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COVER STORY

THE TASTE & CRPS:

The story of a brave Pain Warrior

BY **AUDREY JOHNS**, CELEBRITY CHEF

Did you know that I suffer from one of the most painful diseases on the pain index?

Read my story below and hopefully you will be inspired no matter what disability you may have. You should never let challenges get in the way of your dreams!

Two years ago, after a surgery to repair my right hand, I was diagnosed with CRPS, also known as RSDS, and it is the most painful disease on The McGill Pain Index. The daily pain experienced is greater than natural childbirth, yet thousands of people suffer from this invisible disease daily.

The disease started in my right hand and in the last two years has spread to my entire right arm, lower back and both right and left legs. I'm lucky in that the physical attributes of my CRPS are minimal. Often people's joints become extremely swollen and purple, I'm lucky in that the swelling has not been an issue for me. The scars on my wrist often turn purple, but that's nothing a pretty bracelet can't cover.

This horrible disease claims more lives to suicide than any other cause of death, and why is that? First the pain is excruciating, it feels as though you're sitting in an electric chair with bolts of electricity running through the infected areas. More importantly I believe so many patients give up due to a lack of support. They lack of support from their families, friends and community.

Because it's an invisible disease CRPS patients are often criticized by those who don't "see" their pain. I used to have a handicap placard for the days my legs were exceptionally bad, but I stopped using it after a woman came up to me and my daughter after parking in a handicap spot. She cursed at me asking why I would steal

or borrow my grandmother's handicap placard. This all happened in front of my child! The woman was horrible and since then I would rather suffer in silence or skip leaving the house all together on painful days. Imagine what these words would do to someone on the brink of giving up their life.

Even family members who have known of my disease for two years forget about it and ask me to explain it all over again at family holidays. However I'm extremely lucky, I have an amazing support system in my immediate family and close friends. Without them I would have lost hope long ago. So needless to say when I applied for The Taste I had no intentions of sharing my disease with my cast mates, as I was worried that they would not believe me or assume I was looking for special treatment. I spoke with my doctor and got clearance to compete and went through a round of procedures called nerve blocks to numb the infected grouping of nerves in my right arm and left leg so that I could compete, hopefully without pain. I assumed, after being a fan of The Taste - Season 1 that we would cook for a couple of hours a day, something I was already able to do at home. So with high hopes I invested in some comfortable flats and packed my bags, eager to show that a CRPS Pain Warrior could achieve her dreams and I jumped on the train to Hollywood. When I arrived on set the first day I was feeling good, my nerve blocks were performing their magic and I was excited to get in front of the camera. I walked on the beautiful set and was in awe of all the lights, cameras and cooking stations, I was excited and ready to get the party started.

Then we started what the entertainment industry calls "hurry up and wait". What I thought would be a single two hour cooking day became three 18-hour days, far more than what I was used to doing at home. It was lots of standing around on concrete and sitting in cold metal chairs. My body quickly started to give out. While other contestants went out for dinner and dancing at night and on days off, I was holed up in my room taking long soothing baths and sleeping. The pain immediately



AUDREY JOHNS, CELEBRITY CHEF
WWW.LOSEWEIGHTBYEATING.COM

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started messing with my head, as when you have level 10 pain, your thoughts can become fuzzy and concentrating can be quite difficult.

I knew I was in trouble when I nearly collapsed on stage during the second show. While Jay and I were facing the music and getting our red stars last week, I was doing everything in my power to keep my legs working underneath me, even slumping down to the ground in between takes. I didn't want the other contestants to know so I just blamed it on my "bad back". I remember waking up the morning of the first day shooting for episode 3, I called my husband and told him I couldn't do much more. I put in a call to my doctor and arranged an emergency nerve block procedure for two days later when I knew I would have a day off. Yes, I said it, I was going to use my day off to have a medical procedure so I could keep competing!

I told my husband if it came to being eliminated and it was between me and one of my team mates I would try to bow out gracefully, but only if it was one of my team members. I knew they all were physically up to the challenge, all I cared about at this time was that Team Marcus would win, and if I could sit on the bench and cheer them on then that was good enough for me. So when Sarah's amazing dish was somehow picked as the least favorite in the team challenge; I knew it was time for me to go home. Forced to choose a person to go home, my team members all said my name, and I was relieved. I wanted to bow out but I did not want to "give up" so agreeing with them was the easiest thing to do. I would not fight to stay and take a spot away from one of my team members who could compete. For me it was a no-brainer, I couldn't take one of their spots for my own gain, in this moment it was all about the team!

Gasps were heard when I agreed that I should go home, and my producer Sean was actually mad at me for not fighting harder to stay. I assured him I had my reasons and would share them in my exit interview. No one knew, not the producers, not the director or even my mentor, Marcus knew I had been suffering in level 10 pain for 3 weeks on set. When we sat down to do the exit interview, I opened up about my disease and explained that I had not shared it in the beginning because I didn't want to be treated differently, but most of all I did not want it to come off as an excuse. I wanted to inspire other CRPS/ RSDS patients. I shared my story and quickly noticed that the gentleman in charge of sound was silently crying, he later told me that a family member of his has CRPS and what an inspiration this will be to her. When I cleaned out my locker I left notes to all my team members, telling them that I adored them and that there were no hard feelings, they still did not know about my disease. I told them to meet me in my hotel room for a champagne toast; I had something important to tell them. When the Green Team met for one last time that night I told them my story and told them I could no longer go on, even with the emergency procedure scheduled for later that week. The long hours were too much for my body to handle. They all felt awful for naming me to go home but I assured them it was all for the best. I told them how proud I was to be in their company and to be on their team and that I would be cheering them on.

