Welcome to RSDSA:

The RSDSA is a 36-year old not-for-profit organization. RSDSA’s mission is to provide support, education, and hope to everyone affected by CRPS/RSD while we drive research to develop better treatment and a cure.

We invite you to join our community dedicated to working for you and your future. Being part of our RSDSA community is important. There is power in numbers. We have a community of more than 39,000. But we must increase our community so that Congress, The National Institute of Health, pharmaceutical corporations, and insurers hear our collective voice!

I recommend you sign up for our free electronic e-Alerts if you haven’t done so already at http://rsds.org/joinmembership/ to receive not only the RSDSA Community Update Newsletter but information on upcoming RSDSA fundraisers and other important information.

Please join RSDSA on social media on Instagram @rsdsa_official, RSDSA Facebook and, Twitter #@RSDSA.

RSDSA has state-by-state listings of healthcare professionals interested in treating CRPS. Please call us to obtain a listing in your state.

We also have 170 educational videos on our YouTube channel: RSDSA of America.

It is easy to join our community even if you do not have an email. Just provide us with your mailing address, telephone numbers, and we will gladly enroll you. You are not alone in your fight against this horrific disorder. Please donate to RSDSA today (please use the enclosed envelope or call us at 203.877.3790). If you choose not to join our community, please consider making a good-will donation to cover the cost of this mailing. We will not sell or rent your name.

Sincerely,

James W. Broatch, MSW
Executive Vice President and Director
HELP FIND BETTER TREATMENTS AND HOPEFULLY-A CURE! All proceeds will be invested in RSDSA’s Research Fund

*JEN’S GIFT* is a testimony to Jennifer Abramson’s brief but wonderful and impactful life. Jennifer lived only 31 years; however, she lives on in *Jen’s Gift*. Her goal was to enlighten, transform people’s thinking, and spread faith and hope in the infinite possibilities of this life.

*Jen’s gift will inspire you.* Her wisdom, clever humor and insights paired with her beautiful photos will make you laugh, smile, cry and maybe think about things that haven’t occurred to you before.

May her gift inspire you and may you too be touched by her love and kindness.

How to Obtain the Best Medical Care for CRPS

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If you are reading this, it unfortunately means you or a friend or loved one have been diagnosed with complex regional pain syndrome (CRPS). This article is not about diagnosing and treating CRPS but rather about how to obtain the best medical care for this diagnosis.

There are lots of good reasons to obtain the best medical care possible for this diagnosis. First and foremost is that early quality treatment has the best chance of resulting in the best outcome. Second, the wrong treatment can actually lead to a worsening of this condition. Third, from a practical standpoint your insurance coverage may be limited and thus getting the right treatment first which is covered is very important.

There is both good and bad news. We will start with the bad news. Many of you will not have adequate insurance coverage to provide the absolute best care for CRPS. Problematic as well is that even with good insurance coverage, treatment available in your local community may not be ideal or even available. With that said, the good news is that if you will take time to educate yourself about your CRPS condition, you have a much greater chance of getting what you need to get better and to manage this condition.

While some treating physicians may focus on medications and interventional procedures (i.e., injections, device implantation, etc.), and these can certainly be an important part of treatment, the best treatment is approached from a biopsychosocial perspective by an interdisciplinary team of treaters. This means treating you as a whole person and paying attention to both the physical and psychological aspects of chronic pain. This approach involves coordinated medical care with a treatment team, other than yourself and significant others, including a physician pain specialist, a physical and/or occupational therapist and a psychologist.

In this type of biopsychosocial approach, it is critical that the person with CRPS, become educated about the condition and be the “Caption of the Ship” when it comes to managing medical care. Being passive and leaving it all up to the doctors and therapists just won’t work. The person with CRPS needs to understand about his or her condition and how to treat it. That means becoming informed and
educated. Whatever therapy is provided, it will not be enough if the CRPS patient doesn’t “practice” what they are taught 24/7 both at home and away from the doctor and the therapy center.

The ideal setting for treatment is where the physician is a rehabilitation oriented pain specialist and not just a doctor focused on prescribing pills and doing procedures (i.e., nerve blocks, implanted devices, etc.). This means ideally, that the physician works closely with a physical and/or occupational therapist and a psychologist with expertise in treating CRPS. It is always best if they work out of the same facility as a team (this is called interdisciplinary) but even if they are in separate offices, it is important that they communicate and work together as a team (this is called multidisciplinary).

Getting back to the issue of education, while some physicians and therapists feel threatened by an educated patient who is knowledgeable and asks questions - and you need to be careful not to make the treater feel uncomfortable - it is perfectly okay to be educated about your problem and ask questions. High qualities treaters enjoy questions and are not threatened by knowledgably patients. Have you read up about CRPS? Have you made yourself familiar with the usual medications and treatments prescribed for this condition?

Here are some other things to consider when you are evaluating obtaining the best treatment for CRPS.

1. Identify other individuals with this condition in your community to find how they have done with their treatment and who they have treated with. Does their physician, physical therapist and psychologist listen to them and provide effective treatment? Are they being provided education about the condition and a good home program to expand and work on what they are learning when they’re in therapy?

2. Tell your primary care family physician that you are familiar with the diagnosis and want to make sure you are being referred to a pain physician who is rehabilitation oriented and not someone who focuses on prescribing medications and injections and other invasive treatments.

3. Interview the doctor and therapist to see if they are truly familiar with and experienced in treating CRPS. Is the medical care provided truly coordinated between the various disciplines?

4. Ask the physical therapist how commonly they treat people with CRPS and if they are familiar with some of the more recent graded motor imagery approaches such as mirror box therapy.

5. If there is no physical therapist in your community that consistently treats people with CRPS, ask to treat with the therapist that sees the most people with chronic pain. Many of the same pain management skills can be applied to managing CRPS.

6. As you speak with the physical therapist, see how willing they are to provide full answers to your questions. Quality CRPS treatment requires a lot of education and your therapist should be eager to provide you with the answers to your questions.

7. Many psychologist deal with symptoms like depression and anxiety, but ideally, the psychologist needs to be trained in pain management. It is very important that they use cognitive behavioral therapy (CBT) as part of their therapy as CBT has been found to be highly
effective for managing pain. Cognitive behavioral therapy is a form of psychological treatment that focuses on examining and changing the relationships between maladaptive or faulty thoughts, feelings and behaviors.

The RSDSA web site (http://rdsd.org/) is a great source of information. Another source of good information is The American Chronic Pain Association (www.theacpa.org) in general and the ACPA Resource Guide to Chronic Pain Medications & Treatment (http://www.theacpa.org/Consumer-Guide) in particular.
Pain and Activity
By: Michele Gargan, Ph.D.

