dysautonomia NEWS

a hello & goodbye

in this issue

Dear Friends of DINET,

I am pleased to introduce to you our new president, Carrie Burdzinski! Carrie has graciously accepted the position and we are excited to have her. She is a biochemistry professor at Delta College in Michigan. She holds a bachelor's degree in genetics and a master's degree in molecular biology. Many of you probably already know Carrie from the DINET forum. She is a caring, knowledgeable, and helpful member, and we are grateful to have her stepping into a leadership role with DINET.

Carrie has had dysautonomia since birth, and she understands the challenges that those of us with dysautonomia face in our daily lives. She has a passion to lead DINET and to reach out to those affected by dysautonomia. I have no doubt that Carrie is the right person to lead DINET at this particular time. She has great ideas for future projects and fundraisers for DINET, and I believe that DINET will continue to grow in exciting ways under her leadership.

As for me, my fatigue and muscle weakness continue to slowly progress, and I continue to struggle with migraines. I will be scaling back on my already, substantially, limited activity level. I will be seeking to live well with dysautonomia and will be focusing on being a wife and a mother to the best of my ability. Even though I will not be doing much volunteer work for DINET, you will still find me online, whether on the DINET Facebook page, the DINET forum, or on my blog. Know that you are always welcome to visit me at those places!

Life with dysautonomia is hard, but it has also brought about many good things in my life. Through living with dysautonomia I have learned to have patience and to persevere. I have learned that even when life is physically challenging, there are still ways to do fun things, serve others, and enjoy life. There is hope and joy to be found. I have learned to search for, and fight for, joy. I have learned to embrace this life with dysautonomia and the opportunities that come along with it, such as volunteering for DINET!

I am grateful for all of you here at DINET. Thank you for your friendship and the information and support you have given to me. I know that many of you are very sick, just like me. I encourage you not to lose hope. Medical testing and treatment continues to improve, and there may be better treatment options for us in the

article continues on next page ▶

future. But even if a cure does not come, life is still a gift. Enjoy it, cherish it, and seek hope and joy. Take the time to serve others. You have a unique perspective and talents to offer to those around you! May each of you live well with dysautonomia.

I have enjoyed my time as the DINET president, and I am thankful for the various ways I have been able to volunteer for DINET over the years. It has been challenging, rewarding, and fun. Thank you, DINET, for allowing me this opportunity!

It is with a mixture of sadness and excitement that I pass the torch of the DINET presidency on to Carrie Burdzinski. I am eager to see what is in store for DINET in the future. Please join me in giving a warm welcome to our new president, Carrie!

Warm Regards,
Rachel Lundy
Former DINET President

a LETTER FROM OUR NEW PRESIDENT

Hello friends of DINET:

I feel excited, honored, and privileged to introduce myself as the new president of DINET. This is a responsibility I take very seriously, because in many respects I owe my current state of health to this organization. Like many of you, I searched for answers to the confusing and frightening symptoms of dysautonomia for over 20 years. It was not until discovering DINET's member forum that I felt as if my health concerns were taken seriously.

For the first time, I met other people who experienced the same perplexing issues. This knowledge and support renewed my motivation to pursue a formal diagnosis, and in May 2013 I was finally diagnosed with POTS by a provider from DINET's physician list. While accepting a label of chronic illness can be demoralizing, I actually felt relief after being acknowledged as a visible human being with an unusual but legitimate health condition. Thanks to the support and information shared by forum members, I currently enjoy a functional and active life even while having dysautonomia. So DINET's existence is personally significant to me, and I am dedicated to ensuring that we continue to flourish and touch even more people.

Since childhood, I have always wanted to understand how the body works in order to optimize health. That interest led me to study genetics and molecular biology in college, and today I am an assistant professor of biochemistry and anatomy/physiology at Delta College in Michigan. I hope that as we learn the physiologic mechanisms underlying autonomic nervous system function (and dysfunction), we can come to understand, anticipate, and work with our symptoms rather than suffer and fear them.