So don't be sad that I'm going home this week, I'm proud of what I've accomplished and I hope to inspire CRPS/ RSDS Pain Warriors to stop saying, "I can't" and start saying "I will try" because it's far better to try and fail than to never try at all... And keep watching The Taste; you may see me again later this season!

There's much more in the works for this Pain Warrior, as I refuse to let this disease define me! I will define myself and use my disease to inspire others. No matter your disability, you can reach for the stars, and don't ever let your disability stop you from trying to achieve your dreams. My dreams of a cooking show are not lost, I now know my limits and I will keep pushing until my dreams become a reality! Watch out Hollywood, I'll be back soon! ■

FEATURE INTERVIEW

Two for the Price of One!

A husband & wife team assume the leadership of RSDSA as our new Co-Presidents while reminding us of our organization's inception.

BY **JESSICA L. BEGLEY**, MANAGING EDITOR,
RSDSA COMMUNITY UPDATE

Recently, I had the privilege of interviewing a remarkable couple, Mr. Hank Ludington and Mrs. Mary Beth Kenny Ludington of Princeton Junction, New Jersey. Hank and Mary Beth embody what it means to be a leadership couple — a husband and wife team working together for a cause greater than themselves. A couple solely devoted to one another and to leading a meaningful life. The original Dynamic Duo — 39 years of marriage later, along with 3 daughters, 2 sons-in-law, a brand new grandson, plus the combined work and life experiences they share, and they are still going strong! Hank and Mary Beth are generous with their talents, resources and time, all the while continuing to live with Mary Beth's 30+ years journey with CRPS. They embrace the differentiating value of unselfishness — acting generously, and regarding the welfare of others before oneself. This leadership couple

BRAD JENKINS PATIENTS ASSISTANCE FUND

Mary Beth & Hank would like to ask everyone who reads the community update to consider donating to this worthy cause! It is their goal to ensure that this patient assistance fund continues to serve those in need.

This fund was established jointly by RSDSA and the Jenkins Family in memory of their son, Brad. The fund is designed to help individuals with Complex Regional Pain Syndrome with some of the financial costs associated with living with this syndrome.

Individuals may inquire about applying for a grant sending an email to info@rds.org or by calling 877-662-7737.

demonstrates unselfishness on a daily basis as they spend countless hours raising awareness, promoting advancements in research and campaigning for new treatment options and hopefully a cure for RSDS.

They bring a wealth of personal and professional knowledge, compassion and an unshakable commitment to one another and to the RSDSA community, which is the bedrock of our organization and its founders. We are extremely fortunate getting these two for the price of one! With this husband and wife team as our Co-Presidents, we benefit not only from Hank's 35+ years of experience as COO of Citibank and President of the Premium Audit Division at American International Group, but we also gain Mary Beth's wealth of personal knowledge as a CRPS survivor and patient advocate along with her extensive service as a RSDSA Board Member. Just as the RSDSA founders were two married couples that met in a doctor's office and bonded over shared CRPS experiences with their daughters, Hank and Mary Beth are also a husband & wife co-presidential team that will use their own personal CRPS pilgrimage to guide them as they propel our organization into the future and to new heights!

With a vision to centralize the multitude of various support groups and RSDS/CRPS associations nationwide and to organize our own system of administration and governance within the Reflex Sympathetic Dystrophy Syndrome Association, these two courageous people plan to take our organization from a small kitchen table in a Connecticut home to the boundless Corporate Table. This necessary step forward will place our organization in the corporate arena and provide more opportunities to raise funds, awareness and recognition while also gaining more access to the public eye. With a continued commitment to the original mission set forth by our founders and their unwavering loyalty to one another, this Super Couple will certainly find a way to harness the energy and compassion of the RSDS family and achieve the global alignment that the RSDS/CRPS consortium requires in order to conquer this disease and finally find a CURE! ■

Dentistry and the CRPS patient

BY JENNY PICCIOTTO, RSDSA VOLUNTEER

Most of us are aware that there are factors that cause tooth decay for RSDS/CRPS patients. They include the following:

Medications which cause dry mouth. Saliva protects our teeth, reduces gum disease and dental decay. Information from an article found on the RSDSA website entitled "CRPS Patients and Dentistry: A Dentist's View" states: Many medications reduce saliva flow, causing a completely dry mouth (xerostomia) or they radically alter saliva thickness, causing it to be thick and ropey. Either condition allows bacterial plaque to grow faster and more tenaciously than normal. Combining this with a soft and sugary diet can wreak havoc on dental health. Many people who live with pain may rely upon "comfort" foods, which are often high in fats and sugars, causing overall health concerns and an increase in dental disease.

Bone re-absorption is another serious issue. The entire body is effected by bone re-absorption as the presence of inflammatory chemicals causes a change in polarization and bone material leaches out of the body, leading to osteoporosis (otherwise known as Sudeck's Atrophy). In the article "Systemic Complications of Complex Regional Pain Syndrome" published in Neuroscience and Medicine in 2012 by the Department of Neurology at Drexel University states in Section 8:

"Musculoskeletal System" states: "Bone and joint pain are suffered by a majority of CRPS patients. X-rays of the affected extremities demonstrate bone lakes (intracortical excavation) associated with periarticular, trabecular and periosteal demineralization and bone resorption [151]. These changes are thought to be the result of osteoclastic activation possibly from nociceptor release of substance P [152]. During bone resorption, activated osteoclasts reduce pH enough to depolarize pain afferents which densely innervate bone [151]. Magnetic resonance imaging often reveals bone marrow edema and triple phase bone scans demonstrate pooling in the late phase [151, 153] in 30 to 50% of patients. Pathologic fractures are very common in CRPS-I patients. A frequent fracture occurs in the 5th metatarsal bone. Most patients suffer fractures during their usual activities or with minimal trauma. Experimental evidence demonstrates that bone formation and maintenance are critically dependent on an intact small fiber innervation, which is dysfunctional in CRPS-I patients [2] [154-156]. These fractures are difficult to heal which may also be a reflection of dysfunction of bone innervation."

