Welcome to RSDSA:

The RSDSA is a 33-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 20,000. But we must increase our community so that Congress, The National Institute of Health, pharmaceutical corporations, and insurers hear our collective voice!

We published *Complex Regional Pain Syndrome: Treatment Guidelines* in 2013. The Guidelines are available at [http://rsds.org/clinical-guidelines/](http://rsds.org/clinical-guidelines/). I would also recommend you sign up for our free electronic e-Alerts if you haven’t done so already at [http://rsds.org/joinmembership/](http://rsds.org/joinmembership/) to receive not only the *RSDSA Community Update* but information on upcoming RSDSA fundraisers and other important information.

If you have CRPS, please join our Internet-based study entitled *Long-term Health Effect of CRPS: A 20-year Cross-sectional and Longitudinal, Observational Cohort Study*, funded by a grant from the Brodsky Family Foundation. Anyone with the diagnosis of CRPS Types I and II can participate by visiting [http://www.crpssurvey.org](http://www.crpssurvey.org).

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

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. We have eliminated membership dues; however we will periodically ask our community for their financial support to help us achieve our educational and research initiatives. 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 goodwill 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
One of the most comprehensive, Up-to-Date Guidebooks on RSD/CRPS is now available!

This highly recommended Guidebook from Medifocus contains over 90 pages of vital information including a clear description of the syndrome, treatment options, access to the latest peer-reviewed research and a worldwide direction of RSD/CRPS physicians and researchers. This information is updated quarterly online only.

This unique guidebook is a must have for anyone interested in RSD/CRPS!

For each Guidebook purchased through RSDSA, 30% of the proceeds is donated to our organizations.

The guidebook is available electronically for $24.95 and in print for $29.95 plus $6.00 S&H.

To order the Guidebook, go to http://www.rsds.org/4/resources/index.html.

To order either the electronic or printed of the guidebook go to https://www.medifocus.com/2009/order2.php?ordertype=mail&gid=NR015&a=a&assoc=rstds.org and charge to your credit card.

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RSDSA Launches Major Study on the Natual History and long-Term Health Effects of CRPS

The Reflex Sympathetic Dystrophy syndrome Association (RSDSA) is conducting an Internet-based study entitled Long-Term Health Effects of CRPS: A 20 year Cross-sectional and longitudinal, Observational Cohort Study, funded by a grant from the Brodsky Family Foundation.

Anyone with the diagnosis of CRPS Types I and II can participate via a link on RSDSA’s website, http://www.rsd.org/3/research/RSDSAStudy_1019_197.html or from the study website at http://www.crpssurvey.org.

Potential participants, who are not familiar or comfortable with Internet-based communication can contact the study’s Project Manager to obtain paper forms for registration, consent and enrollment.

All questionnaires and records are confidential and securely held according to HIPAA and WIRB provisions.

Any questions, please e-mail crpsregistry@gmail.com.

If you are interested to becoming a participant, please go to ... www.crpssurvey.org.
CRPS CLINICAL TRIAL

Now Enrolling: Phase 3 CRPS Clinical Trial of an Oral Non-Opioid Investigational Medication CREATE-1 (CRPS Treatment Evaluation 1 Study) is a Phase 3 multinational, multicenter, randomized, double-blind, placebo-controlled trial designed to evaluate the efficacy and safety of AXS-02 for the treatment of pain associated with CRPS. AXS-02 is an oral, non-opioid, investigational drug that has been granted Fast Track and Orphan Drug Designation by the U.S. FDA, and Orphan Medicinal Product Designation by the European Medicines Agency for the treatment of CRPS. AXS-02 is not approved by the FDA. The study is enrolling patients at sites in the United States, Canada, the United Kingdom and Australia. Eligible patients must be at least 18 years of age with recently diagnosed CRPS type 1 related to a traumatic injury. Eligible patients will be randomized to receive either AXS-02 or placebo by mouth once weekly for six weeks. The primary efficacy measure is the change in patient-reported pain intensity at the end of Week 12. Secondary outcome measures include assessments of the change in the Brief Pain Inventory (BPI) score, Patient and Clinician Global Impression of Change (PGI-C and CGI-C, respectively) and other quality-of-life measures. More information about the CREATE-1 study is available at www.clinicaltrials.gov. To learn about eligibility and to find a study site, patients can visit www.CRPSrial.com.
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.
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 knowledgeably 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.

