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 psychologists 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://rds.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
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.
Tips for Managing Complex Regional Pain Syndrome

September 11, 2015 by Jim Ducharme, MD, CM, FRCP

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

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.

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%.
14. Medical Marijuana (CBD, THC, terpenes) Marijuana saves lives

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 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 pumps, 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) & Alldynia (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/](https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/)

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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). Intraocular 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 treating 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.)

**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://rsds.org/accredited-course-on-crps-for-mps-ph-d-s-and-rns/](https://rsds.org/accredited-course-on-crps-for-mps-ph-d-s-and-rns/)
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, 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/Listing of current medications prescribed, OTC, specialty compounded medications (dosage & frequency).
  - List of any AIMD (active implantable medical devices) SCS (spinal cord stimulators), 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)

**Tips for Medical Professional:**

- 2 [Online Accredited Courses on CRPS for Practitioners – Free](https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-mds/)
- 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 toothpick, 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
- **Movement Disorders**
  - Assess the need to alter dental treatment due to motor disorders, involuntary muscle spasms & 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**
4th Annual Long Island CRPS Awareness Walk & Expo

BY JERI KRASSNER • RSDSA SPECIAL EVENTS COORDINATOR

The 4th Annual CRPS Long Island Walk in Eisenhower Park on September 7th was a huge success! Over 500 people showed up and over $75,000 was raised for the RSDSA community.

Luck was with us when the day began beautiful, warm and sunny. By 7 am, a host of volunteers had shown up to organize 28 tables for sponsors, 19 tables for teams, six tables dedicated to education, 12 tables for raffles, silent auction items, breakfast, and the all-important registration and check-in booth. The walk was three events in one!

This successful event was organized by three indomitable CRPS Warriors. Debbie O’Neal, Beth Seickel, and Stacey Udell each bring their own unique strengths to the organization of this Walk. The women share the decision making, but each has their own strengths. Stacey is a public relations expert. She doesn’t take no for an answer and with her perseverance, she wrangled two radio interviews, numerous mentions by local media, promotions on our sponsors’ websites, and two excellent articles in mainstream newspapers. She even got WBAB radio station to attend and DJ the event!

Debbie covered the logistics. What does that mean? She organized the registration, t-shirt distribution, scheduling, supplies, and all our signage. As the saying goes, “the devil is in the details,” and Debbie knows it well. She nailed down all the important and seemingly little details for the walk and kept on going.

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**CALL FOR AUTHORS & IDEAS**

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

**SPECIAL THANKS**

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Baker Family Charitable Trust, Center for Pain Management, Edelman, Krasin & Jaye PLLC, Grünenthal, Law Office of Scott Callahan, MCARE Pharmacy, Sutliff and Stout, NoPainHanna, Oska, Pope/Taylor National CRPS/RSD Lawyers, Shirley Ryan Ability Lab, Vitalitus.
**American Society of Pain Management Nursing (ASPMN)**

Beth Seickel, RN and I presented and exhibited at the ASPMN meeting in Portland, OR in September. There was a great deal of interest in CRPS and especially regarding low-dose naltrexone (LDN), IV ketamine and our guidelines for the Emergency Department, Hospital, and the dental care. A lot of the pain management nurses were not aware that there was a patient advocacy organization for people with CRPS and will utilize our resources in the future. We are researching the feasibility of exhibiting at the American Academy of Nurse Practitioners or the American Academy of Physician Assistants next year.

**Reaccreditation of Adult CRPS Course for Physicians and Nurses**

I traveled to Vernon Hills, outside of Chicago to film Jay Joshi, the CEO and Medical Director of the National Pain Centers. The filming was excellent as Dr. Joshi was very passionate and knowledgeable about CRPS. The video named *The Only Pain Disease with Complex in Its Name: Learn about It and Treat It Well* is in edit and we hope to have it online in early November. We already have an on-line free accredited course on pediatric CRPS on our website: [https://rds.org/rdsa-pediatric-crps-accredited-online-course/](https://rds.org/rdsa-pediatric-crps-accredited-online-course/). I also want to remind our members that RSDSA has a dedicated channel on YouTube where we archive all of our videos from our conferences: [https://www.youtube.com/user/RSDSAofAmerica/](https://www.youtube.com/user/RSDSAofAmerica/)
**Patient Assistance Program in Honor of Brad Jenkins**

I’ve included a thank-you letter from a recipient who we recently helped. Since the programs’ inception in 2012, RSDSA has awarded 209 grants totaling $113,162.40 and the need is increasing. To help RSDSA continue to make a huge difference in the lives of people with CRPS, make a tax-deductible donation today by going to our donate page or call RSDSA at 877.662.7737.