Public awareness of dysautonomia has increased over the past several years. New organizations have formed with an emphasis on fundraising, advocacy, and lobbying. However, much work remains, as countless people still struggle with dysautonomia and do not even know their symptoms have a name. Patients who have been formally diagnosed are often left feeling confused and concerned about their future. DINET's mission remains specific and unique within the dysautonomia community: "to promote education, support, and networking." It is this distinctive framework that guides my hopes for DINET.

Identifying and accessing a knowledgeable physician is one of the most daunting barriers patients face. DINET's secretary Michele Glaser and forum moderator Corina Rietbroek have worked hard to enhance and refine our physician network to ensure that patients are connected with the best experts who can efficiently diagnose and treat our conditions. But I know there are still not enough of these doctors available, so I would like our physician education program to further develop through proactive outreach and an expanded physician brochure campaign.

I know there are still not enough of these doctors available, so I would like our physician education program to further develop through proactive outreach and an expanded physician brochure campaign.

While physician education is essential, another facet of DINET's mission is patient education. Knowledge empowers us with the confidence to be assertive self-advocates who can make sound decisions about our own health. DINET will continue to develop its article database, providing information related to the autonomic nervous system and associated body systems. Through the forum, newsletter, and blog, we will share regular updates on the most recent research in the field. I would also like to see if there is interest in a lending library through which members could borrow books, lectures, and other resources.

Most importantly, DINET is here to support the patients who bravely face the uncertainty and strain of chronic illness. DINET will remain a constructive, encouraging presence via the member forum which many of us visit every day. Additionally, outgoing president Rachel Lundy has been instrumental in developing a 'DINET Connect" program. This will be an enhanced version of the "Meet Others" program to facilitate connections and networking with DINET members in your local area. Long-term, I would also like DINET able to serve as a central resource to support regional groups in planning casual "meet ups" or more formal speaker sessions. And of course, DINET's mission is to be a resource for YOU! Always feel welcome to share your ideas or hopes for this organization, because we sincerely want to hear them and will strive to implement as many "wish-list" ideas as we can.

As we look forward to future projects, I feel grateful to all of DINET's past and present volunteers who are committed to the dysautonomia community. From president, to board members, to forum moderators, DINET is an entirely volunteer-run organization. We pledge to do our best, so please remember that most of these volunteers experience dysautonomia or care for individuals who do. Managing chronic illness affects the pace at which any new projects can be implemented. But it is only because of the work of these sincere volunteers that DINET's activities are possible at all. Thank you for your genuine and earnest dedication!

There seem to be as many variations of dysautonomia as there are individuals with dysautonomia. Our causes are unique, our symptoms are numerous, and our treatments are elusive (and sometimes conflicting)! What we share in common is a desire to be understood, a desire to be well, and a desire to support others on their path to living functional, meaningful lives despite chronic illness.

Sometimes I am discouraged that we have not identified a single cause or an easy cure for dysautonomia. But mostly I remind myself that this is an exciting time to be alive. Whether or not a definitive explanation and cure arise within our lifetime, I strongly suspect that whatever advances are made will be helped along by us -- the persistent and important voices of patients, family members, and friends of the dysautonomia community.

It is an honor to be part of DINET and I sincerely appreciate the opportunity to travel this health journey with each of you.

Wishing you health and happiness,

Carrie Burdzinski,
DINET President

Do you have dysautonomia questions?

Do you have a question that you'd like to have answered by one of the Dysautonomia Information Network's medical advisors? Please submit your questions to Janie@dinet.org.

COMPRESSION STOCKINGS for DYSAUTONOMIA

By Linda N

Compression stockings are not just for those Olympic Marathoners looking like awkward knee socks below tiny running shorts or for those frequent flyers to prevent blood clots, but can worn by anyone throughout the day and can alleviate symptoms of both dysautonomia and Orthostatic Hypotension (OH). Dysautonomia is a disease that affects the autonomic nervous system, often manifested by a low blood pressure and/or a high heart rate upon standing (also, called Orthostatic Hypotension and/or POTS, Postural Orthostatic Tachycardia Syndrome).

