rsdsa community update

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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

Ketamine Treatment Centers Partnership.

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Aetna, Axsome Therapeutics, Grunenthal, Ketamine Treatment Centers Partnership, McLarty/Pope, Medtronic, Neurologic Relief Center, NoPainHanna.com, Purdue and Relax Release Relief. For more information about becoming an RSDSA Partner, please contact Jim Broatch at info@rsds.org.

THE DIRECTOR'S LETTER

Relax Release Relief offers new HOPE

BY E. GLASER, DPM RELAXATION GUIDE

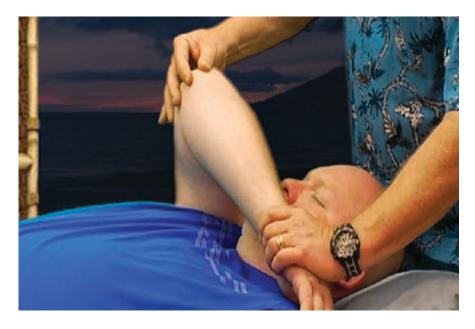
What if a loved one could help you achieve significant pain reductions or even relief at home? Relax Release Relief is a five-video relaxation program that may change your life.

Here are my personal observations, with the hope that this knowledge may be of help to you. I must preface my words with a disclaimer: These observations are in no way medical facts or claims. They are simply honest observations. Medical facts require long-term research with randomized controlled clinical trials.

"The Goal of Science is to have theory match observation." Stephen Hawking

First Observation of Relief

Our story begins with a girl who is only 14 years old. She was diagnosed with CRPS after a softball injury to her left leg and suffered without relief for four years. A small selection of the techniques used in Relax Release Relief was applied for 20 minutes and immediately resulted in complete pain relief which has lasted for over six and a half vears. Since then, observations have shown that such an immediate remission with a single session is extremely rare but in this **one** case the word "cure"



does apply. Again, this is just an observation. If remission does occur from pain, it is usually after the fourth or fifth session.

Was this an isolated miracle or a physical, repeatable thing? These techniques are gentle and simple-could this work?

It Demands a Closer Look

A local RSDA support group spread the word which made it possible for 11 people suffering from CRPS to experience only a few of the releases used in Relax Release Relief during a 25 minute treatment.

The results:

- Four had no effect.
- Four had over 50% improvement, each lasting a different amount of time
- Three experienced a period of complete relief

Mistakes were made. The room was cold, noisy, and too bright. Sitting at an uncomfortable table and traveling long distances put some into travel flares.

Logically, it would yield even better relaxation, release and relief if more releases were used and staged out over more days in longer sessions combined with gentle slow movements and biomechanical correction of the foot's posture using MASS Posture Custom Foot Orthotics.

Relax Release Relief techniques were tested in over forty people who have chronic pain due to multiple causes, including CRPS and fibromyalgia.

The vast majority of participants achieved relief or remission from their pain for varying lengths of time. All except one had

significant improvement. Some experienced complete relief for several months and continue to experience relief. Hope is reborn.

Having witnessed so many miracles, I feel an obligation to get this out ASAP. People in pain need this information delivered to their home, inexpensively and available worldwide.

Imagine the caregiver watching their loved one suffer, wishing there was something they could do to help. Relax Release Relief is something you CAN do.

Relax Release Relief is not rocket science. In fact, it is quite simple to do for almost anyone. That is why I decided to produce videos that teach a healthy able assistant, "Buddy," how to perform these relaxation techniques at home.

Please use these videos safely. Make sure that the table you use can hold the weight of the person. Be careful about the edge of the table. Don't roll off or fall. Sounds like common sense, but it's worth the reminder!

The releases involve NO drugs, needles or machines. Relax Release Relief, is done with your fingers or a small rounded object. It should not hurt. If it does, tell your Buddy to lighten up until it feels okay. If any release is uncomfortable, skip it and go back to it later in the program. No part of this should ever be painful.

In *Relax Release Relief*, I attempt to use simple body landmarks in plain words to explain the techniques while you see them from several angles.



The relaxation points are easy to find. Choose a "buddy" who is strong and healthy enough to perform these techniques and allow them periodic rests.

Relax Release Relief is NOT

a treatment or therapy for any diagnosis and no tests are performed. This is not a substitute for medical care. There are no guarantees for any results. It is simply a selfhelp video series in which one friend or loved one is performing simple, ultra-gentle relaxation techniques and movements on someone they care about who is suffering from CRPS.

There are five videos in total. There is a \$25 fee per 48-hour video rental. You may also purchase all five videos at once for \$100. It's like getting the fifth video free!

Medical professionals can rent these videos to learn about this technique without taking time out of your busy practice. You can do it in your spare time using these videos at home.

Begin: www.RRRTV.net

Relax Release Relief is offered in the hope that you have another path to relaxation, release of tension and relief.

After you have completed the program, please share your feedback and questions. Email yourjourney@rrrtv.net with text, videos, audios etc. about what you have tried, results from past attempts and how you feel your future looks compared to before. Now, take a deep breath; it's time to start: Relax, Release, Relief.

THE DIRECTOR'S LETTER

A Summer Update

BY JIM BROATCH, RSDSA'S EXECUTIVE VICE PRESIDENT, DIRECTOR

Filming of an Accredited **Course on Pediatric CRPS**

RSDSA has received a grant from the Bobby and Lauren Gellert family to film an accredited course with Dr. Elliot Krane, Director of Pain Management, at The Lucile Packard Children's Hospital at Stanford. Dr. Krane will be discussing the diagnosis, management, and treatment of pediatric Complex Regional Pain Syndrome (CRPS). The accredited video will be available and free of charge to physicians, nurses, and physical therapists. We hope that the RSDSA community will help promote the course when it is completed.

RSDSA Co-Sponsors Pediatric Pain Week in Kentucky Again

RSDSA, in conjunction with US Pain Foundation, TCAPP, and Rock Out to Knock Out RSD cosponsored a free summer camp experience for children in pain. This year, 37 families with a total of 68 children will attend the Center for Courageous Children in Scottsville, Kentucky (http://www. thecenterforcourageouskids. org/). Under RSDSA's Board of Director Sue Pinkham's leadership, the camp's enrollment has grown from 16 families/19 children to 37 families/68 children in three short years. To get involved with fundraising for the camp, please call us at 877-662-7737 or email us at info@rsds.org and request



a "penny pig" and your spare change can help send a child to camp next year.