The human body is meant to move. Yet a person who experiences intense, persistent pain will probably move less and less over time. He or she is also likely to develop a number of “pain behaviors” such as lying down for long periods, using unusual postures to brace against the pain, or favoring one side of the body over another when moving. After a while, these pain behaviors take on a life of their own and actually add to the pain.

Long periods of immobility disrupt the body’s pain sensing mechanisms because pain perception relies on feedback from normal muscle activity, particularly the larger muscle groups of the body. Avoidance of activity under stimulates the large sensory nerves and results in more pain when movement is resumed. The habitual use of unusual postures results in secondary pain in other areas of the body as certain muscle groups go into chronic spasm while other muscle groups atrophy from lack of use. So rather than decreasing pain by avoiding certain patterns of movement, a person is actually increasing his or her pain as well as creating new pain.

A common pattern that I see in my pain patients is a burst of activity on a good day followed by several days of increased pain and immobility. As much as I preach consistently moderate activity, my patients habitually try to get everything done when they feel good. But when they do this, they get nothing at all done in the following two or three days. A prudent and effective pattern to follow is to do the approximately the same amount of physical activity each day. On “bad” pain days, you will have to push yourself, while on “good” days you will have to hold yourself back. If you do this, you will see that you get the same amount done as when you do a burst on Monday and nothing on Tuesday and Wednesday. If you do a little each day, you will get the same amount done without misery on Tuesday and Wednesday.

The following are some suggested techniques you can use to maximize you functioning:

- Keep an activity log for a two day period. Write down everything you do including quantity (how many dishes you washed) and how long you spent at it. You will probably be surprised at how much you do accomplish even though it feels to you as if you are doing little or nothing. Keeping this type of log will make you more aware of your patterns as well as help you set reasonable expectations. Challenge the artificial deadlines you set for yourself. What does it matter if the whole task is completed in one hour or one day, or in three hours or three days? How perfect does the work have to be? Learn to say, “That’s good enough.”

- Breathe while you move. Be aware of using your breath to support physical exertion instead of holding your breath again pain. Also be aware of the amount of energy you are using to accomplish a task as well as the quality of your movement. Replace short, quick intense movements with longer, slower, lighter movements. Elongate the muscles when dusting, scouring, or reaching, and low down to allow a full range of motion.

- Take frequent breaks. Every twenty minutes or so, change positions, change activity, or just rest. It may take you longer to do what you used to do in the blink of an eye. So What? It is important to learn to pace yourself.

- Schedule a rest period in the middle of the morning and the middle of the afternoon. A half-hour is usually effective, but some people take an hour or longer. If you have to nap, go ahead. But many people find that just relaxing, listening to music, taking a bath, daydreaming, or meditating is effective in extending their ability to function throughout the day. Go back to your activity log and find the natural breaks where you can insert rest periods. If you think there is not time to rest, you are trying to accomplish too much.
• Make conscious transitions between tasks. For example, if you are cooking dinner, take a few seconds to breathe and stretch between peeling the potatoes and molding the meat loaf. This allows you to release muscle tension and adjust your posture as well as tune into your physical effort in order to maintain a steady, easy pace.

• Put some type of regular physical exercise into your life. Don’t deprive your whole body of exercise and fitness because part of you is in pain. Yoga is excellent for person with pain because it increases flexibility and strength while focusing on breathing to support movement. Most yoga instructors will modify the poses to fit your needs. Walking and swimming are also good activities to keep the whole body healthy.

• Explore new recreational activities. If you used to play soccer or go skydiving for fun, you have to find new pursuits. Music, painting, gardening, creative writing, and handicrafts do not offer the same physical thrills, but they are relaxing and rewarding. Make time for fun even if you have not completed all the chores that need to be done.

If you have a chronic pain condition, you have to accept that much of your life has changed permanently. This does not mean your life is over. It just means that you can’t do things the way you used to before the pain set in. If you set realistic goals, learn to pace yourself, maintain a moderate level of daily activity, and engage in pleasurable pursuit, you will be able to have a full life.
Complex regional pain syndrome (CRPS), previously known as reflex sympathetic dystrophy (RSD), is a chronic neuropathic pain condition that can arise from trauma of any kind. It can be the result of something as minor as a blood draw that initiates a reaction. The condition arises more frequently than many emergency physicians may realize: roughly 3 percent of patients suffering a Colles fracture develop CRPS. Often the traumatic event cannot be remembered, and CRPS has been associated with trauma happening anywhere from a day to a year after the event. Its most consistent feature, however, is how often physicians fail to make the diagnosis on initial presentation. Furthermore, our lack of understanding about how to manage the severe pain that occurs during acute flare-ups of this chronic condition worsens the suffering that many patients with CRPS endure over decades.

Early Diagnosis Is Key

As can be seen with diabetic neuropathy, CRPS has both a sensory and an autonomic dysfunction. Unlike patients with diabetic neuropathy, both will be present from the start. Not only do patients suffer from intense pain that does not correspond to a specific nerve distribution, they also suffer visible changes as the result of their autonomic dysfunction.

Initially, the involved painful area (usually part of an extremity) becomes red, warm, and edematous; it is often initially misdiagnosed as cellulitis. The presence of severe allodynia (pain induced with a nonpainful stimulus such as light touch) should make the physician consider the true diagnosis. It is very important that CRPS be diagnosed early on because active treatment can reverse and eliminate the condition. Treatment includes neuropathic analgesics (eg, tricyclics, gabapentinoids) combined with active physiotherapy and mindfulness. Many patients who develop this condition will come to the emergency department with their painful condition when it begins, so the emergency physician needs to be able to diagnose and refer appropriately. I personally diagnose two to three new cases per year in my emergency medicine practice.
Failure to treat within the first weeks of symptom onset will allow the physical changes to start. The involved area will develop dystrophic skin changes: a shiny, thin, erythematous appearance. Underlying muscles atrophy so that the involved area becomes wasted in appearance over time. Typical burning neuropathic pain persists. If left untreated (or if poorly treated), CRPS can spread, involving larger parts of the body.

**Treating Flare-ups**

Patients will also present to the emergency department because of an acute flare-up of their chronic pain. CRPS can become acutely more painful because of N-methyl-D-aspartate (NMDA) activity and hyperresponsiveness to NMDA. NMDA is a neurotransmitter present in the dorsal horns and spinothalamic tracts, and it is the number-one initiator of wind-up in acutely painful conditions. With CRPS flare-ups, it is almost as if wind-up starts over again. The burning pain becomes acutely worse; pain is severe and unresponsive to almost all analgesics. Opioids will not control the pain of a flare-up unless given in a quantity that would make the patient somnolent. Opioids should not be considered a first-line treatment in this situation. It is recognized that many patients with CRPS ask for opioids for their severe pain. As with any patient asking for opioids when suffering from a chronic pain condition, this can create distrust and a stressful environment. Increasingly, national patient groups are educating patients that opioids will not be effective.

