

DYSAUTONOMIA NEWS

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Dysautonomia Information Network - Summer Newsletter 2015



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WHAT'S NEW AT DINET.ORG

SUPPORT GROUPS

Dysautonomia Support Group of Los Angeles

Meetings held at the Good Samaritan Hospital, Moseley-Salvatori Conference Center, Los Angeles, CA

Next meeting – August 16th

RSVP Lynn at 213-977-7423

For more information about this group, email ecaldwel@lacard.com

Michigan Dizziness Support Group

For more information, please contact Karen OLoughlin at midizziness@gmail.com for meeting times and information.

North Carolina and surrounding areas.

dysLife Carolinas is a multi-chapter group for people living with dysautonomia and related conditions.

Check them out on Facebook at <https://www.facebook.com/groups/371932662940208> or email them at dysLifeCarolinas@gmail.com

For more listings and information about groups in your area, please visit:

<http://www.dinet.org/index.php/information-resources/support-groups>

Know about a support group that is not yet included in our list?

Please email the name of the group, location, contact name and phone and/or email address for more information. It is also helpful if you include a brief description of the group. Email your info to webmaster@dinet.org

DINET CONNECT LAUNCHED

If you have been a member of DINET for some time, you might recall the Meet Others Program we ran for many years. This program essentially matched people to others in their area with dysautonomia. It served both patients and caretakers. The goal was to connect people to others in their geographical region for friendship, networking and support. Some of the people in our Meet Others Program actually met in person, and this was often the first time either person had met someone else with dysautonomia.

Today I am happy to report that our Meet Others Program has expanded. Users can now login to the program via our website. You can create a profile, specify who you would like to meet, and search for other people living around you all online. If you ever need to change your contact information or update your profile, you can just login and do it instantaneously.

We encourage you to sign up for the new Meet Others Program, which we are now calling “DINET Connect.” We also encourage you to report any quirks or errors you receive while using this new program to webmaster@dinet.org. We hope you will help us build a positive and helpful new DINET support community. We hope to see you in DINET

SPREAD THE WORD AND EDUCATE!

How many doctors did you see before you were diagnosed with POTS?

Now you can easily help educate the medical community through an informational brochure geared towards physicians specially created by DINET.

As a DINET member, you have the opportunity to submit up to 5 doctor's names to DINET and we will send them this brochure so that they will be better informed the next time they see a patient with the same symptoms. To view the sample brochure and get the ball rolling, visit <http://www.dinet.org/index.php/help-us/physician-brochures>

MY POTS STORY

PART 2

by, Alexandra Merullo

EDITOR'S NOTE: *Part 1 of Alexandra's story was published in the Spring edition of the DINET newsletter. Part 1 is available in the newsletter archive on dinet.org*

January 18th of 2014, after living with POTS for nearly two years, my family accompanied me to the Boston airport, knowing they wouldn't see me for 6 months. Despite my sickness, I had decided to spend a semester abroad in Italy. If there is one thing that is true about chronic illness, it's that it changes you. After trying acupuncture, craniosacchral therapy, dozens of medicines, massage, homeopathic healers, and raking through the internet for the cure for POTS, I hoped

a change of scenery might allow me to get some of my life back. So, on that brutally cold January day, I said a teary goodbye to my loved ones and crossed through the security line, waving until I could no longer see their faces. Suddenly I realized I was completely alone and chronically ill. And for the next six months I would live in Italy with a family I had never met before.

Although I took precautions on the flight (aisle seat so

I could get up and walk around to get blood pumping, hydration, taking extra Fludrocortisone), jet lag hit me hard. When you live with chronic fatigue, any extra fatigue feels crushing. Before arriving, I had attempted to explain my disease to my host family, but due to a language barrier, they had no idea as to the degree of my illness. Attending school in Italy proved to be one of the most challenging tasks in my POTS experience. Every day I had to wake up early, get dressed and have breakfast and wait for my host sister and brother to finally get ready and then be dropped off at school to begin classes at 8:20. Luckily, the Italian high school day lasts only until 1:20 as opposed to the American 3:00. Right after classes finished, I would be driven home along the beach-front and arrive at the house where a two-course meal awaited me. First came a heaping pile of pasta, then a breaded cutlet dripping with olive oil or a piece of delicately fried fish, then a salad soaked in vinegar and oil. Then the whole household would grow quiet as the family took the

customary two hours after lunch to rest.