"In Pain and Agonizing over the Bills: A Financial Assistance Resource Directory"

RSDSA will publish the third edition this Summer. The publication has been delayed due to the replacement of the Affordable Care Act and the political stalemate and the uncertainty surrounding the introduction of the American Health Care Act.

RSDSA's Patient Assistance Fund in honor of Brad Jenkins

For the past three years, RSDSA in conjunction with Andrea Jenkins and her family, has helped many

people experiencing a financial emergency. Brad Jenkins was a young man with CRPS who died tragically from an accidental opiate overdose.

The requests we receive vary between helping with overwhelming medical bills and purchasing durable medical equipment, providing assistance with living expenses and grocery gift cards to feed a family. However, the request we receive most often is to help fund travel expenses to visit CRPS specialists.

Most recently, we paid a bill of \$343.61 for a woman who needed that money to resolve an outstanding debt at a local hospital before being allowed to have surgery to insert Spinal Cord Stimulator (SCS). She has been fighting for assistance from the Social Security Administration

for five years, and had written to both her governor and senator to help resolve her plight. RSDSA was her last resort. We provided another patient with funds to travel to the Hasbro Children's Hospital in Rhode Island. Finally, the Patience Assistant Fund was able to help a single mom with CRPS who had been hospitalized. She has a disabled daughter and was having difficulty paying her \$501.00 electric bill, which was so high because they live in an allelectric apartment.

The one-time grants generally average \$500-600. For more information about the fund, please call us at 877-662-7737 or email us at info@rsds.org and request an application.

100 percent of all donations to the Jenkins Fund are directly invested into helping individuals and families affected by CRPS. Please consider donating by visiting http://rsds.org/donate/ or by calling us at the number above.

RSDSA's YouTube Channel

Did you know that RSDSA has posted 131 videos related to the diagnosis, treatment and living with CRPS on the rsdsaofamerica YouTube channel? The recent presentations at the Nashville and Fayetteville conferences are available there. It's a treasure chest.

Corporate Sponsorship of the RSDSA Community Update

Years ago, the RSDSA Board of Directors voted to eliminate its membership dues to subscribe to our quarterly newsletter because some individuals with CRPS could not afford that expense. In a subsequent

cost-saving measure, RSDSA began to publish the newsletter electronically with an occasional "paper newsletter." So many individuals of our community without Internet access felt abandoned. We have heard you. At our June meeting, the RSDSA Board of Directors voted to publish the newsletter four times a year, two electronically and two via postal mail.

This issue is being sponsored by Dr. Edward Glasser of Solesupports.com. Dr Glasser has also written an article on page X about Manual Ligament Therapy. If you or your corporation is interested in sponsoring a future issue, please contact me directly at info@rsds.org

WAYS TO DONATE

- Make RSDSA your charity of choice on GoodSearch.com and use that as your search engine of choice.
- Use AmazonSmile.com and make RSDSA your charity of choice while shopping online.
- If you're selling items on eBay, you can set up your account to give a portion of your the profits directly to RSDSA.
- Set up a collection canister in your local grocery store.
- Plan an event with the help of Special Events Coordinator, Sammie Anderson, by emailing SBarrett@rsds.org

James W. Broatch



4th Annual Color the World Orange is NOV 6.

Help us Color The World Orange™ on November 6 by turning the night orange! A number of buildings and landmarks have the ability to be cast different colors and we want to request that they turn orange for CRPS/RSD Awareness. In 2016, almost 50 buildings and landmarks in four countries turned orange-let's try to top that this year!

For more information please visit www.colortheworld. com

Does CRPS Spread?

BY PHILIP GETSON, DO

DOES CRPS SPREAD?

To those of us who treat patients with Complex Regional Pain Syndrome on a regular basis, the answer to this question is simple. Absolutely yes! However, many uninformed clinicians and allied healthcare practitioners dispute this fact. They seem to feel that once the disease presents itself in one area of the body, it is "impossible" to spread to other areas.

Reviews of literature have shown that the first formal explanation of this comes from an article written by Dr. Schwartzman in 2000 entitled "Patterns of Spread in Complex Regional Pain Syndrome, Type I."1

In 2011, an article called "Spreading of Complex Regional Pain Syndrome: Not a Random Process" provided some additional opinions.2

Also, in the journal "Pain" in 1996, Veldman and Goras authored an article called "Multiple Reflex Sympathetic Dystrophy. Which patients are at risk for developing a recurrence of reflex sympathetic dystrophy in the same or another limb."3

The one common denominator in these articles is that they discuss the spread from one limb to another. It seems to be the consensus that when the disease spreads it does so horizontally or vertically (left arm to left leg, left

arm to right arm, etc.) 95 percent of the time with a contralateral spread (left arm to right leg) about five percent of the time.

There does not seem to be a known etiology or "time table" for spread. However, it has been offered as an opinion that most of the spread occurs within the first year of the onset of symptoms but can also take as long as 12 years to spread.

From a clinical perspective, however, what is clear is that the disease most certainly does spread. Almost universally, individuals afflicted with this disorder report that the pain in the second limb is "worse than the first." It is difficult to determine whether the subjective perception of pain is because the condition is more amplified in the second limb or whether individuals have "gotten used to" the pain in the first limb causing the "new" pain to feel more intense. Additionally, spread is not limited to just the other limb. There are also individuals who have three or four limbs affected over a period of time.

A recent article from a Scandinavian journal suggests that patients with CRPS are at risk for spread following a second traumatic event including surgeries or injury to a previously unaffected limb. Although there is some credibility

to this report, more often than not, the spread is spontaneous and not secondary to such a traumatic event. Further, the term "traumatic event" needs to be classified downward to include such seemingly innocuous occurrences such as a venipuncture, blood pressure cuff that is too tight, etc.