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.
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
   (https://painsandiego.com/2016/11/06/medical-marijuana-proven-to-save-lives-science-november-4-2016/). Entire issue of Science, November 4, 2016, devoted to pain. NAC and alpha lipoic acid are noted by research from the Netherlands.

Appendicitis

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

Medications target 3 main systems, as discussed at the conference

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

The glutamate NMDA receptor – ketamine, memantine.

Glia, the innate immune system – glial modulators.

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

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

MOVEMENT

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

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

Disclaimer

The material on this site is for informational purposes only. It is not legal for me to provide medical advice without an examination. It is not a substitute for medical advice, diagnosis or treatment provided by a qualified health care provider.
From One Family to Another- A Pediatric CRPS Journey

By Guest Bloggers Bobby and Lauren Geller

The Gellert’s daughter, Zoe, has faced CRPS head on. She has been inspired to do some great things. See what Zoe and the Gellert family are doing and what they learned about pediatric CRPS.

“Dad! You need to come home. The doctor said nothing is broken or torn, but I still can’t put my foot on the floor. It feels like someone is sticking a knife through my heel and it’s burning inside”.

These were the words of our 11-year-old daughter, Zoe Gellert, who the day before was involved in a crush injury to her right ankle. Zoe was immediately non-weight bearing and was describing pain symptoms that made no sense based on the findings from her X-rays and MRI. She was diagnosed with Complex Regional Pain Syndrome six weeks later. For my wife and I, this was the first moment in our lives that ‘brought us to our knees’. Having a child that is constantly in pain with symptoms that got worse over time was a devastating situation that immediately threw us into acute survival mode to obtain the best and most immediate treatment for our daughter.

Zoe is very intelligent, passionate and determined – a born leader. Over the past nine months since her injury, Zoe has learned an incredible amount about herself and her disorder. Today, although Zoe is fully functional and playing sports, she continues to manage her daily pain with techniques that she has learned and that she is enthusiastic about sharing with other kids that are suffering. Zoe is committed to creating overall awareness about pediatric CRPS and to raising money to help fund vetted treatment and research projects and to help support parents seeking financial assistance for their child’s necessary treatments. Attached below is a detailed video of Zoe’s story that we would like to share. We hope that you enjoy it and that it is inspirational for you or someone that you know with CRPS. If you would like to email Zoe, please contact her at zoesheroes@icloud.com. We hope to hear from you!

My wife and I are very grateful that within three months of Zoe’s injury she was diagnosed, admitted into the hospital for intensive multi-disciplinary treatment and was released from the hospital walking without any support. However, the feeling of being ‘a fish out of water’ is still very fresh for us. Being thrown into the abyss of CRPS – whether during the pre-diagnosed, treatment or recovery stages – is completely overwhelming. Throughout our research, it was very important to us to consider treatment options that were non-narcotic, non-invasive – but aggressive and appropriate for a child. There were always many things to consider and everyday brought new challenges. So below, we feel compelled to highlight and share what we have learned about pediatric CRPS and what has worked for us and our family thus far in our journey…

Top 20 dos, DON’Ts, SUGGESTIONS AND PRACTICALITIES FOR PEDIATRIC CRPS*

- Do not apply ice
- Do not cast or immobilize
- Do not get a flu shot
- CRPS can spread throughout the body over time without treatment
- Emotional stress can increase the baseline pain endured daily
- Blood tests do not support or exclude the diagnosis – which is clinical and primarily based through observation of a variety of classic symptoms
- Thermography may be the most effective non-invasive diagnostic tool
• If your child must have an IV or get a shot, use the smallest needle possible – sometimes called a butterfly needle
• Discuss with your doctor administering an appropriate dosage of Ketamine along with any anesthesia during surgery
• Your child must be encouraged to stay engaged in everyday life activities while in pain – endure as much daily physical activity or physical therapy as your child can tolerate
• Continually touch, rub and desensitize the affected area – this will facilitate the circulation of blood and oxygen flow and eventually reduce pain
• Recovery is mostly about function over pain – explain to your child that he/she will not hurt himself/herself – if your child can function while in pain he/she will feel in control of the pain and the pain level will be reduced
• Do not ask your child about the pain he/she is feeling
• If your child complains about the pain, be sensitive, acknowledge the pain and distract him/her with homework, chores, physical or social activity – but move on from the conversation
• Your child must accept and surrender to the pain without letting the pain identify who he/she is – do not allow your child to mentally cut off the affected area from his/her body
• Seek a Cognitive Behavioral therapist so your child has someone other than you to talk with about what they are going through and to learn visual pain management techniques
• All family members should be encouraged to discuss with a therapist how they are coping with the affected family member’s diagnosis
• Do not allow CRPS to take over the household or to be the main topic of conversation with family, friends and work colleagues
• Consider Osteopathy and Homeopathy as regular, not alternative, treatment options
• Five books to read:
  • Get Out of Your Mind and Into Your Life – Spencer Smith and Steven C. Hayes
  • Conquering Your Childs Chronic Pain – Lonnie K. Zeltzer M.D.
  • The Mind Body Prescription – John E. Sarno M.D
  • The Power of Now – Eckhart Tolle
  • Fulford’s Touch of Life – The Healing Power of the Natural Life Force – Dr. Robert Fulford