Exhausted from trying to stay awake in school, where it was hard to follow the lessons in Italian, I would fall asleep for several hours. In the afternoons, as my brother and sister were brought to dance and guitar lessons, friends' houses, catholic school, I would be free to roam around the city on my own. Since I had grown up in the middle of the forest where a 20 minute drive from the nearest grocery store was typical, the busy streets and 10 minute walk into the city of Rimini was incredibly exciting for me. The doctors had advised me to get exercise in order to subdue POTS symptoms, so I signed up to swim at the local pool where my host brother took swimming lessons. I went once a week and swam for half an hour, pushing my body to the very limit just to make one length. Once I even took a water aerobics class with my host mother and a posse of other mothers who gossiped as they kicked and twirled and lifted and stroked. What was a simple workout for them felt like a marathon to me. My body ached and screamed and each limb felt like it weighed a hundred pounds. Somehow, I managed to make it through the class. The next morning a heavy exhaustion and pain overcame me, and I didn't go to school for three days.

It wasn't until spring time that I started to feel a difference physically and mentally. I began to accept POTS as part of my life, to realize that my illness and happiness were not mutually exclusive. Instead of being driven to school, I used the family's rusty yellow bike and rode

to school by the beach where I could taste the salt air. I had found a group of friends who saw beyond the language barrier and supported me even though they didn't understand my illness. My host mother became a close friend, and we talked about the greater implications of suffering in life, and she assured me there would come a time when my greatest worry was not my physical state.

Outside of school, I had found a weekly religious group that met at the house of the local priest. It felt like a place where I belonged -- we ate and sang together then ate and sang some more and I began to explore my religious curiosity. With the addition of a bike, which allowed me to get exercise in a sitting position, while also transporting me to school, to friends and into the city, I felt stronger and more independent. At school I was able to participate more in class without feeling like I would fall asleep. At home I took shorter naps less often. I had fallen in love with the Italian lifestyle, the Italian language and culture, and an Italian boy. I'd found something to live for.

The summer after returning from Italy was one of the best of my life. I would have days in which I felt like my old self, with enough energy to go about my day, and even with a little extra! I went for runs, I walked around, I participated in family activities. I felt alive again. Now, a year after that summer, I have recently come off Fludrocortisone. I no longer am tired every day. I no longer have lights flashing in my eyes. I'm no longer dizzy and nauseated and sore. I completed an entire

year at a rigorous high school with good grades, got regular exercise, and was happier than I have been in years. Finally, I feel like myself again. In pictures, the life and light has come back to my face and I look healthy and alive. In the midst of the dark disease that is POTS I thought there was no hope - that I was destined to be sick forever. It took a trip outside of my comfort zone for me to fall back in love with life, and become healthy and happy again. For me, POTS was mental, spiritual, and physical. I worked hard to break the iron grip it had on me mentally and spiritually, and I was lucky enough to recover physically.

Whether growing out of POTS was a result of my time in Italy and what I was able to do there or not, I can only wonder. However, I am sure that my time in Italy reminded me that even with POTS I could be happy, and that was the greatest gift I could have received.

DEPTHS OF DYSAUTONOMIA

by, Jac Daffern

With the weather getting warmer, I think of my childhood summers. When given a chance to swim, I wouldn't jump in the water voluntarily no matter how hot I felt. I crept in

slowly, splashing myself with water until I felt comfortable. My friends would cannonball into the water... with what seemed to be no thought to the water temperature or depth. I felt more

*Looking for a doctor in your
area?*

*Check out our new &
improved physician search at
[www.dinet.org/index.php/
physician-list](http://www.dinet.org/index.php/physician-list)*

comfortable in calm water where I could touch and not have to tread water. Once in, I enjoyed it.