**Cross-Country Bike Ride in 2020**

Eric Moyal is getting back on the road again next year to raise funds and awareness of CRPS on behalf of his sister Anais and RSDSA. This summer, despite thunderstorms and the sometimes oppressive heat, Eric biked 1,700 miles from Medford, Massachusetts to Bay Harbor Islands, FL (read his interview in this issue with our editor). Eric has asked our assistance in identifying possible corporate sponsors for his cross-country trek to cover his lodging and food costs.

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**4th Annual Long Island CRPS Awareness Walk & Expo Proves You Are Not Alone (continued)**

Beth, or Nurse Beth, as she is affectionately referred to, quietly covered her territory to pull the walk together. She ensured education about CRPS is presented at the walk, medical services are on site in case of emergency, and that we had our venue. She liaised with Nassau County Department of Parks and Recreation to ensure we had a beautiful place to hold our walk. Beth, aided by her husband, Glenn, and his golf cart crew, showed up at sunrise to supervise and set up for the day. And what about our participants? There were 26 registered walk teams, ranging from Amanda’s Angels to Stay Strong Samantha. Some teams had one person, while others had as many as 26 members. They all came together on September 7 to support, laugh, and cry with one another. Most importantly, they came to share with each other. They all brought their stories, like Samantha Strong, a sixteen-year-old CRPS Warrior with a powerful spirit and a heart to match. Every Warrior has a story and overcame the pain to attend the walk like Jennifer Ogle’s Flamestoppers, Team Uncle Roy and Kelly’s Crusaders, to name just a few.

Our attendees and donors also came from all over the map to attend. One team, The Pirates Cassandra and Phelan, traveled all the way from Vermont. Others came from Connecticut, New Jersey, and as far as Minnesota. Thank you to everyone who made this Walk happen.

**Thank you to everyone involved, especially our three intrepid Warriors, Debbie, Stacey, and Beth, the Long Island CRPS Awareness Walk & Expo raised a lot of money for our mission. Our Warriors cast a wide net over the Long Island landscape, searching for suitable sponsors and donations - and we send a giant thank you to everyone who responded. It was a pleasure to see all our sponsors at the event, and to know that we have your support. None of this could have happened without your help.**

Thank you to the firefighters who took the time to prepare and cook the barbecue lunch. They even went the extra mile to serve veggie burgers and offer gluten-free buns, right alongside the classic hamburgers and hot dogs. This is a group that cares for our community and we applaud their dedication.

This year’s Long Island Walk & Expo was bigger and better than ever before. There were over 75 raffles and silent auction items, including signed Duke basketballs, gift baskets of baked goods, homecare, and bath items, and tickets to a Broadway musical! There was something for everyone to enjoy, and the ice cream truck giving out free treats at the end was the pièce de résistance.

Let’s give a shout out to all the amazing people who helped make this event possible. It isn’t easy to keep people entertained, educated, and engaged, but they gave everyone a reason to come out and support the cause. It is extraordinary what a small community can do.

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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 jjkrassner@rsds.org
One of the most effective ways to bring the CRPS community together and raise awareness in your hometown is to host an event. These may come in various shapes and sizes, and some may serve gumbo, but it all comes back to the RSDSA’s mission of providing support, education, and hope to all affected by the pain and disability of CRPS/RSD, while also driving research to develop better treatments and a cure.

One example of a fun and unique fundraiser is the Mardi Gras Jeep Show and Gumbo Cook Off that was held last February in Scott, Louisiana. This was the fourth year the Louisiana Jeepers held this event and they managed to raise an incredible $55,000 for the RSDSA. The Mardi Gras themed fundraiser featured local musicians, live and silent auction, lots of jeeps to see and gumbo to taste.

As event organizer Brandy Romero said “the day was perfect gumbo weather, sun was shining, people dancing and will to open their wallets to show their support! It was amazing to meet new people with this disease and share our story.”

Is there a tradition, food or season that is unique to your home town? Get creative and think about how it could be turned into a fundraiser or special event.

If you are interested in learning more about hosting an event, please contact Jeri Krasser, the RSDSA’s Special Events Coordinator at jkrasser@rsds.org or Jim Broatch, RSDSA Director, at jwbroatch@rsds.org

Plan on attending next year on February 1, 2020.
Opportunity

BY LAURA HINKLE • JUST41KH@OUTLOOK.COM

On August 24, 1994, I fell climbing up to Grinnell Glacier in Glacier National Park and had a minor break to my ankle. My life changed forever as I was diagnosed with RSD. I went through the common treatments of the time. The only thing that I found helpful was methadone and methadone became my answer to my RSD pain. But by 2013, the methadone was destroying my heart. In 2014 after 20 years on methadone, I was told that if I stayed on methadone I wouldn’t live much longer, or I could detox off methadone and live experiencing more pain. What a choice! I opted to detox off methadone and had to do it cold turkey because I was allergic to the detox meds. It was terrible! After 2 months, I thought the pain would once again kill me. I returned to my chronic pain doctor and he wanted to put me back on methadone in order to give me some type of life until my heart gave out. I filled the script and went home. However, after taking the first set of pills, I realized what I was doing. I had just detoxed off it and now I was actually taking it again! Once again, I stopped taking methadone and returned to my pain doctor. That was when he told me that if I didn’t stay on narcotics that I would not be bringing money in for the clinic. I got up and walked out of my appointment. I never returned. But now what?