Compression stockings come in a variety of different styles and grades to suit everyone's needs while making work and daily activities easier. Compression stockings are different than regular socks or hosiery. They are constructed to provide a certain amount tensile support around the ankle that gradually lessens up the leg (aka "graded compression" usually denoted in "mmHg"). This extra support can help alleviate the symptoms of OH and POTS, by normalizing the heart rate and blood pressure and reducing fatigue.

How compression stockings may help:

The compression of the stocking promotes better circulation throughout the entire body by creating better blood flow through the veins of our legs. Putting the right amount of pressure around the legs improves the functioning of the one-way valves within the veins and prevents the old blood from pooling (aka "venous stasis"). Instead, the old blood can then make it back to the heart and lungs where it receives a fresh oxygen supply. Improving the circulation in your legs will thereby make your legs less fatigued because they are not being fueled by the pooled, oxygen-deprived blood.

Wearing compression stockings promotes health in other parts of the body as well. For example, with less blood pooling in the legs, more blood is able to reach the brain. This can decrease the dizziness or lightheadedness that occurs with standing such as in those with OH. In addition, increasing the amount of blood returning to your heart and lungs may help, to some extent, with other symptoms of dysautonomia (ie: tachycardia, shortness of breath, palpitations, and, general fatigue).

What compression stockings may prevent:

There are a variety of venous disorders that benefit from the use of compression stockings. Daily, appropriate use can help with the management of spider veins and varicose veins, while preventing the new occurrence of other unsightly veins. Open leg ulcers, thrombosis, inflammation (of veins) are some of the more serious conditions that may warrant compression therapy under the supervision of a healthcare professional. For those without any apparent venous disease, compression stockings can still help alleviate swollen ankles at the end of a hard workday, while protecting against future venous disease.

Who should wear compression stockings:

Individual needs may vary depending on your medical issues and level of activity. It certainly may help with the venous disorders listed above and for those with dysautonomia. There are also compression stockings designed specifically for pregnancy and athletics. For overall, healthy individuals, wearing compression stockings during times of prolonged standing may improve leg fatigue and prevent venous problems later in life.

It is important to realize that not all companies that market their socks as "compression" offer the same quality of medical grading as more reputable suppliers. And remember, size does matter! Be wary of one-size fits all companies that don't provide detailed instructions on how to fit yourself before purchasing their product. Better yet, many medical supply stores will provide you with a free fitting for compression stockings from a trained professional.

The level of compression delivered by the stocking depends very much on the size and length of your calf or leg. Therefore, it is important to take careful measurements and wear the right size stocking. A poorly fitted stocking may feel very uncomfortable and may not provide very much symptomatic relief. Your height will also affect the size of hosiery that you should buy. Many companies therefore provide both petite and regular sizes. However, caution should be taken if you have any type of hypertension, neuropathy, or arterial disease. Compression stockings may not be useful in these cases. It is always good to consult your healthcare provider about wearing stockings, especially if you have a medical condition that would merit this discussion.

When to use compression stockings:

Compression stockings can be worn throughout the day, although it is best to put them on in the morning before any blood has pooled in the legs. The benefits of compression stockings can definitely be felt during periods of prolonged standing where gravity is the most likely cause of blood pooling. In addition, many athletes wear them to improve their performance during physical activity and to help with muscle recovery.

It is very important to remove compression stockings before sleeping or lying down. Removing the stockings before lying down will help your body to sense the right amount of fluid in your body, which is needed to prevent the worsening of your symptoms when you are not lying down.

