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AN INTERVIEW WITH COCO VANDEWEGHE: TENNIS PRO AND CRPS WARRIOR

By **LAUREN BENTLEY**

Staying active while battling chronic pain can be extremely challenging. Some days, simply getting dressed can feel equivalent to running a marathon. The RSDSA recently sat down with Coco Vandeweghe, an American professional tennis player and CRPS warrior. At the age of just 28 years old, this California girl has certainly accomplished a lot. From Wimbledon to the U.S. Open, Coco has competed all over the world and, in 2017, earned herself a spot as one of the top ten tennis players in the world. Not only does she have one of the strongest serves in the industry, her drive to persevere through CRPS is equally as strong. Check out Coco's tips for managing an active lifestyle and career while having CRPS.

1. Please give us a glimpse of your background and career as a professional athlete
 - a. I come from a family of athletes, so I was always surrounded by sports my entire life. I have an older brother and when I was child, I did what most other younger siblings did and followed my big brother around. That's actually how I landed in tennis. He enrolled in lessons and I just tagged along. My mom saw that I had a pretty good eye and skill at a young age, so we decided to pursue it further. I didn't fully turn pro in tennis at a super young age, like so many other tennis players do, which I think has helped me tremendously over the course of my career. I try to maintain a life outside of tennis because that grounds me as a person, especially when you are on the road 35-40 weeks a year.
2. What do you love about playing tennis?
 - a. Tennis is amazing because it takes you to places all over the world and introduces you to a number of different cultures and traditions. When I was younger and first traveling on tour, I didn't appreciate the new places that I was introduced to. However, I now always take time in between matches to walk around the cities and explore as many new things as possible. I love tennis because it's an individual sport, and as much as I love team tennis competitions, I love that if I win or lose the match, it all falls on me. There is nothing better than walking out onto the court and then walking off with a win.

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This issue was funded by a donation in memory of Ronni Jill Zager by her parents Lawrence and Judy Zager

Read Dr. Joshi's article on Centralization of Pain on page 10

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Editor

Lauren Bentley

laurenbentley93@gmail.com

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

We would like to acknowledge our Corporate Partners whose generosity helps to underwrite issues of the RSDSA Community Update. Our Corporate Partners include Abbott, Baker Family Charitable Trust, Center for Pain Management, Edelman, Krasin & Jaye PLLC, Grünenthal, Law Office of Scott Callahan, Sutliff and Stout, NoPainHanna, Oska, Shirley Ryan Ability Lab, Vitalitus and Michael & Lynn Coatney.

The Director's Update

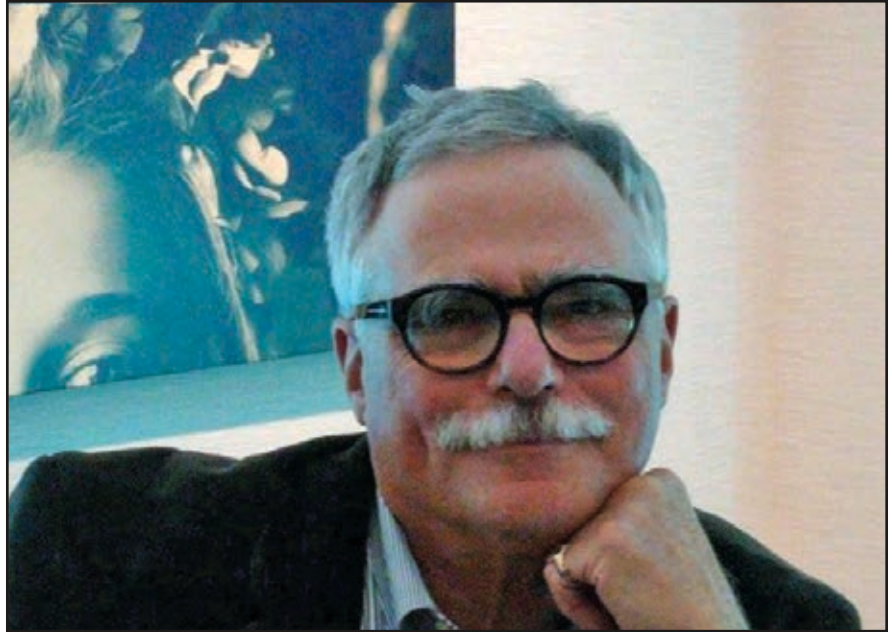
BY **JAMES W. BROATCH, MSW** • RSDSA EXECUTIVE VICE PRESIDENT, DIRECTOR

Zoe's Heroes

Zoe's Heroes (<https://rds.org/crps-pediatric-family-journey/>) is a not-for profit organization whose mission is to raise awareness and money for pediatric CRPS to fund vetted treatment & research projects and to provide financial assistance for treatments. When the US Pain Foundation withdrew their financial support for this summer's Courageous Kid's Camp for children in pain, Zoe's Heroes stepped up and agreed to help RSDSA, The Coalition for Pediatric Pain, and Knock out RSD to finance this year's camp. This wonderful organization created by Zoe Gellert and her parents also financed our pediatric CRPS accredited video for physicians, nurses, and physical therapists.

