needed/wanted to be out and active. That wheelchair gave me my life back. I cried and went through this same process when a ramp was added to the house to make it easier to get in and out. It took me quite some time to get used to it but it has been a life-saver on more than one occasion.

I'm still the same stubborn Becia that my friends and family know. I'm still the hardhead who will be the definition of insanity (doing the same thing over and over, but expecting different results). But I'm also the same Becia who craves to be independent. I still fight change, but I think that's my minds way of processing the change that it is about to make. I think it solidifies it in me somehow. Sometimes, I'm sure the people in my life are ready to pull their hair out in the time it takes for me to finally say "Okay, I can't do it this way, how do I adjust?"

Change can be the greatest motivator for success or the greatest upset. For me, it's been a mixture of both. Do I think these will be the only things I ever have to change? No, not by a long shot, as there are changes everyday I need to weather. I'm a bit worried that sometimes I'm not ready to handle some of the bigger changes, like living on my own, but then I also realize that Rome wasn't built in a day. Sometimes changes and adaptations take time, trials, and some errors, before they are successful. Sometimes the trials are the most entertaining and rewarding because you can learn so much about yourself in the process. The key seems to be just being open to them, and if you don't succeed, try, try again.

# Meet the Member: Rachel's Story

Photography by, Be Couper

*She spends most of her days, propped up on pillows in her room, looking out at the world she used to participate in. She's still part of the world, but on a cerebral level more than a physical one. Those days of being able to rush about, are gone. Bike riding with the family through the local park, energetically circling the classroom or toting armloads of books between classes, racing between after-school activities, dancing; those things are not part of her world right now. But they are still waiting in the wings… just in case. That is what she tells herself as she watches her world pass her by, through the windows of her bedroom.*

*She still has a special kind of freedom. She has time, she has ideas. Her computer is usually on her lap and her fingers tap out pathways into other worlds as she writes. She likes the sound of those staccato keys. It*

*is a productive sound; she is still doing something. Something useful. She is waving across the ether to others like herself. Saying a cyber-hello to her new social circle. She writes, she researches, and she keeps herself afloat. Sometimes, she keeps others afloat too, with her blog and her other writings; her thoughts turned into type, turned into something for others to think about, too. She loves that she can still give.*

## She is Rachel. She's me, but not the me that I thought I would be.

I am a writer and I am from New Zealand, a tiny country at the bottom of this planet. I have Pandysautonomia, a diagnosis I received three years ago. For me, the road to this diagnosis really began when I was a young girl. I grew very rapidly and reached six feet tall by the age of twelve. My fainting was chalked up to heat, or puberty, or a simple quirk of my system. Someone once teasingly suggested I was fainting because there was less oxygen up at my height! My family moved a lot, in and out of many countries. I remember how, at the twelfth school I attended, we had to assemble every morning in a courtyard for notices to be read out. We had to stand at attention in the hot Australian sun. That was where I acquired the nickname of "Falling Tree". Apparently that was funny, because my faints were like watching a tall pine fall in the forest. But still there were no answers, no real investigation. It was just the way I was.

I can fast forward through my twenties to my thirties. The fainting had mercifully abated. I danced, travelled, studied, and worked hard at a job I loved and met my man. We started our family. I was fighting with constant dizziness and other symptoms, but I didn't bother having it looked at. I honestly felt like everyone must feel the way I felt, they were just better at coping with life. I felt like a failure. I berated myself for not being more active, more energetic. I struggled through both pregnancies and hid away so I could get horizontal; to store up enough energy to deal with the vertical demands to come. Then I was hit with the worst flu I have ever had.

In the emergency department, I had an ECG. It showed a long QT. I was

referred to the cardiology department for investigation. After taking a lengthy history, I was put on a Tilt Table. After nine minutes upright my heart stopped. Just, stopped. And that was how I came to find out that my structurally normal heart wasn't behaving in a normal way. Those faints I had been having were not faints at all, but asystolic episodes. I was diagnosed with POTS, even though I wasn't a perfect fit for the diagnosis. A pacemaker was fitted and I tried to carry on with my normal life. Teaching, mothering, wife-ing. Exhausting.

Then, my symptoms grew more widespread. My general physician sent me to a neurologist. He was so rude. His first comment was that having POTS did not mean I needed a team of doctors, and in fact he wasn't even sure why I was there. "*Because I am having neurological problems, and you are a neurologist*" I whispered, staring at the floor. "*What problems?*" he said, turning to look at my history. After a series of 'hmmm's, he turned back to me and said "You don't have POTS. *You have Pandysautonomia. Pan meaning 'all', dysautonomia meaning dysfunction of your autonomic nervous system. Your pupillary problems, your sweating irregularities, your labile blood pressure and heart rate, your digestion problems, pseudo-obstructions, urinary retention, constipation and problems with thermoregulation all suggest this diagnosis". I swallowed. He went on to explain that my blood labs did not indicate an autoimmune problem, I clearly had a progressive form of pandysautonomia; there was nothing he could do for me. And then he stood and asked me if I had any questions.*

Since that day, I have been busy in a new kind of way. Making sense of the literature surrounding Dysautonomia, writing about my journey, advocating for people with invisible illness, working on awareness and systematically eliminating things from my list of possible causes. I've been making memories with my beautiful little family, cherishing the important things in life and generally getting on with things as best I can. I blog about my journey with Dysautonomia at www.rachelfaithcox.com. At present, we think I have sero-negative AAG. I am waiting for approval for IVIG therapy.