On a personal note, I have worn compression stockings myself for the last 5 years to help lessen the orthostatic symptoms of my dysautonomia. In conjunction with medication and lifestyle changes, I feel like they played an important role in helping my recovery and reconditioning. When I am at school or Zumba, I'll use the 30-40 mmHg knee-high; when I'm at home (sitting usually), I'll wear the 20-30 mmHg. Although stockings alone are not a cure-all for dysautonomia, I have found that they lessen my feelings of lightheadedness and general fatigue, especially when I have to stand for extended periods of time. However, it is important thing to realize is that everyone is different and unique, as will be their journey to health. Trial and error is often necessary along the way, but eventually you will find what works best for you. Fortunately, compression stockings come in a variety of different grades and styles to suit everyone's individual needs as they are on their path to wellness.

Best wishes to everyone for better health and wellness!

meet the member

Robin & Tara Lynn's Story

In interviewing Robin, the mother and caregiver of her dysautonomia-affected daughter, I could not ignore the empowering yet cartoonish image that kept creeping into my imagination. Robin and her husband are adorned in matching super hero outfits. Their chests are puffed out and their capes blowing in the wind. They are flanking their daughter, Tara Lynn, in her own bedazzled uniform ready to fight the ultimate enemy, dysautonomia. Tara Lynn has a confident grin on her face, knowing that the thoughts and actions of this super hero team are so in sync that they will never be defeated by dysautonomia. My cheesy image grew from the many ways this family has worked as a unit to circumnavigate the roadblocks of dysautonomia, to facilitate understanding among friends and family, and to use this experience as a foundation to help others. They are one example of the countless parents and families who rally behind their children affected with challenging situations or illnesses like dysautonomia.

Tara Lynn was first diagnosed with Cholinergic and Cold Induced Urticaria as a child, though she presented several symptoms that would not neatly fit into that diagnostic box. Her array of symptoms, like early satiety, headaches, blood pooling and the inability to sweat, in addition to Robin's persistent quest for answers, led some doctors to give up on them. It led other physicians to professionally diagnose Robin and her husband, Dennis, with "hyper-vigilant parent" syndrome. After several rounds of doctors and a mass of dismissals, the family ultimately determined that Tara Lynn's Cholinergic Urticaria was secondary to dysautonomia and POTS. She was twelve years old.

Tara Lynn's life changed significantly throughout this process. She was a competitive dancer for nine years. Her symptoms overcame her when she was eleven years old—just short of reaching her goal to study Pointe. In school, she occasionally used a wheelchair, she could not participate in PE and she was unable to join her peers at recess. School, ultimately, became too great a struggle for Tara Lynn and the school administration was not particularly helpful or understanding. Her family made the decision to home school her. While Tara Lynn had dreams of becoming a doctor since preschool, she realized her body could not handle the vigorous training required to obtain an M.D.

Robin and Dennis did not become defeatists even though they had their moments of struggle, as we all do. Robin cried all day when she decided to purchase Tara Lynn a wheelchair. That day was the first time Robin was forced to physically see her daughter as disabled. She and Dennis took on the guilt for Tara Lynn's dysautonomia and, like so many other parents, it made them feel like they had damaged their daughter.

However, with every roadblock, with every small battle, this team banded together to find an alternative route, a way to give Tara Lynn a purpose and a future. Robin was determined to ensure that Tara Lynn's young, ambitious spirit would not remain broken. When Tara Lynn could no longer dance, she picked up violin. Her instructor allows her to sit during lessons and recitals, she works at Tara Lynn's pace and she gives her breaks when needed. When Tara Lynn was unable to participate in PE or recess at school, she used that time to tutor her struggling peers. Although homeschooling was an enormous step for this family, Tara Lynn was able to excel. Homeschooling also allowed her to choose outlets for positive socialization versus being exposed to the unsympathetic, negative attitudes of some peers at public school. Tara Lynn made a very pragmatic, mature decision to no longer pursue her dream of becoming a doctor, knowing that her body could not handle the stress of the required training. However, this allowed her to realize another passion—language and culture. She now wants to pursue a career in linguistics.