When I was diagnosed with dysautonomia, I felt like I had been pushed into the pool. Me, the person who didn't want to cannonball. I didn't know how deep the water was, or who would be in there to help me. I felt like I was in a completely different body of water and needed to learn how to swim again.

It's interesting to see the varying degrees of dysautonomia within our DINET community and how the seasons effect each person. Overall, summer seems my best season. Mild summers, with lakes and streams in my region are in my favor. Although a short season, at about two months, I hope the summer is a good time for you. See you next season!

Blessings, Jac

UNOFFICIAL TIPS FOR SUMMER:

1. Hydrate ... even more. Electrolytes are beneficial.

2. Sunscreen, sunglasses and a hat. Our eyes and skin are more sensitive with dysautonomia.

3. Think cooler. Whether you wear it or eat it. A cooling vest and other cooling products such as towels, neckties and head bands are helpful products to consider. Enjoy ice cream or freeze your electrolyte drinks into Popsicles.

4. Time of day. Venture out later in the day when it's not so hot and the rays are at bay.

5. Float or Swim! Bring a buddy. I've read the effects of the pressure from water helps improve orthostatic symptoms. *

*Always consult your physician before beginning any exercise program. To learn more about the effects of water and swimming on dysautonomia, you can read the following articles:

<http://www.dinet.org/index.php/information-resources/pots-place/pots-what-helps>

<http://m.jnnp.bmj.com/content/65/3/285.full>

<http://www.dysautonomiainternational.org/page.php?ID=43>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2888469/>

PARENTING CORNER: A NOTE FOR THE TEACHER

by, Rachel Faith Cox

Before I got sick, I was an elementary school teacher. When I look back on that time now, I wonder if I was responsive enough to the parents in my class who were struggling. When a parent was sick, did I actively support their child's unique needs? Did I really understand the impact a parent's illness can have on children? I think I did. I hope I did. I know that for every child I taught, their overall welfare was of utmost concern to me. This holds true for the majority of teachers. What I know now is that I would want to keep in communication with a parent who is struggling with an illness and I would want to help that child.

Appropriate methods of communication between parents and teachers will vary depending on the school. You may want to open communication between yourself and your

child's teacher with a shorter note or an email. Depending on your unique circumstances, what you discuss with them will vary. They do not necessarily need to know every detail about Dysautonomia, but they will need to know how it impacts your child's life at school. Explain the direct impact on your child as it relates to things like homework, home/school participation, and behavior. The following is a letter I would have liked to have received, as a teacher, and would have been relieved to send, as a Mom. But it should not be seen as a form. It is just one example of a way to explain your child's needs as they begin the new school year. Perhaps writing your own, just for your own thought processes, would be helpful before beginning to discuss things with your child's teacher. What is your most effective way to communicate with the school at the beginning of the school year?

Dear Teacher,

I am Zed's Mom, Rachel. He is super excited about the year ahead with you! I am writing to explain how it is for him at home as we have challenges that most families do not.

Zed has a very busy Daddy and a sick Mommy. I have a medical condition called Dysautonomia. It means that I am functionally disabled. I can't walk far without a mobility aide and I certainly can't stand for long, I am often admitted to hospital at little notice for short or long stays. I have a strict medication regime and my daily activities are limited.

An illness like mine can have far-reaching effects on the lives of my immediate family, especially my children. They are empathetic kids and they carry a lot on their shoulders, much more than the average children their ages and they frequently have worries that are difficult for them to express.

Because I am not able to be physically active with them, they miss out on opportunities to have a good run or play sports. It can make my son fidgety and restless. Sometimes, I am even unable to supervise homework because I feel too unwell. Other parental tasks might slide. I will rarely be able to attend school social functions, performances or competitions. I wish I could. It breaks my heart that I can't be there for my child. Whenever possible, my husband will be there, but I am conscious that our lack of presence in the wider school community may further reduce my son's self-esteem and social opportunities. That makes me sad for him. Please help him to feel noticed when I can't be there to cheer him on.

