rsdsa
community update

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We are very pleased to publish our first print newsletter in two years thanks to the very generous donations by **Lynn and Michael Coatney and Dr. and Mrs. Lawrence and Judy Zager in memory of Hunter Lia Zager**.

RSDSA's income was adversely impacted by the pandemic and the print newsletter became a casualty of our reduced budget. To compensate, RSDSA began our monthly electronic newsletter, *In Rare Form*, because a single printed issue of this newsletter costs almost $14,000. All issues of previously published print and digital newsletters are archived on our website at bit.ly/rsdsanewsarchive.

This issue contains the most informative articles and important announcements previously published in *In Rare Form* as we realize that a significant number of RSDSA community members do not have access to the internet. It is our intention to publish additional printed issues as funds become available. To kickstart a print newsletter fund, we have included a special donation envelope with this newsletter. Thank you for your understanding.

Kelly Considine Joins RSDSA's Board of Directors

It is with great pleasure we announce that Kelly Considine will be joining the RSDSA Board of Directors in 2023!

Kelly developed CRPS in 2005 after an ankle sprain while playing volleyball. Since then, she has become a fierce advocate for CRPS Warriors across the globe through numerous efforts, including a Color the World Orange™ proclamation in Torrington, Connecticut.

She has taken on many roles within RSDSA over the years, such as Chairing the 2nd and 3rd Annual Virtual CRPS Awareness Walks and through membership of RSDSA's Development Committee, Patient Protective Task Force, and the Patient Representative on the Practical Pain Management Advisory Board.

Kelly has met with members of Congress regarding ADA accessibility and regularly participates in events as a part of Rare Disease Legislative Advocates' Advisory Committee. In addition to CRPS, Kelly also suffers from Ehlers-Danlos Syndrome (EDS) hypermobility, dysautonomia, Postural Orthostatic Tachycardia Syndrome (POTS), and gastroparesis.

Kelly resides in Connecticut with her service dog, Gunner. You can follow their adventures on Instagram at instagram.com/gunner_the_golden_boy.

INSIDE THIS ISSUE

RSDSA's sponsored scientific meeting on CRPS subtypes charts new direction for future CRPS research See. Page 4

INSIDE THIS ISSUE

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CALL FOR AUTHORS & IDEAS

Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? ***Is there a special topic you would like to see included in the RSDSA Community Update?*** *We would love to hear from you. Please email your thoughts to info@rsds.org.*

SPECIAL THANKS

Our title sponsors make RSDSA events and awareness activities possible. Please join us in thanking and supporting them! Abbott | The Baker Family Charitable Fund | Diana and Peter Smith in memory of Stephanie Theresa Smith | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager | Lynn & Michael Coatney | The Cochran Firm, National CRPS/ RSD Lawyers

Updates

2022 Treating the Whole Person: Optimizing Wellness Virtual Conference Videos

Thank you to everyone who joined last month's virtual conference! All sessions were recorded and have been uploaded to the RSDSA YouTube Channel. Be sure to subscribe to our channel while you're there! https://www.youtube.com/@RSDSA/videos

Looking for a therapist trained in Graded Motor Imagery?

Last year, the NOI group launched a NOI clinician directory of clinicians who have attended a recent Explain Pain course. You can search by location in the filters, then in the search tab type graded and it will filter down to clinicians who have also attended a Graded Motor Imagery course: https://www.noigroup.com/clinician-directory/

Interested in writing for the RSDSA blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog! If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or to help those who may be in the same part of their journey as you, send us an email at alexisdavis@rsds.org.

Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines

RSDSA has funded the publication of the fifth edition of *Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines* in the May issue of Pain Medicine. The Guidelines are intended for a medical audience. We hope to publish a lay version for the CRPS community in the future. https://rsds.org/wp-content/uploads/2022/06/CRPS-practical-diagnostic-treatment-guidelines-5-edition.pdf

Moms and Future Moms with CRPS

If you are a mother or mom-to-be who has CRPS, then consider joining the Moms and Future Moms CRPS/RSD Facebook Group to find support and resources that you need during pregnancy and motherhood. https://www.facebook.com/groups/crpsrsdmoms/

WANTED

Individuals to:

- ✔ Set up a collection canister in your local grocery/convenience store.
- ✔ Plan an event with the help of RSDSA by emailing us at info@rsds.org.
- ✔ Fill up a Penny Pig with your spare change to help RSDSA sponsor children in pain at summer camp.
- ✔ Help educate health care professionals by promoting the availability of our accredited courses on adult and pediatric CRPS.
- ✔ Blog for our weekly Tuesday's Burn. Do you have a story or experience to share?
- ✔ Write an article for the RSDSA Community Update.
- ✔ Promote awareness of CRPS by sharing your story with TV or newspapers (we can help you).
- ✔ Share your story of hope. Inspire others who are struggling as you have.
- ✔ Join our peer-to-peer program (see our back cover.

Are There Distinct Subtypes of CRPS?

BY **STEPHEN BRUEHL** • PH.D.
PROFESSOR OF ANESTHESIOLOGY AT VANDERBILT UNIVERSITY SCHOOL OF MEDICINE, RSDSA BOARD MEMBER

In 2013, the U.S. Food and Drug Administration for the first time granted CRPS the designation of an Orphan Condition, providing important financial incentives for development of CRPS-specific drugs. Despite much promise, large-scale clinical trials funded by pharmaceutical companies over the past 10 years have failed to show efficacy for several potential CRPS drugs evaluated. As a result, development of promising CRPS interventions has been halted, to the detriment of those suffering from CRPS.