Given the cause of the pain flare-up, the treatment needs to be directed at stopping the NMDA activity. This is best accomplished with ketamine, an NMDA antagonist. A patient can only receive intravenous ketamine in a hospital environment, so emergency physicians need to be able to recognize and treat these severe pain flare-ups.

**Treatment Is Straightforward:**

1. **Initial bolus of 0.2–0.3 mg/kg of ketamine infused over 10 minutes.** Giving this dose as an IV push will produce a high rate of dissociative side effects (up to 75 percent of patients) and should be avoided. Almost diagnostic is the patient’s response: severe pain should be resolved by the end of the 10-minute bolus.

2. **An infusion of ketamine (0.2 mg/kg/hr) for four to six hours.** Although the medical literature for this is almost nonexistent, clinical experience has shown that an infusion of this duration resets the NMDA activity to baseline. Patients can return home on their usual medications, with the expectation that the flare-up, which can normally last weeks, will be over. Return rates for the same flare-up after ketamine treatment approach zero. For readers who feel four to six hours is too long, I encourage them to try shorter periods (two or three hours) and publish their results. No discharge prescription from the emergency department will be required.

Patients do not require admission, and they should not receive opioids. They do require the acute ketamine intervention, or they will suffer severe pain for weeks as a result of the flare-up. To date, there is no other effective treatment for a CRPS pain flare-up. Some researchers have studied an infusion of 5 mg/kg of lidocaine over a 60-minute period as an alternative treatment plan, but results are variable. Referral of newly diagnosed patients to physiotherapy and a comprehensive pain program is critical.

With better understanding of CRPS, emergency physicians will know when and how to intervene. Concern over drug seeking should be allayed, allowing appropriate care to be provided.
Medication Summary for Intractable Pain, CRPS/RSD

Published on November 15, 2016 under Guest Blogger for RSDSA

By Nancy Sajben, MD

The following blog post was written on 11/6/16 by Nancy Sajben, MD for her website. You can visit her website by https://painsandiego.com/2016/11/06/medication-summary-for-intractable-pain-crpsrsd/.

I spoke only briefly this morning at the RSDSA conference but there is so much to add. Most importantly, thanks to RSDSA for helping so many people with CRPS. They fund pain research, they are starting a free children’s camp, and now offer physicians one hour free CME (http://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/) teaching about CRPS.

Holistic view, 36 points – that’s how I view caring for brain and nerves, very similar to the details used by UCLA Alzheimer’s Research Unit. In June 2015, I posted on their work on memory loss, dementia (https://painsandiego.com/2015/06/27/dementia-memory-loss-brain-atrophy-not-always-alzheimers-disease-we-are-all-at-risk/). We know chronic pain means inflammation in the brain, excess of proinflammatory cytokines. CT scans show memory loss and brain atrophy in those with chronic low back pain. Can this inflammation lead to Alzheimers? Even if it doesn't, why not maximize what we know we can do to help brain. As I view it, simply be meticulously detailed in giving the central nervous system (CNS) the best chance to relieve or prevent pain or disease.

Below is a brief list.

To find detail and sometimes depth, check the alphabetical lists on either side column [on Nancy Sajben’s website] until you see the category or tag when I first posted on that. Or simply plow through 7.5 years of detail with references. You do the work to check the side columns as I have no time to embed links below, taken from throughout this site.

For now just a list of medication players that may be strikingly important in trying to bring intractable pain into remission even after 20 years. Yes, even chronic for decades. The list applies to intractable pain of all causes. I omitted listing standard interdisciplinary approaches commonly used by every pain specialist around the world. My patients have failed all those.

Some patients with CRPS combine my medications with ketamine infusions.

For those who remain on opioids, ultra-low dose naltrexone (10 to 60 mcg three times daily) can significantly reduce pain, reduce opioid induced hyperalgesia, reduce windup, and thus reduce the dose of opioid needed to give improved relief. Opioids cause pain and trigger pro-inflammatory cytokines that create more pain. I strongly recommend slowly, gently tapering off opioid, and remaining off for 3 weeks before the following is trialed:

1. Vitamin D is anti-inflammatory. Important. Helps pain, depression. If bone loss is an issue, you will not absorb calcium from food if D is low. Mayo Clinic’s publication in 2012 showed more morphine is needed for pain if D is low. Huge literature of its benefit for depression. First topic I posted on – it is that important.74.

2. Vitamin B6 can cause burning pain from scalp to toe, a toxic neuropathy. It can be toxic to brain. It is loaded in tons of soft drinks, “energy” drinks, and supplements.

3. MTHFR mutation may be present. Body cannot process the B12 and folic acid you are eating or taking in supplement. A simple blood test, costly. Treatment is as simple as buying methyl folate and methyl B12 – no prescription needed. Folic acid in particular is profoundly important for one of the major energy cycles in the body. Can cause multiple conditions, some fatal, all from one single cause.

4. Minocycline 100 mg/day is the dose I use but higher doses could be given. It is used daily for decades for acne. I may prevent spread of CRPS if given before surgery, dental work, even minor procedures. I start 24 hours before, and continue for days after full recovery from surgery.

5. Testosterone in either male or female is depleted by opioids, it may be depleted by stress. Low T is a risk for depression, weakness and osteoporosis.
7. Dextromethorphan – reduces hyperexcitable glutamate
8. Oxytocin
9. Memantine – double the Alzheimers dose for CRPS. Like ketamine, it blocks the NMDA receptor.
10. Lamotrigine
11. Palmitoylethanolamide (PEA, PeaPure) a glial modulator, also acts on mast cells. A food supplement. No Rx. Your body makes it. Plants make it. Capsules & cream
12. Ketamine via nasal spray, under tongue combined with IV or not, works on glutamate-NMDA receptor. Not an essential drug. Where ketamine has stopped working, patients have become pain free after years of CRPS.
13. Creams combinations, so many. Most of my CRPS pts very much like Mg++/guai 10% each. You may or may not trial various combinations lido/keto/keta, etc. Numerous. DMSO 50%.

Appendicitis

If it has not burst, treat it like the infection that it is. Surgery may never be needed. I posted details of publications early 2016 with a case report. That young man was being rolled into the OR, instead was discharged 100% better without surgery 2 days later.