Fundraising for the Courageous Kid's Camp for Children in Pain

Recently, we surprised our eldest son and celebrated his birthday in San Diego. One of our pleasant surprises was that our grandchildren Britten, aged 13 and Mazie, aged 11 Broatch had been filling their "penny pigs" to help send children in pain to camp this summer. Please consider donating your spare change or request a "penny pig" to join them and many others in sending children with CRPS and other pain syndromes to the CCK camp this year. Please email us at info@rds.org or call 877-662-7737.



Free Accredited Online Courses on Pediatric and Adult CRPS

Often, individuals with CRPS ask us how they can get involved in promoting greater awareness of CRPS in the medical community. RSDSA has developed free accredited courses for medical professionals on the diagnosis and treatment of pediatric and adult CRPS. We will gladly send you postcards about the courses to distribute to medical professionals in your community along with guidelines for hospitals, emergency departments, and dentists on how to care for people with CRPS. Please email us at info@rds.org or call 877-662-7737.

Anti-Inflammatory Cookbook

RSDSA is creating a cookbook filled with anti-inflammatory recipes that can assist with CRPS! If you're interested in submitting a [recipe](#), please fill out the form found here: <http://bit.ly/3b7tPbS> or email us at info@rds.org or call 877-662-7737 and we'll send you a form.

James W. Broatch

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@rdsd.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).

My Journey with CRPS

BY **KELLY HODGKINS** • KELLY@PURPLEMOOKITING.COM

My journey with Complex Regional Pain Syndrome (CRPS) began in 2008. I experienced incredible pain in my wrist that interfered with my ability to use my right arm. I went to my family doctor who referred me to an orthopedic surgeon. The surgeon diagnosed me with having a ganglion and recommended it be surgically removed. Following this surgery, my pain increased, and I was referred to a hand specialist in Johannesburg, who, after conducting several tests, scans and shots of cortisone, operated on me again. This time, they removed three centimeters of inflammation and prescribed six months of rest and rehabilitation. I was on a cocktail of potent anti-inflammatories and painkillers, none of which made an iota of difference. My occupational therapist and physiotherapist worked tirelessly to help me regain my movement and relieve my pain. Six months on, the hand specialist offered to fuse the bones in my right arm or remove the nerves. I was shattered! I couldn't believe that was the answer.

I was in excruciating pain and spent most days in bed or on the couch crying. Physically, I was a wreck. No longer able to write, I completed my BBA degree through "writing" my exams orally. Unable to relax through any of my hobbies, I relied heavily on my horse Texie. He knew I was in pain and spent time just sitting with me, no need for a rope or saddle.

I did my best to work, but it was a disaster. I could barely manage a few hours on a good day.

By divine intervention, an associate of my mother referred me to a local neurologist. Dr. Sacoer took the time to understand my pain and checked me into hospital for two days of extensive testing. On the evening of the second night, Dr. Mohomed, a specialist physician, and rheumatologist came in diagnosed me with Complex Regional Pain Syndrome. I was his first patient!

When I came into the care of Dr. Mohomed, the relief was astonishing! Just to know what was wrong, that I wasn't dying or crazy, and have someone in the medical world believe and understand me were answers to my prayers! To this, he added a treatment program which, after a few trials and errors, settled as 60mg of Cymbalta (Duloxetine) once a day and a chronic anti-inflammatory. I experienced migraines for the first time when I developed CRPS so he prescribed a migraine medication, Naramig. It took six months to feel the improvement take full effect, but it was amazing to know we were working on it!

The medication made me tired and nauseous so my homeopath doctor, Dr. Makris, worked hard to find herbal remedies to alleviate the symptoms and help my liver function. She did a fabulous job!

To this, I added a bio kineticist (a physical therapist in America). Bryce is a friend and, while he didn't know much about CRPS when I was diagnosed, he was prepared to learn. He helped me to get fit again, have my brain understand where my right arm is within space, and taught me exercises to release tension building in my muscles and reduce pain. I also regularly saw a psychologist, Gail, to help work through the trauma and grief that comes with having a chronic condition as well as how to set healthy expectations and boundaries.

Now, at 32 years old, I am so much healthier. I'm still on the Cymbalta and homeopathic medication but the anti-inflammatories aren't necessary. My pain levels are lower than they've been in eleven years. I'm back working nearly a full day in my marketing consultancy alongside my mum, just as I had dreamed I would as a child. I get to ride my horse and I'm back to doing the hobbies I love such as drawing, knitting, gardening and playing piano.

Bryce, who I see once a week, has created a program that ensures I maintain what muscle strength and mobility I have as well as stabilizing weak points. He works slowly and within my capabilities, extending them bit by bit, to avoid a flare-up of my CRPS. Charting my progress is very rewarding and it's given me a sense of control and hope that I can prevent deterioration and restore what has been lost. It also keeps the rest of me fit and healthy.

My psychologist continues, less frequently now, to be a great

resource to lean on when it feels like I've leaned on my friends enough. Sometimes it helps to vent to somebody else who has a bit more distance.

I've learned what I can do on flare days including spending time in the field with my horse as well as with my dog at home. Grooming both of them calms me and does great rehab on my hands. They don't need me to speak, they just know what I'm feeling. My horse, in particular, adjusts his behavior to compensate for my arm and my pain. He guards the arm for me and takes responsibility for me when I'm riding to ensure I don't fall off. Reading, movies and audible books are such great distractions.