*We are parents, not doctors; hence, we are not making any representations or warranties regarding the above information which is based solely on the results of our own research and experiences.

As you saw in the video, Zoe created a GoFundMe site. Please click on the link if you are able to make a tax-deductible donation and/or please share the GoFundMe site on your Facebook page or any other social media outlet. We thank you in advance for your support and for your donation.

We also have an Instagram account – called “Zoesheroes” – that it would be super if you would “like” and follow us on our journey!

With appreciation and gratitude,
Lauren and Bobby Gellert
Original Research

Outcomes of Children With Complex Regional Pain Syndrome After Intensive Inpatient Rehabilitation

Valerie Brooke, MD, Steven Janselewitz, MD

Objective: To examine the effectiveness of an inpatient treatment program on eliminating pain and increasing function for children with complex regional pain syndrome.

Design: A retrospective chart review and follow-up telephone survey.

Setting: A tertiary care hospital.


Intervention: Intensive inpatient physical and occupation therapy in conjunction with psychological counseling, art therapy, recreational therapy, and child life specialists who focused on improving physical function and conditioning, stress management, and the development of self-efficacy related to pain and stress.

Main Outcome Measurements: Resolution of pain and restoration of full function by patient or family report.

Results: All the children had failed various prior treatment approaches: 34% had resolution at the time of discharge; 78% of admissions and 89% of those with follow-up had eventual resolution of pain; and 95% had full restoration of physical function at a median time from start of treatment of 2 months. Seven had recurrence and 5 were able to resolve the recurrence without further intervention from the medical community.

Conclusions: Intensive inpatient rehabilitation is effective for children with complex regional pain syndrome. Additional studies are necessary to compare this treatment with other approaches.

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INTRODUCTION

Children with pain out of proportion to any initiating injury, or amplified pain, can pose both a diagnostic and a therapeutic challenge for physicians. Some children have autonomic signs such as swelling or changes in skin temperature or color, which lead to a diagnosis of complex regional pain syndrome type 1 (CRPS-1), formerly referred to as reflex sympathetic dystrophy (RSD) [1]. Other physicians have also used the term reflex neurovascular dystrophy (RND) [2-7]. Pain conditions in children without autonomic signs have been referred to as diffuse idiopathic pain syndrome, localized idiopathic pain syndrome, psychogenic pain, psychosomatic pain, pseudodystrophy, growing pains, primary fibromyalgia syndrome, or fibromyalgia [7-15].

Many different treatment approaches have been attempted for these pain conditions in children, including nonsteroidal anti-inflammatory drugs [16-20], steroids [16,19,21-23], prostacyclin analog [12], pamidronate infusion [24], splinting or immobilization [18,20,25,26], transcutaneous electrical nerve stimulation (TENS) [17-19,26-30], sympathetic nerve blocks [6,19,22,25,26,30,31], and spinal cord stimulation [14], all with varying degrees of pain resolution and functional restoration. The most commonly used treatment for children with CRPS-1 is physical therapy (PT). A few studies show the effects of a single treatment modality for the treatment of these pain conditions. Frequently, multiple modalities are used simultaneously, which make it difficult to determine the effectiveness of any single treatment.