How should we best communicate with you? Email, note, phone call? We so appreciate that you will work with us to help our child have the best year possible. Thank you in advance for your sensitivity and flexibility about the normal expectations around homework, assignments, bring-from-home tasks, field trips and parent support in general. If there is any way you think I can be involved, please don't hesitate to ask. We are always looking for ways to make things work.

Thank you so much for caring about our son,

Warm regards,

Rachel Cox

Morning Yoga Can be for Anyone (*or almost*)

by, Judith Pettibone

Greetings, DINET Readers,

While I usually serve as the volunteer editor on this publication, I thought I might venture a suggestion for your health. I became interested in DINET because I have a daughter with the disorder. Therefore, I don't have personal experience with the symptoms many of you deal with on a daily basis. But I have experienced the challenges of injuries, and yes, now a body that is - gulp - aging. Modifying any exercise routine has become second nature to me and having recently had a serious fracture, I now have different modifications to integrate. Still, when I was finally able to get back to the routine I will describe below (just this past April), my body did a sigh of relief as did the rest of me.

Several years ago, I was snowed in at a friend's home. Before the roads were clear, she suggested we do "Morning Yoga." Now I am usually open to new things, but I found

that I sighed inwardly and thought, "I am not good at Yoga." Oh, I have tried. I have even left money on the table for a series (thinking I was tricking myself into compliance). I never

saw me again. My intentions were good. It's just that I didn't like it! I have friends that go three and four times a week. And I believed them when they told me how good they felt and how this body part felt better and that one was stronger. But my mind felt too busy, or my body refused to go into those postures and I was too impatient to be patient, or the instructor was too fast, too slow, too, too.

So, imagine my surprise when after that morning, I immediately ordered Rodney Yee's "AM/PM Yoga." (1999 Gaiam America's Inc - available Amazon.com \$11.59). What is even a bigger surprise is that three years later I have done this 15-20 morning program nearly every day. I have taken my yoga mat camping and have used it in some pretty incredible campgrounds and occasionally on picnic tables.

Depending on my day, I arise at my normal time, put on exercise pants, a long sleeved shirt in the cool weather and warm socks. The kettle is on low and I bring a small pillow and a scarf that I use for a strap, to a room with enough space for me to spread my arms out. The routine is loaded on my iPad (my daughter has it on her iPhone and a friend uses the DVD) but I have long since stopped watching it and merely follow Rodney's audio until we both say "Nameste." When I'm finished, the tea kettle is usually about to whistle. Is this Yoga for people who don't like Yoga, or don't think they do? Yes. Is it for people with dysautonomia? I think so. It, of course, depends on your current state of health.

You would think that by now I could do it without prompts. I have tried and but memorization doesn't seem to work. It works best for me to concentrate on following the words thus paying more attention to the 'doing' than to the 'remembering'. You might imagine I would be weary of the same voice and same moves some nearly 900+ days later but I am not. Surprises the heck out of me, too.

So, what has changed, against all odds, to keeps me at it? Well, for one, an old knee injury seemed to be getting worse and much to my dismay, I could no longer sit cross-legged. Perhaps that sounds silly, but it was a loss for me. And that loss certainly indicated a lowered functional activity ability. It was not getting better even with physical therapy. After three months with Rodney, I realized that one day I was sitting like the proverbial tailor. I don't know about a "wakened mind" except that during this time period I wrote my first mystery novel. I never wake up feeling stiff. And perhaps most importantly, I look forward to it.

It is a good way to start my day. And I wonder, with the challenges that dysautonomia brings, if you might like it, too. If this is not a good time for you to begin anything new, why not suggest it to a caregiver or anyone in your family or friend circle. I now have my own little 'posse' doing morning yoga and it give me great pleasure to think of them (far away and near) as I am doing the routine. It can be another spoke in anyone's stress reduction wheel.