All of these FDA-regulated clinical trials have studied samples of patients meeting the current international diagnostic criteria for CRPS (i.e., the Budapest criteria). CRPS is a broad diagnostic category with multiple contributing mechanisms, and in many cases, any two given patients meeting diagnostic criteria may look very different due to various mechanisms being involved to differing degrees. For example, one patient may have an exquisitely sensitive cold limb in which touch is painful, whereas another may have a hot, sweaty limb that is extremely swollen. Large clinical trials carried out to date have all tested efficacy of the drugs in samples that lump together these patients showing very different CRPS characteristics, so in essence have tested drug efficacy in a hypothetical average CRPS patient. Intriguingly, results of some trials have hinted that the drugs being tested may have worked well in certain types of CRPS patients and not in others, resulting in overall negative findings for the average patient. This situation highlights the importance of testing potential CRPS interventions working via specific mechanisms in CRPS patients likely to be experiencing those particular mechanisms. This approach, termed precision medicine, is now quite common in cancer treatment but has yet to be applied widely in pain management.

For a precision medicine approach to be applied successfully to improve treatment of CRPS, it is crucial to identify mechanistically-distinct subtypes of CRPS patients. On September 18, 2022, the RSDSA sponsored a meeting of international CRPS experts in Toronto, Canada with the goal of coming to a consensus as to the key CRPS subtypes relevant for targeting in future clinical trials and to identify the mechanistically-relevant interventions for each. Attendees included Stephen Bruehl, Norman Harden, Gary Bennett, and Peter Moskovitz (U.S.); Candy McCabe (U.K.); Frank Birklein, Ralf Baron, Heike Rittner, and Christian Maihofner (Germany); Peter Drummond (Australia); and Lone Knudsen (Denmark). All participants reviewed the research literature relevant to CRPS subtypes prior to the meeting and made recommendations based upon this literature review and their own clinical experience. One broad recommendation was to focus on subtypes of CRPS-I in precision medicine trials given potentially unique involvement of neuropathic pain mechanisms in CRPS-II. Although optimal subtype terminology remains to be determined and there may be some overlap among subtypes, the group identified several potentially distinct CRPS subtypes supported by existing research. These include:

1) Warm vs. Cold CRPS (overlaps to some extent with #2)
2) Early Acute vs. Persistent CRPS (Immune/Inflammatory vs. Non-Inflammatory)
3) Sympathetic-Mediated vs. Non-Sympathetic CRPS
4) Regional vs. Centralized + Regional CRPS
5) Sensory CRPS Subtypes (Thermal Hyperalgesia vs. Sensory Loss vs. Allodynia)
6) Painful Bone CRPS vs. CRPS Without Bone Involvement
7) CRPS With and Without Significant Psychosocial Involvement

As a proof-of-concept to demonstrate the value of targeting specific interventions towards distinct CRPS subtypes to optimize intervention responses (i.e., precision pain medicine), the group recommended initially conducting a clinical trial focused on Warm vs. Cold CRPS subtypes. The trial would use objective temperature asymmetry (≥1.5-2.0 deg C) between the affected and unaffected limb to identify patients with Warm CRPS (i.e., affected side warmer) vs. cold CRPS (affected side colder). Patients with atypical symptom patterns (Early Acute Cold CRPS and Chronic Warm CRPS) would be excluded. Based on prior research and hypothesized mechanisms, the intervention provided to both groups would be high dose oral steroids, with the expectation that steroids would be significantly more effective for pain and CRPS symptom reduction in the Warm CRPS group than in the Cold CRPS group.

RSDSA is committed to funding this type of proof-of-concept trial in order to demonstrate to the field of CRPS research the value of adopting a precision medicine approach for optimizing CRPS intervention efficacy.

SCAN THE QR CODE TO DONATE

Support RSDSA's End of Year Appeal

For the second year in a row, the pandemic has impacted all our lives. Some of us have lost loved ones, some have lost their livelihoods, still others have lost their good health. Many businesses, including non-profits, have had to close their doors. We were fortunate here at RSDSA. We were able to continue serving those who suffer from unimaginable pain, for whom the isolation imposed by COVID-19 is particularly devastating. Your generosity made that possible.

Your donation enabled us to expand our online presence during the pandemic. By helping us raise awareness of new pain management techniques, you provided hope and critical information to the community plagued by constant pain, a community which too often considers suicide their only option. Last year, we lost 244 individuals that way. At each of our presentations, over 1,000 CRPS Warriors have taken the opportunity to become informed and to engage with others. With your help, we will continue providing information and support to our community. Together, we can work to reduce that staggering statistic.

Your support gives hope. You help provide a place where one can search for information on the latest research and treatments. Your contribution enables the community to share experiences and connect with others.

Finally, you helped us publish the 5th edition of CRPS: *Treatment Guidelines* (last updated in 2013) an invaluable resource for both the medical community and those with CRPS.

None of this is possible without you! Please consider making a gift to our end of the year appeal here. TOGETHER WE CAN MAKE A DIFFERENCE!

The Importance of Developing a Special Care Plan for ED/ Hospital Care

CRPS Warrior Jeff Doyle has several health conditions which necessitated frequent trips to Emergency Department (ED). In the beginning, the ED and hospital were not helpful as they were not familiar with CRPS or his comorbidities. He was treated as a "drug-seeker."

After several visits to the hospital and advocating strongly for himself, Jeff successfully had what's called a special care plan put in his electronic health record. This notifies the staff when he goes to the ED what are his health conditions, his medications, and his special needs. It took two years to establish this plan.

But now, when Jeff recently went to the ER with his care plan in place, it was flawless. He arrived, was admitted, and they started administering pain medicine. His recommendation is that others with CRPS schedule a meeting with the hospital social worker to set up a special care program.

A special care plan will allow you to go into the hospital and be known. Now the Danbury, Connecticut ED has stopped dismissing him as a drug-seeker.

Asking for Help: Why Does it Feel so Hard?