Medications target 3 main systems, as discussed at the conference

The opioid receptor – opioids create pain. They trigger glia to produce pro-inflammatory cytokines. Opioid induced hyperalgesia may occur. Cannot be used with low dose naltrexone.

The glutamate NMDA receptor – ketamine, memantine.

Glia, the innate immune system – glial modulators.

Before they see me, my patients have failed all prior therapies even ketamine coma. I view it like football. You have one guy running down the field with one ball. Do you want to win the game? You’ve dealt with this for years. Let’s not prolong it. Hit it with my main choice of meds all at once. Jump on it. What if you get 10% relief – will you even notice 10% after many years of severe pain? But if you get 10% from each of 5 meds, then you are talking 50% relief as a start. Address those 3 main pain systems – even without ketamine – and I have posted a case report after 20 years and 3 suicide attempts before seeing me, she has been pain free for about 4 years as I recall. A surgeon nicked her sciatic nerve when she was 27. Two years ago, pain free, running on her treadmill, she twisted her ankle. She has permanent foot drop from the sciatic nerve injury, but even spraining her ankle did not flare her CRPS. Twenty years of CRPS, pain free for about 4 years. And ultimately, years ago, she was tapered off all the drugs with one exception: LDN lifelong.

Most importantly, I did not have time to relay a very special message from my patient in Brooklyn: “Surround yourself with friends and family who love you. Never give up hope.” She had her first 2 or 3 pain free days this week, as she slowly increases doses of medication. She’s not yet at maximal effect and even then there can be increases. Sending love and courage.

MOVEMENT

Watch this on the RSDSA video [to be posted soon], afternoon speakers, the parents of young ones who had RSD discussed today all the toys and games they had to devise to slowly force yourself to move through the pain, every single day, several times a day, all day, begin to move the body as much as you can. Set goals and slowly, at a pace you set, do the work. Make progress. Go forward. Keep moving. Do whatever you can to keep moving.

RSD support groups are essential and I am glad to see the RSDSA list (http://rsds.org/find-a-support-group-near-you/) of so many throughout the country. There is so much more. Indeed, at least 36 points discussed on June 2015.

Disclaimer

The material on this site is for informational purposes only.
It is not legal for me to provide medical advice without an examination.
It is not a substitute for medical advice, diagnosis or treatment provided by a qualified health care provider.
Hospital Guidelines for CRPS/RSD Patients Handle With Care!

Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a “neuro-inflammatory” condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

**Tips for Patients**
- Carry a copy of the RSDSA Hospital and Emergency Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Have your health insurance information.
- Have a list of ALL your allergies, medical conditions, and physicians treating you.
- Have a copy of ALL your medications, dosages and frequency prescribed, including vitamins, over the counter and compounded specialty medications as some may not be on hospital formulary.
- Have a list of ANY medical device and or implants including: spinal cord stimulators, intrathecal pain pump, implantable cardioverter defibrillators, pacemaker, cardiac stents, etc.
- Be patient when educating others about CRPS
- Consider having a letter from your doctor and or pain specialist as to conditions you are being treating for and your medical regime.
- Ask hospital staff to always ask before touching
- When possible, ask for a quiet, temperature/light controlled area to minimize triggers (allodynia). Dark sunglasses may help.
- When possible ask for hypo-allergenic items to minimize skin sensitivity (allodynia), such as; sheets, blankets, gown, cardiac monitoring EKG leads, tape, soap, cream, etc.

**Tips Medical Professional:**
- When possible, avoid frequent needle sticks or injections as CRPS can cause increased sensitivity to pain (Hyperalgesia).
- If PICC site is available, see if blood can be obtained from PICC instead of using vena puncture technique.
- When possible, use smallest gauge needle and topical numbing cream as many have thin and fragile veins. (EMLA, Synera, Lidocaine).
- When possible, obtain blood work during IV insertion to minimize additional trauma.
- Some are sensitive to rate and temperature of IV fluids, responding better to slower infusion.
- Hypoallergenic materials may be needed for Allodynia (things that shouldn’t be painful are)
- Frequent linen changes may be needed for Hyperhidrosis (increased sweating).
- Avoid ice to CRPS limb to prevent nerve damage
- Patients may not be able to tolerate hospital socks
- Identify affected limb/s to avoid blood drawing, vital signs and or sheets/blankets from touching.
- Before moving/transporting patient, assess for possible limb atrophy (skin, muscles, and bone weakness) and for adaptive equipment and mobility aids.
- When moving/transporting patient avoid sudden movements and or bumps which can increase Dysesthesia (Creepy, crawly sensation to touch) and Dystonic movement (abnormal movements, involuntary muscle spasms) & Allodynia (things that shouldn’t be painful are painful).
- A minor/major injury or surgery can require additional pain management plan, IV ketamine should be considered.
- CRPS is a REAL medical condition requiring support, education, and a plan of action.
- Accredited Courses on CRPS for Practitioners
  https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/

TJC provides accreditation to healthcare institutions to evaluate standard compliance. TJC requires each organization to create Pain Policies to Assess, Manage and, Respect the “Patients Right” to pain management.
Emergency Department and Urgent Care Guidelines for CRPS/RSD Patients: Handle With Care!

Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a “neuro-inflammatory” condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, pathological changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

**Tips for Patients**

- Carry a copy of the RSDSA Hospital and Emergency Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Have your health insurance information.
- Have a list of ALL your allergies, medical history, and physicians treating you.
- Have a copy of ALL your medications, including: dosage and frequency prescribed, vitamins over the counter medications (OTC), and or compounded specialty medications as some may not be on hospital formulary. *Bring your own medication.*
- Have a list of ANY active implantable medical device (AIMD): spinal cord stimulators, pain pump, cardiac pacemaker, defibrillators, stents and monitoring devices, etc.
- Have a list of ANY implants: breast, cochlear (ear). Intracocular lens (eye), heart valves, contraceptive, hip, heart, valves, etc.
- Have a list of ANY organ transplants and or prosthesis devices.
- Consider having a letter from your doctor and or pain doctor with conditions you are being treated for and your medical routine.
- When possible, bring someone with you, keep a journal.
- Ask hospital staff to always ask before touching, share where you can be touched and or positioned.
- When possible, ask for a quiet, temperature and light controlled area to minimized triggers (allodynia) especially if staying overnight in the Emergency Department. Dark sun glasses may help with bright lights.
- To minimize allodynia (things that shouldn’t be painful but are painful) bring items that are helpful with you.
- Ask the staff to use hypoallergenic items when possible (sheets, blankets, gown, cardiac monitoring EKG leads, paper tape, soap, cream, band aids, etc.)