I began my search on what to do. I came across PEAPure® and tried it. I had some good results. I also went into counseling and learned to mourn the death of my dreams through RSD. I learned how to make peace with my RSD instead of always being in a battle with it. I learned that I had been missing a very important pain coping mechanism, called my brain. My pain was still there, just as intense, but I slowly started developing a new life.

Part of my new life was swimming. I’ve always enjoyed swimming, though I’ve never thought I did it very well. My primary doctor encouraged me to go to this place called OPC and use their therapy pool. At first, I could barely last even 5 minutes. But I kept going back. I started to meet people and develop friendships. By the end of the first year, I could tolerate a half hour or so. The following year, I increased my time even more. One day, I took a leap of faith and went into their lap swimming pool. I swam one length. Everyone applauded for me. I was shocked at the support. They knew what a milestone this was for me.

Flash forward to August of 2018… My RSD is now everywhere in my body. I’m still using my walker. I’m often rescued from the pool by the lifeguard, because my legs, and my body in general, just stop working because the pain is too intense. Yet, I’m so thankful that I’m in a safe place and around understanding people. They help me out when I need it. I also met two people who were part of the Senior Olympics and they started encouraging me to go to the next Olympics. I started training yet took it as easy as possible for my RSD. And, I continued to be rescued monthly.

This year, 2019 has been a game changer for me. It started with me landing in the hospital because in January, I fell from the pain and didn’t regain consciousness for about 8 hours. But in April, I felt strong enough to no longer use my walker. The pain was still there, but I was physically stronger. In May, I walked the first mile I’d ever walked since August 24, 1994. (I couldn’t even walk to my mailbox in 2017! I just started slow. Halfway to my mailbox, and kept increasing the distance.) I was still being challenged to do swimming in the Olympics. My problem is that my pain skyrockets with vibrations. In the water, the vibrations were bruising my entire body. I was scared that my body would give out and I’d have to be rescued at them. I was going to dive into the pool, and even though it was off the side, that “smack” into the water was sometimes paralyzing me. I also had never competed in any athletic event my entire 59 years of life. I was terrified. I had a long list of reasons not to do them.
My new friends kept encouraging me. Lisa told me that life has opportunities in it. It was up to me if I seized them and lived in that moment for all it had to offer. Or, if I declined the opportunity. RSD had and does take away opportunities in my life. Maybe it was time to do something different. To know that I could rely on people if my pain went out of control. To seize the opportunity that was before me.

So, I signed up for the Olympics in July. Deciding that if I didn’t go, the cost would be a donation to them. By the end of July, once again, my RSD was so flared that I could barely walk or do much of anything.

Forward to August 12, 2019… at 8:00 in the morning, I was warming up for two swimming competitions at the Michigan Senior Olympics. It was all just blowing my mind. I dove in about 9:15 AM for the 50-meter breaststroke. I dove in again about 11:15 for the 200-meter breaststroke. I was high on adrenaline and competing in my very first athletic competition. Yes, I was still doing it. I was swimming in the Senior Olympics. Much to my surprise I received a silver medal in the 50 and a gold medal in the 200! I had won 2 Michigan Senior Olympic medals! I was blown away.

This week, I’ll have had RSD for 25 years. Every day I hurt and wonder how I’ll get through the day. And yet, now I’ve learned how to challenge myself in small opportunities that accumulate into big adventures. I have been able to develop a new life with RSD that I keep tweaking daily. I keep looking for those opportunities now that I can work towards obtaining. I’ve learned my brain has just as much to do with my RSD as my body.

My newly found friends who are swimmers ask me what my goals are for next summer. My response was that I hope to try kayaking. (I have no idea how I will ever get my legs into the kayak.) I also want to try paddle boarding. (I have no idea how I’ll ever be able to stand, and even fall into the water with my RSD taking over my body.) My friends clarified their question by asking me what I’d be doing for swimming. My response was simple. To get physically stronger, swim faster by swimming more effectively. I was told that next summer are qualifiers to go to the National Senior Olympics (All the winners of each state come together to compete) They want me to attend the Nationals. I explained that my RSD doesn’t permit me to travel more than several hours in a car, and there’s no way I can go on an airplane. There are way too many vibrations. I live in Michigan and the Nationals are in Florida. They looked at me, smiled and said that I never thought I’d be able to swim in the Michigan Senior Olympics either!