Just recently, I joined the staff of contributors to this newsletter. I'll be writing for the Parenting Corner and I am already loving it! Dysautonomia is a challenge. Parenting is a challenge. I aim to write about all the issues that relate to having both challenges; to provide a voice to express just what it is like to be us. Parenting *with* Dysautonomia. I'm Rachel, and it is wonderful to meet you!

# Parenting Corner:
# How Do You Spell Love

**by, Rachel Cox**

It's one of those mornings. I know it the moment my eyes crack open and the light floods my eyes. There is a flash of pain as my pupils struggle to assimilate the light. Too bright. The nausea grips my abdomen and somehow, I make it to the bathroom to vomit. I am there on my hands and knees when I feel a small, warm, hand on my shoulder. My daughter. She passes me a hair elastic.

"Here, Mom …to keep your hair back" she says, quiet; matter-of-fact. She is a special soul, my girl; kind, thoughtful, empathetic. I so wish that these traits had not developed through living with a sick Mom. But that fact is something I can't change. It just is. We are in this together. My son, too, has known it his whole life.

Recently, I was again, in the bathroom. For weeks I had been unable to poop. But this day: success. My son raced into the bathroom. "It's good to poop!" he whooped, grinning and tossing me an extra roll of paper with an exaggerated wink. It

might be a strange thing to celebrate, in average households, but not when Dysmotility will drive you to hospital. I shook my head in wonder. What kind of grown-ups will my kids be? They already know how to respond to the distress of others, not just how to articulate their concern, but how to behave in a responsive, helpful way. They are matter-of-fact in their understanding that some things just require action. And they have the ability to see the funny side of things other kids might find horrifying. They just get on and do what needs to be done. Practical, kind, funny kids. Extraordinary.

Empathy is a skill that has been researched thoroughly by those in the fields of psychology, sociology and genetics. There are genes that have been identified as being markers of hereditary empathetic tendencies. But empathy itself can be taught and learned. It is easy as parents with Dysautonomia, to think about all the things we don't get to teach our kids; about every lost opportunity or failed parenting moment. But today, I want us to reflect on the gift our illness does give us and our children, in particular: a head start on how to be good humans. We can look at our illness as the taker of so much. Or we can choose to remember that character is built on adversity. Ours, but also that of our kids. Have you ever considered that you look at the world differently since you became ill? Your kids will too. They will have a heightened experience of beauty, a deeper appreciation for relationships, a better understanding of why it is important to make the most out of every situation. They will have that, especially if we are modelling it for them.

Studies show that as many as 1.4 million children in the US, aged between 8 and 18 are caring for a parent, grandparent or sibling with disability or illness. The numbers are undoubtedly higher now. We can't change the fact that our children shoulder more burdens than many. But we can be mindful of what they need as caring kids of people with Dysautonomia. Here are three things we can make sure we are doing to help them.

## TALK ABOUT IT, BUT NOT TOO MUCH

Make sure your kids have age-appropriate information about what is wrong with you. Don't discuss it constantly, but make sure it is a natural and easy thing to talk about. Be open to answering their questions. This will help them to reduce the stress and not worry about it. It also helps them to have the vocabulary to explain things to their friends and people in their circle. There might be scary situations that happen; like passing out in front of them. Make sure they have a clear plan for what to do and reassure them that your body is trying to do what it needs to do, but sometimes it doesn't work right. My son is seven, he explains Dysautonomia this way: "something isn't working right with how Mom's brain tells her body what to do". And that is no more and no less than he needs right now. If you talk about your every symptom with your kids, it can increase their emotional burden. Try to generalize. We talk trends rather than specifics wherever we can.

## IDENTIFY A SUPPORT CREW

Caregiving kids need someone outside the immediate family that they can talk to about things. It is best if this person understands the situation thoroughly, is trusted and chosen by your child. They will need to talk sometimes about the difficult stuff. But don't take that personally, it is a natural and healthy thing for children to be able to discuss things without feeling that they will hurt your feelings. They need the freedom for that. This support person/crew might provide time and activities that you can't. If you don't have a

network around you, try contacting community organizations, churches or your child's school. There are organizations who can provide more information, see below.

**RESPOND TO THEIR EMOTIONAL NEEDS**

We can do that. Many a deep conversation and tearful commiseration has been given right here on my bed, with my kids in my arms. I am able to be present to their feelings. I can empathize with their problems. They both say they love having time with me here. They love that I have time to spend with them. Many well Moms are too busy for that. It's a gift. It reminds me of that saying by John Crudele: "How do kids spell love? T.I.M.E".