**TJC provides accreditation to healthcare institutions to evaluate standard compliance. TJC requires each organization to create Pain Policies to Assess, Manage and, Respect the “Patients Right” to pain management.**

**Tips Medical Professional:**

- CRPS has both a sensory and autonomic dysfunction resulting in Central Sensitization of pain, causing:
  - **Hyperalgesia** (increased sensitivity to pain)
  - Avoid frequent needle sticks and injections
  - Assess if patient has PICC line access for bloodwork, medications, and infusions
  - Use **smallest gauge** needle (butterfly) when possible.
  - Numbing cream prior to needle sticks can be helpful as many have thing and fragile veins (EMLA, Synera, and Lidocaine).
  - Obtain blood work during IV insertion minimizes trauma.
  - Adjust **rate and temperature** of IV fluids if possible, as some respond better to slower and warmer infusions
  - Illness, injury, trauma can exacerbate CRPS symptoms.
  - **Allodynia** (pain induced from non-painful stimulus such as touch, clothing, sheets, temperature, exam, diagnostics).
  - Hypoallergenic materials may be helpful.
  - Patients may not be able to tolerate hospital socks.
  - Bright lights and temperature variations can be painful.
  - Avoid ice to CRPS limb, prevent further nerve damage
  - Use **NON-CRPS** limb for vital signs when possible
  - Identify CRPS limb(s) to avoid blood drawing, v/s, and or sheets/blankets from touching.
  - Moving and transporting patient: avoid bumps, sudden movements, vibrations and touch of affected area.
  - Noise from monitors, pumps, diagnostics, voices, phones, TV, intercom, can elevate pain.
  - **Atrophy** (skin, muscles and bone weakness)
  - Assess for limited ROM, weakness and need for adaptive equipment and or mobility aids.
  - **Hyperhidrosis** (abnormal sweating pattern)
  - Frequent linen changes may be needed.
  - **Abnormal Skin Changes**
    - Color changes (mottle, cyanotic, red, purple).
    - Skin temperature difference.
    - Hair/nail changes and swelling
  - **Movement Disorders**
    - Assess for motor disorders, involuntary muscle spasms and movements (bradykinesia, dystonia, myoclonus, excessive startle, and tremor).
  - **Dysesthesia** (creepy, crawly, sensation to touch)
    - Avoid using CRPS limb for treatment

**Overview:**

- **A minor**/major injury or surgery may require additional pain management plan, including IV Ketamine.
- Many have secondary conditions (POTS, MCAS, EDS)
- CRPS is a REAL medical condition requiring support, education, and a plan of action.

**Accredited Courses on CRPS for Practitioners**

- [https://rbsd.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/](https://rbsd.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/)
**Dental Guidelines for CRPS/RSD Patients: Handle With Care!**

Complex Regional Pain Syndrome (CRPS), previously known as Reflex Sympathetic Dystrophy (RSD), is a “neuro-inflammatory” condition causing the nervous and immune systems to malfunction, sending constant pain signals to the brain. CRPS is characterized by severe burning pain, pathologic changes in bone and skin, excessive sweating, tissue swelling, and extreme sensitivity to touch. The McGill Pain Scale rated CRPS higher than childbirth, amputation, and cancer pain. Those with CRPS are extraordinarily sensitive to certain stimuli, such as touch, movement, vibrations, noise, light, and needle sticks.

**Tips for Patients**
- Carry a copy of the RSDSA Hospital, Emergency, Dental Guidelines, along with the “I HAVE CRPS” card, to validate and educate practitioners.
- Hand the following to your dentist:
  - A computer printout of your detailed medical history since your 1st episode of CRPS, including the precipitating event.
  - Your treatments for CRPS and treating physicians. List of any allergies/List of current medications prescribed, OTC, specialty compounded medications (dosage & frequency).
  - List of any AIDM (active implantable medical devices) SCS (spinal cord simulators), pain pumps, cardiac pacemakers, defibrillator, stents, and monitoring devices.
  - List of any implants: breast, cochlear (ear), intra-ocular lens (eye), heart valves, contraceptive, prosthesis, etc.
  - List of any organ transplants. Research practices specializing in treating patients with chronic pain conditions (American Dental Association) and willing to learn about CRPS. [http://rds.org/crps-and-dentistry/](http://rds.org/crps-and-dentistry/)
- Be patient while educating your dental team: dentist, dentist anesthesiologist, periodontist, orthodontist, dental assistants/hygienist, lab technicians, etc.
- To prevent losing YOUR teeth and maintain YOUR overall health, begin with a comprehensive dental evaluation to develop a treatment plan to suit YOUR needs as a CRPS patient.
- Share any dental and oral health issues including:
  - Allergic reactions or sensitivities to dental products or ingredients
  - Burning mouth, dry mouth, erosion, dental decay, chronic mouth inflammation/irritation, orthodontics, muscle issues of the head, neck and jaw, the tongue, or salivary glands changes.
- Develop YOUR daily oral hygiene plan with practitioner including:
  - Type of toothbrush i.e. soft bristle
  - Use of mouthwash and or moisturizing spray
  - Use of floss
  - Adopt a Health dental diet and take vitamins (approved by your doctor)

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**Tips for Medical Professional:**
- 2 Online Accredited Courses on CRPS for Practitioners – Free [https://rds.org/accredited-course-on-crps-for-mds-ph-d-s-and-ms/](https://rds.org/accredited-course-on-crps-for-mds-ph-d-s-and-ms/)
- CRPS is a REAL medical condition requiring support, education, and a plan of action to minimize further pain.
- CRPS has both a sensory and autonomic dysfunction resulting in Central Sensitization of pain, causing:
  - **Hyperalgesia** (increased sensitivity to pain)
  - Consider anesthesia options including: topical anesthesia, numbing gel, prior to injections, cleanings, X-Rays.
  - Consider anesthesia options including moderate sedation & general anesthesia with long dental appointments or procedures such as a root canal treatment which can exacerbate CRPS symptoms.
  - Extreme gentleness using dental equipment (spit suction, drill, eater spray, dental tooth pick, etc.) to minimize pain.
- **Allodynia** (pain induced from non-painful)
  - Hypoallergenic materials may be helpful with sensitivities.
  - Bright lights can be a patient trigger, sunglasses may help.
  - Room temperature may need to be adjusted per patients’ needs.
  - Avoid being in the path of vented air from HVAC systems or fans.
  - Avoid ice to CRPS area, prevents further nerve damage.
  - Avoid anything bouncing into patient.
  - Patient position is key to positive outcomes consider utilizing bolsters, pillow, gel support, blankets to support patient.
  - Noise from monitors, dental equipment, diagnostics, voices, phones, TV, intercom, etc. can elevate pain.
  - Shorter treatment sessions may help minimize CRPS flares.
- **Atrophy** (skin, muscles and bone weakness)
  - Assess for limited ROM, weakness for assistance in and out of the dental chair.
  - Assess patient need for adaptive oral hygiene devices
- **Hyperhidrosis** (abnormal sweating pattern)
  - Abnormal skin sweating, skin temperature and skin color changes (mottle, cyanotic, red, purple) may require adjustment of environmental room controls including use of fan for some patients (do NOT place patient in the direct path of a fan).
  - Hair/nail changes and swelling
  - Hair/nail changes and swelling
- **Movement Disorders**
  - Assess the need to alter dental treatment due to motor disorders, involuntary muscle spasm & movements (bradykinesia, dystonia, myoclonus, excessive startle & tremor); use of (bite blocks, positioning the patient, use of sedation or general anesthesia) can be helpful
  - **Dysesthesia** (creepy, crawly, sensation to touch)
    - Avoid coming into contact with affected CRPS sites.
    - If more comfortable for the patient & if possible, provide dental treatment standing/sitting