ABOUT THE AUTHOR
Laura Hinkle is a 25-year warrior who is also a frequent RSDSA donor.
CRPS Changes Lives

By Jenny Picciotto

On the morning of May 15th in 1973, Steve Shisler was enjoying the second week of summer after his sophomore year of college. He said goodbye to his Grandmother and hopped on his motorcycle to head to his summer job. When a car pulled into the intersection he was crossing, he swerved to the right and tried to lay the bike down to get out of the way, but the car just kept coming. He woke up in the hospital five days later. That morning would change his life forever.

His left arm was paralyzed because of damage to the nerves attaching the arm to the spine. Two nerves were partially torn from his spine, another two were completely torn from his spine. After his shoulder muscles atrophied his shoulder kept popping out of the socket. He was diagnosed with a severe brachial plexus injury and Reflex Sympathetic Dystrophy, which has since then been renamed Complex Regional Pain Syndrome (CRPS). For several years he underwent numerous surgeries to recover movement in his arm, and treatments for CRPS.

Severe pain prevented him from completing his studies on time, and ultimately shaped the direction of his career.

For two years he wore his arm in a sling, and his shoulder repeatedly subluxed, partially dislocating. After the partially severed nerves regenerated, he regained limited use of his arm. He could close his hand, open his thumb and first finger, and regained the ability to slightly pull the arm toward his body.

During this time, he was also being treated for CRPS. Pain medications were not sufficient and made concentration difficult. He underwent 32 cervical nerve blocks. He remembers the day the doctor forgot to put a cloth over his eyes to prevent him from seeing the needle approaching his throat. “Wait, wait, Doc,” he said, “you forgot the blindfold!” But the doctor jokingly told him he didn’t need it any longer because he already knew what was coming. After that a “blindfold” was no longer used during the injections.

He was referred to a surgeon who recommended a surgical sympathectomy of the nerve ganglion to stop the pain signals. He remembers his dad’s face draining of blood as the procedure was described. Ultimately, he declined the surgery because he would no longer have control over the facial muscles on one side, leaving his face permanently drooping. At 20 years old, he didn’t want to look like he had suffered a stroke for the rest of his life.

He also tried acupuncture, which he had to travel to Washington DC to obtain, because it was not yet legal in Pennsylvania. While standard acupuncture did not help, he received some relief from electroacupuncture, which uses an electrical frequency pulsed through the needles. But it wasn’t until he underwent surgery that he began to get relief from CRPS.

Two years after the accident, he underwent additional surgeries to regain use of his arm. His neurologist referred him to an orthopedic surgeon who surgically fused his shoulder, relocated muscles in his forearm to create a bicep, and tied the extensor tendons of his fingers together to allow him to open his hand. The joint fusion surgery involved breaking the bone and placing three screws in the shoulder to fuse the upper arm to the shoulder blade. Once fused, it no longer pulled on the nerve plexus or pulled out of the socket. With the nerve irritation reduced, his CRPS symptoms died down, but have never disappeared completely.

Today he has some pain free days, some days with tolerable pain, and some wicked pain days when he diverts his frustration into his work.

Steve was able to complete his coursework and graduated from college with a degree in English Literature. He taught English in a preparatory school for four years, but as he approached 30 years old, his experience attempting to
“What began as a carefree day during summer recess in the life of a 20-year-old college student became a life’s work. Steve has fueled his passion for helping people with CRPS with the fire of his own experience, turning tragedy and persistence into dedication and purpose.”

get compensation for his injuries inspired him to go to law school. He wanted to change the law which at that time in Pennsylvania held that if a plaintiff was even one percent at fault for an accident, they were not entitled to collect anything.

Although that particular law changed before he entered law school, Steve has been at the forefront of other changes in the way the law is practiced. After working for over a decade at other firms, in 1996 he opened his own practice which focuses on representing people with CRPS, appearing on television and radio programs and as a guest speaker at legal and medical events. He is on the faculty for the American Association for Justice (Association of Trial Lawyers of America), and is the co-founder of the Association’s Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy Litigation Group. He was instrumental in drafting and causing enactment of Social Security Policy Ruling for disability claims involving Reflex Sympathetic dystrophy/Complex Regional pain syndrome. He works with attorneys across the country to help people with CRPS.

Through clients and friends with CRPS, he became aware of the RSDSA and became a supporting member in 1996. He has written articles about Worker’s Compensation and retaining legal advice for the community, and been a speaker at RSDSA conferences. In 2013 he was elected to the Board of Directors and currently serves as Secretary.

“As Secretary,” he says, “I am responsible for producing minutes of the meetings. But all of us on the Board are engaged in trying to help people with CRPS, through outreach, presenting at conferences, and funding medical research.”

What began as a carefree day during summer recess in the life of a 20-year-old college student became a life’s work. Steve has fueled his passion for helping people with CRPS with the fire of his own experience, turning tragedy and persistence into dedication and purpose.