However, what is not reported is the spread of Complex Regional Pain Syndrome to internal organs. Clinically, there are many manifestations of this disease that often go unnoticed and untreated. Some of these include:

- · Cardiac: Sensitization of the intercosticobrachial nerve causes cardiac arrhythmias. These manifest themselves as tachycardia and bradycardia most often with occasional ectopy noted as well. Unfortunately, some patients require the use of pacemakers to deal with the bradycardia as it becomes so pronounced they become markedly symptomatic with rates as low as 40. Hypersensitization of the same nerve causes atypical chest pain which is non-cardiac in nature.4
- Visual disturbances can include double-vision, blurred vision, ocular migraines, vision loss with field cuts, photophobia and burning of the eyes. Headaches tend to emanate

- from sensitization of the greater occipital nerve. Other headaches are migraine type, ocular migraines, and tension headaches.
- Otorhinolaryngologic symptoms occur. These include otophobia, intermittent and transient hoarseness which comes from the effect of CRPS on the branchial plexus and an increase of hypersensitivity to sound, especially bass. I have seen one patient who began to stutter uncontrollably as a consequence of his Complex Regional Pain Syndrome.
- Dental issues are rampant. Part of this stems from dietary indiscretion, part from immune system compromise, and part from disruption of the dental nerve roots. However, poor oral hygiene, poor nutrition, and a loss of saliva due to dry mouth results in decay, periodontal disease, and ultimately tooth loss.
- Dermatologic issues can occur in the form of neurodermatitis, excessively dry skin or hyperhidrosis. A dermatologic condition that is little understood and rare in its presentation is Dercum's disease. This is manifested by multiple painful lipomas occurring mostly on the trunk, upper arms, and upper legs. The etiology is unclear. Yet another dermatologic manifestation is that of livedo reticularis.
- Gastroenterologic manifestations occur in better than half of the patients. Most commonly this takes the form of gastroparesis with its associated side effects of nausea and

- vomiting. Acid peptic disease and irritable bowel syndrome are common as well. Dysphagia, indigestion, biliary dyskinesia, and diarrhea and constipation (the latter exacerbated by the use of opioids for control of pain) have also been seen.
- Urinary spread of Complex Regional Pain Syndrome takes the form of symptoms that mimic interstitial cystitis. These include urinary incontinence, dysuria, or the inability/ difficulty to void. Bladder pacemakers have been used for this purpose. Botox injections into the pelvic floor have helped. This misdiagnosis of interstitial cystitis can be complicating and prolong the treatment. If the patient does not respond to common modalities of treatment to I.C., a spread of Complex Regional Pain Syndrome to the urinary bladder should be considered.
- Gynecologic manifestations include polymenorrhea, dysmenorrhea, secondary amenorrhea, and menometrorrhagia.
- Neurologic symptomatology such as vertigo, syncope, seizures, and pseudo-seizures can be seen as well. Other neurologic manifestations include cognitive issues, most often short-term memory loss, word retrieval, and difficulty with expression. Some believe that this is due to medication while others believe it is due to the diminished use of brain function caused by the isolation that is sometimes experiences by patients who are no longer a part of the workforce and have a reduced role in society because of their Com-

- plex Regional Pain Syndrome.
- Other generalized symptoms include lethargy, fatigue, weakness, sleep disturbance, shortness of breath, neurogenic edema, muscle weakness and atrophy, adrenal, thyroid, and hormone imbalance, and of course, to varying degrees, anxiety and depression.

There is an article that elaborates further on the internal organ involvement of Complex Regional Pain Syndrome titled "Systemic Complications of Complex Regional Pain Syndrome" by Dr. Schwartzman in 2012.5

There is great concern as to what can be done to minimize the likelihood of spread. A concurrent article discusses the issue of spread from a patient perspective. It is important to understand that in elective surgical procedures there is something that can and should be done! In 2012, an article titled "Ketamine as Adjunctive Anesthesia and Refractory Complex Regional Pain Syndrome Patients: A Case Series," authored by Dr. Schwartzman and myself, provided details with regard to a study of a limited number of patients who had undergone various surgical procedures using adjunctive Ketamine intraoperatively.6 In my portion of that study, as well as in patients treated in a similar fashion subsequent to the publication of that paper, no episodes of spread of CRPS following elective procedures, ranging from dental extractions to podiatric procedures, have been reported. The use of Ketamine intraoperatively (with any adjunctive agent that the

anesthesiologist chooses) seems to have the effect of blocking the spread, or at least up to and inclusive of this point in time, has worked in that fashion. It is therefore recommended that in cases of surgery, regardless of how innocuous that procedure may be, Ketamine be used during the course of the procedure in a dosage ranging from 80-150 mg of the drug. The dosage depends upon body weight, length of procedure, and involvement of the nervous system in the proposed surgery.

Such procedures as dental cleaning, endoscopies, etc. do not appear to require the buffering.

Once the spread of CRPS has been identified, it is strongly suggested that treatment be initiated to the secondary limb or internal organ as soon as possible. Once symptoms begin to manifest themselves, immediate intervention seems to minimize and in some cases. cause a recession of those symptoms. For example, a patient whose disease spread from the leg to the arm and has received a series of three sympathetic nerve blocks into the stellate ganglia at weekly intervals has a much better chance of minimizing the effects of that spread than someone who waits until the symptomatology becomes more amplified.

Finally, in an interesting observation, I have noted patients who have presented for a full body thermography due to the presence of Complex Regional Pain Syndrome in a single limb. Thermographic

images clearly portray sympathetic dysfunction in a second limb while the patient manifests no clinical symptomatology. It would be ideal if interventional blockade could be given before symptoms presented themselves in the second limb. This, of course, is precluded by insurance denial of treatment in an asymptomatic body part.

In conclusion, the spread of Complex Regional Pain Syndrome is common and multifaceted. It is clearly important for afflicted individuals to be cognizant of the potential sites of spread in order to report symptomatology to their treating clinician. It is similarly essential that physicians make themselves aware of the fact that the disease does in fact spread and can have constitutional manifestations, not simply those that occur in one or more limbs. It is not necessary for there to be an inciting traumatic event for this spread to occur.

As always, the earliest possible intervention leads to the best possible outcomes.

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ABOUT THE AUTHOR

Philip Getson, D.O. is a member of the RSD scientific Advisory Committee and a designated speaker for the Association. *He is a full-time practitioner* in Marlton NJ working almost exclusively with patients with CRPS.