While I cannot claim all the many amazing benefits that more advanced yoga practitioners experience, I also do not practice in the same way. But it works for me in many small ways and some bigger ones, and for right now, if you are not able to take classes or indeed, do any exercise, it might also work for you.



In the morning the body is rested but stiff from inactivity, to gradually waken the body mind, I've designed a gentle yoga series that will increase circulation, improve mobility, and bring clarity to the mind.

~Rodney Yee

My Unofficial Tips:

- Watch the entire video a couple of times - or until you feel sure what modifications you might need to make. And you will find that making modifications along the way is fine as well.
- Remember, this is new. If you have not done yoga before, be patient. It might take several months for it to feel easy. I believe it is worth the time.
- There is one posture that takes you from hands and knees to upright. If you cannot manage the change to standing, you can modify. While healing, I was not able to manage the “Downward Dog” pose, so I stayed on my hands and knees and did the angry cat (arching back) and the sagging cow (spine curves). Repeat until the upright pose is finished. (see illustration)
- Make this your own. Pause the routine if you want more time on a certain pose. As you become more familiar with the routine, you will find that you can move into the next pose and get a few more seconds of stretch.
- Optional: I end the routine with something a friend taught me - the “Circle of Love.” Still sitting cross-legged, clasp hands and make a circle with your arms. Lift circle over your head with arms beside your ears. Unclasp hands and stretch arms to the side and lower them to behind your back. Give a gentle stretch by pulling your shoulders down.

LIFESTYLE CHANGES EQUAL FREEDOM FOR TEENS WITH DYSAUTONOMIA

by, Alexis Pacheco

Dealing with Dysautonomia at any age is difficult and often disheartening. For teenagers, Dysautonomia steals adolescence. According to the Dysautonomia Project, POTS affects 1 in every 100 teens, and 25% of POTS patients experience symptoms so severe that they are unable to attend school, work, drive, and some are even bedridden. With these sobering statistics, it is not surprising that teenagers experience drastic lifestyle changes effecting their education and relationships.

However, coping with Dysautonomia and functioning to the best of your abilities as a teen is not an unattainable dream. POTS changes the body, but most teens can find ways to cope. I have suffered from Dysautonomia since the age of 11, and I personally know how it can rip away the joys of adolescence. From my own experience, I have learned various

tactics to battle my own Dysautonomia in different facets of my own life. Maybe they can help you as well.

Here are a few tips from my own journey to help other teens and parents adjust to life with POTS:

Be Realistic.

Know your limits. As a teen, I know how hard it is to be realistic about your diagnosis. However, being realistic is one of the first steps to taking care of yourself. It is okay to accept that you are sick, but the key is not to allow yourself to become your sickness. If you and your friends decide to do something that requires physical activity, allow yourself time to stop and rest when you're feeling weak. Stay cool as much as possible, and plan to find places that are shady for a break.

Be Honest.

It is not only important that you are honest with yourself, but it is equally important that you are honest with your friends and your family. If your friends are planning an outdoor adventure, don't be embarrassed to inform them about your illness and your limitations. If you aren't feeling well, tell your family—they need to know the severity of your symptoms so they can help you. I know what it's like to feel abnormal because of your illness, but honestly, staying shy about your symptoms is only alienating yourself more from living a fulfilling life.

Hydrate, Hydrate, Hydrate!

Drink water, Gatorade, Powerade, etc. throughout the day to retain fluid and electrolytes. This is a key to helping yourself stay well. It's easy to slack off from hydration -- you're busy at school, you're busy after school, you have homework, and let's be honest—drinking water constantly as a teen is usually not a priority. It needs to be #1. If you're going on a trip with friends or family, pack a small ice chest with water and/or electrolyte fluids. Summers are the absolute worst. Heat can worsen your symptoms, and it's imperative that you monitor your water intake.

Salt, Salt, Salt!

Salt is equally as important as hydration. Do you have any favorite salty snacks? It's a good idea to keep them handy, especially when you are hanging with your friends or going to school. Keep a fanny pack or fill your backpack with snacks like sunflower seeds or a small bag

of pretzels. Salt will help you retain fluid, and who doesn't enjoy snacking throughout the day?