BY **ELISA FRIEDLANDER** • LMFT

What Does Grief Have to Do with It?

It's that time of year, when we tend to make more space in our lives for gratitude, giving, and even miracles. And considering the unique challenges of this particular holiday season, perhaps we're turning toward these notions even more.

Yet even in non-pandemic times, the holidays can be difficult, especially for those dealing with loss of any kind. Feelings of longing or loneliness are especially highlighted in contrast to seemingly unending snapshots of togetherness on social media and television's portrayal of the ideal.

Part of the fallout that comes from a CRPS diagnosis – and any condition causing high-impact chronic pain – is that we begin to see ourselves through the lens of what we did, and who we were, prior to life with intractable pain. In other words, we become involved in an intimate relationship with grief.

When we ask for help it can remind us (consciously or not) that we're no longer able to do things we could do pre-diagnosis days, at least not in the same way. On a deeper level, needing help can remind us that we've lost a part of ourselves. No wonder the topic of asking for help is so weighted. Who wants to open up to feel that sense of loss? Who wants to be reminded about something that's so hard to accept?

A Foundation of Self-Acceptance

A friend of mine who, gratefully, does not live with a pain condition, recently lost one of the most important people in her life, her precious aunt. Not knowing how I could possibly help (*do we really ever know what to do or say when somebody dies?*), I reached out to express my condolences, and asked if there was any way I could support her in this time of grief. She responded by saying she finds poetry to be of comfort and asked if we could read some poems together over the phone (if not for the pandemic, I imagine we would have met in-person, somewhere in nature).

As much as I love poetry (and all things related to the written word), it wouldn't have occurred to me to offer to help her in this way, and hearing her request gave me a surprising sense of relief. I couldn't bring back my friend's loved one, or take away that gut-wrenching sorrow, but I could - in a clear and concrete way – give her something she needed.

I also felt a sense of admiration. I don't know if she would have directly asked me for these poetry sessions if I hadn't reached out, but she responded, and did so with clarity and a quality that should always be a priority for people with high-impact pain - *self-care*. Ultimately, my friend's ability to make this request came from a place of self-awareness, as if to say, "*I need the comfort of poetry right now" and self-acceptance, which might sound like this: "I'm in a lot of emotional pain… I lost somebody I love dearly" or, "As hard as it is, I will feel these feelings of grief", or "I don't need to go through this alone"*.

> *"Why not find ways to let our loved ones experience what my friend gave me - the chance to help in a concrete, doable way."*

Challenges to Asking for Help

Most people have at least some skills to communicate their need for help. So, what gets in the way?

My friend had clarity about what she needed, but her response, and why it was so striking to me, was not the norm. Most people have difficulty identifying what they need from a loved one in the first place (which of course makes asking for help impossible).

Another barrier to asking for help has to do with feelings of vulnerability. As children, we didn't learn how to express our vulnerabilities (much less how to grieve, or how to ask for help). Underneath that vulnerability usually lies a sense of fear, so it's helpful to ask ourselves, "What am I afraid of?" For some, the fear is about appearing weak; others fear rejection or even abandonment. All of these feelings are amplified by the magnitude of physical pain and other symptoms secondary to CRPS.

We must also acknowledge our societal value of independence (and our hard-wired propensity toward it), and look to our family upbringing and cultural beliefs to understand our feelings and behaviors about asking for – and receiving –help. From that point, we can move to a place of self-acceptance and make choices that are in our best interest. Easy-peasy? Nope, it's a psychological process made more doable by – you guessed it, getting some help!

Chronic pain also tends to evoke feelings of guilt. If you feel guilty about asking for "too much" from people, consider one of the greatest antidotes to pain and suffering: being of service. Contributing to the world, even in small ways, connects us to humanity and gives us a role in repairing society. When we ask ourselves, "How can I be of service to others?" we show up more presently in all of our relationships and worry less about asking for help.

Like my friend did, we must allow ourselves to grieve and become open to self-acceptance. Only from that place can we become curious about what we need and ask for it, and we can best learn this through mindfulness practices (e.g., meditation, journaling, yoga). Mindfulness practices should be part of our daily lives, as they are the entrances to self-acceptance.

Asking for Help and Needing Help

Ask yourself if one of these statements resonates more:

"I don't know how to *ask for help*" or

"Asking for help feels *awful* because I don't want to accept that I need the help?

However related, distinguishing between these two issues is the place to start. Here are some tips for both that I hope you find helpful.

- Clear communication (begin from a place of "I…")
- Specificity (ask – in simple terms – for exactly what you need)
- Express gratitude (versus apologizing for needing help)
- Use your resourcefulness (access various means of support so you're not relying on only one person)
- When it feels particularly hard, shift to asking for help from a place outside of yourself. This, of course, is different for each of us, depending on our beliefs. We might ask:
    - *Please help me accept my pain levels today*
    - *Please help me find self-compassion in this moment*
    - *Please help me be okay with asking for help*

Where we might seek help for deeper inner-wisdom:

- prayer
- poetry
- angels
- nature
- journal writing
- G-d or a higher power
- a loved one who has passed
- the animal world (oh, the wisdom animals have to offer!)
- photographs
- the Universe
- the dream world

People who care about us want nothing more than to take away our pain. So, until a day comes when they can hand us the key to a cure, why not find ways to let our loved ones experience what my friend gave me – the chance to help in a concrete, doable way. These opportunities are sacred gifts, and who doesn't want an unexpected gift – especially this time of year.

Read a bit about my life at elisafriedlander.com/blog/independence-redefined, and my personal story of how I redefined the notion of independence.

Have you been told that CRPS is not real?

Eleven internationally renowned CRPS researchers have published a recent article in the Journal of Pain Research debunking this absurd assertion.