**Overview:**
- A minor/major dental procedure may require: pre-medication, additional pain management plan including Ketamine (IV, troche), Nitrous Oxide, oral, topical anesthesia (numbing gel) to minimize exacerbations.
- Maintain access to emergency equipment and certifications.
- Many have secondary conditions (POTS, MCAS, EDS)

Revised 03/2/18
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.

Continued on page 13
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.

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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/](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](http://bit.ly/3b7tPbS), please fill out the form found here: [bit.ly/3b7tPbS](http://bit.ly/3b7tPbS) or email us at info@rds.org or call 877-662-7737 and we’ll send you a form.
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.

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!

WANTED

Individuals to:

✓ Set up a collection canister in your local grocery/convenience store.

✓ Plan an event with the help of RSDSA by emailing us at info@rsds.org.

✓ Fill up a Penny Pig with your spare change to help RSDSA sponsor children in pain at summer camp.

✓ Help educate health care professionals by promoting the availability of our accredited courses on adult and pediatric CRPS.

✓ Blog for our weekly Tuesday’s Burn. Do you have a story or experience to share?

✓ Write an article for the RSDSA Community Update.

✓ Promote awareness of CRPS by sharing your story with TV or newspapers (we can help you).

✓ Share your story of hope. Inspire others who are struggling as you have.

✓ Join our peer-to-peer program (see our back cover).
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-inflammatory agents 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 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

“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!”
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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**EASY WAYS TO GIVE**

- Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.
- Use AmazonSmile.com and make RSDSA your charity of choice while shopping online.
- If you’re selling things on eBay, you can give a portion of the profits straight to RSDSA.
- Set up a collection canister in your local grocery store.
- Plan an event with the help of RSDSA by emailing us at jkrassner@rsds.org

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**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.
- Including RSDSA as a beneficiary in your life insurance policy.
- Including RSDSA as a beneficiary in your will.

Tax benefits apply to each of these options.

Please contact your attorney or a financial advisor. For more info, contact RSDSA at info@rsds.org or go to https://rsds.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 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.

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!

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
Motivators.com
Nationaldaycalender.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 CARDENTEY • 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. 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 what 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 honesty, 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

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.
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

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

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

Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rsds.org
Mirror Therapy and Other Brain Retraining Treatments

By Sarah M. Whitman, MD

The abnormalities in CRPS are not confined to the parts of a patient’s body which hurt, but are also found in the central nervous system, particularly the brain. Ongoing pain signals may cause disturbances in the brain’s “body map,” which is the internal representation of the body in the brain. Patients with CRPS often use the painful parts of their bodies less. This causes fewer signals of normal movement to feed back to the brain, lessening any opportunity to correct the abnormal body map.

However, this knowledge presents an opportunity for new treatment approaches, and exercises which retrain the brain can decrease pain.

Mirror therapy uses a patient’s visual system to register normal movement in the brain. The patient’s painful, difficult-to-move body part is hidden behind the mirror, while the contralesional body part is moved. The patient watches the reflection, and this simulates comfortable, easy movement. When successful, mirror therapy reverses abnormalities in the body map and decreases pain.

Graded motor imagery is a step-wise program which breaks down movement into components. This allows a more gradual resumption of movement without producing pain. The components include right/left discrimination, imagined movement, and lastly actual guided movement.

Research has demonstrated mirror therapy to be effective in early CRPS, and graded motor imagery in chronic CRPS. These are exciting, effective treatments. Once a practitioner understands the underlying theory and how to implement the treatments, they can be used creatively in most patients with CRPS. An excellent website for more information is www.noiigroup.com.

What People with CRPS Should Expect from Therapy

By Anita L. Davis, PT, DPT, MSM, D-AAPM

Before developing CRPS, chances are you have never had a major injury or illness, but now you may find yourself going from doctor to doctor and have a shelf full of medications. Some have worked, some have not, and others had such side effects that you had to stop taking them. The doctors have talked about injections and maybe neurostimulators—and, by the way, now you need to start physical therapy.

The intent of therapy is to help you regain your strength and mobility, and even reduce your pain. There will be days you would rather not follow the home program or go to therapy, and moments that your pain increases and you question the reason for making yourself hurt even worse. In those moments, let your hope of recovery and the support of close ones cheer you to continue.

Therapeutic activities that involve walking, stepping, carrying, or lifting present their own challenges. The aim of these types of tasks is to simulate a normal, functional motion while allowing your nerves to adapt to the sensation by readjusting their sensitivity. The pain will increase with these tasks, since your nerves have become so sensitive that they overreact to what used to be normal. It takes time and repetition to retrain this response. Medical literature and clinical experience tell us that this ultimately leads to less pain within 10 to 14 days.

In the midst of performing these painful activities, you should have strategies to reduce the flare-up. Your therapist may share relaxation techniques, imagery, breathing, or other movements that can ease the pain. Learn these and use them—for in this you can gain confidence in your ability to control what has otherwise seemed uncontrollable.

Home Exercise Programs

A home exercise program is a select group of exercises or activities that a therapist designs. Frequency/participation in therapy sessions may vary from one week to the next, but what is done outside of therapy can have a significant impact on the patient’s overall progress.

Following an individualized home exercise program can be an important component of treatment as it helps the patient continue to make progress in strength, endurance, movement and function in between therapy sessions.