Needle stick Injuries. The primary issue for CPRS patients, in my opinion, is how to obtain effective dental care while overcoming the worries and concerns of receiving dental care which many fear may cause their CRPS pain to intensify. This fear is due to the dentist's use of needles, as many of us have heard of needle stick injuries causing CRPS symptoms to spread. The fear of surgical operations such as root canals and deep drilling, and inadequate sedation to prevent muscular tension and emotional distress are but a few of the concerns.

SLOW COOKER TURKEY BREAST

PREP TIME: 10 min / COOKING TIME: 10 hrs

SERVINGS: 10

Ingredients:

- 6 lb bone-in turkey breast
- 3 tsp olive oil
- Salt and pepper to taste
- 1 medium onion, quartered
- 4 garlic cloves, peeled
- 1/2 c water to taste

1. RINSE turkey and pat dry with paper towels.
2. PLACE turkey in the crock pot and pour the oil and water over the turkey. Sprinkle with salt and pepper. Be sure to place, meaty side up, in slow cooker.
3. PLACE the onion and garlic around outside edges of cooker.
4. COVER and cook on low 9-10 hours, or until meat thermometer stuck in meaty part of breast reads 180.
5. REMOVE from the slow cooker and let stand 10 minutes before slicing.
6. SERVE with creamy scalloped potatoes, cranberry salad, and corn or green beans.

NUTRITION: (per serving) 386 cal, 82g pro, 1g carb, 0g fiber, 0.5g sugar, 3.5g fat, 1g sat fat, 143mg sodium

I have come across two articles which provide advice for CRPS patients undergoing dental treatment. These articles may prove helpful for those whose dentists are unfamiliar with the risks and complications stated above.

These resources can be found at the following websites:

- a) http://www.rsd.org/pdfsall/Siegelman_Summer.pdf
- b) http://www.rsd.org/3/education/rsd_dentistry.htm

Another option is to work with your PM and your dentist to obtain appropriate “sedation” during the dental procedure to prevent pain during the dental appointment and reduce the inflammation after the work is complete. When I had a crown replaced, I was unable to manage with nitrous oxide and Novocain, and opted for a “Sedation Treatment” which included taking a Valium the night before the procedure, another the morning of the procedure, and receiving a sublingual agent which completely relaxed my body leaving me in a state of sub-alert but not unconscious anesthesia. I did have some swelling for a week afterward, but the procedure was comfortable for me and I am sure that if I were subjected to the same treatment using traditional methods, the simple muscular tension would have caused more follow up pain. To read about Dental Sedation go to: <http://www.kailuadentalarts.com/Sedation.aspx>

What is Sedation Dentistry?

“Sometimes referred to as “comfortable” or “relaxation” dentistry, the terms describe the feelings most patients experience during their oral sedation appointments. The purpose of oral sedation is to allow a dentist to work more effectively by helping a patient become as comfortable as possible with the use of sedative medications administered orally and sub lingually. Certain dentists and doctors have been specially trained using safe medications that help CRPS patients be completely comfortable while their dentistry is being done. One of the benefits of sedation is that patients remember little to nothing of their time in the dental chair by the next day. With sedation, a patient’s apprehension and hypersensitivity to pain is virtually eliminated, thus reducing the likelihood and severity of post-operative discomfort.” ■

TREATMENT

PeaPure and CRPS

BY JAN M. KEPPEL HESSELINK

There is a new, natural painkiller available, a molecule with a difficult name, palmitoylethanolamide, it comes as the supplement PeaPure and seems very promising for CRPS patients.¹

While analgesics may occasionally decrease pain in CRPS, very often increasing dosages are not well tolerated and patients refrain from treatment.

There is clearly an urgent need for new innovative therapies in CRPS that are not only effective, but also have a favorable profile in terms of side effects and drug interactions. In particular, multimodal treatment strategies for complex pain syndromes, such as neuropathic pain and CRPS, are needed to effectively alleviate symptoms. Multimodal therapy for CRPS means an optimal combination of analgesics, chosen in such a way to enhance efficacy and minimize the risk for side effects and drug-drug interactions. Palmitoylethanolamide (PeaPure), a natural painkiller is most suited for such an approach. Palmitoylethanolamide is a body-own compound produced in our body to bring balance in states of chronic pain and inflammation. Its safety and efficacy has been proven in many clinical trials in a total of many thousands of patients.² The compound is not only part of our body, but can be found in many foodstuffs.

Palmitoylethanolamide harnesses the endogenous regulatory mechanisms suppressing chronic neurogenic inflammation, and can be well combined with all other analgesics and co-analgesics as well as with topical compounded analgesic creams, such as ketamine or amitriptyline creams.

Combination of PEA with analgesics, such as tramadol, pregabalin, gabapentin, amitriptyline, and duloxetine, has not thus far been reported to create adverse interactions.