As a family, Robin, Dennis and Tara Lynn began to enjoy life at a slower pace. Dysautonomia taught them that they did not always have to keep up with the Joneses. Instead of being overcome by her guilt and sense of helplessness, Robin decided to research her daughter's conditions. She became empowered through knowledge. This knowledge not only strengthened Robin, but it also helped her spread a sense of understanding among friends and family.

To me, this is one of the most courageous and powerful things that Robin has done as her daughter's caregiver. Initially, Robin and Tara Lynn were isolated from many family and friends who did not understand Tara Lynn's struggle. Instead of dismissing these people as "not real" friends and family, Robin used her research to educate them. In her words, she worked to "make an invisible disease very visible." Many of us living with a misunderstood condition, myself included, often respond to people's offensive or ignorant actions and comments with anger. We can easily build walls between others and ourselves. Robin worked to break down these barriers and, as a reward, her friends and family have become understanding and helpful to Tara Lynn on her daily journey with dysautonomia.

Robin did not stop at educating friends and family. Neither did Tara Lynn. Robin documents their experiences on her blog at www.inrarecompany.blogspot.com. She also regularly participates in online forums and discussions to encourage and empower other parents. Tara Lynn creates videos for "Teen Potsy Productions" on YouTube. She also participates in a local group called "Miracle League", which allows her to be a kid in the company of other children with disabilities. She learned about "Dogs on Call" through this club, an organization that uses their dogs to cheer up others. She was so touched by the pups that she trained her own dog to be part of the league. I'm pretty sure Tara Lynn's puppy deserves a superhero cape, too! Robin and Tara Lynn not only found ways to overcome their own struggles with dysautonomia, but they selflessly share their strength with anyone who needs a dose of it. That sounds like superhero quality to me. In the words of social Media… #TeamTaraLynn&Parents

Gastrointestinal Symptoms, Mast Cell Activation Syndrome (MCAS) & Dysautonomia

PART I: Signs, Symptoms and How Physicians Diagnose

Written by Kelly Freeman, M.S.
*Edited by Matthew J. Hamilton, M.D.**

After years on the DINET forum, I have noted that one of the common problems discussed among patients are Gastrointestinal (GI) symptoms. Last fall, when Dr. Matthew Hamilton, at the "Mastocytosis Society's Conference" in Greenville, SC, spoke about mast cells and how they interact in our bodies to cause GI symptoms, I paid attention.

At the conference I hoped to learn more about mast cells because along with dysautonomia, I've also been diagnosed with Mast Cell Activation Syndrome (MCAS). I expected to be one of the only patients in attendance with both a mast cell disorder and dysautonomia. Strikingly, more than half of the patients I met had some form of dysautonomia (POTS), Neurocardiogenic Syncope (NCS), and/or Orthostatic Hypotension (OH). The corresponding mast cell disorders included patients with MCAS but also other disorders along the mast cell spectrum including IgE-mediated Anaphylaxis, Cutaneous Mastocytosis, and Systemic Mastocytosis (SM). Clearly, there is a connection between dysautonomia and mast cell activation (MCA), but what?

Not enough is known about MCA -- yet. However, it may be one of the more important medical findings of our time. In a follow up interview with Dr. Hamilton, he shared that there are many theories about the basic mechanisms of MCA that may contribute to GI symptoms including diarrhea and abdominal pain. For example, mast cells may activate near the nerve synapses in the smooth muscle walls surrounding the lining layers of the GI tract possibly changing the "leakiness" of the gut. At this time there is not enough clinical evidence to understand the full relationship between GI problems and MCA. We know that mast cells have the capacity to release chemical inflammatory mediators including; histamine, leukotrienes, prostaglandins, proteases and cytokines. In the GI tract, it is possible that these mediators may be affecting smooth muscle contraction (to increase or slow the propulsion of food through the GI tract) and may increase leakiness and mucus secretion (to cause more watery-type diarrhea). But understanding how MCA actually works in patients to cause symptoms, requires further clinical research.