For more information please refer to www.drgetson.com

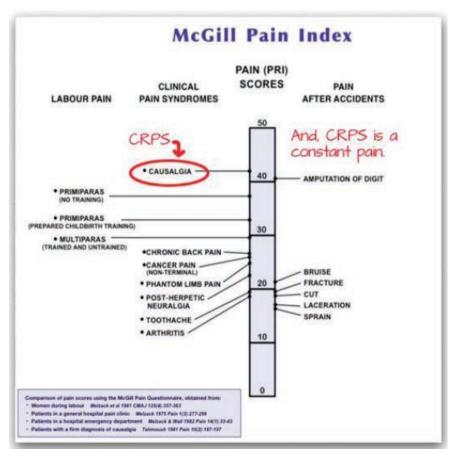
EVENTS

WordUp!

BY JULI WORDGIRL



Juli Wordgirl is Juli Manz. Juli has CRPS in both feet, her arms and hands, her thoracic and lumbar spine, and her glutes. She lives in Edina, MN, with her husband of 18-years and their 17-year old daughter. Juli considers herself to be an eccedentesiast: "someone who hides pain behind a smile." Wordgirl fell in love with books during a fifth-grade reading class, and is now a confirmed bibliophile (lover of books); she is also a logophile (lover of words). Since diagnosis with CRPS in 2008, Juli burns to spread CRPS awareness in every way possible.



McGill Pain Index http://www.rsdhope.org/what-is-crps1.html (https://www.pinterest.com/pin/573364596281759931)

Causalgia, Greek for "heat, fever," or even "burning fire" is the American Civil War's name for today's Complex Regional Pain Syndrome (CRPS). I am Juli Wordgirl, and I'm proud to introduce WordUp! back into the RSDSA's Community Update! After a several year hiatus, WordUp! is back to use and define words for readers of all levels of learning.

William Shakespeare wrote, "That which we call a rose by any other word would smell as sweet" (2.1: 85-86). But is pain by any other name anything other than painful? According to the McGill Pain Index, Complex Regional

Pain Index (CRPS) is the most painful known pain on Earth. It also has a very a confusing name change history.

Jerome Groopman's "Where Pain Remains," explains how Causaliga was first introduced in the 1872 by Dr. S. Weir Mitchell, a renowned student of "human nervous systems." He served as a surgeon during America's Civil War and observed injured soldiers exhibiting signs of extreme types of pain exceeding that of their injuries. He applied the name 'Causalgia' based on his observations of what is now known as allodynia (severe sensitivity to light touch, wind,

CRPS is truly complex. There are many different body systems affected by this disease: central and peripheral nervous systems, limbic system, vascular system, immune system, cerebral cortex. spinal glia, and who knows what else will be found

sound, and other innocuous stimuli) and hyperalgesia. Dr. Mitchell observed that Causalgia 'torments the temper...the most amiable grow irritable,'

In 1946, James Evans from Boston changed Causalgia to the more familiar name Reflex Sympathetic Dystrophy (RSD). Evans was describing what he felt was a disorder that involved patients "who had no discernable nerve damage," and was not complete damage to the nervous system. A lot of confusion followed for the next few decades. With little understanding of a complicated disease and several names, including the name "Sudeck's Atrophy" (a related branch of CRPS), the International Association of Pain introduced Complex Regional Pain Syndrome as a name to represent the whole

disease in 1994. According to Canada's version of the RSDSA, called PARC ("It's not a walk in the P.A.R.C."), the name change from RSD to CRPS was made "to unify the 30 or so confusing terms into one appropriate label for worldwide research purposes." At that time it was thought that there were two types of CRPS. Type 1: no nerve damage and called RSD; Type 2: with nerve damage and called Causalgia or CRPS. Later, Anne Louise Oaklander, of Harvard Medical School, said in "the distinction between the two types of CRPS is artificial...a single neurological disease."

CRPS is truly complex. There are many different body systems affected by this disease: central and peripheral nervous systems, limbic system, vascular system, immune system, cerebral cortex, spinal glia, and who knows what else will be found. How do you say CRPS? Do you say CRPS? Or RSD? Or CRPS/RSD? Or RSD/CRPS? Any way you say it: pain by any other name is ... PAIN!

Let's learn together! Do you have a word you want to understand better? Please write to Juli Wordgirl at WordgirlRSDSA@ gmail.com and submit a word suggestion (not a question). Wordgirl loves to spread CRPS Awareness with the RSDSA through using and defining words of all sizes. The RSDSA cares about what you want to learn, and so does Juli Wordgirl.

WORD UP! SOURCES

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RESEARCH & MEDICAL

Moving Forward

BY JENNY PICCIOTTO

One of the most powerful aspects of the RSDSA is the sense of community created between CRPS fighters, their families, medical practitioners and volunteers. Through this community comes encouragement, support and empowerment. In this article, one of our newsletter columnists and CRPS patient, Jenny Picciotti, connects with a family impacted by CRPS and captures their remarkable journey of strength and resilience.

The RSDSA has recently received a generous contribution from the Mike and Lynn Coatney Family Foundation. The Coatneys are thankful for the support and community that the RSDSA has given to their family. They hope their contribution will have a positive impact on education and research. The Coatneys are also supporting the Brad Jenkins Assistance Fund, which helps families in financial crisis.

When I talked to Lynn, it became clear that generosity comes naturally to her. She is a volunteer foster mom for the Louisiana SPCA and has recently welcomed an abandoned kitten into her home. Lynn has worked with handicapped students and volunteers on the board of Dignity Period, a non-profit organization that serves women and girls in Ethiopia.

Lynn's commitment to service developed early in life. "The

experience of helping others is a wonderful feeling, to know that you can make someone's world a little better." It's important to find something you are passionate about, she told me, and then find a way to make a difference, whether donating money, service or time.

The Coatneys discovered the RSDSA six years ago after their daughter, Laura, was diagnosed with CRPS. Laura was in her second year of college when she tripped on a stair in her dorm. The Health Center checked for a sprain or fracture, but found no obvious injury. She continued to have severe pain in her right foot and visited the emergency room. The ER doctor suspected CRPS and sent her for a follow-up appointment with an orthopedist, who confirmed the diagnosis.