² How to use PEA in CRPS: dose recommendations

The first weeks one should (could) start with 3 times 400 mg PEA, either given three times daily, or in the morning 2 capsules and 1 capsule in the evening. After some weeks, in the case of insufficient effects, one should (could) increase the dose to two capsules three times daily (or two times daily). Response mostly occurs in the first 1-2 months.

The first things to notice are a general feeling of increased comfort, and a decrease of the intense peaks of pain. In the following weeks responders note a less intense inflammation (less swelling, less temperature differences, less redness or bluishness).

PEA is very safe and even in children doses up to 50 mg per kg Body weight were tolerated without side effects. For adults the max dose tested was 100 mg/ kg Body weight.

If after 2 months not sufficient results have been seen, one can either increase further (up to 30 mg PEA/ kg body weight) or try a week 3 times daily the content of a capsule under the tongue. Let it melt. The resorption via the oral mucosa might give an extra impulse in non-responders. As said, PEA can be combined with any kind of other medicine.

Patient example: 13 years of swollen feet and wheelchair

The case report published in article ¹ describes a patient suffering from intractable CRPS type 1 for 13 years. Due to her swollen painful feet and left knee she is wheelchair-

Description of PeaPure[®] 400 mg capsules

PeaPure[®] is a food supplement based on a natural and fatty-acid like compound. The substance palmitoylethanolamide (PEA) is a physiologically active molecule that the body produces naturally.

What the user should know prior to ingestion:

- There are no known significant side effects.
- PeaPure[®] can be taken simultaneously with other medicine. In case of doubt, it is recommended to first consult your doctor or a pharmacist.
- Use during pregnancy is NOT recommended.
- PeaPure[®] does not contain sugar, yeast, allergens, sorbitol, magnesium stearate, povidone or other ingredients.

bound. The combination of palmitoylethanolamide and ketamine 10% cream reduced her pain by more than 50% after 1 month of treatment, and a marked reduction in swelling and skin discoloration was noticed. Furthermore, she could walk independently again and she experienced no side effects. In a video the case is also presented. The value of PEA in other neuropathic pain states can be followed in reference 3-5.

How to get PeaPure?

Via the webshop of JP Russel Science, www.rs4supplements.com, or via PJ's Prescription Shop in San Diego, PJ is a compounding pharmacy in San Diego that carries PeaPure. They order in bulk from the Netherlands. ■

“There is clearly an urgent need for new innovative therapies in CRPS that are not only effective, but also have a favorable profile in terms of side effects and drug interactions.”

1. Keppel Hesselink JM. Treatment of chronic regional pain syndrome type 1 with palmitoylethanolamide and topical ketamine cream: modulation of non neuronal cells. *Journal of Pain Research* Volume 2013;6 Pages 239 – 245
DOI: <http://dx.doi.org/10.2147/JPR.S42417>.

2. Keppel Hesselink JM. New targets in pain, non-neuronal cells, and the role of palmitoylethanolamide. *Open Pain J.* 2012;5:12-23.

3. Keppel Hesselink JM, Hekker TA. Therapeutic utility of palmitoylethanolamide in the treatment of neuropathic pain associated with various pathological conditions: a case series. *Journal of Pain Research*, October 2012 Volume 2012;5: Pages 437 – 442

4. Gatti A, Lazzari M, Gianfelice V, Di Paolo A, Sabato E, Sabato AF. Palmitoylethanolamide in the treatment of chronic pain caused by different etiopathogenesis. *Pain Med.* 2012 Sep;13(9):1121-30.

5. Palmitoylethanolamide in neuropathic sciatic pain: clinical results; <http://www.neuropathie.nu/gliopathic-pain/normast-palmitoylethanolamide-in-neuropathic-pain-clinical-re.html>

Caregiver stress and strain takes its toll: Tips to help caregivers care for themselves

BY **JESSICA L. BEGLEY**, MANAGING EDITOR,
RSDSA COMMUNITY UPDATE

Caregivers often go through the same emotions as the loved ones for whom they are caring. They too fear the loss of control over their own lives and the lack of power they have to do anything about this new way of life. Add in feelings of guilt felt due to the inability to alleviate their loved ones pain and their new additional responsibilities and you have a recipe for caregiver stress.

Caring for a friend or loved one places stress and emotional strain on even the most resilient of people. Therefore, if you are a caregiver of someone with RSDS/CRPS, then you must be diligent to take care of and preserve your own health and well-being first. And while being a caregiver for someone who needs your assistance can be very rewarding, it can also take its toll. Caregiver stress is a common issue, it is the physical, emotional and psychological strain created from constant caregiving. And caregivers who experience constant stress are the ones most likely to deplete their own health. Many caregivers fall into the trap of believing that they are the only ones who can truly understand the needs of and adequately help their loved one. Therefore, they feel they must do everything themselves. Please don't make that same mistake! Take advantage of any resources and tools available to help you provide care for your loved one. And remember this... if you don't take care of yourself, then you won't be able to care for anyone else.

Watch for the following warning signs of caregiver stress and strain:

- Do you feel exhausted most of the time?
- Do you feel overwhelmed or irritable?
- Are you sleeping all the time or never sleeping?
- Have you lost interest in activities and hobbies that you used to enjoy?
- Are you gaining or losing a lot of weight?
- Do you feel depressed?

Consistently feeling overly stressed can harm your health, and as a caregiver, you're more likely to experience symptoms of depression and anxiety. In addition, you may not get enough physical activity or eat a well-balanced and nutritious diet, which will only increase your risk of future medical problems. Try and remember that your loved one needs you, but they need you to be happy and healthy.