You can learn more about Steve at his website: [www.shislerlaw.com](http://www.shislerlaw.com)


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**ABOUT THE AUTHOR**

Jenny Picciotto is a writer and CRPS patient who enjoys reading and playing the piano. She was a yoga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.
Physical therapy is a first-line intervention for individuals with pain. However, when it comes to chronic pain, particularly Complex Regional Pain Syndrome (CRPS), working with an interdisciplinary team of healthcare providers can be a more effective treatment approach. Often, the responses to physical therapy as a stand-alone intervention can vary. Physical therapy alone may have no effect on pain and functioning, or result in triggering flare-ups, leading to increased debility.

At times, individuals may believe during physical therapy sessions that “pushing through” the pain will be beneficial – the “no pain, no gain” mindset. However, these beliefs run counter to the goal of increasing function while managing pain or sensitivity symptoms associated with CRPS. In the setting of an interdisciplinary healthcare team, the physical therapist’s approach involves providing a graded exposure to exercise partnered with integration of active pain management techniques from other disciplines.

At the Shirley Ryan AbilityLab Pain Management Center, interdisciplinary team members include a pain physician, physical therapist, occupational therapist, pain psychologist, biofeedback therapist, and vocational rehabilitation counselor. These team members each have a role in optimizing different aspects of the individual’s function – biological factors (medications, sleep, strength, conditioning), psychological factors (depression, anxiety, fear), and social factors (roles, responsibilities, recreation). Collaboration between team members allows for integration of techniques from other disciplines into physical therapy treatment in order to more effectively manage CRPS symptoms during physical therapy treatment.

Over time, CRPS symptoms limit an individual’s function, resulting in deconditioning, muscle tightness, and weakness of foundational muscle groups. Active physical therapy techniques, such as therapeutic exercise, cardiovascular conditioning, and education have been shown to be more effective than passive techniques, such as modalities (heat, ice, electrical stimulation) and manual therapy (soft tissue mobilization, joint manipulation). Passive techniques may provide short-term reduction in symptoms but lack evidence demonstrating long-term benefits, and can also lead to dependence on healthcare providers to receive the passive treatment.

Physical therapists have a variety of active interventions to draw on when treating a diagnosis such as CRPS. Therapeutic exercise can include stretching to address muscle tightness and guarding, gradually increasing adaptability of structures to being stretched during exercise and functional movements. Strengthening of deep neck, shoulder blade, core, and hip stabilizer muscles will reinforce utilization of endurance muscles and, by result, decrease compensation from other muscle groups. Performing aquatic-based exercise is another evidence-based tool at the physical therapist’s disposal. Water decreases load of body weight on joints by up to 65 percent. Performing walking activities, functional strengthening, and balance exercises in water allows for optimization of movement patterns for eventual carry-over into land-based exercise. In an interdisciplinary model, the physical therapist will partner with the occupational therapist to develop a graded desensitization program for individuals with sensitivity to water.

Initiating a cardiovascular conditioning program is another intervention that is essential for addressing overall endurance. The American College of Sports Medicine recommends 150 minutes of moderate-intensity conditioning per week. The endorphin release that is associated with cardiovascular exercise in a target heart rate zone can be utilized as an active pain management strategy. Additionally,
cardiovascular conditioning can increase overall endurance for functional mobility. Thorough education allows individuals to have the skills to progress their home exercise program and cardiovascular conditioning efforts for continued long-term gains. By the conclusion of their intensive therapy program, individuals will have the knowledge to be aware of how to be more functional while keeping CRPS symptoms under better control.

Within a physical therapy treatment session, the interdisciplinary model allows for integration of active pain management techniques from other disciplines. For example, the physical therapist will often encourage patients to perform a biofeedback breathing technique during a pacing break to reinforce optimal breathing patterns and as pain management tool. Likewise, psychology techniques can be leveraged to reframe maladaptive thoughts, such as fear of movement or anxiety related to exercise. As a patient makes progress with occupational therapy interventions, such as desensitization techniques and graded motor imagery, the physical therapist can then begin to incorporate exercise with the affected body region into physical therapy treatment.

Current evidence supports the role of active physical therapy techniques for individuals with CRPS. By addressing the underlying flexibility, strength, and endurance impairments, combined with interdisciplinary pain management techniques, such as pacing, mindfulness, and biofeedback, individuals make progress in physical therapy to improve their function and quality of life. An interdisciplinary pain management program like the Shirley Ryan AbilityLab Pain Management Center empowers individuals with the insight needed to apply pain management techniques for the lifespan.