POTSie Momsie

By Clare Armstrong

I am a mom, and I have POTS. I am not defined by my illness. And the ability to make that statement with confidence was not handed to me, it was earned. Here is the story of my journey to diagnosis.

I have had health issues since childhood, but when you are a child you lack the ability to discern what is "normal" and when something is more serious (parent intervention is key). My stomach was a problem for me as long as I can remember but it was always chalked up to over-eating or nerves. I was in the advanced distance running group in high school and yet sometimes felt extremely weak just standing in line to get my lunch. After passing out in several times in public (the shopping mall) and not so public (the shower), I began to guess that my body "didn't like me" (a phrase I'm sure every POTS patient has muttered at some point). I became frustrated and began to ask questions. That's when the diagnosis journey began.

At first, I was diagnosed with Irritable Bowel Syndrome to explain my constant stomach issues and told to "eat more yogurt" (HA!). I wore a 48-hour Halter Monitor and endured a grueling treadmill stress test and was diagnosed with Vasovagal Syncope after nothing concrete was found. I passively accepted these conditions, not completely convinced but also utterly overwhelmed with the multitude of possibilities that WebMD had to offer (hint: stay away from that "devil website" -- "stomach pain?" and within two seconds you might have cancer... or it perhaps just a virus. Talk about unnecessary anxiety!).

Fast forward five years and two children later and I was still pushing for answers. More than ever I needed to know what was going on -- not only for myself but out of concern for being home alone everyday with my babies. Upon another visit to my family doctor she suggested that I might have something called "POTS", a type of Autonomic Dysfunction. I went home and immediately started to Google this syndrome. Not surprisingly, I had never heard of it and was amazed at what I read. It was as if I had made a list of all my symptoms and someone copied and pasted it onto these websites. I was nervous and thrilled at the possibility that I might finally have an answer about why my body wasn't functioning "normally." I pushed to get an official diagnosis and a Tilt Table Test was eventually ordered. Upon miserably failing the Tilt Table Test within the first 3 minutes in the standing position, I was officially diagnosed with Postural Orthostatic Tachycardia Syndrome. I had a label and I was oddly proud.

Now, it's not like the clouds parted and the sun shone down on me and all my troubles melted away. But it was comforting knowing that I wasn't totally nuts. After so many years of symptoms you begin to wonder if you are crazy. Are you over analyzing your body? Are you just thinking about it all too much? After all "no one really feels good all the time."

Now that I officially knew what my challenge was, I could properly confront it and find out how to convey it to others. I found that the easiest way for me to describe my POTS symptoms to people is by saying: "Imagine when you are about a day out of recovering from the stomach flu. Your stomach is still unsettled, when you stand up you get dizzy, you feel like you need to take a nap after walking to the kitchen for a drink of water, even lifting the TV remote feels like a work out. That's how I feel every day."

Here comes the "mom" part of my equation. My children are my fuel to fight. I get out of bed every day for them. I attend cardiac rehab and consult with a nutritionist to make sure I stay strong and healthy so I can keep up with them. I want to be able to do whatever they want me to do with them -- and that takes a lot work on my part. I have to be conscious of my fluid and salt intake. I have to make sure I am getting plenty of sleep each night and plenty of calories each day. POTS has forced me to consistently and conscientiously take care of my body, which is a real commitment with two young children under my constant care. But it is do-able. With real teeth gritting determination, it is possible to do it all at a nice steady "POTSie" pace (with a few naps in there too when possible).

So this leads me to the point where I can stand (not for too long) and say with confidence: I am a mom, AND I have POTS, AND I am not defined by my illness. Watch out world, this lioness has finally found her roar and although it may be a bit timid and tired at times, it is not without fight.