With a diagnosis, the Coatneys turned to the computer to research treatment options. With the limited and conflicting information they found online, their family became frustrated. But after finding the RSDSA website, they finally felt as though they had a "one-stop-shop" for information, treatment options and clinical trials. It became their primary source of information. As Lynn recalls, "it was our biggest encouragement and hope."

As we shared our stories, I felt a deep connection with Lynn and her daughter. I related with them on several levels. As a mom. I

empathize with the fears and hopes she has for her daughter. Laura's experience as a patient closely resembles my own. I was reminded how much people living with CRPS have in common, yet how each of our stories is unique.

Before her injury, Laura was an active and engaged student who enjoyed cross country running and swimming. But sadly, her symptoms spread to both hands and feet. When she developed full body CRPS, she had to take a leave of absence from school. She moved home where her parents could support and help her with tasks she could no longer do on her own. It was challenging to lose her independence and to put her hopes and dreams on hold. As is so often the case, her treatment plan was a matter of trial and error.

Laura's doctors inserted a tunneled epidural catheter, a thin tube that delivers pain medication directly to the spinal nerves. The goal of this was to get enough pain relief to participate in physical therapy, but the catheter became infected and had to be removed. Laura then tried a spinal cord stimulator, which increased her pain levels. After trying several treatments, they learned about a program in Australia that uses Graded Motor Imagery (GMI) to treat CRPS. GMI is a combination of techniques that retrain the brain through mirror box therapy, sensory

discrimination, visualization, and left/right body awareness. Stimulating motor and sensory brain activity, this therapy helps the brain reintegrate the body and reduce pain signals. After finding and working with a specialist who was trained in this technique, Laura began to make progress.

They continued to research treatment options and discovered Dr. Pradeep Chopra, a pain management specialist at the Interventional Pain Management Center of Rhode Island and Assistant Professor at Brown Medical School. Dr. Chopra is a frequent speaker at RSDSA sponsored patient education conferences, where he encourages patients to take an active role in managing CRPS. Dr. Chopra frequently takes three to four hours to evaluate patients with complex conditions like CRPS, Fibromyalgia, and Neuropathic pain.

Nearly four years after being diagnosed, Laura reached a turning point with Dr. Chopra. In addition to CRPS, Dr. Chopra diagnosed Postural Orthostatic Tachycardia Syndrome (POTS), which causes dizziness, sweating, and brain fog. He also diagnosed Mast Cell Activation Syndrome (MCAS), an immune response in the central nervous system in which histamines and cytokines in the blood cause itching and hypersensitivity. His holistic evaluation helped drive a new treatment regime that includes aqua therapy, supplements, antihistamines, ketamine infusions, and low-dose naltrexone.

Rhode Island soon became their "CRPS home." On their monthly trips to the clinic, they met other patients and caregivers who shared their experiences and became like a second family. "Sharing our stories was healing," Lynn told me. "We suffered alone in silence. Knowing that someone else has been through the same physical, mental, and emotional struggles and found a way forward is inspiring. We aren't alone. If someone else can do it, I am encouraged to try too."

Lynn says that Dr. Chopra's help was life changing. Laura now lives independently and returned to school. She can drive again, and uses a cane to help her walk. She has learned to adapt to living with pain, taking practical measures like giving herself extra time to get to class to avoid being bumped by hurried students. She has developed coping skills to manage stress, flares, and life's inevitable problems. It's her "new normal," and she is once again pursuing her hopes and dreams.

I asked Lynn how Laura's journey has affected her. "Laura inspires me with her outlook," she said. "I better understand people in pain, and that success comes in smaller doses. I am happy that CRPS is not going to take away her goals and interests. I grieve for her, that she will have to make some different choices, but I see her commitment to moving forward, to trying new things. Moving forward, I think, that's the most important thing."

RSDSA is grateful to the Coatney family for their generous contribution to CRPS research, education, and emergency support for patients facing

financial crises. The RSDSA is an international leader in providing resources to CRPS patients, and funding research for better treatment options and a cure for this devastating condition. Our mission statement is to:

"provide support, education, and hope to all affected by the pain and disability of CRPS/RSD, while we drive research to develop better treatments and a cure."

Our mission draws on the support we received from a multitude of sources, including small businesses, corporate sponsors, and individuals. We are grateful for every contribution we receive, no matter the size.



ABOUT THE AUTHOR

Ienny Picciotto is a writer and CRPS patient who enjoys reading and playing the piano. She was a voga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.

CRPS: Progress in understanding mechanism and future advances in treatment.

TONY L. YAKSH, PH.D. DEPARTMENT OF ANESTHESIOLOGY, UNIVERSITY OF CALIFORNIA, SAN DIEGO

Following tissue trauma, we are not surprised that the patient expresses pain referring to the injury site. Such injuries often resolve with little consequence. In a significant population of patients, however, there is a progression over time to a severe pain state characterized by a painful dysesthesia and extreme sensitivity to light touch (allodynia). This pain development is paralleled by evident changes in the physical appearance of the injured limb. In its most severe form, the limb or joint may present early on with pale skin color, sweating, local swelling (edema) and reduced skin temperature, which is indicative of vasospasm. Over time the injured limb/joint may display trophic changes including skin thinning, brittle/cracked nails and loss of bone density with muscle wasting. An important characteristic is that the pain state may be diminished by sympathetic blockade (hence the designation as a sympathetically maintained pain). This syndrome, arising from injury to a nerve (at the trunk or the distal terminals) and adjacent tissues, has been recognized for well over 150 years. Yet, its origin remains poorly understood.

Commonly referred to as Complex Regional Pain Syndrome (CRPS), we now recognize that

this injury phenotype results from a complex cascade of reactions involving not only the injury sites, but reactive changes in the sensory ganglion of the injured afferents and spinal cord. Let us consider some of the potential mechanisms that we have come to appreciate.