Regular prayer, Bible reading, and soul searching have guided me through the really tough times along with amazing friends and family. Having a support system that understands my needs and adjusts to my condition has been invaluable! I keep in touch with their lives through social media and instant messaging on days when talking or leaving the house is too much.

I find reading medical journals, magazines, blogs, websites, and Twitter feeds helps me feel active and a part of a broader community. It keeps me in touch with progress that is being made and reminds me that I am not alone with the problem. Sometimes others with the same problem phrase it differently to me, cast a new light on it or just allow me to empathize with them.

I still get frustrated, scared, angry, tired, lonely and sad. Having a chronic pain condition

reorganizes your life without your permission and makes planning tricky. It takes a lot of explaining, forethought and effort to stay well enough. But, 11 years on, I look back and am amazed at all I can do now, how much research is available and how much I've gained from it. Who knows what the next 11 years will hold! So now I am also hopeful, excited, faith-filled and joyful.



Kelly Hodgkins

I'm looking for joy despite the pain and limitations of CRPS.

I love being a brand strategist in my own business, Purple Mookiting, alongside my mum.

I find sanity through God and my horse, Moonglo Texas, my beautiful GSD Teddy and my friends.

I love to read and enjoy volunteering with a number of organisations.

An Interview with RSDSA Vice President, Sharon Weiner

BY KELLY HODGKINS • KELLY@PURPLEMOOKITING.COM

Sharon Weiner, Vice President of RSDSA, is the embodiment of the organization's mission to provide support, education, and hope to all affected by the pain and disability of CRPS/RSD. Her voice bubbles with enthusiasm as she discusses the work she is doing to connect and engage with those affected by CRPS and share information about the syndrome.

Unable to write due to pain in her right hand, Sharon began her journey to being diagnosed with CRPS in 1996. Originally misdiagnosed, she bounced from doctor to doctor undergoing tests and physical therapy but saw no improvement. The pain was excruciating, and she recalls asking her husband to please just knock her out for a break from it. Finally, a physical therapist suspected the real condition and referred Sharon to a pain specialist who diagnosed her with CRPS. The relief of being diagnosed, and no longer feeling crazy, was huge but the doctor explained how life altering the syndrome is and Sharon fast realized life wouldn't be returning to normal any time soon, if ever. As a mother of two who worked full time, she consistently found herself in the hospital being treated for her extreme pain made worse but just living her busy life. Her pain specialist gave her six months to adjust her life or he would no longer treat her. Sharon made the tough decision

to quit her job, as heartbreaking as it was to make.

Sharon sought a new positive focus while finding her balance with her CRPS and being an awesome mom. Being a natural learner, she looked for more information about CRPS/RSDS and support. Her first experience with a support group was depressing rather than helpful and, being a go-getter, she decided to investigate starting her own support group. After she attended an RSDSA conference in 1997, she began her first group in New Jersey under the auspices of her non-profit organization, Living with RSDS. Her objective was to create a safe space in which CRPS patients could discuss how to do life with CRPS, share information on how to adjust to it and support each other. Sharon commented that "Part of the challenge of CRPS is there is no 'one size fits all' treatment. Each person has to find the combination of medication, diet, exercise and lifestyle that works for them. The support group allows people to discuss what works and what doesn't and creates a platform for professionals to share what they know."

Sharon emphasizes how rewarding she finds running the support group. "It doesn't matter how many people attend. It's about the quality of the

"She reassures me, she's not always upbeat, she allows herself to be sad, but doesn't wallow, she finds what she can control and the things she can do, and she does it!"

discussion and knowing that it's positively affecting those in the group and bringing hope to a difficult situation." She shares a powerful story of receiving a note from an anonymous attendee that simply said, "this group saved my life." With CRPS being known as the "suicide disease," it's hard to quantify the impact and importance of these support groups.

Meeting once a month, the groups don't only focus on the medical aspects of CRPS, they discuss all the aspects of life with CRPS, such as raising kids and even self-defense. They create a community of people who "get it." Her first group gained such traction she began another in a different area and then added a virtual support group for people who are not able to travel. The CRPS support group program has continued to grow and there

are now over 60 CRPS support groups, in-person and online. Read more about the support groups in the Spotlight On Support section.

Sharon identified young adults, ages 21 to 31 years old, as needing a different kind of support group. In 2016, with the backing of RSDSA, Sharon and Sue Pinkham started a young adult weekend where 10-15 people traveled to a fun venue. Sharon remarks "Often times, the attendees arrive with no hope and no support system. They don't know how they are going to tackle the 'normal life' things such as driving, working and studying. They don't know how to find their independence with CRPS." The weekend is designed to teach them how to navigate the world while having CRPS through art therapy, community building and advocacy sessions as well as excursions. Sharon speaks to attendees about creating a life worth living with CRPS and finding the things you can do rather than what you can't do.