This is a interesting research problem because MCA appears to be more common than initially thought. It is now implicated in many chronic medical conditions. Dr. Hamilton said, "I've never seen something so important" that we must better understand because most researchers studying MCA see correlations with other chronic illnesses. It is possible that MCA is occurring in conditions such as Irritable Bowel Syndrome (IBS), Fibromyalgia and Chronic Fatigue Syndrome (CFS). Emphasizing that without further study we can't be sure about the exact numbers, Dr. Hamilton said, "It is likely that all physicians see at least a handful of these patients in their practices…MCA may be playing a role in as much as 15-20% of the chronically ill patient population."

Another challenge is that very few physicians know how to assess, diagnose and treat mast cell disorders. Like dysautonomia patients, MCA patients present heterogeneously with complaints that differ greatly. This makes it difficult for doctors to recognize and diagnose MCA. It is also difficult to know to where one can refer the patient or where to find a local doctor to treat them. Further, most primary care physicians, ER physicians, and even specialty medical physicians are unfamiliar with MCAS. This is why it is helpful when patients know the symptoms and signs of MCA so they can help guide their medical care.

The 3 most common GI symptoms that accompany mast cells disorders are:

1. Abdominal Pain- (Some component of this is seen in nearly all MCA patients. Note: this is also common in many other GI issues.)
2. Diarrhea
3. Bloating

Additional GI complaints include: constipation, gastro paresis (slow emptying of the stomach), nausea, vomiting, and reflux (causing heartburn and occasional swallowing difficulties).

When patients are evaluated for the above GI symptoms, health care providers often consider and rule out other inflammatory conditions such as celiac disease, and inflammatory bowel disease (Ulcerative Colitis, Crohn's disease, microscopic colitis), infections (such as Giardia), malignancy (colon cancer), and functional GI disorders where there is no obvious abnormality detected on testing such as Irritable Bowel Syndrome (IBS). It is important to note that many of these disorders may present with similar symptoms so specific testing may be required to distinguish them.

An important clue that a patient may have a mast cell disorder is the presence of complaints and ongoing symptoms in many other organ systems (GI tract, skin, lungs) of varying severity and intensity. The symptoms may also include; flushing, dermatographism, memory/ concentration difficulties and headaches. Symptoms tend to wax and wane and may be triggered by various environmental factors such as certain foods, temperature changes, and strong inhaled scents. When present with dysautonomia it is common to have orthostatic issues, peripheral neuropathies and GI issues that trend towards the upper GI tract including gastro paresis, reflux, and nausea. Although Dr. Hamilton does not specialize in dysautonomia, he has seen POTS patients in his mast cell clinic. He noted, "MCA appears to be fairly prevalent in the POTS population."

In diagnosing a patient with MCAS, it is important that the patient and physician look to objective findings rather than relying on the symptoms alone. As noted above, it is also critical to evaluate for other conditions. Dr. Hamilton and others use the following criteria at the Center for Excellence in Mastocytosis at the Brigham and Women's Hospital in Boston:

1. A case history that fits with multiple organ symptoms as listed above.
2. Objective laboratory findings such as elevated mast cell mediator levels (such as tryptase in the blood serum, and metabolites of histamine and prostaglandins detected on a 24-hour urine specimen (n-methylhistamine and 11-beta prostaglandin-F2).
3. Significant improvement in some or many mast cell symptoms following medical therapy that blocks the mediators (trial of Benadryl with onset of symptoms).
4. No other condition that explains the array of presenting symptoms.

The process of diagnosing MCAS and other mast cell disorders along the spectrum can be lengthy and time consuming. It is important that both patient and physician are diligent, and that patients strive towards the detection of objective findings that can validate the suspected condition. Although this diagnostic process may be frustrating to the patient, having a high suspicion for a mast cell disorder is a valuable first step.