Nerve spouting-Nerve injury leads to sprouting of the damaged axons. These sprouting axons fail to reach their target and develop neuromas which, unlike the normal nerve, develops spontaneous activity that is interpreted by the spinal cord as a shooting pain. This spontaneous activity occurs as a result of the formation of a variety of growth factors and abnormal protein from the injured nerve and tissues, stimulating the nerve to over express "sodium channels" and under express "potassium channels." This altered channel expression greatly increases sensory nerve excitability. Increased release of growth factors also results in a profuse excitatory sprouting of the sympathetic nerves into the injury site and cell body of the injured axons. This permits sympathetic activity to abnormally activate these injured sensory nerves, reflecting the mechanisms for a sympathetic dependency of the pain states.

Migration of inflammatory cells-Peripheral injury further leads to the migration of inflammatory cells (macrophages and lymphocytes) into the neuroma, the sensory cell body and, surprisingly, the spinal cord. These inflammatory cells secrete biologically active cytokines, which are molecules that have potent stimulatory properties.

Peripheral release of Neuropeptides-While we strongly believe that many of the consequence of nerve injury pain represent changes in the way the nerves and spinal cord function after injury, there are interesting hints that the peripheral sensory terminal may be relevant. Nerve injury leads to an increased release of neuropeptides from sensory afferents. These neuropeptides can lead to some of the symptoms observed in CRPS including vasodilation, plasma leakage and activation of skin cells (keratinocytes) to release inflammatory cytokines that can activate injured sensory terminals. The development of agents blocking these neuropeptides and cytokines is considered to have promise.

Innate and Adaptive immune signaling-A very exciting area of research is the developing hypothesis that innate and

adaptive immunity play a major role in the development of the nerve injury-CRPS phenotype. The defining property of *innate* immunity is the existence of families of receptors, toll like receptors (TLR), with which we are endowed at birth and which recognize foreign protein (bacterial cell walls). These receptors are classically found on inflammatory cells and allow them to target pathogens for destruction. We now know that these TLRs are not just on inflammatory cells, but on sensory neurons where the TLRs are activated by pathogens and products released in the body as a consequence of tissue injury and inflammation. Research conducted by the University of California San Diego has shown that spinal TLR activation results in the conversion of a "simple" inflammatory pain state to a neuropathic condition. Linda Watkins at the University of Colorado has suggested that TLRs sensitize the nervous system to worsen the consequence of moderate nerve injury. Adaptive immunity is a process that permits the body to develop antibodies to novel targets. These antibodies bind and mark those cells expressing this target for destruction. In some cases, the system may inappropriately target protein that is expressed on our own nervous tissue, leading to neuronal damage as in neurodegenerative disorders or activating neural systems that lead to pain. Work by Camilla Svensson and her colleagues at the Karolinska Institute has shown that antibodies released prior to the onset of arthritis can affect bone cells leading to bone

loss and, in turn, release a pain inducing cytokine. The possible relevance of this scenario to CRPS is an exciting possibility. In short, CRPS represents a true pathology yielding trophic changes in tissue and an enduring pain state. The advances in our understanding of the biology of nerve injury has generated considerable hope that these advances will lead not just to the development of approaches to block the pain, but to be disease-modifying and prevent the changes that lead to the pain state.



ABOUT THE AUTHOR

Dr. Tony Yaksh is a professor and vice chairman for research in the department of anesthesiology and professor of pharmacology at the University of California, San Diego. He became a distinguished professor in the School of Medicine in 2004. Dr. Yaksh has written more than 780 scientific papers and cited more than 45,000 times in medical literature.

POETRY CORNER

Always

Wherever we go, whatever we do There is this pain that's stuck within you Sometimes it's nagging and keeping slow Most times it's raging, and it won't let go There are times we cry just getting out of a chair or from taking a shower and brushing our hair.

We hide behind our smile, We don't want it to show We want to get ready We want to go RSD doesn't care it's always there, *Reflex sympathetic dystrophy* or as you have come to be known, complex regional pain syndrome won't leave us alone.

This pain gets worse throughout the years, Always bringing us to tears It settles in our bones, It calls Us home. It can spread to other parts of our bodies with pain that brings Us to our knees I wish this was a dream and it will all end We need something to help us mend

Most Drs don't know What RSD & CRPS Is Education & Awareness is the key If there is going to be a Cure for you & me. Send a Message that's heard loud an clear. So in the future others won't have to deal with this Pain & Fear.

Janet & Sami's Story

BY SAMI SMITH

"We wrote a story of love. We wrote a story of friends. We wrote a story that would never end"...or at least we thought it would never end. We were young and in our prime. I was 33 and Janet was 30. We had the world by the tail. We were producing and recording our own music, selfpublishing spiritual books and, most importantly, loved each other unconditionally. We were happy and quite content. It may sound silly, but Janet and I both truly believed we would be called "home" when we were old. We believed that when this time came, we would be together, hand in hand. We would step beyond the veil of this world into the next while greeting Heaven's gates with everlasting joy.

Tragically that's not what happened. I wanted to share our story in hopes it will help someone else in their journey.

In 1993, we were getting ready to go see a play. Janet, who was 33 at the time, hit her funny bone before leaving the house that catapulted the us into an arena we could have never imagined. When she was diagnosed with RSD, Janet poured herself into her neurology textbooks. Being a neuro trauma RN and having never heard of RSD, it perplexed and aggravated her to the core. Over the span of 20 years, we saw a multitude of doctors. Sometimes we had to battle the doctors just to keep her pain under control. We were spurned by many of these doctors as drug seekers. Pharmacists at times denied filling legitimate prescriptions. Despite undergoing countless sympathetic nerve blocks and two thoracotomies. Janet remained symptomatic. Anesthesiologists and surgeons passively blamed Janet's anatomy for the failed procedures and surgeries. At

one point, she was treated as if she was a drug seeker. The way we were treated was incorrigible.

In 2001, Janet took a nap for an hour. When she woke, she had no pain. She experienced an "unexplainable nonmedical remission where she was completely asymptomatic." No pain anywhere! There had been numerous occasions where this happened. Her doctors didn't know how to respond to this walking miracle. But sooner rather than later, the RSD would once again raise its ugly head, invading her temple with a deliberate vengeance of total destruction of her health. I became angrier with God. I was so frustrated. I felt guilty after complaining that I couldn't handle anymore. The hectic schedule of never-ending doctor appointments began to interfere with my job requirements. I worked full time as a paralegal and was fired from many law firms because I chose to stay home with Janet on her many low days instead of going to work.