Try the following strategies when you are feeling stressed:

Focus on the positive and on the things you ARE capable of providing for your loved one. Do not give into feelings of guilt or inadequacy!

- Be open and willing to accept help. Be prepared with a list of ways that others can help you and then let them!
- Stay emotionally connected. Do not give up friendships, social networks or activities that bring you joy. Whenever it is possible, make plans to get out of the house.
- A support group can be a wonderful source of encouragement. Join a support group or even better, more than one!
- Set health goals for yourself and then work to attain those goals. Stay physically active, get sleep and eat a well-balanced meal.
- Don't forget to visit your doctor. Always remind your doctor that you are a caregiver and don't miss appointments or yearly screenings.
- Investigate and research all possible resources and support services. Check at work and ask your human resources department about resources your company may offer, check out government funded support, local charities and churches and organizations such as RSDSA. ■

A Nurse Becomes the Patient – With RSDS

BY ASHLEY J. MCAFEE, RN

My journey started with a serious automobile accident in November 2006. My injuries included cervical spine injury, dislocated shoulder, 1st and 2nd ribs broken, brachial plexus damage, winged scapula and closed head injury. At the time, I was an operating room nurse, working with doctors every day. As my injuries healed the symptoms progressed, none of the physicians I was seeing as a patient could diagnose me. I had symptoms that would not go away and, unfortunately, they got worse – terrible, unrelenting pain, discoloration and temperature changes in my arm, and motor dysfunction. Fortunately, a surgeon with whom I worked in the OR, who was also active-duty military, suggested the possibility of RSDS – with the comment that he had “seen it before” in practice. I went through five doctors of different specialties at several major hospitals in the Baltimore-Washington metropolitan areas before finally getting a proper diagnosis of RSDS in 2009.

I had previously tried everything recommended — from biofeedback, massage, trigger point injections, to medications — even a pain psychologist. I have since undergone three shoulder surgeries on the affected side of my body to repair damage from the accident as well as placement of a neuro-stimulator in my cervical spine. My last surgery (the third shoulder surgery) was my best experience, and a true demonstration of what providers from different specialties can accomplish when they all come together for a patient. My orthopedic surgeon Peter Johnson, MD; anesthesiologist Harold Lee, MD; and pain management specialist Cecelia Gramsky, CRNP, all

communicated for both pre-operative and post-operative plans of my care. I assisted by providing them with the most current research available, which I was able to glean from the RSDSA, RSD/CRPS Research and Developments (on Facebook) and the nlh.nih.gov to name just a few. All were willing to take the time to be open to research results and suggestions, and to actually listen to the patient, and to treat accordingly.

As most people affected by CRPS know, such collaboration among providers and the patient is truly a rare occurrence, but one that should be applauded. Because of such teamwork, I was able to have an excellent outcome (by far, the best of my four surgeries). I continue to work in a less physically-demanding role as an RN Case Manager, where I have the opportunity to help others receive the services and equipment they need. I also provide staff education at the hospital where I work, promoting CRPS awareness. I hope my story inspires others to never give up hope. Continue to push through the pain until you get answers and suitable treatments.

Ashley J. McAfee, RN
MedStar St. Mary's Hospital
Leonardtown, Maryland ■

“As my injuries healed and the symptoms progressed, none of the physicians I was seeing as a patient could diagnose me.” – Ashley

Word Up!

BY JULI “WORDGIRL” MANZ,
RSDSA VOLUNTEER

dys·to·nia: noun \dis- t -n - \

Dystonia is a neurological movement disorder, in which sustained muscle contractions cause twisting and repetitive movements or abnormal postures.

Dystonia causes my toes to twitch and painfully curl under themselves.

Source: <http://en.wikipedia.org/wiki/Dystonia>

Mast Cell Activation Syndrome and CRPS

BY PRADEEP CHOPRA, MD

Complex Regional Pain Syndrome (CRPS) and Mast cells may be closely related. Inflammation and central sensitization plays a key role in CRPS. Mast cell has been known to be involved in inflammation and possibly central sensitization.

Blood is composed of many cells. Broadly speaking blood is a collection of red blood cells and white blood cells. White blood cells are a collection of many different type of cells one of which is called - Mast cell. Mast cells are also found in other parts of the body including skin, lining of the stomach and small intestine, around blood vessels, nerves, lungs, mouth, and nose. They are known for their part in allergy, wound healing, and defense against infection. They are part of the immune system that protects the body. Mast cells contain granules that are made up of histamine and heparin. They have an important role to play in the inflammatory process. When they are activated they release histamine. Histamine release causes the classical symptoms of redness, itching seen in allergic reactions. Mast cell disease consists of Mastocytosis and Mast Cell Activation Syndrome (MCAS). In Mastocytosis the body produces excessive numbers of mast cells. In Mast Cell Activation Syndrome (MCAS) the number of mast cells are normal, but tend to release their contents easily or what is known as they tend to degranulate easily. The chemicals released by mast cells especially histamine can cause a variety of unpredictable symptoms including anaphylaxis, skin rashes, vomiting, nausea, bloating, abdominal pain, flushing.

MCAS and CRPS: A study from the Netherlands showed that mast cells are involved in inflammatory reactions in CRPS 1. They play a role in the production of cytokines such as TNF- alpha. The presentation of MCAS is very diverse and may produce symptoms in most parts of the body.