Realizing the strain group facilitators take, Sharon began a program to support them. She has created a place to be encouraged and explore new ideas. There is also a grant program to support these group facilitators, which is run by Sharon, to help set up more of these groups and keep them running. It funds many of the expenses we don't think about that make these groups possible such as handouts and snacks. As an additional resource, Sharon is hoping to publish a book on how to facilitate these groups in 2020.

Sharon is also an incredible advocate for CRPS awareness and education. She champions it throughout her home state of New Jersey by taking every opportunity to share about it such as setting up educational displays and planting gardens to draw attention to the syndrome.

When asked about her life outside of CRPS and work, she exclaimed, "I'm a hobby enthusiast!" She loves reading, cooking, creating art and gardening, all paced to what her CRPS allows her to do each day. She has also created beautiful habits, such as making a list of three to five things she has to do in a day and calls "everything else is gravy." This helps her prioritize and creates a sense of achievement at the end of each day. Each Friday morning she goes to see a movie. She calls it therapy, a time to take her mind off her pain once a week. It's an apt example of how Sharon has created pockets of joy in the hard day to day life with a chronic condition like CRPS. She has adapted to each challenge CRPS has given her. She reassures me, she's not always upbeat, she allows herself to be sad, but doesn't wallow, she finds what she can control and the things she can do, and she does it!

Through each story Sharon shared, I saw the theme of compassion. She sees the needs of those suffering with CRPS and seeks a way to make it better for them through support and education. What she has achieved, and continues to do, is truly inspiring.

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- **Plan an event with the help of RSDSA by emailing us at jjkrassner@rds.org**



HAVE YOU THOUGHT ABOUT YOUR LEGACY?

Are you looking for a long-term way to make a meaningful difference in the lives of people with CRPS?

Please consider making a planned gift to RSDSA today. Planned giving options include:

- Gifts of Stocks and bonds.
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Please contact your attorney or a financial advisor. For more info, contact RSDSA at info@rds.org or go to <https://rds.org/donate/>

Your struggles don't have to be lonely or a family struggle! There are good people out there to help!

BY CHRISTOPHER SKINNER

I'm a Christian man with full body Complex Regional Pain Syndrome (CRPS). I've had full body CRPS for about a year now. I was playing basketball with two students at a drug and alcohol rehabilitation school, where I served as a student advisor/teacher, when I was forcefully pushed from behind, causing me to fall into a heavy stage bench. This caused me to tear my rotator cuff, hit my head, and hurt my neck. Either this event or the surgery about five months later caused me to develop CRPS in my entire right arm and I believe my neck, although I had never looked into any further into that beyond having an MRI. I have experienced significant spread of CRPS over the past six years. As far as diagnosis goes, my orthopedic surgeon was hinting at that fact for a while. However, I wasn't officially diagnosed until my birthday by a Worker's Compensation Independent Medical Evaluation doctor about a year and a little under 2 months later. I didn't fully understand the diagnosis for about three years after that and now there are still a lot of things that "defy any logic!"

I have been fighting for some assistive devices since 2015 and other devices since June 2018. Bills and everything else got way ahead of us. Sometimes you have to reach out for assistance, even if you have a lot of pride due to a previous

"When someone offers their help and support, don't shut them out due to pride."

situation. This is the purpose of this article. Never be ashamed to ask for help if you need it. The first time we received help was from the RSDSA Jenkins Patient Assistance Fund. I thank God each and every day for the help they provided with our heating during a long winter. Perhaps the greatest gift was the gift of a person reaching out to me. I was stuck in the phase "maybe this is as good as it gets" for a really long time. Most of the ideas were shot down by the fastest gun in the east, but one stuck which led me to another method of help. This person knows who she is and I'm forever in her debt as I am firmly the "Engineer behind my own healthcare." She also taught me that, "Physical illness is not a weakness of yourself. Rather, a weakness of the body and strength is measured by your heart and your mind."

When someone offers their help and support, don't shut them out due to pride. Years ago, when I was a lot younger, I was disabled and had to ask for help. Because of this, asking for help is the most painful thing for me now. I received help and I was grateful for it, but after a year and a half

into my disability and receiving \$499 of cash assistance and having two children, I was judged by people that I loved. This made it hard for me to ask for any help ever again. I had my cyst removed in 2007 and started working so much I missed life. I even began to go for my Master's degree in Mental Health Counseling during this point and had all of my coursework completed. I developed so many new roles that it made the process of becoming disabled so much more difficult for the second time.

When I was injured in 2013 and later in June of 2018, I was prescribed the wheelchair accessible van and electric wheelchair. I'd been fighting ever since for OT items and PT items including the ramp, and a lift chair. The current law in New York for Worker's Compensation may not allow for a wheelchair accessible van in full. Many of my falls were a result of going up or down our stairs. Even though NY Worker's Compensation law 442.3 was on my side, the bills were submitted, causally related, and not paid or challenged within 45 days for my wheelchair and the van. I could've been all set up by the end of August for these two items.

Needless to say, I was left with no other option than to ask for help - which I am so happy that I did. I learned about the Grace Ridge Church through a program that

they did at the Damascus School and learned at the Area of the Aging that every once in a while, they did projects like wheelchair accessible ramps for those in need. I contacted my fourth-grade teacher that I knew went to the church, who then contacted George Maxson from the Grace Ridge Church. A few days later, I received a phone call from George saying that out of dozens of people, I was chosen for the project.