Home exercise programs vary depending on your individual needs. Often home exercise programs will initially focus on scrubbing/weigh loading and desensitization techniques to begin actively engaging the muscles in the affected area and help you manage your pain better. After the initial phase of scrubbing and desensitization, the home exercise program may be upgraded to focus on increasing range of active movement and improving strength.

Many home exercise programs will include functional activities in addition to stretches and exercises. Such activities may include drinking from a cup with the affected hand or wearing a shoe on the affected foot. Often these activities are based on tasks that the patient currently has difficulty performing. They may be things that you do for short periods of time frequently throughout the day to help you incorporate the affected area back into routine activities. Consistent participation in exercises/activities outside of therapy sessions, as directed by a therapist, may help the patient achieve his or her goals more quickly.

Reflex Sympathetic Dystrophy Syndrome Association

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Milford, CT 06460
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Email: info@rdsda.org
Web: http://rdsda.org

Raising awareness of complex regional pain syndrome since 1984
What is Complex Regional Pain Syndrome

Complex Regional Pain Syndrome (CRPS) is a chronic pain syndrome. CRPS generally involves a dysfunctional response of the nervous system and may develop after a traumatic injury or a period of immobilization.

CRPS is divided into two categories: Type I (formerly known as Reflex Sympathetic Dystrophy) and Type II (formerly known as Causalgia).

What Does CRPS Look Like?

CRPS pain is often described as deep, aching, cold, and/or burning and is frequently associated with increased skin sensitivity. Pain is generally rated moderate to severe and is disproportionate to any inciting event. Symptoms of CRPS can include abnormal swelling, abnormal hair growth, abnormal skin color or temperature changes, abnormal sweating, limited range of motion, and movement disorders.

Evaluation of CRPS for Functional Rehabilitation

Principal areas to evaluate are range of motion, strength, edema, dexterity, skin/vasomotor changes, pain/sensation, the presence of abnormal guarding or protection postures/movements and active use of the extremity during activities. Barriers to movement that are important to assess include fear and avoidance, reliance on passive coping tools, lack of education on CRPS and motivation/readiness for change. If psychological distress such as depression and anxiety is noted, a psychological evaluation may be required.

Treatment Protocols

Treatment objectives for CRPS are to minimize edema, normalize sensation, promote normal positioning, decrease muscle guarding, promote use of active pain management skills and increase independence in all areas--mobility, work, leisure and activities of daily living (ADL). Education on CRPS, chronic pain and appropriate goals should be an emphasis early on and throughout treatment. Active movement and weight bearing exercises are emphasized. Treatment of CRPS can be painful and both mental and physical active coping tools are useful.

Edema is managed using specialized garments (Jobst® garments, Isotoner® gloves, Coban®) and sustained compression. Soft padding and AROM (active range of motion) activities are also fundamental in managing edema. Elevation of the extremity can be effective; however it can sometimes become part of a cycle of guarding and disuse.

Desensitization techniques are implemented to assist with normalizing sensation to the affected area. This consists of progressive stimulation with very soft material to more textured fabrics or materials. Stimulation can be graded from light touch to deep pressure and from comfortable to uncomfortable for each material. Wearing jewelry, clothes and shoes on the affected areas are also ways to normalize sensation.

Contrast baths that gradually broaden the temperature difference between the two can work toward tolerance of heat or cold.

Posture is an important component to consider in treating CRPS. Proper posture and alignment can minimize protective guarding of the extremity, promote balanced use of muscles and facilitate improved functional use of the affected extremity. Relaxation breathing and awareness can help to decrease guarded posturing.

Stress Loading consists of two principles: scrubbing and carrying. A stress loading program promotes active movement and compression of the affected joints for a minimum of 3-5 consecutive minutes, three or more times each day. Though stress loading may initially produce increased pain, the symptoms of the extremity, after several days a decrease in symptoms will begin to be evident. Use of the affected extremity in daily tasks is encouraged throughout rehabilitation to inhibit muscle guarding and disuse atrophy.

Scrubbing consists of an altered extremity in a back/forth motion while weight bearing through the extremity. The patient scrubs a hard surface, keeping the bristles of the brush in constant contact with the surface, while maintaining constant pressure on the brush. The amount of weight placed through the affected extremity and the duration of the activity are gradually increased.

Scrubbing is performed with the patient in quadruped for upper extremity involvement and in elevated sitting or standing for lower extremity involvement. For upper extremity involvement it is important to use a scrub brush with the affected hand. For lower extremity involvement, a long Veler® strap can assist in fastening the brush to the bottom of the affected foot.

Modifications can be made to enhance performance or compliance. For example, upper extremity scrubbing may be performed standing at a table or counter. Persons with limited wrist extension may benefit from using a handled brush. The Dystrophile® can be used to gauge reliable performance. It is a device designed to facilitate consistent weight bearing and compliance during scrubbing by activating a light when the patient has reached the preset load.

Carrying or loading, is the second component in the stress-loading protocol. Small objects are carried in the hand on the affected side, progressing to a handled bag loaded with increasingly heavier weight. Carrying should be performed at least three days a week, the day when the patient is standing or walking. The lower extremity can be loaded in a variety of ways. Walking is an important loading technique if care is taken to ensure weight bearing through the affected leg during gait, especially when an assistive device is used. Increased weight bearing can be accomplished with verbal/physical cueing or by having the patient carry a weighted object or bag on the affected side. Loading can also be facilitated by engaging the patient in activities that promote weight shifting and balance (i.e. stepping forward with the affected foot onto a small footstool during static standing tasks).

Mind-Body Interventions facilitate stress reduction, desensitization of the nervous system and provide coping tools for dealing with pain. They include relaxation, meditation, guided imagery, biofeed-back, hypnosis and/or meditation. Mindfulness-based stress reduction (MBSR) is a form of meditation practices that is commonly used to help treat chronic pain. The practice of these interventions should begin immediately.

Bracing/Bracing is a set of rehabilitation processes used to treat pain and movement problems related to an altered nervous system, including the brain. The three different treatment techniques include limb laterality training, graded motor imagery exercises, and mirror therapy. These techniques are delivered sequentially or individually. This type of treatment is done over a long period of time and fast results should not always be expected.

Splinting is used in severe cases of CRPS. Splinting or bracing may be utilized to promote immobilization or to stabilize the extremity and facilitate normal tissue length, and improve functional positioning.

Functional Training begins once the patient is actively engaged in an edema management and stress-loading program. As the pain and edema decrease, the patient should be more able to tolerate and participate in AROM, coordination, dexterity, and strengthening tasks. Proprioceptive neuromuscular facilitation (PNF) patterns are often well tolerated during treatment.