Patients with MCAS usually present with diffuse pain. The pain is migratory, but is usually described as an aching and often severe pain. They may be diagnosed to have fibromyalgia or polymyalgia rheumatica by their physician when they fail to identify any specific cause. The pain usually affects joints and bones. It waxes and wanes and may migrate to different parts of the body. Patients present with symptoms of Complex Regional Pain Syndrome, chronic low back pain, interstitial cystitis. They also present with excessive hypermobility of their joints and are often diagnosed to have Ehlers-Danlos syndrome.

Patients with MCAS may present any or all of these symptoms:

- **Abdominal pain:** They present with intestinal cramping, bloating, and often diarrhea. They usually have nausea.
- **Mouth:** They complain of burning pain.
- **Lungs:** They have asthma like symptoms, shortness of breath, sinusitis, and cough.
- **Eye symptoms:** They may have difficulty focusing and redness of the conjunctiva.
- **Liver:** They may present with elevated liver enzymes and enlarged spleen.
- **Heart:** They often have symptoms of dizziness with low blood pressure, syncope, hot flashes, racing heart (tachycardia). They may even present with non-cardiac chest pain.
- **Pain:** They present with neuropathic pain, CRPS, headaches, joint pains, bone pain.
- **Neurological symptoms:** Brain fog, difficulty concentrating, forgetfulness, lightheadedness, vertigo, and tinnitus (loud ringing sound in the ears).
- **Skin:** MCAS may present with itching of the skin, hives, and flushing.
- **Blood:** They may present with abnormal bleeding.
- **Muscle:** They present with muscle pain, osteopenia (thinning of the bone), osteoporosis, and joint pain.
- **Bladder:** They may present with interstitial cystitis.
- **Symptoms in general:** They may present with fatigue, sensitivity to multiple drugs, environmental allergies and fever.

The diagnosis of MCAS is made based on clinical examination. Since the symptoms are widespread and heterogeneous, a detail clinical examination is needed. The symptoms may present in a waxing and waning fashion over months to years. They may have increased symptoms for a period of time and then they may have very few symptoms for a while. They usually start during adolescence or childhood and are often missed. Testing for Mast Cell Activation Syndrome may or may not be positive considering that the condition waxes and wanes. Some other tests that may be done are - blood test checking for histamine, heparin, and elevated tryptase levels. A urine test for methylhistamine during a flare-up may be helpful. A blood test during flare-up positive for increased eosinophils, basophils, and monocytosis may be observed. Other tests that may be done which are somewhat specific for Mast Cell Activation Syndrome include serum chromogranin A (in the absence of cardiac and renal failure, neuroendocrine cancer, and proton pump inhibitor use) and serum and urinary leukotriene and prostaglandin isoforms. Diagnosis is predominantly made with a clinical examination. Patients with MCAS often have large symptom free intervals and over the years these symptom free intervals become shorter and shorter. MCAS may also be diagnosed with a bone marrow biopsy, especially if mast cell activation syndrome is suspected with serum tryptase elevation and frequent unprovoked anaphylactoid events.

Treatment of mast cell activation syndrome:

- Avoid any identifiable triggers such as extreme changes of temperature, mechanical irritation, alcohol, certain medications such as aspirin, opioids, radiocontrast agents, animal venoms. Some patients may not have any identifiable triggers.
- Treatment with drugs for patients with MCAS is highly individualized. Each patient should be treated based on their symptoms and complications. Each therapy should be allowed for at least four weeks to see a suitable response.
- Multiple drug therapies should not be started at the same time.
- Histamine receptor antagonist (H1 histamine receptor blockers may be tried.)
- H2 histamine receptor antagonist such as ranitidine, famotidine should be tried.
- Cromolyn sodium oral pills may be tried.
- Slow release vitamin C not to exceed 750 mg per day.
- Ketotifen may be tried to stabilize mast cells and to block activating H1 receptors on mast cells.
- Symptomatic treatment for other symptoms should be continued. ■

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Massage Therapy Can Help Ease a Child's CRPS Pain

Complex Regional Pain Syndrome is a debilitating disease that can turn the life of a child upside down. Many children with CRPS live in constant pain and the recovery process can be long and difficult, but thankfully some new therapies are being discovered to help decrease their pain levels. Massage therapy has been used at multiple pediatric hospital outpatient clinics within the past few years. Massage therapy can provide a welcome oasis amidst the intense treatment protocols and offers a great deal of relief.

CRPS begins with a confused central nervous system.

Most of us, after some kind of trauma or accident, will begin to heal and recover. But for some people, a particularly traumatic injury will result in a nervous system that doesn't react or understand that the injury has healed. Children and adults with CRPS will experience all kinds of strange neurological symptoms, such as pain, heat, throbbing, flushing, pins and needles, and cold. Even the slightest touch directly to the affected area results in immediate and excruciating pain. How then, can massage therapy help? It does seem to be counter intuitive, but it does work.

Massage therapy is an opportunity for the child to take a rest from strenuous therapies and to be taken care of and nurtured.

A massage can be a welcome break from difficult exercise and stretches, the ordeal of attempting to desensitize a painful area, complex instructions, attempts to learn school materials in spite of pain, or even just trying to be a normal kid under difficult circumstances. Children with CRPS become hyper-vigilant about their bodies, because they are in constant pain until suddenly they are not — and that's the tricky part! Somewhere along the recovery process, children need to learn to trust their bodies again, and to not fear being touched. The turning point occurs

when the child starts to really relax and that is where massage therapy plays a crucial role.

Progressive desensitization is a common recovery protocol in pediatric CRPS, but is not required during massage therapy.