Mrs. Alexander and her husband were both teachers of mine and I sent just a five-paragraph message explaining what I had and what was going on. George came to our house and I thought it would just be for a wheelchair ramp, but then he asked what else needed to be done. Our house was built in 1806, I believe, but it's in great shape for its age. However, there is quite a bit of work that needs to be done to our house to fix it 100 percent. Back in my prime, I would have been able to do much of the work, but I'm not a Spring chicken at 38.

The greatest gift George gave to us was inviting the family to 3:16 fest in Honesdale, PA. Brit Nicole spoke to my family, which sparked a significant change. Their mission group was going to come earlier, so George was able to bring several guys together to make the ramp functional until the Men's mission group from the First Presbyterian Church in Endicott, NY was able to come to finish the ramp. The men from the Grace Ridge Church came here on Saturday morning and didn't complain once about using their days off to help my family and me.

I won't say there weren't hiccups but I've never seen a more patient bunch of men. We will never forget what they did for us. Then November came and I was able to educate individuals from the First Presbyterian Church in Endicott, NY about CRPS and other struggles that we face on a daily basis. The added struggles that each of us face can make our lives harder and even unbearable. The men that took the time to come here prayed with our family on a daily basis, listened to my testimony, prayed over me, and allowed our boys to work right alongside them while sharing their lives with them.

When they were done, we had working electric in our basement again, trees cut up out of our yard, a beautiful wheelchair ramp, our old windows covered with plastic, a clean yard and newer furniture. Perhaps the greatest gift of all was a brand new bible with explanatory text at the side.

Each of the men signed the bible with a special message not just for me, but for our entire family. Chris shared a special bible verse for the boys and it has become my new favorite verse. Each man shared a piece of themselves in some way that touched us forever. One way I'm able to deal with a flare better is with God's help and that's through reading the bible, listening to Christian music, listening to sermons, or by reaching out to friends for help. Here's a photo of some of the men who helped us out. The wheelchair ramp is unfortunately covered up, but the work by their hands is impeccable. Pastor Tim is missing from the photo. Vinnie Canosa who took the photo from Grace Ridge, and the other men from Grace Ridge Church are also missing except for George Maxson was with us the entire time. Thank you to everyone and God bless all of you!



Central Sensitization

BY **JAY JOSHI** • DABA, DABAPM, FABAPM

NATIONAL PAIN CENTERS, NATIONAL PAIN CENTERS, VERNON HILLS, IL

There are four types of pain: Nociceptive pain, Neuropathic pain, Inflammatory pain, and Central Pain Amplification or Central Sensitization. Ask most physicians if they can identify all four subtypes and you will find that the majority cannot. Even worse, a significant number of physicians have not even heard of central sensitization and cannot define it. This is important because it helps explain why most physicians do not understand Complex Regional Pain Syndrome (CRPS). They simply do not understand the fundamentals of the pathophysiology. It also helps explain why there seems to be a resistance with coverage from insurance companies. Central sensitization is a manifestation of activity-dependent plasticity due to an increase in synaptic strength, driven to a substantial extent, by N-methyl-D-aspartic acid glutamatergic receptors. Central sensitization occurs after noxious stimuli, peripheral inflammation, and nerve injury in the spinal cord and higher brain centers. It involves multiple presynaptic and postsynaptic changes producing changes in transmitter release and action, as well as synthesis of novel neuromodulators. Central sensitization is produced not only by increases in excitability but also by a reduction in inhibitory transmission due to

reduced synthesis or action of inhibitory transmitters and to a loss of inhibitory interneurons, which may produce a persistent enhancement of pain sensitivity. In addition, altered gene expression in dorsal horn neurons, microglial activation, and thalamic and somatosensory cortex changes occur in central sensitization. Many features of central sensitization resemble those that are responsible for memory.

Types of central sensitization include anxiety, chronic pain (in general), CRPS/RSD, depression, fibromyalgia, headaches, opioid induced hyperalgesia, phantom limb pain, and Post Traumatic Stress Disorder (PTSD). **Simply stated, CRPS is a regional manifestation of central sensitization.** Obviously, the pathophysiology and comorbidities of CRPS is far more complex, hence the “C” in CRPS! You can read more about central sensitization and CRPS on my website at www.nationalpain.com or watch videos at www.youtube.com/nationalpaincenters. There have been countless reports by patients stating that physicians, other healthcare providers, and insurance companies do not believe that CRPS and central sensitization exist. I would like to address that as I perceive those statements as either ignorant or fraudulent.

We will briefly discuss two current cases. The first is a patient that fractured her wrist at work, which required surgical intervention. She developed CRPS as a result. Her delayed insurance approvals and inability to work resulted in anxiety and depression, forms of central sensitization. Fortunately, she has received 100% relief of her CRPS and central sensitization symptoms with ketamine infusions. She has been able to get married and hold a job now due to the relief of her symptoms. Her previous employer is still pretending that she does not have CRPS and is fighting her legally. They hired an anesthesiologist who is well known nationally as an “IME Whore” (a physician that conducts fraudulent Independent Medical Exams sponsored by the insurance company/employer). On record, he stated that central sensitization does not exist and is a made-up diagnosis. If this were true, CRPS would not exist and even more dramatically, the brain and spinal cord would not exist. The great irony is that this unethical physician sees patients with central sensitization and CRPS routinely and performs ketamine infusions (albeit, poorly).