In the next 2014 DINET newsletter look for part two of this article: Part II: Recommendations, Treatments and Research

**Dr. Hamilton sees a large number of patients with various mast cell disorders at the "Center for Excellence in Mastocytosis" at the Brigham & Women's Hospital and the Harvard School of Medicine where he is on faculty. He specializes in both Gastroenterology and Immunology and has been studying the role of mast cells in intestinal inflammation in the laboratory and through clinical research.*

questions & answers

DOCTORS ANSWER YOUR DYSAUTONOMIA QUESTIONS

Q: *I'd really like to know why surgery has such an impact on my body. I have always had problems due to general anesthetics -- low blood pressure, high heart rate and I get very ill (bad headaches, severe vomiting) whereas having surgery under a spinal anesthetic was fine. Recently, after being in recovery from symptoms (due to being on Octreotide) from surgery, my dysautonomia came back. I had a spinal this time and it didn't make a difference. My blood pressures got low again and during surgery I got a few epinephrine injections. Is it the effect of surgery on my body or is it something in spinal anesthesia that made the dysautonomia flair? Octreotide seems to no longer help me. Thanks for taking the time to answer my question!*

Corina in The Netherlands

A: I think this is currently in the realm of opinion but is very interesting. I believe that there are a number of illnesses, disease states, and conditions of altered physiology including concussion, POTS when upright, surgery with general anesthesia especially if there are features of blood loss or effects on the circulatory system, certain anemias, obstructive sleep apnea, stroke, subarachnoid hemorrhage, etc in which abnormalities of cerebral blood flow occur and can affect the normal functioning of the brain particularly pertaining to cognitive tasks. After my own surgery I could not read for a week.

Sincerely,
Dr. Julian Stewart

Q: *Are there forms of POTS where a patient can have an abnormal tilt table test but a normal TST (thermoregulatory stress test)?*

Yvonne in OH

A: Thermoregulatory and other small fiber tests assess peripheral neuropathy, mostly sweat related which is controlled by the sympathetic nervous system. In many diseases such as diabetes, when there is a peripheral neuropathy there is also a circulatory autonomic neuropathy. However, this is not always true. Thus, many POTS patients have little or no QSART findings.

Sincerely,
Dr. Julian Stewart

Q: *I have been diagnosed with POTS/Dysautonomia by my neurologist, and cardiologist in Florida. I have also been told that at age 60 it is rare to have this autonomic condition. My symptoms certainly sound like dysautonomia, however there are not any doctors in this area that treat or seem to know much about dysautonomia. I have been referred to the Cleveland Clinic. My question is do you know of other patients who have this condition at my age?*

Thank You and sincerely,
Catherine in FL

A: Catherine, it's important to get an accurate diagnosis. A diagnosis of POTS requires the presence of appropriate symptoms and an objective evidence of heart rate elevation by at least 30 bpm during 10 min standing or a tilt table test. I don't know how your doctors arrived at the diagnosis of POTS/dysautonomia, but I recommend having complete autonomic function tests with Valsalva, deep breathing and QSART tests. These tests can be done at Mayo Clinic in Jacksonville, Fl or Cleveland Clinic in Cleveland, OH. These tests would make your diagnosis accurate. Yes, POTS can occur at age 60, but it is important to make sure that the diagnosis is accurate and based on the results of the autonomic function tests.

Sincerely,
Dr. Svetlana Blitshteyn

Q: *"Brain fog" seems to be a relatively well accepted symptom of POTS. I've read that the brain fog is caused by the lack of blood to the brain because of blood pooling in the legs. Is there any long term effect on brain function due to this repeated lack of blood supply? I don't have hypotension so I can force myself to stand even if I feel terrible while doing it. Is it ok to do this, or am I causing more damage? Thanks!*

Kirsten from MI

A: "Brain fog" is fairly common in patients with POTS and may be due, in part, to the reduced - not absent - blood flow to the brain. It's important to note that even if your blood pressure at the arm is normal or even elevated, you may still have reduced blood flow during standing secondary to impaired cerebro-vascular auto regulation. To our knowledge, there is no evidence that long-term brain fog in POTS causes any brain injury or damage - i.e. there is no evidence of cognitive impairment, dementia or cerebral atrophy on neuroimaging in patients with POTS.

Sincerely,
Dr. Svetlana Blitshteyn