For those reading this story who have been diagnosed with RSD, you know all too well the relentless, never-ending 24/7 physical and emotional pain caused by this disease. Janet tried to explain her painful symptoms to me. "A sheet feels like it's ripping my skin off; I feel like red-hot coals are being placed all over my flesh; I have an onslaught of incessant burning/ stabbing pain in my head, eyes, neck, back, arms, legs, feet, ribs, sciatica, and scapula; I have some sort of bone crushing pain in those areas, as well as a deep bone coldness throughout my body." With tears in her eyes, she said the list could go on ad infinitum: balance issues, eyesight issues, feet issues, dystonia, thought

process and speech issues. It was difficult for Janet to accept the neurological and speech issues because she was a member of Mensa and she knew her brain had turned against her. I became even angrier with God! I was scared. We were both scared. I couldn't even hold or hug Janet to comfort her because it was too painful for her body. Janet couldn't get stressed or angry because those emotions would trigger a flare that could last for days or even weeks. As members of the RSDSA community, we all know RSD invades the lives of the warrior as well as family members and caregivers. With an RSD diagnosis comes the baggage of pain levels greater than cancer or childbirth, grief, guilt, shame, frustration, anxiety, confusion and, of course, anger.

In 2011, I was once again frantically searching the Internet for treatment options. I had previously read an article about ketamine comas being conducted in other countries, but we simply did not have the financial resources to travel overseas. Janet became weary and hopeless and I became tormented, withdrawn and still hating God even though I never stopped my prayer time with Him. Strange, right? I felt we were at a crossroad.

Miraculously I somehow stumbled across a support group for those who suffered with RSD. It was after speaking with Nancy Cotterman that a glimpse of hope presented itself. She informed me that there was a doctor in Clearwater, Florida who performed Ketamine infusions a mere four hours from our home in Ft. Lauderdale. I was ecstatic! I remember running into Janet's bedroom beaming with the

news. She underwent the infusion and when she woke she was asymptomatic! She raised her arms straight up in the air and hollered loudly "no pain!" Coincidentally, Nancy was there to witness Janet's results. We were elated and ever so grateful to Dr. Hanna and Nancy for steering us in this direction. My anger at God began to diminish and was slowly being replaced with gratitude in lieu of fear.

As the months passed, Janet remained asymptomatic. But sadly, this relief was interrupted as she kept losing her balance and falling. This led to fractured ribs, two incidents of a broken foot and three broken wrists. Her symptoms returned vehemently. We were heartbroken. I one again found myself seriously angry at God.

"Screw gratitude!" I screamed loudly in my car as I banged my hands on the steering wheel. Janet and I cried together knowing she had not an ounce of fight left in her. Even though I had made her another appointment with Dr. Hanna, Janet cancelled it and told me she would reschedule when and if she was ready. I didn't push the subject because she was adamant in this decision. Little did I know what she was contemplating.

One day out of the blue, Janet repeatedly told me how much she loved me. She thanked me for not abandoning her during all these years and for taking such good care of her. She continued saying that I did everything I knew to do and that I should never think I didn't do enough or could have done more. I just stood there baffled at what she was saying to me. The words echoed in my brain. She smiled at me like only she could do, turned around and silently went to her room. For years, we slept in separate bedrooms because she had interrupted sleep or no sleep. All of a sudden, she was eating in the living room rather than her room. She was jovial. She wanted to watch movies together

and sleep side by side holding hands in the recliners with our dog lying in her lap. This went on for three days and three nights. The fourth night I fed her an ice cream sandwich and kissed her on the cheek whispering my never-ending love and that I would see her in the morning.

I missed "the signs." By dawn, Janet had overdosed and stepped behind the veil into the other world, leaving RSD and its destruction behind. RSD had finally divided and conquered our once precious world.

At the age of 55, I became a survivor of my Janet's action of suicide. This disease attacks the mind, body, and spirit. RSD/CRPS is commonly known as "the suicide disease." At the age of 53, my RSD Warrior earned her wings and took flight evolving into an RSD Angel on October 12, 2013 10 days before my 56th birthday. Despite my emotional collapse, I understood it was hopelessness, solely, that pushed her into the darkest place she had ever been. She was no longer willing to endure the endless suffering nor emotional torment. Her courageous fight for 20 years against all obstacles is a testament to her strength and character. Neither dusk nor dawn has brought me solace. I aimlessly wander this earth without my soul mate, best friend and confidant. I anxiously await the time I am called "home" and I step behind the veil and see her once again, whole.

For those of you who are caregivers, loved ones or family of an RSD Warrior, please believe them when they take a risk to voice their pain to you whether it's emotional, physical, or both. Their pain is real. They are suffering more than you can even begin to comprehend. Presently, there is no cure, but there are Ketamine infusions and that in and of itself is a miracle. Many Warriors go into remission at times for years while others find relief for only several months. Unfortunately, the number of warriors like Janet who

take matters into their own hands is astronomical. The suicide rate from this disease is alarmingly high and needs to be addressed in depth. Please heed my words and do not miss the signs. They are called warriors for a reason. They endure pain levels none of us can begin to fathom but they are also human. You never know what the dawn may bring so treat them with love, patience and understanding.

I know you're curious if I'm still angry with God. Sometimes I am. Other times I'm not. I do know I am loved unconditionally by my God. He can handle my fear, anger, and hurt until I can fearlessly walk onto a new journey's path without Janet by my side. I am grateful He placed such a beautiful soul in my path. I am still lost without her. I miss her. It doesn't get better. She was my world, my heart, and my soul. The nights I was unable to sleep due to RSD have been replaced by sleepless nights without her near.

Fly high Janet with the other RSD Angels as you bring comfort and strength to our Warriors. We we will continue to search for a cure to once and for all decimate RSD.



ABOUT THE AUTHOR

After Janet's death, Sami moved from FL to LA to be near family. She is the administrator for RSD/CRPS Loved Ones &,Caregivers Support Group on Facebook.