Your Doctor Knows His/ Her Stuff.

Listen to your doctor's advice and take your medications regularly. As a teen, I found a cute pill box to carry my pill that I kept it in my purse. I felt much more comfortable taking my medications when I didn't have to pull out a million bottles. This may seem silly to some, but it brings a bit of normalcy into your life as a teen. Guys, there are pill boxes available that are not stylishly "cute." You can find something a little tamer.

Rest.

I know how tempting it is to stay up late when you're young. Rest is critical with Dysautonomia. The chance of your feeling worse heightens when you aren't well rested. Plan for at least 8 hours of sleep every night, even if your friends are staying out late. One late night is not worth days of feeling unwell!

While these tips might seem obvious, they are often overlooked as a teen -- because teens do not want to accept the reality of their condition. I know this all too well from personal experience. Small adjustments can make the biggest difference in your symptoms, and big differences allow more freedom from Dysautonomia. More than anything, wake up every morning thankful that you are alive and know that Dysautonomia does not define your youth. You may be young, but you are smarter than the illness, and you have the courage to fight harder with each passing moment or momentary setbacks. You are young, you are beautiful—you are MORE! Believe it and live it.

MEET THE MEMBER:

Chelsea Goldstein



Dear reader,

I write to you as I return from a trip to Iceland. This was a poignant trip for me, as it was the first time in over five years that I completed vigorous hikes, traveled internationally, camped and carelessly explored. I am drained, yet I am renewed. Being able to travel to Iceland represents a return to the old me, but it also signals a transfiguration of the person I used to be.

For several years now, I have been sharing stories of struggle, triumph, acceptance and hope through this column. Sharing the stories of others is easy for me. My interviewees aid me in comprehending some of my own anxieties surrounding my Dysautonomia. They also

provide me with renewed inspiration each time I write their stories. I have found my voice in others. But, now, I think it is time you hear my voice. Or, maybe, it is time for me to learn my own sound.

My symptoms began about five years ago while completing research in a remote area of China. Approximately a year after my return from China, I felt all but useless—unable to eat and walk. It was determined that I picked up two forms of food poisoning during my travels, undoubtedly from some of the questionable dishes I ate without hesitation. My symptoms persisted once the food poisoning was treated with heavy doses of antibiotics. After six months of doctoring, it was determined I had POTS and EDS (Ehlers-Danlos Syndrome).

The first year was tough. Prior to illness, I was an invincible twenty-one year old who was about to graduate college, was dating the man of her dreams, was a strong contender for a national scholarship and had a research project that was gaining recognition. I quickly learned the world kept moving,

whether I moved with it or not. I postponed graduation, my boyfriend couldn't handle the stress of a sick girlfriend, the scholarship committee chose a healthier, viable candidate and my research lost its momentum. Unable to work and pay rent, I had to return to my childhood home -- the very place I had tried so hard to escape. Right when I thought I was moving upward, I fell down. Far down.

The past five years have been an incredibly challenging and inconsistent journey. I have been in the hospital for weeks at a time, on a feeding tube and I have needed help bathing. I have also cried watching fireworks, and screamed at the top of a mountain after I fought my way up. I have learned to love with more compassion and appreciation. Life with Dysautonomia is inconsistent, misunderstood and, often, painful. But with it, I have also learned to live more fully than most people I know-- including the old me.

Now, I have a boyfriend, who occasionally drives me mad, but mostly shows me unconditional love. The old me would never have appreciated his quiet strength. I am starting a company caring for the elderly, a career path that, prior to my illness, would have been too slow. I am learning to travel again. Now, I travel slowly -- and slowing down may mean that I miss the "loudest" travel thrills. In Iceland, I sat. I saw a seal swimming in a glacier pool. I found a hidden waterfall at a campsite. I discovered puffins nesting on a cliff side. I found these things because Dysautonomia has taught me to fight for my dreams. And while

fighting, it has showed me that if I stop rushing through life, those dreams may come to me.