Their conclusion is, "the level of evidence for the claim that CRPS does not exist is very weak. Published accounts concluding that CRPS does not exist, in the absence of primary evidence to underpin them, can harm patients by encouraging dismissal of patients' signs and symptoms."

To access the article visit bit.ly/crpsreal

Food for Thought: Benefits of an Anti-Inflammatory Diet

BY **PAMINA BARKOW** • CNC

As a clinical nutritionist in a pain management clinic, I see people suffering in varying degrees of pain. Few cases have touched me on a personal level like those with advanced complex regional pain syndrome (CRPS). Perhaps that's because the more the medical field learns about CRPS the more we realize there are variables and unknowns and that often there are more questions than answers. Luckily, there are many indicators that show that changing dietary habits, specifically following an anti-inflammatory diet, can have a significant positive effect on people with CRPS.

What is inflammation?

Inflammation, from the Latin meaning "I ignite," describes the body's biological defense response to remove harmful or irritating events to our bodies and to begin the healing process. Inflammation is initially a positive and necessary response that can manifest as pain, heat, redness, swelling and loss of function. For example, if you fall and hit your knee and then it swells, inflammation is telling your body that your knee needs rest in order to heal.

Chronic inflammation has drastic effects on the body. Moreover, it becomes a self-feeding cycle that prevents the body from working optimally. Chronic inflammation has ties to cancer, diabetes, depression, heart disease, strokes, Alzheimer's, muscle loss, and many other conditions including pain, nerve damage, and CRPS.

CRPS is often described as injury to a nerve or soft tissue that does not follow the normal healing path. Many physicians agree that the complications and pain stemming from CRPS are due to exaggerated local inflammation. Basically, this means that if you have CRPS, you also suffer from chronic inflammation.

What is an anti-inflammatory diet?

An anti-inflammatory diet focuses on eating foods that heal and naturally reduce inflammation and also reduce triggers of inflammation. It means seeking out fresh greens, vegetables and fruits, giving up processed foods, watching salt and sugar intakes, eating whole grain carbohydrates, increasing intake of legumes and healthy fats, cutting out unhealthy fats, seeking out grass-fed and wild sources of proteins and increasing daily water intake.

Foods in an anti-inflammatory diet are nutrient dense; they provide a high nutrient ratio for the amount of calories. They are easy for our body to break down and extract nutrients from and in turn we get energy and healing agents from them. We call these foods anti-inflammatory foods because they literally promote calming of inflammation in our bodies. On the other end of the spectrum are foods that are difficult to break down, don't provide much nutrition, and actually increase inflammation in our system. We call these foods pro-inflammatory foods because they add fire to the inflammatory cycle.

Benefits of an anti-inflammatory diet

Following an anti-inflammatory diet provides the building blocks to:

- prevent further nerve damage
- help heal current nerve damage
- increase circulation
- improve sleep
- increase overall health
- restore optimal weight
- improve nutrient absorption
- increase energy
- decrease pain perception
- improve mood
- increase joint mobility
- prevent major and minor illnesses
- strengthen immune system

Super-foods and super-nutrients for those with CRPS

Four primary groups of foods directly fight inflammation:

Healthy fats, especially omega-3s, decrease cholesterol, hypertension, clumping of blood vessels, increase circulation, aid the cardiovascular system and are COX-2 inhibitors (decrease inflammation and pain pathways).

Examples: fish, olive oil, flaxseed oil, canola oil, walnut oil, nuts (especially almonds), and avocados.

> *"There are many indicators that show that changing dietary habits, specifically following an anti-inflammatory diet, can have a significant positive effect on people with CRPS."*

Foods that contain bromelain, carotenoids, flavenoids, and magnesium salicylate work to decrease inflammation in the body. Magnesium salicylate is even classified as a NSAID (non-steroidal anti-inflammatory drug) in high doses.

Examples: artichokes, spinach, sweet potatoes, apples, all berries, basil, mint, broccoli, cucumbers, parsley, onions, tomatoes, and many more.

Foods that contain amino acids glutamine and lysine. Glutamine aids in anti-inflammation, especially in the lower digestive tract, while lysine decreases inflammation by maximizing other molecules' effects of anti-inflammation.

Examples: fish, seafood, poultry, grass-fed beef, bison, soy, lentils, peas, and many more.

Anti-inflammatory herbs decrease inflammation by "altering the levels of molecules that stimulate inflammation."

Examples: Aloe vera, echinacea, garlic, ginger, licorice, tumeric and many more. In addition, those with CRPS benefit from a daily multi-vitamin, high doses of omega 3s capsules along with vitamin E (protects the anti-inflammatory powers of fish oil), complex B vitamins, and vitamin C (to increase circulation and blood cell production).

Pro-inflammatory triggers for those with CRPS

There are a number of pro-inflammatory triggers that are particularly important to watch, including:

Unhealthy fats (over-consumption of omega 6s and saturated fats as well as hydrogenated [trans] fats; found in high-fat cuts of meat and whole-dairy products) promote increases in blood cholesterol and LDL cholesterol as well as increases the risk for atherosclerosis, increased triglycerides, increased C-reactive proteins (which lead to inflammation) and decreased HDL (good) cholesterol. They increase the risk of heart disease and type 2 diabetes and contribute to the development of cancer. Trans fats are the worst of the bunch because they provide no benefit whatsoever.

High levels of sugar and empty carbohydrates (high glycemic index foods) provide no nutritional value and are pro-inflammatory. Sugars along with alcohol block absorption of many nutrients including water-soluble B and C vitamins that are crucial for people with CRPS.

Smoking (cigarettes, pipe or marijuana), exacerbates the activity of your body's inflammatory cells... and accelerates the formation of highly toxic and mutagenic substances... fueling inflammation.