The second patient was rear-ended while driving on the job. Her injuries required cervical fusion and extensive physical

therapy. She developed CRPS as a result of the accident. She is a government employee so her workers compensation case is handled by the Department of Labor (DOL). Certain individuals at the DOL have delayed her treatment and created multiple hurdles for her, increasing her anxiety and depression, thus worsening her central sensitization and CRPS pain. In an effort to sabotage her case, one of the DOL employees forced her to have multiple IMEs in the hopes that they would discount her injuries and make a false conclusion that she does not have CRPS and central sensitization. This strategy backfired as the IMEs (and her other physicians) have all stated that she has CRPS. Because the DOL is a government agency, she cannot sue the DOL and it appears that the employee that has tried to harm her and discriminate against her may be immune to prosecution and legal liability.

I am confident that most of the readers of this article can relate to these case reports. Know this: you are not alone. There are many treatments available for central sensitization and CRPS that can help people live more normal lives with more good days than bad days. The biggest hurdles are physician education, ignorance (or maybe arrogance), and fraudulent insurance company decisions regarding treatment coverage. There is a need for continued advocacy and a strong collective voice. Here is to hoping that 2020 will be a turning point for patients with CRPS and central sensitization!



ABOUT THE AUTHOR

Dr. Jay Joshi is a nationally recognized board certified Anesthesiologist and fellowship trained Interventional Spine and Pain Management physician who has distinguished himself via his solid reputation, education, experience, and leadership roles in national activities, including Advisory Boards, Educational and CME Programs, Publications, Speaking Events, and Consulting.

He is considered a National "Key Opinion Leader" in pain management and he has presented to a variety of audiences, both large and small, over 600 times. Internationally, he has worked in the Department of Substance Abuse at the World Health Organization in Geneva, Switzerland. He has been featured on major TV networks, Radio, Print, and the Internet.

Facilitator Support Group: Spotlight Tip

BY **SHARON WEINER**
SLWEINER@HOTMAIL.COM

When I run into the issue of planning or running out of ideas for a topic for a support group meeting, whether it be next month's meeting or one that is months away, I sometimes look into the monthly or daily national awareness observance calendars. There are many different awareness listings that can be related to living with CRPS. Usually, there will be an abundance of information available leading up to and during that awareness month. Who wouldn't want to celebrate Slow Cooker Month by sharing healthy and quick prep recipes? The awareness observances can also tie into fundraising, awareness or advocacy projects.

You can find different awareness observance calendars here:

[Healthfinder.gov](https://www.healthfinder.gov)

[Motivators.com](https://www.motivators.com)

[Nationaldaycalendar.com](https://www.nationaldaycalendar.com)

For submissions for tips or support group accomplishments, please email Sharon Weiner at: fsg.rsdsa@gmail.com

Vitalitus: the small American company responsible for the Palmitoylethanolamide revolution

BY **EDDY CARDENTY** • President and CEO

Vitalitus, a small family-owned company founded in 2014, is single-handedly responsible for sparking the Palmitoylethanolamide revolution in the United States. The company realized early on that there was a wonderful and naturally occurring molecule being used successfully overseas to help patients with various kinds of neuropathies. This molecule had an enormous potential to help many in the U.S., but very few doctors even knew about it. What's more, those that were aware of this had to endure long shipping times, high shipping costs, and customs uncertainty when importing it from the Netherlands. Given these factors, Vitalitus felt it was its duty to produce and distribute the highest-quality PEA this side of the Atlantic.

Five years later, Vitalitus is still the premiere producer of PEA in the United States. Over the years, they've perfected their patent-pending formula to manufacture the most bioavailable form of the product, making it significantly more effective than competitors' PEA. Vitalitus PEA can be taken orally as a capsule, but it's also designed so that the capsule can be opened and the powder poured directly under the tongue. This is helpful for customers with various malabsorption ailments or other gastrointestinal issues. Since this method bypasses

the GI tract and first pass metabolism in the liver, it can also be highly effective for other customers as well. Vitalitus PEA contains no synthetic excipients and is packaged in vegetarian hypromellose capsules. It is not made from soy, peanuts or any common allergens, so it is safe to use for people with various food allergies.

The product was first thought of as an endocannabinoid, but it is more properly defined as a cannabimimetic autacoid, since it's a nuclear factor agonist normally produced by healthy tissue at an injury site. PEA acts as a messenger molecule and downregulates the inflammatory action of glia cells and mast cells, reducing the release of histamines, NGFs and pro-inflammatory cytokines in the degranulation process. As such, its usefulness for neuropathies is not by blocking the pain signal, but rather by gradually reducing the neuropathic inflammation that, in many cases, causes it. Based on the cell receptors it binds to, it is said to mimic the action of certain cannabinoids, but structurally the molecule is a fatty acid amide and very different from classic cannabinoids such as THC or CBD. This is why it is of special interest to customers who may respond well to classic cannabinoids, but are unable to use them due to employment

drug screenings or living in a state where THC and/or CBD are not legalized for medicinal purposes. PEA is not psychoactive and will not test positive in a cannabinoid screen because it is not structurally one.