CHOOSING THE RIGHT MEDICAL ID

by, Meredith Wells

You are grocery shopping alone. You pick up a few different cans of soup to compare sodium contents when, all of a sudden, tunnel vision takes over, your legs give out and you collapse to the ground. A grocery store worker finds you unconscious and calls 911.

This is a very possible scenario for someone with Dysautonomia. Without proper medical identification, you could potentially be administered wrong medications that could cause tachycardia or low blood pressure -- putting you at risk.

Choosing the right medical ID can seem like a daunting task. With all the different styles, materials, and price ranges, how do you know which one to select? Finding the best medical ID comes down to your personal needs. What is the severity of your condition? How often are you alone? What types of activities do you do on a daily basis? How much money are you willing to spend? To help you decide I've created a breakdown of some different Medical ID styles.



Silver Chain Bracelets

Silver chain bracelets are durable and range in material and price. They are the easiest bracelet to recognize as medical identification and therefore one of the more popular options.



Leather Bracelets

Leather bracelets are a great option for patients who want something stylish but, do not want to sacrifice easy identification. Leather bracelets come in a variety (added the word "a") of styles and colors. Some even have the option of interchangeable bands.

In addition to wearing a medical bracelet, I also carry a medical card in my wallet. A wallet card is like an extension of a medical bracelet. It allows you to include the rest of the important information that did not fit onto your medical ID. Wallet cards generally have places to write your address, emergency contact information, medications and medical conditions.

Before you engrave your medical ID, make a list of your medical information in order of importance. For example, if you are deathly allergic to anything, that is more important than an emergency contact number. Because Dysautonomia is very complex, there is a lot of important information that unfortunately, will not fit on most medical ID'S. In this case, I recommend putting the bare minimum on the ID along with “(WALLET CARD)” at the bottom of the engraving to indicate to first responders that you have a medical wallet card.

Medical ID's are a worthwhile investment and a decision that requires careful consideration. It's important to choose the ID that best suits your needs so you are more likely to wear it at all times. Remember, wearing a medical ID could be a lifesaving decision that will help you get the medical treatment you need in an emergency. By wearing a piece of medical identification, you will be able to increase your independence without sacrificing your peace of mind and that of your loved ones.



Dog Tags

Dog Tags are the medical identification for the military. They are durable and come in a variety of different metals. If outside of the shirt, their medical emblems make them easy to recognize as medical identification. You can also put multiple tags on a chain if you need to double your identification space.



Beaded Bracelets

For the fashionable at heart, beaded bracelets may be for you. These stylish bracelets offer medical identification without the more obvious reference to a medical condition. However, if the medical emblem is not visible enough, your bracelet may not communicate a medical condition to EMT's.

*All of the medical ID's pictured can be purchased at Americanmedical-id.com and other similar companies.



Silicone/Rubber and Steel Bracelets

This style combines the affordability of silicone/rubber bracelets with the customization of steel bracelets. Silicone and steel bracelets are comfortable and water resistant. Their only downfall is that they are not adjustable.



Silicone/Rubber Bracelets

Silicone and rubber bracelets are a very affordable option. These bracelets are not customizable and come with more common illnesses and allergies such as diabetes, asthma and peanut allergies printed on them. Unfortunately, I've yet to find one of these for Dysautonomia.

MEDICAL Q&A

Answers to your questions By DINET's Medical Advisors

Q: Is there any correlation with POTS and immune deficiency?

from Judy, Ohio

A: There is not great data on this question. There is a lot of interest in autoantibodies in POTS, which would suggest "hyperactivity". Dr. Blitshyen recently published a paper about this, and reported 1-2 patients in a small cohort of 100 POTS patients. This incidence was felt to be much higher than expected in the general population. However, this data must be interpreted very cautiously as these were not randomly selected patients.