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistive exercises or gait training. The patient should be encouraged to gradually return to daily life activities. These treatments and activities can be very painful and the therapist must understand and be able to explain the differences between pain and damage to alleviate the fear of the patient. While these treatments should be done within the patient's tolerance, the patient must understand that they will have to push through pain to achieve their goals. Care must be taken to ensure safety of the anatomical structures in insensate situations (as after a nerve block). Pacing and pain management techniques, such as appropriate rest breaks, alternating tasks, thermal or cold biofeed-back, diaphragm breathing, and relaxation techniques, can assist the patient in minimizing pain flares while participating in intensive rehabilitation.

Treatment Summary

The overall role of the therapist during rehabilitation of CRPS is to guide the patient through a program designed to minimize pain and edema, maximizing functional use of the extremity. As CRPS varies greatly in severity and duration, it is very important for the therapist to demonstrate enthusiasm, support and encouragement of the patient during the treatment process.

The patient, in turn, must be actively involved in integration of treatment techniques into daily activities to achieve optimal function of the affected extremity.

References

CRPS is a multifaceted medical condition best managed by an interdisciplinary team coordinated by a physician or pain specialist with a special interest and experienced in treating CRPS. You must become the “captain” or CEO of your team. No one treatment works for everyone. Your first step is to educate yourself. RSDSA’s website has a very informative section, Diagnosed: Now What?

Your treatment goal is to reduce your pain while focusing on improving function. Other members of your team may include physical or occupational therapists, psychologists or counselors trained to help individuals learn how to manage their pain, anesthesiologists or interventional pain specialist (when warranted), and your support people.

Treatments may include: medications, topical medications, interventional therapies such as nerve blocks, intrathecal drug infusion, warm-water-therapy, physical and occupational therapies, psychological support, neurostimulation, IV ketamine or IVIG infusions or, participation in a clinical trial (clinicaltrials.gov).

RSDSA is committed to assisting those who suffer from CRPS as well as the people who support them.

RSDSA offers emotional, financial, and medical support to people suffering with CRPS. Please visit our website if you are in need.

If you think you or someone you know has CRPS/RSD, please visit your physician and provide him or her with educational information about the disease. Much more may be accessed on our website. You may also contact our organization.

THE DIAGNOSIS

There is no single diagnostic test for CRPS. Only a careful exam can produce the proper diagnosis.
**HOW CRPS CHANGED A CHILD’S LIFE**

Once a successful swimmer and a student council member, fourteen-year-old Natalia is now trapped in her body.

After a mild wrist sprain, Natalia’s fingers swelled into blood-red sausages. The pain prevented her from even holding a pencil.

Exactly a week after her thirteenth birthday, a neurologist finally diagnosed her with CRPS after many ER visits. In the following months, she was hospitalized more than a dozen times.

Just as she began to show improvement, a car collided with her school bus, and her CRPS spread. Pain covered every inch of her body; Natalia has not walked since.

Her parents have been unable to hold her hand or hug her for over a year.

Natalia’s story is not unique. In the U.S. alone, nearly 200,000 people suffer from CRPS, the most painful medical disorder. Like Natalia, these people need help.

To receive help, they must be heard.

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**THE FACTS**

**WHAT IS CRPS/RSD?**

CRPS/RSD is a rare neuro-inflammatory disorder that causes severe inflammation in the sympathetic nervous system.

**WHAT CAUSES IT?**

It occurs after a trauma, such as a musculoskeletal or nerve injury, surgery, or broken bone.

The trauma causes the sympathetic nervous system and the immune system to malfunction—the nerves throughout the body misfire, overwhelming the brain with pain signals.

**WHAT ARE THE EFFECTS?**

CRPS is devastating. It causes severe pain, swelling, and sensitivity. Many people are unable to walk, work, or wear clothes.

**WHO CAN DEVELOP CRPS/RSD?**

Anyone may have CRPS, regardless of race, age, or gender. However, research shows that it is most common in women.

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**WORKING FOR A CURE**

Since the Federal Drug Administration classified CRPS as a rare disease, RSDSA has been committed to finding a cure.

In 2014, RSDSA established the International Research Consortium, uniting forty-seven CRPS clinics and specialists worldwide to develop better treatments for the disease and to work toward a cure.

**COMMON SYMPTOMS**

- Pain described as deep, aching, burning, or stinging
- A prior trauma (fracture, sprain, surgery, etc.)
- Abnormal swelling
- Excessive sweating in the affected area
- Changes in skin color
- Noticeably altered skin temperature (increased or decreased) in the affected limb
- Weakness of affected limb
- Limited range of motion
- Paralysis or dystonia (muscle contractions resulting in abnormal positions)
- Allodynia (pain from stimuli that is not normally painful—the touch of fabric or the wind blowing)
- Hyperalgesia (excessive sensitivity to pain)
I have CRPS

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.rds.org and learn all you can.
CRPS is a diagnosis of exclusion for anyone who suffers with moderate to severe pain that exceeds the scope of their original injury and who presents with some of the following characteristics:

- Pain is described as deep, aching, cold, burning, and/or increased skin sensitivity.
- The presence of an initiating noxious event (sprain, fracture, surgery, etc.).
- Continuing pain (moderate to severe) associated with allodynia (hypersensitivity), or hyperalgesia.
- Abnormal swelling in the affected part.
- Abnormal hair or nail growth.
- Abnormal skin color changes.
- Abnormal skin temperature (greater than 1°C asymmetry).
- Abnormal sweating.
- Limited range of movement, weakness, stiff joints, or other motor disorders (paralysis, dystonia, etc.).
- No single test can diagnose CRPS. Physical exam and medical history are the main criteria. Diagnosis is challenging and is made by ruling out other conditions.

Pain Scale

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

rdsda
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PLEASE CONSIDER MAKING A DONATION
Thank you for considering a donation to RSDSA. Your unrestricted gift is vital to RSDSA because it gives us the crucial flexibility to respond to immediate needs and opportunities as they arise. Such contributions also help build a strong RSDSA financial foundation. To fulfill our mission, RSDSA must be able to meet the changing needs of the CRPS/RSD community, in order to continue improving the quality of life for people with CRPS. By making an unrestricted gift, you enable RSDSA to provide financial assistance, conferences, grants, support programs and much more to people across the United States.

RSDSA is a 501(c)3 not-for-profit organization. All donations are tax-deductible.

Thanks to the generosity of donors like you, RSDSA has been fighting CRPS/RSD and supporting the CRPS/ RSD community for more than 30 years. We are grateful for your support!