ABOUT THE AUTHOR
Wendy Wurtzel PT, DPT is a senior physical therapist at the Shirley Ryan AbilityLab Pain Management Center, specializing in both pain management and vestibular rehabilitation for adolescents and adults. Wendy graduated with a Doctorate in Physical Therapy from the University of Florida in 2012. She serves as a District Representative in the Illinois Physical Therapy Association and as a member of the Scientific Planning Committee for the Midwest Pain Society. Wendy has also been involved in research throughout her career, publishing in peer-reviewed journals and presenting at national conferences.
RSDSA Approves New Grant Application for Research Study

BY JASON HALE, MD • HALEJ3@CCF.ORG

The RSDSA Board of Directors recently approved Jason Hale’s, MD’s grant application. According to Dr. Hale, a resident physician in anesthesiology at the Cleveland Clinic, the goal of the study is to determine whether nitrous oxide, also known as “laughing gas,” would be effective in treating pain caused by CRPS. Essentially, Dr. Hale wants to see if brief periods of nitrous oxide exposure can treat CRPS pain. Dr. Hale is working with Dr. Jijun Xu, MD PhD, and Dr. Alparslan Turan, MD, who are staff physicians in the Anesthesiology Institute at the Cleveland Clinic.

The rationale for the research trial is based on the molecular mechanism, or how a drug works at the molecular level, of ketamine, a powerful intravenous pain medication. Brief periods of ketamine therapy are sometimes effective in treating CRPS pain, even after the effects of ketamine have worn off. Unfortunately, ketamine is fraught with side effects such as hallucinations, the therapy is costly and requires intravenous access, and toxicity can limit the amount of medication that is able to be used.

Ketamine’s primary molecular mechanism is NMDA antagonism, meaning it blocks NMDA receptors in the brain, and this underpins its efficacy as a pain medication. NMDA receptors are believed to play an important role in the development and persistence of chronic pain, especially neuropathic pain in CRPS. Blocking NMDA receptor activity in the brain is also believed to be important in treating chronic neuropathic pain. Unfortunately, there are very few medications that act as NMDA antagonists (like ketamine), and the true utility of NMDA receptors as a therapeutic target remain unclear.

Nitrous oxide, however, is also an NMDA antagonist. This explains why nitrous oxide, while also being sedating, directly treats pain. Nitrous oxide is cheap, safe, and easy to administer with a simple breathing mask. Based on some scientific studies in animals, the research team believes the pain relieving effect may continue even after a patient recovers from breathing nitrous oxide. Temporarily exposing neurons in the brain to an NMDA antagonist is believed to help “reset” the maladaptive cellular mechanisms that contribute to neuropathic pain.

This small research trial will help us determine if nitrous oxide can provide effective pain relief, reduce oral opioid medication use, and improve functional status in patients with CRPS. If beneficial, nitrous oxide could become an alternative treatment option for patients with CRPS and other chronic pain conditions. Dr. Hale and his colleagues are excited to start this clinical research trial at their institution!

Jijun Xu, MD, PhD (1) and Jason Hale, MD

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@rds.org or go to https://rds.org/donate/.
Spotlight On Support: A Newsletter Addition

BY SHARON L. WEINER • FSG.RSDSA@GMAIL.COM

Spotlight On Support is a new addition to the RSDSA newsletter that focuses on showcasing the accomplishments and activities of the over 60 CRPS support groups, including in-person, online and virtual groups. Support groups, whether our in-person, online, or virtual groups, can be crucial to our community and the wellbeing of those with CRPS, along with their family, friends and caregivers.

If you are interested in submitting information about your support group’s activities, please send an email to FSG.rdsa@gmail.com.

If you wish to start a new support group, please contact RSDSA.

This Edition’s Spotlight: The Northeast Philadelphia RSDSA Support Group, a newly formed group, recently welcomed Stephen Shisler Esq. to speak at one of their meetings. He discussed the critical need for medical teams to use the precise language of the “Budapest’s Criteria” in medical records for CRPS patients to increase their chances for success when winning legal challenges presented by both Workman’s Compensation and Social Security Disability cases. “Many of the patients attending our support group meeting and especially our newly diagnosed members have never heard of the “Budapest Criteria” much less knew the importance of using this very specific diagnostic language,” says support group founder and facilitator, Kimberly Russo.

For more information about this support group and the Budapest Criteria, please email: rsdphilly@yahoo.com

The Longest Day of Golf

BY JERI KRASSNER • JKRASSNER@RSDS.ORG

On Monday, September 30, 2019 Josh Rosen teed up to play golf for RSDSA’s third Longest Day of Golf fundraising event. The Longest Day of Golf (LDOG) is a unique fundraiser that costs RSDSA no expense. Josh plays golf from 7:00am to 7:00pm on the day of, during which the golf club is closed to members. Individuals contribute by pledging either an amount per hole played or by making a one-time gift to aid RSDSA’s mission of education, support and research. A round of applause goes to our Co-President Hank Ludington for organizing and promoting this special tournament.

For the second year, Josh lent his prodigious talent to the event, playing from 7 a.m. till 7 p.m. He loves playing golf, especially when it benefits RSDSA. He played a grand total of 128 holes. It was a beautiful day on the links, during which Josh was accompanied by Hank and Jim.