In addition to the Vitalitus PEA capsules, a topical cream was also developed by the company. This topical cream is meant to deliver PEA directly to localized affected tissues. In addition to PEA, the cream also contains myrrh, frankincense, and a number of other natural compounds used since ancient times to help with pain and inflammation.

Vitalitus PEA can be purchased online only from Vitalitus.com, although the company's website lists the locations of practitioners, pharmacies, and other select locations where the product can be purchased. To purchase Vitalitus PEA, go to <http://vitalitus.com> or scan the following QR code with your phone:



3. When were you first diagnosed with CRPS? What were the initial signs that told you something was wrong?

a. I had been dealing with some ankle and foot injuries for a few months at the time we discovered the injury was worse than we initially thought. Towards the end of 2017, I was playing a tournament in Hawaii and woke up one morning in extreme pain. I flew home ASAP. My mother took me to the emergency room because I was in serious pain. We went to a number of different specialists and it took some time before we finally came to a conclusion that it was CRPS.

4. Had you been familiar with this condition prior to diagnosis?

a. I was not too familiar, but I had previously heard about CRPS. I had some family members who suffered from similar nerve damages but, in all honestly, I was no expert on it like I am today. As I mentioned, this is something that I will just have to manage over my career and it's something that I will take head on.

5. Once diagnosed, how did you manage treating your CRPS? Were there any treatments you feel helped?

a. The first thing that I did was rest and work out other muscles until the pain went away, and it was more tolerable just from a day-to-day perspective. There were days that my pain was so intense that I couldn't walk. Mentally, I was really down, but I have such a great support team from my mom, brother and family that they were able to keep a positive outlook on it and always encouraged me to keep fighting. One of the first things I did was look at my tennis shoes and we decided that a wider model was vital for me since it helped with the pain and we were able to manage everything better. I also saw multiple doctors in New York and Las Vegas who specialized in this and we went over everything from vitamin intake to exercises. The most important thing I found that helped was time and rest which, to me, was the most frustrating because there was nothing else that I wanted more than to get back out on the court.

6. As a Star Athlete, what do you eat to maintain a healthy diet? Are there easy go-to meals you can share with our readers?

a. I have a team at the gym I use in San Diego that helps oversee my diet especially when I am in training blocks where recovery and maintaining energy is crucial. When I'm at tournaments, we always try to eat clean meals with protein to help me compete the following day. I don't have an "easy go-to meal" because the tournaments are all over the world, but I do have my favorite spots depending on where I am in the world!

7. How do you balance playing tennis professionally with having CRPS? What is your advice for helping our readers stay active?

a. After the long process of getting diagnosed and after my medical team finally figured it out, I knew right away that this was something that I was going to have to deal with for the rest of my career. Some of my friends on tour have had career-ending injuries so I was very blessed and fortunate that I did not have to deal with that. However, it is something that I just have to manage which means changing my tournament schedules around, warming up properly and making sure that I have wide shoes, so the nerves don't get damaged. Like I mentioned earlier, it's all something that is manageable.

8. Do you have any tips for managing pain that you have learned over the years?

a. The most important tip that I have is that you have to listen to your body. Before this injury, there were times that I would play through pain and I will still do that now, but it's important for me more than ever now that I listen to my body. I have to properly warm up because I can't afford to have another setback.

9. What are your tips for traveling with CRPS? How do you prepare to travel?

a. The tips to traveling with CRPS are similar to what I do when I manage the pain of CRPS. Listen to the body and listen to the people around you who are the experts. I have a great physio who will help me in my warm-ups and cool-downs after and before every match.

10. What inspires you to get up and go every day?

a. I just feel so lucky that I'm able to compete and play tennis again at a high level. This comeback has taken a lot of time and I am still nowhere close to where I once was and want to be. I know it will take time but that is what inspires me. I want to inspire people who have CRPS or other tough injuries that you can come back and it is not the end just because of a condition like CRPS.

11. What is one thing readers can take away from learning about your journey?

a. When times get tough, there are always better times ahead. I went from being top 10 in the world to not being able to play tennis because I literally couldn't walk without pain. Time heals and as long as you have a positive outlook on life, then it's always worth the wait. During this time off, I've been able to develop friendships with people that I know will last a lifetime and it has given me a new outlook on what is important. I don't get upset over the little things anymore because I remember not too long ago I was sitting on my couch just binge watching Netflix shows. I am just so appreciative of everything and I feel so lucky that I'm able to get back on the court again. I know this time around that I will get back into the top 10! I won't stop fighting!



RSDSA YOUNG ADULT WEEKEND

Friday June 5th to Monday June 8th



RSDSA is excited to announce the first Young Adult Weekend of 2020! This event will be held in Philadelphia, PA from Friday June 5th to Monday June 8th. Young adults with CRPS from the ages of 21-31 will spend the weekend in this historic city with people that understand what they are going through to the fullest.

The Young Adult Weekends have been a great success and offer young adults with CRPS the chance to network, take part in workshops, learn about advocating for themselves, gain a support system and plenty of time to sight see and have one of a kind experiences.