Become a volunteer! Would you like to volunteer for DINET? We frequently need reliable volunteers for our newsletter, website maintenance and more. Please contact our Volunteer Coordinator at janie@dinet.org to get started.

## RESOURCES

**Care Giver Action USA :** http://www.caregiveraction.org/resources/
**Young Carers UK :** http://www.youngcarers.net/who_we_are
**Young Carers Australia :** http://www.youngcarers.net.au/kids-under-12s/
**Carers NZ :** http://www.carers.net.nz/

# Medical Q & A

Answers to your questions from DINET's Medical Advisors

## Q

Hi, I have a few questions I'd like to ask for newsletter.

Why is it really important for people with POTS to exercise, even if exercise makes them feel progressively worse?

Thanks,
Jessie U.K.

***Editor's note:*** *This question was edited from the original submission for space considerations.*

Do you have a question for one of DINET's medical advisors? Send your question to Janie@dinet.org

## A

There is now very good evidence that many patients with POTS have a low stroke volume (amount of blood squished out per heart beat). This gets worse with upright posture. The dramatic increases in heart rate may in large part be an attempt to compensate for this at times when more blood needs to be pumped to the body (e.g. with minimal exertion).

At least 2 studies have shown that exercise training (focus on aerobic reconditioning) can help to cause "cardiac remodeling" with an increase in stroke volume, heart mass, orthostatic tachycardia and symptoms.

The challenge with exercise, is that it can be difficult to stick with it long enough to see benefits. In the Dallas study, it could take about 5 weeks of exercising 4 times per week before any symptomatic improvement was noted. In the short-term, many/most of these patients felt worse.

Exercise might not be the only answer for all patients, but it is certainly an important part of the treatment plan.

Dr. Satish Raj

## Q

I have experienced slow but steady improvement in my POT/OI symptoms over the past 3 years. I am still symptomatic, but it's generally mild (I can work full time and exercise). I have some concern that I could relapse in the future and wanted a general opinion on the frequency of POTS patients suffering relapses and if there are particular triggers. Thank you,

Glen from Australia

## A

I cannot speak towards long term follow up with any accuracy. I have seen sub-acute patients in whom improvement has been thwarted by intercurrent illnesses such as upper respiratory infections and so forth. My guess is that this patient has weathered such infections and is still trending better. I think, therefore, that short of a major illness the patient will continue to improve.

Julian M. Stewart MD, PhD
Professor of Pediatrics, Physiology and Medicine
Associate Chair of Pediatrics
Director, The Center for Hypotension
New York Medical College
Valhalla, NY

## Q

Do you know if dysautonomia ever gets better or have you ever heard of a feeling of clogged ears without any clinical issues in the ears? I have been checked for Meniere's. My ENT thinks it's from autonomic issues. Thanks.

Lisa from NY

## A

The dysautonomia does improve it depends on cause. I am not familiar dysautonomia causing clogging of ears. We are in the process of compiling a case series of POTS and Menier's disease patients and treatment options. Will be glad to share our findings.

Amer Suleman MD, FSCAI FHRS
Adjunct Professor, UT Dallas

Q

What is known about POTS and pregnancy?
What is known about the use of Mestinon during pregnancy?

Shannon from ND

A

There are several studies on topic of pregnancy in women with POTS. In my study, about 60% of women felt either same or better during pregnancy compared to before pregnancy, and about 50% of women were stable 6 months postpartum. All of the studies agree that there is no contraindication to pregnancy in women with POTS as far as we know it. Mestinon is a pregnancy category C drug, which means the safety during pregnancy have not been established. As with any medication during pregnancy, the benefits have to be weighed against the risks. In addition, you may not have the need to be on Mestinon if you feel better during pregnancy or may need to be switched to another medication, such as a low dose of a beta blocker, for example. I recommend you discuss this question with your POTS specialist and a high-risk OB/GYN.

Dr. Svetlana Blitshteyn

Q

Where can I find information about women who are diagnosed with POTS during a pregnancy or POTS pregnancies in general? I'd like more info about POTS deliveries, recovery afterward, and if symptoms lessened or went away at all after delivery.

Thank you!
Maria from Utah

A

We only have 4 studies done on the topic of pregnancy in women with POTS, including my study. Read free abstract here (http://informahealthcare.com/doi/abs/10.3109/14767058.2011.648671). In the full-length article, I also review results of the other 3 studies. To briefly summarize the findings are that

POTS is not contraindication to pregnancy and doesn't appear to carry any adverse maternal or fetal events, as far as we know it. A vaginal delivery with early epidural placement for pain control is the preferred method of delivery. Six months post-partum, about 50% of women with POTS reported feeling either same or better compared to before pregnancy, but you have to have a plan in place in case you feel worse after pregnancy (such as a good support system, help with the baby and scheduled breaks and naps).

Dr. Svetlana Blitshteyn

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