Josh had a slow start toward his goal to birdie every hole. He missed the green on a short approach shot on the first hole, then hit two balls in the water on the second hole. Despite his inauspicious start, Josh quickly got back on pace with a par and two birdies on the next three holes. Josh kept going and going. It’s his ability to stay undaunted and persevere that makes him the perfect representative for our community. And thanks to Jim he can now tell the difference between an Osprey and a Hawk.

The RSDSA Board set an ambitious goal of $50,000 and we are 1/3 of the way to goal. However, it is not over and there is still time to contribute to this fundraiser. LDOG campaign is open and we accept donations to the end of the year. You can still be our best hope and help fulfill our mission by making a donation to https://www.firstgiving.com/event/rsds/2019-Longest-Day-of-Golf.
Ride for Warriors Recap - An Interview with Eric Moyal

BY LAUREN BENTLEY • LAURENBENTLEY93@GMAIL.COM

Driving from Medford, Massachusetts to Miami, Florida takes approximately 23 hours and 47 minutes. Hop on a flight at Medford’s nearest airport and you’ll land in Miami in just a few hours. So, how long does it take on a bike? Two and a half weeks. That’s the amount of time it takes to bike the seventeen thousand miles between Medford and Miami.

How do we know this? Eric Moyal biked those 1,700 miles in the Ride for Warriors campaign, a fundraiser created by Eric and his family to raise money for research and awareness of CRPS. It was also inspired by Eric’s sister, Anais Moyal. She was 15 years old when she was diagnosed with CRPS. Anais was enjoying a bike ride when she was suddenly hit by a car. After over a year of going back and forth with doctors trying to determine why she was in pain, Anais was diagnosed with CRPS. Since then, Anais, Eric and their family have been dedicated to raising awareness of “the most painful disease known to man.”

During the summer edition of the RSDSA Update, we sat down with Eric as he prepared to hit the road. In the weeks leading up to the ride, Eric felt in good shape physically. He trained and had previously completed a 120 mile bike ride in just about ten hours. Mentally though, Eric questioned whether he would be able to bike those 120 miles for ten hours every day for two weeks. Would he get bored? Would he get discouraged? Not to mention, it was hard to condition for a ride that would take him through the hot and humid southern heat when he was living in the northeast.

When the ride began in Medford, Eric says he struggled to get a rhythm down. In order to complete the ride in the two week timeframe and to stay on schedule with meeting RSDSA community members along the way, Eric had to determine the speed he would need to take in order to complete 120 miles every day. Luckily, Eric had the help of his mom, Anat Moyal, throughout the entire ride. Anat drove beside Eric with a car full of water, snacks, and extra bike supplies. Talk about teamwork!

Eric and Anat traveled down the East Coast, passing through eleven states along the way. He described this journey as an amazing and once-in-a-lifetime opportunity. They saw beautiful parts of the country for the first time. “I also had no idea how many people were following the ride!” Eric exclaimed. People shared Eric’s updates from the road on social media. He spotted Ride for Warriors stickers in local towns. Donations continued to flow in. But perhaps the most meaningful part of the journey was the people they met along the way.

“If there is one thing Eric has learned during the Ride for Warriors, it is that CRPS Warriors are doing amazing things. “Do not undermine your accomplishments!” he says.

“The East Coast, passing through eleven states along the way. He described this journey as an amazing and once-in-a-lifetime opportunity. They saw beautiful parts of the country for the first time. “I also had no idea how many people were following the ride!” Eric exclaimed. People shared Eric’s updates from the road on social media. He spotted Ride for Warriors stickers in local towns. Donations continued to flow in. But perhaps the most meaningful part of the journey was the people they met along the way.

“I loved talking and hearing people’s stories with CRPS,” says Eric. “It was amazing to hear how people are still doing incredible things in their lives despite this debilitating condition.” While biking through New Jersey, Eric was invited by board members Hank & Mary Beth Ludington to have lunch at their home. Mary Beth was 21 when she first experienced symptoms of CRPS, but was not diagnosed for many years. With support from her family, she was able to get
married, have 3 girls, 4 grandkids and go to grad school. However, Mary Beth did have a fear that she was holding her family back from different experiences because of her physical limitations. This is a fear that many people living with chronic illness have faced with loved ones. When Mary Beth apologized for feeling as though she was holding her family back on a vacation, her family’s response was “are you kidding me?!” Mary Beth’s children felt this statement could not be farther from the truth. In fact, they expressed gratitude and love for the experiences and memories she provided her children.

Although the beginning of the ride was difficult, Eric says the very last weekend was the hardest part of the journey. Up until this point, Eric could see clear progress as he moved from town to town and state to state. However, Florida was one long stretch of hot and humid heat and the highway. The wind was strong from the coast. Eric struggled to keep pedaling.