Alcohol (regular drinking) raises your body's inflammatory level by increasing oxidative stress and blocks the absorption of essential nutrients (water soluble vitamins in particular).

Lack of sleep (less than six hours of sleep per night) raises pro-inflammatory markers IL-6 and TNF-alpha and C-reactive proteins. Sleep is also the time that your body uses to heal and create new tissue.

Excess weight/overweight not only promotes inflammation but is considered a "state of low-grade systemic inflammation," which is also a state of chronic inflammation.

Gluten intolerance does not simply manifest as digestive unrest or inflammation but it can cause nerve damage. Therefore, people with any sort of neuropathy, including CRPS, are at higher risk for having this intolerance. I suggest that people with CRPS do an elimination diet (remove all triggers) or some other type of testing to measure food intolerances.

Although CRPS can be difficult to manage, making even small changes to your diet can help you feel better.

Pamina Bakos is a clinical nutritionist, works with her husband Stephen H. Barkow, MD, DABPM, at Orange County Pain Management in Newport Beach and Mission Viejo, California. Learn more about them at painconsultant.com.

Mast Cell Activation Syndrome and Its Role in Pain

BY **PRADEEP CHOPRA** • MD
ASSISTANT PROFESSOR (CLINICAL) OF BROWN MEDICAL SCHOOL AND STEPHANIE CARROLL, RN OF THE PAIN MANAGEMENT CENTER IN PAWTUCKET, RHODE ISLAND

What are mast cells?

Mast Cells are normally found in our body. They are an important part of the initial defense system. These cells are found in most body tissues and tend to accumulate in tissues that have contact with our external environments, such as mucous membranes, the lining of airways, intestines, skin, and bladder lining, as well as being within the spine and brain. Mast cells contain many granules rich in heparin and histamine. When mast cells are activated they release compounds (also known as mediators) which cause inflammation (redness, swelling, pain). So, for example, if a person was exposed to a trigger (infection, allergy causing agent) or injury, the immune system of the body activates mast cells. These mast cells then head over the affected body part and release mediators that cause inflammation, resulting in pain, swelling and redness.

What is MCAS?

Mast Cell Activation Syndrome (also known as MCAS) is a condition where mast cells are inappropriately activated, leading to a wide array of symptoms. In MCAS, these mast cells start misbehaving. The inappropriate activation of mast cells causes persistent inflammation that is widespread in the body. It is important to note that the number of mast cells are not increased in MCAS. There is a condition called Mastocytosis where the number of mast cells are increased. MCAS and Mastocytosis are two completely different conditions. This article is about MCAS only.

Signs and Symptoms

MCAS can present differently in people. It is essentially a painful condition because it causes inflammation of tissue. Some of the symptoms are:

1. Rashes: unexplained, random rashes, patches of redness
2. Itching: unexplained itching in random areas of the body. They may complain of an itching sensation deep inside their body. Itching can be triggered by water (usually warm water), sun exposure.
3. Multiple chemical intolerances or sensitivities. They may be intolerant to perfumes, chemicals, foods.
4. Skin flushing after a shower
5. Temperature instability: patients report a sense of being either too cold or too hot.
6. Fatigue: the fatigue is very disabling. Patients report a feeling of 'flu-like' symptoms
7. Sweating: they may have unprovoked sweating, especially at night
8. Gastrointestinal symptoms: may vary from loss of appetite, bloating, nausea, alternating diarrhea and constipation, belly pain.
9. Weight: they may have weight gain or weight loss or fluctuations in their weight without any change in life style.
10. Headaches
11. Acid reflux
12. Hair loss, dry hair
13. Dry eyes
14. Ringing in the ears

However, one aspect of MCAS that is far too often underestimated is the amount and severity of pain it can cause. The prostaglandins released by activated mast cells can lead to significant bone, muscle, and joint pain. Tryptase, another substance released by inappropriately activated mast cells, can further increase pain. Other mediators released during this activation process can lead to headaches, fatigue, brain fog, and muscle cramping. Pain from inflammation is a prominent symptom in patients with MCAS. Mast cells are involved in causing and contributing to inflammation in both chronic and acute pain. MCAS can cause inflammation in almost any tissue including muscle, nerves, joints, intestines.

Mast Cells and CRPS

The immune system in our body is in constant communication with the brain and spinal cord (Central Nervous System). They communicate by 'text message' called pro-inflammatory cytokines (it means 'text messages' that promote inflammation). Over 70% of the brain is made of glial cells. These glial cells pack around the nerves in the brain. Mast Cells can activate the glial cells to release inflammatory chemicals that cause the neurons in the brain to become inflamed. This is the basis of some of the cases of CRPS-I. Not all cases of CRPS – I are a result of MCAS. Mast cells communicate with glial cells. Chemical mediators such as tryptase and histamine can activate glial cells. Once the Mast cells activate the glial cells, the activated glial cells then release other mediators (pro-inflammatory cytokines IL-1β, IL-6 and TNF) that cause neuroinflammation of the nerves in the brain, causing a sensation of severe pain. On the flip side, the inflammation as a result of misbehaving Mast cells can be reduced by medicines that inhibit mast cells.

When the skin in patients with CRPS was studied, it was shown to have increased Mast cell tryptase (one of the many chemicals released by Mast Cells). Mast cells in the skin are a major source of chemicals such as cytokines, histamines, and prostaglandins that causes inflammation. They sensitize the nerve endings in the skin.

It should be noted that not all patients with MCAS present with CRPS. In patients who already have pain from an injury, if they develop MCAS, the pain may increase many fold. Unfortunately, pain is also a trigger for MCAS.

For people with MCAS, not all days are the same. There are some days when the mast cells are not as activated, which would show up as relatively low pain days. They may have some days when the mast cells are misbehaving and overly active. Those days, patients would have a lot more pain. A lot would depend on avoiding triggers, keeping the mast cells stabilized and blocking the effects of inflammatory chemicals released.