We are asking participants to pay \$250.00 for the weekend. With help from sponsors or donations, RSDSA will sponsor the additional costs for rooms, meals and speakers. Please note that all participants will likely be sharing rooms.

We have limited space so please let us know as soon as possible if you wish to attend. A \$50.00 non-refundable deposit is required to reserve your spot or you may pay in full at the time of registration. Check or credit card is acceptable. Final payment of any outstanding balance is due by May 20, 2020 along with all emergency and information forms.

If you have any questions or concerns, please contact RSDSA YAW Committee at RSDSAyaWKND@gmail.com

We look forward to seeing you there!

Holiday Inn Express
1305 Walnut Street
Philadelphia, PA 19107
215-735-9300

RSDSA is also planning a Young Adult Weekend in Columbus, OH on August 7-9



Last year we successfully launched our Annual Fund on #GivingTuesday with a matching gift and a modest goal of \$15,000. For RSDSA and our community an annual fund is an inevitable next step for our growth. Our annual fund will support both our stability and sustainability. Annual Funds support general operating expenses to meet the day to day needs of an organization and provide the seed money to support programming, personnel, and communications. For example, RSDSA has published the newsletter in both electronic and print versions at no charge to the community. It is mailed to over 13,500 community members at a cost of approximately \$12,000.

Our Spring and End of Year appeals will be incorporated into the Annual Fund. Your donations support:

- Research for treatments and a cure
- Treating the Whole Person: Optimizing Wellness Conferences
- Two Young Adult Weekends a year
- Kids going to Courageous Kids Camp for free
- Emergency financial aid via the Jenkins Patience Assistance Fund

Please consider a donation.



I have CRPS card

RSDSA has revised and is reprinting its popular and informative **I have CRPS** card.

The card explains what is CRPS, how it is diagnosed, describes the experience of having CRPS, and how each day is so unpredictable.

The two-sided card pictured below can be obtained by calling RSDSA at 877-662-7737 or emailing info@rsds.org. We are asking that you consider making a small good-will donation to support our work.

I have CRPS

rsdsa

What is CRPS?

- Physicians do not know why CRPS develops or what causes it, but CRPS is a nerve disorder that usually occurs after a traumatic injury, surgery, sprain, fracture, or a period of immobilization. **The principal symptom is chronic pain that is dramatically disproportionate to the original injury.**
- More than 150 years ago, Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.
- CRPS can lead to depression for those who can no longer work or participate in life the way they did before the onset of CRPS.
- CRPS can lead to disability. CRPS can spread to other body parts that were not originally affected.
- I may look "healthy," but I often suffer unbearable, unrelenting, and burning nerve pain. The McGill pain scale rates the pain of people with CRPS higher than that of people with cancer, amputation, kidney stones, and childbirth.
- My skin may swell, sweat, change colors, change temperature, or hurt to the slightest touch.
- For some, lights, noise, or vibrations can cause disproportionate pain.

Here's How You Can Help Us

- My pain is real even though it is sometimes invisible and may not be readily apparent in my demeanor or activities.
- I am learning various coping mechanisms to get through the day, but the chronic pain is always there. I have good and bad days; my pain may even change hourly, and I cannot predict how I will feel each day.
- Sometimes it hurts to be touched anywhere so please ask before you touch me.

It is OK to ask me about CRPS.

Better yet, visit www.rsds.org and learn all you can.

Poetry Corner

RSD

(Reflex Sympathetic Dystrophy)

By Melva Smith

*I walk through the world
in a wounded haze
while my life is a maze of drugs and tears*

*I feel alone, helpless, lifeless, and confused
No friends can hold me,
no one can touch me
No one who understands
this pain from within*

*My heart says be free, run, and be me.
The pain consumes me,
the drugs they lose me.
My mind is gone, along with some
memories of yesterday.*

*Yesterday has come and gone,
now some memories say so long.
My heart weeps for someone to love.
My body yearns to be held but I am alone.
Walking in this cloudy haze.
Longing for a way to be me—to be free of*

RSD

*At times I'm angry, sometimes I am sad.
But I ask myself, why not try
something else instead?
Know you have God,
know you live,
know you have family*

RSD

I'm going to fight!

Ms. Smith has published a book of poems - Peelin' the Onion - which is available on Amazon for \$14.

**REFLEX SYMPATHETIC DYSTROPHY
SYNDROME ASSOCIATION**

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TEL: 877.662.7737
FAX: 203.882.8362
WWW.RSDS.ORG

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



MARCH	
3/28/2020	Ribbon of Hope Fundraiser - Mahopac, NY - Marianne DeMasi
APRIL	
4/22/2020	Ted Talk about Giving Back - Eric Moyal
MAY	
5/31/2020	Saving Those Overwhelmed by Pain (S.T.O.P.) Family Fun Event - Montclair, VA - Christina Whearley
JUNE	
JULY	
SEPTEMBER	
9/12/2020	5th Annual Long Island Awareness Walk Eisenhower Park, Long Island, East Meadow, NY
9/13/2019	Flame Out - Walk to Extinguish the Pain, Oakhurst, NJ - Linda & Bob Hopkins

PEER TO PEER

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

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

Don't see an event near you?

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



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