It was the second to last day of the ride when the front tire of Eric’s bike hit a crack in the pavement. He flew over the handlebars, injuring both his leg and his bike. “Do you want to call it?” Anat asked. There was about a half a day worth of biking left. If he threw in the towel now, at least he could say he biked most of the way. But to Eric, calling it quits wasn’t an option. “The people I met along the way gave me the strength to continue the ride,” says Eric. “Biking was nothing compared to the fight people with CRPS battle every day.”

The last day of the race finally arrived. Eric and Anat met some fellow bikers after lunch who were going to finish the race alongside Eric. After peddling thousands of miles of unknown land, Eric was back in his hometown. It was comforting to ride through familiar territory and not need directions – or so he thought! As the excitement of reaching the finish line was upon him, Eric missed the last turn! A quick U-turn was made and the bikers were back on track. By then, the leg Eric had injured the previous day was numb.

Finally, the finish line was in sight! Dozens of people, including Eric’s friends and family lined the street to cheer him along. Seventeen thousand miles had brought him to this point. When asked how it felt to cross the finish line, Eric replied “It felt surreal. I put my hands up, got to the finish line and hugged my sister.”

Approximately two months later, Eric still finds it hard to believe such an accomplishment was made, even after watching the highlight reel created by his sister. The Ride for Warriors exceeded its $5,000 fundraising goal, raising a total of $6,069. One hundred percent of these proceeds went to the RSDSA to further research efforts.

If there is one thing Eric has learned during the Ride for Warriors, it is that CRPS Warriors are doing amazing things. “Do not undermine your accomplishments!” he says.

Eric and the RSDSA would like to thank everyone who supported this cause, whether that was by donating, sharing posts on Facebook or providing a meal for Eric along the ride. Without this support, the ride would not have been possible. They would also like to extend a special thanks to:

- Jessica Kennedy Dutkiewicz who drove for an hour with her husband just to meet Eric in Georgia. She shared her story and treated him to dinner.
- Linda Horan who housed Eric and his mother, made them dinner and shared her story.
- Mary Beth and Hank Ludington who met Eric and Anat for lunch, shared her story and helped sponsor the ride.
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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Don’t see an event near you?

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

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.

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 contralateral 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 mostly 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.noigroup.com.

What People with CRPS Should Expect from Therapy

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

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 reasons 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/weight 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.

Treating Complex Regional Pain Syndrome

A Guide for Therapy

Reflex Sympathetic Dystrophy Syndrome Association
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Web: http://www.rdsd.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 or nail 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 daily 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 manual lymph drainage. First and second intercostal spaces 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 contracted to relaxed postures on 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.1

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: scrapping 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 guarding and pain, typical findings include improved extremity sensation, decrease in swelling and joint fluid absorption. However, pain can be intense and significantly limit function. 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.2

Scrubbing consists of affected extremity in a back/forth motion while weight bearing through the extremity.3 The patient scrubs against 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.4 For upper extremity involvement, the pt. grasps the scrub brush with the affected hand. For lower extremity involvement, a long Velcro® 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 have a decrease in resistance by using a large towel. 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 handheld bag loaded with increasingly heavier weight. Carrying should be performed three or four times a day, whenever the patient is standing or walking.4,5

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 on the affected foot or by placing the unaffected 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, biofeedback, hypnosis and the Mind-Body Stress Reduction (MBSR) program. MBSR is a form of meditation practices that is commonly used to help treat chronic pain. The practice of these interventions should begin immediately.

Functional Training 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/Bracing is used in severe cases of CRPS. Splinting or bracing may be utilized to promote incorporation of these techniques, to 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.6

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistant 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 insensitive situations (as after a nerve block). Pacing and pain management techniques, such as appropriate rest breaks, alternating tasks, thermal or cold sensation feedback, diaphragmatic 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.

WE ARE HERE TO SUPPORT YOU
- YOU ARE NOT ALONE -

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Website: http://rsds.org

Raising awareness of CRPS since 1984
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.

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.

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

I have Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy Syndrome (RSD).

- Physicians do not know why it 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 pain dramatically disproportionate to the injury.

- More than 140 years ago Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.

- CRPS can lead to disability. CRPS can spread.

- 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.

- My skin may swell, sweat, change colors, change temperature, or hurt to the slightest touch.

- Often it is difficult for me to sleep so I may have trouble with attention and concentration.

- I may be taking powerful medications prescribed by my physician with many side effects that may affect how I feel or how I react.

- It is often hard to move easily or keep my body steady.

- Chronic pain, like that caused by CRPS, often leads to depression because we undergo significant, and often negative, life changes.

- I have good and bad days; my pain may even change hourly. Stress increases my pain.

- Presently, there is no cure for CRPS. I always have hope because of the support of my family and friends and ongoing research.
Here's How You Can Help Me.

- My pain is real even though it is 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.r ds s.org and learn all you can.

Pain Scale

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

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Funded by Kansas City Awareness
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!