Diagnosis

The diagnosis of MCAS is frequently a diagnosis of exclusion. Patients present with array of baffling multi system symptoms. As a result they wind up seeing multiple physicians, who in most cases look at the patient from the lens of their own specialty and not holistically.

Due to the unpredictability of this condition on a day-to-day basis, testing may be unreliable. Consequently, many tests that are routinely ordered may come back as being within normal limits. This does not dispute the fact that many patients have debilitating and disabling symptoms. Yet, there are a number of tests for MCAS that can be performed, including a 24 hour urine collection for N-methylhistamine and Prostaglandin D2. Another test is tryptase levels. The tryptase levels in MCAS is normal in 85% of cases, which makes the test unreliable. Blood tests for histamine, Prostaglandin D2 and Chromogranin A are very difficult. The blood has to be drawn while the patient is going through a flare. The blood has to be chilled immediately. The patient has to be off a lot of medications, including ones that are used to treat MCAS.

For patients who have undergone a gastro-intestinal biopsy (usually done because MCAS affects the GI system a lot), a specialized stain for mast cells looking at the count and shape of the mast cells may be a far more useful test. In general, the diagnosis of MCAS is based on clinical symptoms and not as much on laboratory findings.

MCAS and COVID-19

MCAS may be a sign of many underlying autoimmune dysfunctions. Patients with MCAS are at increased risk when exposed to COVID-19. As mentioned earlier, mast cells release inflammatory mediators such as cytokines. In patients with severe Covid-19 there is a cytokine storm leading to a state of hyper-inflammation. There is a suspicion that patients who develop a cytokine storm may have had a pre-existing MCAS, either as a full blown condition or as an underlying condition, making these patients more prone to the disastrous effects of COVID-19. Patients who have their MCAS well controlled may have a less severe time with COVID-19.

Management of MCAS

The management of MCAS has to be individualized to each person. A discussion on managing MCAS is very complex and has to be based on the patient's underlying condition, but it can be broadly based on the following steps.

- Anti-histamines.
- Mast Cell Stabilizers
- Avoiding triggers.
- Management of any underlying autoimmune dysfunction.

Ketamine and Low Dose Naltrexone: Some useful tools in your toolbox

BY **CHRISTIAN STELLA PHARMD** • ABAAHP

As the supervising pharmacist/ owner at Precision Compounding Pharmacy, I often come into contact with patients who all commonly suffer from chronic pain disorders. What is profoundly unique about compounding pharmacies, is that we have the ability to formulate and hand tailor a prescription, all with FDA approved raw materials and ingredients. Something to consider though, are the opportunities and specific guidance provided to you when you begin to work with a compounding pharmacy. There is a level of comfortability and a grasp of personal progression upon treating with a compound. This is something not often found in a Retail Pharmacy setting. The versatile nature of compounded medications allows pharmacists to formulate and treat with a myriad of different preparations, all of which meet and reach patient expectations, as well as preferences. Experiences such as the aforementioned, allow us to carefully treat conditions like CRPS on a case by case basis. As a result of CRPS having no specific treatment regimen or medication, it has become extremely common for CRPS patients/warriors to seek out the help and care of compounding pharmacies. At Precision Compounding, we are available at your convenience for consultation and counseling services. Additionally, we have multiple nationwide shipping options.

Extensive pain management experience and research has brought about some groundbreaking treatments of Complex Regional Pain Syndrome, or CRPS, one of them being the use of Ketamine. Ketamine is a rapid-acting, non-barbiturate dissociative anesthetic that was initially approved in 1970 in an injectable form. Ketamine works by blocking a receptor called NMDA (N-Methyl-D-Aspartate) which thereafter stops glutamate from activating excessive brain inflammation. What exactly does this mean for you? Ketamine works to stop the over excitations being caused from pain. As Ketamine is only currently approved as an injectable medication, it remains in the hands of compounding pharmacies to formulate and treat via capsules, creams, troches, suspensions, nasal sprays, etc., all of which are not commercially available through a retail pharmacy. At Precision Compounding Pharmacy, one of our most commonly used compounds is a Ketamine Transdermal formulation. For CRPS/RSD patients, our pharmacists recommend a simple formulation containing 15% Ketamine and 15% Lidocaine. We compound this in conjunction with transdermal pain cream, a highly absorbable base cream. This compound can be applied to any part/region of the body in pain. Lidocaine is a sodium channel blocker that works as a local numbing agent. Although Ketamine and Lidocaine work very differently in the body, they both help combat localized nerve pain. It is imperative for a patient with a chronic pain condition, such as CRPS, to have something in their toolbox to apply straight onto the affected area when they have breakthrough nerve pain. Transdermal pain creams including these two pharmaceutical active ingredients stay in the local area of application which limits the absorption into the bloodstream. As a result, this curbs the side effects drastically.

Ketamine is also very commonly used in a troche formulation. Troches may seem obscure and unfamiliar, but they are virtually identical to a throat lozenge that you place under your tongue or into your inner cheek. Troches are more frequently used by physicians in pain management, as they deliver the active ingredient, in this case ketamine, right into the bloodstream. Receiving a quick and efficient dosage form is important for a patient that is suffering from CRPS. Ketamine can also be dosed in a rapidly dissolving tablet, capsule, liquid suspension, and a nasal spray.