My life as a parent with CRPS

BY PAM BENTLEY

Being a parent can be one of the toughest jobs in the world. But what happens when you add Complex Regional Pain Syndrome to parenthood? I suffered from bulging discs and back problems for years. When it began to impact my ability to run around with my kids in the backyard or make my family dinner, I decided to take action.

Lunderwent a Lumbar Fusion in 2006. Immediately following the surgery, I knew something was very wrong. There was burning, sensitivity, extreme pain in my foot that simply could not be explained. Not knowing the cause, the neurosurgeon ordered a scan and performed surgery to remove bone fragments. As we continued to search for answers, the pain traveled up my leg to just underneath my knee. My doctors went on to perform a variety of nerve blocks, physical therapy and pain management. The pain intensified and continued to spread to my lower back and buttock.

The pain was unbearable. My bed sheets could not touch my foot, leg or lower back and buttock. A gentle breeze or walk through the grass caused me pain. It felt like someone was continually stabbing my leg and holding it over an open flame. After several visits to the neurosurgeon, pain management doctor and physical therapy and no obvious explanation for my pain, it was



ABOUT THE AUTHOR

Pam lives in Pennsylvania with her husband of 28 years. She began her journey with CRPS in 2006 and continues to strive to feel as normal as possible and fight through the pain. She has two grown children who are 22 and 24 years old. Pam enjoys spending time with family, volunteering, reading and visiting the beach.

thought that the nerves needed time to heal, so I continued taking the pain medicine. On one occasion, I went to the emergency room on the advice of my doctor, who thought that my pain may be caused by a blood clot. No, I did not have a blood clot and once again, no one could explain why I was having so much pain.

At my six-month post-operative appointment, the doctor suggested that I see a neurologist at Drexel College of Medicine, Dr. Robert Schwartzman, who specialized in treating a pain

disorder known as RSD/CRPS. Not expecting much, I made an appointment. After months of shuffling from doctor to doctor, a lot of pain medication and feeling like I was going to have a major breakdown, I finally had a diagnosis. Dr. Schwartzman told me I had CRPS. What a relief to have a diagnosis- so I thought! He immediately began a course of treatment, telling me the sooner treatment is started, the better the outcome would be. By this time, it had been almost a year since my surgery.

I tried an inpatient lidocaine treatment for five days, an inpatient ketamine treatment for five days and various nerve pain medications. Unfortunately, I still did not feel much relief and other roadblocks continued to arise. Insurance would not pay for the follow-up outpatient ketamine infusions. I also didn't tolerate the outpatient ketamine. Dr. Schwartzman strongly believed that I would benefit from the ketamine coma which was being performed only in Germany and Mexico because it was not approved in the United States. Being put in a coma, in a foreign hospital, in a place where I couldn't speak the native language was unthinkable. Not to mention I had two children, an eleven and thirteen-yearold, at home who were already experiencing the effects of their mother's ordeal. I was not going to do anything that drastic. After

reading so many articles about the positive results Ketamine has had on chronic pain, my husband and I thought the FDA would approve the treatment any day. To this date, this treatment has not been approved for RSD/CRPS.

This is not an individual disease. but rather a disease that affects the whole family. Here are some things that have helped us as a family impacted by CRPS:

- Get up every day shower and try to accomplish something. This can be as simple as making a meal, food shopping or house cleaning.
- Talk to Your Kids Sit down as a family and explain to your children that you are not able to do everything that you used to do. Everyone needs to work as a team.
- Appearances can be deceiving - Explain to your friends and family that even if you appear ok, you may just be trying to feel "normal."
- Plan Ahead If you know you have a busy day of running errands or volunteering at the kids' school, make dinner ahead of time. Chances are that being on your feet all day will make your pain even worse. If you have something prepped ahead of time that you can easily pop in the oven, it will allow you more time to rest.

- Take Help When You Can Get It - Learn how to let others lend vou a hand. Let vour neighbor pick the kids up from school or run them to karate practice. Allow someone from church to drop a meal off to your house.
- Give Yourself a Break -Spent your Saturday taking the kids to the beach? Allow yourself to take Sunday off. Have a family movie day complete with PJs and takeout.

Parenting and CRPS is never easy, but these adjustments can make it a little bit easier.

HOW GIVING BACK, GIVES BACK

In our last issue, we shared about Fight the Flame's work to spread awareness and raise funds for research for CRPS. In this issue. we're pleased to celebrate Grace Fuller as she has been awarded the first scholarship from Fight the Flame, for her commitment to increase awareness about CRPS.

After her mom, an attorney, took on the case of a client suffering from CRPS - a small injury to the hand turned into life confined to a wheelchair - Grace felt compelled to learn more about this invisible illness.

"...it can happen to anyone, including me."

The most striking phrase from an essay Grace shared with the Fight the Flame organization - and it's completely true. Affecting such a small percentage of the population, CRPS receives a fraction of the funding and research as larger, more wellknown causes. By committing to spread the word, to let people know about this disease and the people it impacts, Grace is helping transform the future for patients suffering from CRPS.

Thank you & congratulations, Grace!

You can learn more about Fight the Flame at FightTheFlame5k. org and Facebook.com/ FightTheFlame5k.



ABOUT THE AUTHOR Jennifer Brien is a CRPS patient living in Seattle. She works in marketing and passionate about wine, dogs, and helping those with CRPS

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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.

EVENTS CALENDAR



SEPTEMBER

September 9: 2nd Annual Long Island CRPS/RSD Awareness Walk-East Meadow, NY

September 16: 2017 CRPS/RSD Awareness Walk-Pennsauken, NJ

September 17: Knock Out Pain 5K and 1 Mile Family Roll & Stroll-Easton, PA

NOVEMBER-CRPS AWARENESS MONTH

November 4: 4th Annual Central New Jersey RSD/CRPS Walk for Hope-Lincroft, NJ

November 5: 5th Annual Fight the Flame 5K- Charlotte, NC and Mentor-on-the-Lake, OH

November 6: Color the World Orange- Worldwide

PEER-TO-PEER CONVERSATIONS



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

VOLUNTEERS:

If you wish to volunteer, please do the following.

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

THOSE IN NEED OF SUPPORT:

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

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

Don't see an event near you?

Contact Samantha Barrett (sbarrett@rsds.org) to discuss planning an event in your area!