Satish Raj MD
Internal Medicine
Alberta, Canada

RESEARCH IN REVIEW

DYSAUTONOMIA – GENERAL

Neurologic Complications in HPV Vaccination

A relatively high incidence of chronic limb pain, frequently complicated by violent, tremulous involuntary movements, has been noted in Japanese girls following human papillomavirus vaccination. The average incubation period after the first dose of the vaccine was 5.47 ± 5.00 months. Frequent manifestations included headaches, general fatigue, coldness of the feet, limb pain, and weakness. The skin temperature of the girls with limb symptoms was slightly lower in the fingers and moderately lower in the toes. Digital plethysmograms revealed a reduced peak of the waves, especially in the toes. Limb symptoms of the affected girls were compatible with the diagnostic criteria for complex regional pain syndrome. The Schellong test identified a significant number of patients with orthostatic hypotension and a few with postural orthostatic tachycardia syndrome. Electron-microscopic examinations of the intradermal nerves showed an abnormal pathology in the unmyelinated fibers in two of the three girls examined. The symptoms observed in this study can be explained by abnormal peripheral sympathetic responses. The most common previous diagnosis in the patients was psychosomatic disease. Recently, delayed manifestation of cognitive dysfunction in the post-vaccinated girls has attracted attention. The symptoms include memory loss and difficulty in reading textbooks and/or calculation.

Ikeda S.

PubMed PMID: 26160812

Department of Medicine (Neurology and Rheumatology),
Shinshu University School of Medicine.

Full Text: <http://www.ncbi.nlm.nih.gov/pubmed/26160812>

POTS

Treatment of Refractory Postural Tachycardia Syndrome with Subcutaneous Octreotide Delivered using an Insulin Pump

Postural Tachycardia Syndrome (POTS) represents a disorder of the autonomic nervous system that results in symptoms of orthostatic intolerance. Despite having a severe impact on the patient's quality of life, the current treatment options for POTS are based on limited evidence. Subsequently, this results in clinicians having to utilize a variety of treatment regimens in the hope of successfully providing symptomatic relief. However, the options available for POTS are not without significant side effects that can worsen an already debilitating condition. Our cases provide a further novel treatment option for clinicians to consider in POTS refractory to established treatments.

Khan M, Ouyang J, Perkins K, Somauroo J, Joseph F

PubMed PMID: 26089909 PMCID: PMC4452321

Full Text: Free PMC Article: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4452321>

Painful temporomandibular disorders are common in patients with Postural Orthostatic Tachycardia Syndrome and impact significantly upon quality of life.

AIMS: To explore the point prevalence of painful temporomandibular disorders (TMD) in a well-characterized clinical cohort of postural orthostatic tachycardia syndrome (PoTS) sufferers and to understand the functional and physiologic impact of this comorbidity on the patient.

METHODS: Patients with PoTS were retrospectively recruited from a previous study conducted in a UK hospital setting. Data had previously been collected on several parameters, including sociodemographic, physiologic, and functional. The participants were mailed a highly sensitive (99%) and specific (97%) self-report screening instrument for painful TMD. Simple descriptive statistics with Fisher Exact and Kruskal-Wallis tests were used to examine the data and draw inferences from it.

RESULTS: A total of 36 individuals responded (69% response rate). Just under half (47%) of the sample screened positive for painful TMD. There was no significant difference between the screening result for TMD or previously reported headaches or joint pain ($P < .05$). Chronic fatigue syndrome (CFS) was diagnosed by the Fukuda

Criteria in 44% of the total sample and in 56% of those with painful TMD. There were no significant differences in physiologic parameters in CFS and TMD. TMD caused a significant decrease in quality of life as measured by the Patient-Reported Outcomes Measurement Information System, Health Assessment Questionnaire ($P < .05$).

CONCLUSION:

TMD are common in patients with PoTS. They have a significant, additional impact on patients' quality of life and should therefore be screened for at an early stage in PoTS.

Durham J, McDonald C, Hutchinson L, Newton JL

PubMed PMID: 25905533 PubMed – Indexed for MEDLINE

Full Text: <http://www.ncbi.nlm.nih.gov/pubmed/25905533>

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