Another compound yielding profound results in the treatment of CRPS is Low Dose Naltrexone, commonly known as LDN. Naltrexone is commercially available at all retail pharmacies in a 50mg tablet dose, used to treat alcohol dependence and opiate withdrawal. In the 1980's, Dr. Bernard Bihari, MD discovered that naltrexone can be useful for patients with HIV/AIDS at a very small dose of 3mg. He coined this treatment discovery under the term low dose naltrexone. In using a notably lower dose, the naltrexone hits the opiate receptor and creates a negative feedback mechanism, therefore releasing endorphins. This process is essential and critical in treatment because endorphins are naturally produced to reduce pain. LDN also works by blocking the toll-like receptors which cause glial cell activation. This mechanism is known as the low dose naltrexone anti-inflammatory process. What is important to note here, is the role a compound pharmacy plays in dosing LDN, in efforts of creating these various anti-inflammatory processes. Compound pharmacists and doctors collaborate in formulating naltrexone on a case by case basis, as it is not commercially available at any dose other than 3mg. Patients with CRPS can benefit from treating with low dose naltrexone in various kinds of dosage forms. Some include, but are not limited to capsules, tablets, creams, suspensions, and troches.

Now, let us put the pharmaceutical jargon aside. Your journey(s) with CRPS is something I am a part of. Not as your pharmacist, but as yet another system of support. I have made it a promise and goal of mine in my professional career to help combat the symptoms and struggles of this disease. Each and every warrior story I have come into contact with has left a lasting impact on me and gives me all the more reason to help your community to the best of my abilities.

Learn more about Precision Compounding Pharmacy at precisionpharmacy.net.

ERs Are a Minefield for People Struggling With Chronic Pain

Dr. Amy Baxter has written a down-to earth, practical guide how to successfully navigate interactions with ER staff when you are seeking relief from chronic pain flares. Here is her introduction: "As an emergency doctor, I know that not all of my colleagues understand chronic pain. To make matters worse, the healthcare environment in the US often pressures doctors to see a new patient every 15 minutes, leading their empathy to wear thin. In the spirit of making things better for both the patient and the doctor, below are a few ways to have a more successful experience in the emergency department (ED). While it's still possible you'll end up with a doctor that seems burned out, these tips should help you communicate what you need in a way that an ED doctor will respond to and respect."

Read the full article at bit.ly/speakingdoctor

Emergency Department / Urgent Care, Hospital, Dentistry, and HCA Guidelines for CRPS Warriors

The RSDSA team has worked with CRPS Warriors and medical professionals over the years to create guidelines to help improve their care before setting an appointment and before a procedure. These guidelines can be accessed online and can also be printed out and kept handy as a part of one's medical toolbox.

Take a look at our current guidelines:

- Emergency Department and Urgent Care Guidelines for CRPS/RSD Patients: bit.ly/crpserguidelines
- Hospital Guidelines for CRPS/RSD Patients: bit.ly/crpshospitalguidelines
- Dental Guidelines for CRPS/RSD Patients: bit.ly/crpsdentalguidelines
- Healtcare Assisant (HCA), Personal Care Aide (PCA), Certified Nursing Assistant (CNA) Guidelines for CRPS/RSD Patients: https://bit.ly/crpshcaguidelines

Living with Chronic Pain: My Path to Freedom

BY **CRPS WARRIOR REBECCA** (LAST NAME OMITTED FOR PRIVACY)

I was injured in a work-related accident in 2011, and sustained significant damage to my leg and ankle. I fractured my fibula, dislocated my knee, tore my peroneal tendon, and damaged my peroneal nerve. Ultimately, in 2014, I was diagnosed with Reflex Sympathetic Dystrophy, now referred to as Complex Regional Pain Syndrome. By 2016 I was begging God to take me.

Throughout the first five years, I did everything in my power to improve, but I couldn't break free from the unrelenting pain. I kept going to physical therapy despite an increase of pain. I tried all of the recommended medications, none of which I could tolerate long term. I did all the standard procedures recommended by my pain management doctors, including injections and nerve blocks. I attempted a series of Ketamine infusions but was forced to discontinue them due to severe side effects. I was devastated because Ketamine gave me miraculous pain relief for the very first time since I was injured. It was a terrible blow, and I began to lose hope that I would ever find relief. I had two surgeries on my ankle, and three surgeries on my knee. Some were successful, some not.

I took steps toward emotional and mental health as well. I tried to continue practicing meditation every morning as this was my routine for over 20 years prior to my accident. I knew that I had to stay disciplined because if I didn't, that would mean I had completely lost myself on the very deepest level. I tried my best, but pain was a major distraction. I also spent one year seeing a Pain Psychologist every week. This was my saving grace. I was fortunate to talk with someone who understood the hopelessness a person feels when they lose their livelihood, their career and their body as they knew it, to chronic pain. By 2015 the CRPS had spread up my left leg and into my left arm. For the first time in my life I could truly define agony and despair. Although my Pain Psychologist gave me a safe place to express my feelings and to examine the enormous losses I was suffering, my depression and anxiety still held me down. I wasn't able to climb out from under it. With no relief in sight, I truly wished my life would end. My desperation scared me. I didn't trust myself anymore. I thought if the opportunity presented itself, I would choose death. Finally, one day I told my doctor that although therapy had been invaluable, it was not enough. I needed more.

He understood and told me about the Inpatient Pain Treatment Program at Johns Hopkins Hospital in Baltimore. He described the program to me and sent me home with a packet of information about it. There were aspects of the program that sounded perfect for me, and there were some that would give anyone pause, but I was truly desperate and willing to do anything.

I was terrified the day I admitted myself into the hospital in 2016. The unit was located on a locked floor where I was not permitted to bring any items that could potentially hurt me. The staff was kind, professional and most of all, empathetic. Never once did any doctor or nurse question my level of pain. That made me feel comforted and understood. They operated under the assumption that what we feel is to be taken as truth. No judgements, no feeling criticized or being doubted.