Using massage therapy techniques on children must be done with great care and the technicians need to be very careful not to touch the area of the body that hurts. A good therapist will let the child tell them what they will allow and what they feel is acceptable. When a child is made aware that this form of therapy is solely for the purpose of relaxation and not another desensitization exercise which can often prove painful, then once the child knows that no one will push them then they begin to relax. Massage therapy applied to the areas of a child's body that can be touched, coupled with some specific foot reflexology and craniosacral balancing, can decrease pain. After all — touch has been proven to stimulate the production of endorphins, which is the body's own natural pain killer.

For children with CRPS, massage therapy can be a very helpful addition to the treatment plan when performed with respect and attention to the patient's individual needs. ■

YOUTH & ADOLESCENCE

I'm Maddy Begley and This Is My Story

BY MADISON LYNN BEGLEY, AGE 10

CRPS AWARENESS WARRIOR

I remember the first day that it began to hurt. It all happened in a flash, a complete blur! It was right after softball practice, and it felt like I had a huge knife stabbing me in the side of my foot and I had never had this experience ever in my life. It was about to the point where I just wanted to cut my whole foot off of my body to get rid of the pain.

I had such extreme pain in my foot that I could barely walk off the softball field; I had to stop walking for a few minutes. And when I started again, it hurt so badly! I sobbed all the way home from practice. When I got home my Daddy carried me into the house and laid me on the sofa and I was still sobbing and shaking. My Mommy rushed over and gave me an ice pack; she was as quick as a race car driver getting to me. And next she brought pain relief medicine, placed a wet rag on my head and propped up my right foot on a pillow with the ice on top. The next day I couldn't go to school, instead I went to the foot and ankle doctor for the first of many times to come.

They checked me in at reception and soon the doctor came and asked me what had happened to my foot, what part hurt, what kind of pain I felt and if I thought it was broken. So my mom and I began the story about softball practice...then the doctor asked some more questions and then he took x-rays. He came back a few minutes later and told us that I had fractured the growth plate in my heel and arch and that I probably had planter fasciitis. He showed us the x-rays and gave me a cast.

But sadly, nineteen weeks, four casts, two months of physical therapy and one boot later — I was still dealing with an indescribable pain. Now that the boots, braces and casts were gone my foot should feel better, but it didn't! It was worse and getting worse every day! So we return to the orthopedist and after a long and painful

examination, more x-rays and many more tests... I heard the doctor say, "You have CRPS or what's also called RSDS. I am sorry that we didn't find out earlier."

The first thing I thought of was remembering my mom and what she went through two years earlier when she was diagnosed with the very same disease. I knew she was about to watch me go through those same steps.

At first, I was really worried that I was going to go through and feel the same hard time that she did and I spent an entire year without a mom! I did NOT want my mom to have a year or more without her daughter! So I decided right there and then that this disease would NOT beat me! It did not stop my Mommy and I am just like her, so it wouldn't stop me either!

Throughout the adventure of having CRPS/RSDS, I now know that my mom really helped me and she gave me the courage to get through the long steps of overcoming this painful disease. Even though there is no cure for CRPS/RSDS, you can still go through the steps of recovery and learn to manage it daily, maybe even go into remission like my mom, and encourage yourself to go back to living the same life you did before you were diagnosed!

Today I am feeling well and while my doctors have not officially told me that I've gone into remission, I know that it is on the horizon. I can feel it and I keep active and busy and that is a big help, as it keeps me happy. I still play softball – my first LOVE and I work with my fabulous teachers, principal, counselor and all my friends at school to bring about CRPS awareness and awareness for all rare diseases.

The Addition of a New RSDSA Program Offers New Hope

BY **LINDA LANG**, RSDSA BOARD MEMBER
& CO-CHAIR RSDSA SUPPORT
& ADVOCACY COMMITTEE

Living with the chronic pain and disability of RSD/CRPS is a tremendous challenge. The loss of who you were before the syndrome struck, the loss of financial security and even the loss of loved ones complicates things further. Add to that the feelings of uselessness, isolation, hopelessness and even deep depression and you have a formula for a life that doesn't seem worth living. This was my life for many years and many of you may recognize it as yours as well.

Right now there is no one medical treatment that helps everyone. The best treatment we know of for the time being is support. The Support Committee has established a new program we call Peer-to-Peer Conversations. We know that support groups work to help those with RSD achieve more fulfilling lives. This is an individual kind of support that we believe will have the same positive results. Well-screened volunteers have committed to supporting those of you who are struggling with their lives. This will provide a conversation between equals, a conversation that will help you learn from each other to develop more satisfactory lives. You will feel freer to reveal your fears and your concerns because the person at the other end of the line will have experienced them as well. The end goal is to see yourself not as a disease, but as someone who happens to have RSD. RSDSA will help with information, tools and advice.

Science has discovered an interesting fact: your brain cannot process two sets of information at once. This means that you cannot feel pain while you are concentrating on something else. It is a matter of finding those things that can hold your interest. One Veteran with RSD told me he was more surprised than anyone else to discover he loved making jewelry. This has become his passion and he has been able to develop it into a business.

With patience and encouragement, each of us can find something we love to do even though we have CRPS. The possibilities are almost endless- it can be photography, art, or writing a story for a child. Some help others as a way of helping themselves. Whatever you find, it will help shape your life with a sense of purpose and a sense of pride. Uselessness and hopelessness will no longer be a part of your vocabulary.