While the medical team worked diligently to find the right combination of medications for me, I was kept very busy with an interdisciplinary program which was designed to treat all aspects of life with pain. It included a host of therapeutic modalities used to educate and develop coping skills for chronic pain patients. Twice daily I attended nurse-led classes where I was constantly learning and developing skills relevant to life with chronic pain. Throughout the weeks I participated in physical therapy, occupational therapy, individual therapy, group therapy, bio-feedback, and learned about cognitive behavioral therapy. I used journal writing and art projects in my personal time as a creative outlet. I ate a healthy balanced diet and used that time to connect with other patients. I put everything I had into the program and found that I had become so busy engaging in healthy activities that pain was no longer the very first thing on my mind at every moment. Thoughts of pain were still there, of course, but more in the background. I would be amazed every time I would catch myself "not" focusing on pain. I had learned the art of distraction.

I stayed the course, and after two months Inpatient and one month in Day Hospital, I was well enough to be discharged. The combination of medications plus mental, physical and emotional support worked for me. Of course the pain was still there, and still is, but I had learned to separate the physical pain from the emotional pain. I left feeling renewed. Integrating back into normal life, however, was unnerving. Going from such a rigid routine to having total freedom scared me. I didn't know if I'd continue to be successful without the support I had grown accustomed to. But I was. This had been a life-changing experience. I had truly come to accept myself and my situation, and that changed my entire outlook on my future. I made the decision to carry on with grace and with faith that things were going to be okay no matter what, instead of living in fear and resentment. I understood that I am much more than my diagnosis, that I am an entire being with a life and a purpose.

These are some of the lessons gleaned from my time in the program at Johns Hopkins Hospital:

- The more I do, the more I "can" do.
- We are not alone. There are professionals who do understand and who are determined to help us.
- I can relate to all chronic pain patients, not just those with CRPS.
- Practicing mindfulness reduces stress, which reduces pain.
- Remember to challenge negative thoughts with fact-based evidence and replace those thoughts with positive ones.
- Eliminating alcohol, cigarettes, caffeine and sugar brings some relief.
- The way I feel physically is not a reflection of who I am as a person.
- My label, title, profession does not define who I am, and does not determine my worth. My heart and soul do. And they remain unchanged with CRPS.
- When I accept my situation instead of fighting it, a more hopeful outlook emerges.
- Most importantly *CRPS is not going to kill me, but depression could. So, treat what is treatable.

One of the aspects of the program that I missed the most was group therapy. I was unable to find a local support group, so six months after being discharged, I founded an in-person, patient-led support group which I facilitate in New York. Eventually I moved to Connecticut and started another support group. My goal is to start more groups in years to come. Connecting CRPS patients with one another has become the single most important thing I've ever done. I've had the pleasure of watching group members help one another, and improve the quality of their lives. Most are managing well and living full lives despite their diagnoses.

I feel extremely fortunate to have learned so much from my time at Johns Hopkins. The program helped to reduce my pain to a more manageable level, improve my functionality, and leave me with a hopeful outlook. I owe everything to my pain psychologist, Dr. Allen Lebovits, who put me on the path to healing by recommending me for the program. The Inpatient Pain Treatment Program at Johns Hopkins Hospital was nothing short of transformative. The outstanding team of doctors, nurses and staff saved my life. This experience changed me forever and I am forever grateful.

New Suicide Hotline Number Established

The 988 Suicide & Crisis Lifeline – formerly known as the National Suicide Prevention Lifeline – collaborates with more than 200 local crisis centers across the nation to provide the free, confidential service 24 hours a day, seven days a week.

The hotline is operated by the nonprofit Vibrant Emotional Health on behalf of the Department of Health and Human Services' Substance Abuse and Mental Health Services Administration. Learn more at 988lifeline.org

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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.

RSDSA UPCOMING EVENTS

WWW.RSDSA.ORG

JANUARY

- Facebook Live with Carol Charland-Cliche, Author & Wellness Coach

FEBRUARY

- Facebook Live with Apkar Vania Apkarian, PhD on Brain Mechanisms of Chronic Pain
- Louisiana Jeepers Jeep Show & Gumbo Cook-Off

MARCH

- Pediatric Networking & Fun Event - TBA

CAROLYN'S CARDS

Carolyn's Cards is a program led by Carolyn McNoldy that sends cards and other small surprises through the mail to individuals with CRPS and to their caregivers. Carolyn wants to help those feeling isolated or down to not feel alone, and to ensure they feel encouraged, supported, and part of a community. Most importantly, she wants to give them a smile.

The program was inspired by Carolyn's mother who would send her cards when she was down, in a lot of pain, or recovering from surgery as they would help to brighten Carolyn's day. She thought it would be great if she could reciprocate that feeling for others. She started sending cards to the attendees of the first Young Adult Weekend as a way to stay connected to them and show support. Carolyn was surprised to hear how much they genuinely enjoyed the cards. She has continued to add names to her list after each Young Adult Weekend.

If you would like to send a card to a Warrior as the holiday season approaches, please send the person's name and address to carolyns.cards2@gmail.com.

YOU CAN PLAN A SPECIAL EVENT WITH RSDSA

You can make a difference in the lives of CRPS Warriors and those who love them by organizing a special event. When you host a special event you increase awareness, build community and raise funds. Invite your friends, family, coworkers and everyone you know to get involved in our events.

You can organize in-person, virtual or hybrid events. Special events can be opportunities for fun, engagement, and education. Every dollar raised supports RSDSA's mission and makes our work possible. Your donations are gratefully received, impactfully used, and profoundly appreciated.

We are here to help you plan your own special event. When you are ready, please contact Jeri Krassner, RSDSA's Special Events Coordinator at jkrassner@rsds.org or call or text (917)597-7256

Please provide your email, contact number and your location.

Thank you

Don't see an event near you?

Contact Jeri Krassner jkrassner@rsds.org to discuss planning an event in your area!

Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rsds.org