Living with CRPS is a journey. Some of us get stuck at the very beginning, living a life defined by pain. Sometimes change itself is so difficult that we chose to live with the pain we know rather than take the chance on bettering our lives. This is the definition of being stuck. If we announced that medicine had come up with a treatment that would take away a good deal of the pain of CRPS with no harmful side-effects, we would probably all take advantage of it. This is no different. You just need to take a chance on bettering your lives. You need to find the courage to take the first step so that you are no longer stuck.

If you wish to volunteer, you will learn a lot from this experience. Please email me at LindaLang@rsds.org and tell me something about yourself. Include your email and a phone number. We especially need more teens and parents of children with CRPS.

If you wish to take advantage of this program, again email me at LindaLang@rsds.org, provide your email, phone number, and some brief information about yourself. We would like to match teens with teens, men with men, parents with other parents, etc. so that all peers will be able to share the same kinds of experiences.

It is our sincere hope that many of you will find the courage to involve yourself in this program. It is the best hope we have to change our CRPS community from victims to strong human beings, human beings who can come together to help make all of our lives better. Perhaps that strength can even translate into working together to find a cure for this disease. ■



[See more about the new Peer-to-Peer program on the back cover.](#)

Money Well Spent

BY DORIS SWERTFEGER

Each month a check arrives at the RSDSA office in Milford, CT with a Canadian postmark. It is a donation sent by a very important member and loyal donor, Mr. Shawn Ool.

“RSDSA makes a difference in connecting people with RSDS,” said Ool. Not that he personally has ever needed help from the organization. This humble donor does not have CRPS himself, but a friend of his does have the disease. Ool says he’s seen first-hand how debilitating the disorder can be and by giving to the organization he is helping bring about new treatments and possibly a cure for the disorder.

RSDSA interviewed Ool and Jim Broatch, executive director of RSDSA, to learn more about the impact his donations have had on our organization.

You do not have RSDS/CRPS, so how did you first learn about the disorder and about RSDSA?

Shawn Ool: I first came to hear about RSDS/CRPS from my friend’s girlfriend, with whom I later became friends. I heard about the really bad—worse than cancer patient pain—that RSDS/CRPS causes. I heard about the flare-ups and how the pain would be really just horrible. I later became a donor to RSDSA because I wanted to help her and the other people with RSDS/CRPS.

You’ve been a donor to the RSDSA for many years. What motivates you to continue to support the organization?

Shawn Ool: If I could do something to alleviate her pain and other people going through CRPS/RSDS then, well, that makes me very happy, like I contributed some good in the world, to making it a better place to live in. I hope to speed up the process of finding a cure, and also for there to be more effective treatments in the time leading up to a cure. Also, it’s reassuring to know that most of the money that is donated goes into funding RSDSA’s program services. And, that the money that goes into fundraising

generates a lot of money for RSDSA as well. Its all money well spent. RSDSA makes a big difference in connecting people with RSDS too, and I’m happy and excited to hear about the progress RSDSA is making.

We have donors from many different countries. How is the organization uniquely qualified as the national and international authority on RSDS?

Jim Broatch: Although RSDSA is based in the United States; our reach is global as evidenced by the two recent international scientific conferences organized by RSDSA to investigate activated microglia in neuropathic pain and recent advances in pain imaging. In 2012, RSDSA also funded an international conference in the Netherlands, which highlighted recent advances in CRPS treatment and research.

What impact has Shawn’s support had on our ability to fulfill our mission?

Jim Broatch: Ool is a unique RSDSA donor who first learned about this disorder when a close friend developed CRPS. Since 2009, Mr. Ool has consistently donated close to \$5000 to help individuals affected by CRPS, despite the fact that his donations are not tax-deductible because he is a Canadian citizen. We are utilizing his monthly gifts to provide support, education, and hope to everyone affected by the pain and disability of CRPS/RSDS and to drive research into more effective treatments and a cure. Through partnerships with members like Shawn Ool, the RSDSA is able to continue its mission driven work of providing support to all those who are impacted by the pain and disability of CRPS. If you would like more information about how you can help, please contact Jim Broatch at jwbroatch@rdsda.org or (877) 662-7737 or make your donation at RSDSA.org today!

PEER-TO-PEER CONVERSATIONS

The rsdsa Support Committee proudly presents a new peer support program.

VOLUNTEERS:

If you wish to volunteer, please do the following.

- Please contact LindaLang@rsds.org
- Please tell Linda something about yourself and your experience with RSDS
- Please include your email and a phone number where you may be contacted.
- We especially need teens and parents of children with CRPS to volunteer.

THOSE IN NEED OF SUPPORT:

If you wish to take advantage of this program, please do the following.

- Please contact LindaLang@rsds.org
- Please provide your email, phone number and a little bit about yourself.



SPONSORSHIP OPPORTUNITIES

HELP US BRING INTEGRATED SOLUTIONS TO CRPS TO...DALLAS!

WHEN: FALL 2014

WHERE: DALLAS, TEXAS

SPONSORSHIP: \$500

FOR MORE INFO: CHRISTINE HOMA, DIRECTOR OF DEVELOPMENT

CONTACT: 860.987.8994 OR CHOMA@RSDS.ORG



EVENTS CALENDAR

MARCH

17 — Saint Patrick's Day

1 - 31 — National Nutrition Month

Don't see an event near you?

Contact Christine Homa (choma@rsds.org) to discuss planning an event in your area!

APRIL

1 — April Fool's Day

20 — Easter

26 — RSD Festival, Kansas

1 - 30 — National Stress Awareness Month



THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

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P.O. BOX 502
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FAX: 203.882.8362
WWW.RSDSA.ORG

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