The few previous studies of children treated primarily with inpatient or outpatient therapy show rates of long-term full resolution that ranged from 60% to 100% [2,32-34].
Bernstein et al [2] reviewed charts of 23 children with RSD who had been treated with intensive outpatient PT of 2 to 3 PT sessions per day. Twelve patients had resolution of their pain, and 20 patients had full functional restoration after a mean follow-up time of 2.4 years. Blau [32] indicated full resolution of pain and function in 10 children with RSD after PT, with no patient spending more than 2 days in the hospital. The mean follow-up time was 1.1 years.

Sherry et al [33] studied children with CRPS-1 with either home-based exercises or inpatient therapy. Outcomes after a mean of 5.25 years showed pain resolution in 88% and functional restoration in 98%. Sherry did not elaborate on how many patients received inpatient versus outpatient therapy and drew no conclusion as to whether one was better than the other. A later study by Sherry [10] also included children with more diffuse musculoskeletal pain as well as patients with CRPS-1. Treatment consisted of an average of 2 weeks of intensive inpatient or outpatient PT, followed by a 1-hour daily home program performed for another 2-8 weeks. He reported that 80% of children had no pain and were fully functional after 1 month of treatment, with 15% having some pain but full function, and 5% with no improvement at all. At the 5-year follow-up, 90% of patients were free of pain and fully functional.

Lee et al [34] provided treatment of 1-hour weekly outpatient PT with cognitive behavioral therapy for 6 weeks or 3 hours of outpatient PT per week with cognitive behavioral therapy for 6 weeks. At follow-up, both groups had improvements in pain and function, with no significant difference between the groups, which suggests that more hours of PT may not improve outcomes. All the patients contacted at a mean follow-up of 2.5 years had resolution of their pain and restoration of function.

Although some of these studies used inpatient treatment, the studies did not look at this treatment approach exclusively. The aim of our study was specifically to evaluate the outcome of an inpatient rehabilitation treatment program of intensive rehabilitation therapies followed by a home program for children with complex regional pain syndrome.

**METHODS**

After institutional review board approval was obtained, a retrospective chart review included 33 admissions for inpatient treatment of complex regional pain syndrome at a tertiary care hospital between February 2007 and July 2010. Exclusion criteria limited data collection to first-time admissions, which eliminated 1 repeat admission for a total of 32 unique admissions and subjects for this study.

The diagnosis of CRPS-1 was made by 1 of 3 pediatric physiatrists working at the clinic and hospital with experience in diagnosing and treating children with CRPS-1. The diagnosis was based on symptoms of pain, focal or diffuse, hyperesthesia or allodynia, swelling, changes in skin color or temperature, decreased mobility or function, effects of prior treatment approaches, and lack of other diagnoses. These signs and symptoms form the basis for the diagnosis of pediatric CRPS-1 as suggested by Stanton et al [20], which include pain out of proportion to the inciting event combined with evidence of neurovascular dysfunction as manifested by dependent edema, dependent rubor, skin mottling, hyper-sensitivity to light touch, skin temperature changes, altered perspiration, and/or changes in patterns of hair growth. Patients were admitted for treatment based on diagnosis, patient and family willingness to enter treatment, and approval from insurance.

Admission and discharge data for pain and functional status were obtained by chart review. Pain was rated on a 0-10 numerical rating scale, with 0 being no pain and 10 being the worst possible pain. Data on long-term outcomes were obtained by a follow-up telephone survey completed 6 months or more after discharge. The telephone questionnaire included questions regarding the number of recurrences, resolution methods for any recurrences, any further treatment provided after discharge, and pain and functional levels on the day of the telephone interview. The parents were interviewed, unless the child was older than age 18 years at the time of the telephone interview, in which case the patient was interviewed.

**Treatment**

Inpatient lengths of stay varied depending upon the needs of the child and response to treatment, but all children participated in 5 hours of therapy per day, 5 days per week. The 3 hours of daily PT included timed, high-intensity aerobic activities, lower and upper extremity strengthening, core strengthening, stretching or yoga, and balance or coordination activities. Aerobic activities included the treadmill, stationary bike, step-ups on a bench, sprints, and various nontraditional mobility activities. The patients were required to beat the previous day’s timed aerobic activities by 1 second before moving to the next activity. Daily occupational therapy included 2 hours of exercises such as push-ups, sit-ups, plank exercises, or using an upper extremity bike. Desensitization exercises, such as brushing, towel, lotion rubbing, or fluidotherapy, were performed on the affected extremity for 15 minutes twice a day. Also, during the weekdays, the patients performed school activities for 30 minutes, had psychological counseling that taught stress management and pain coping skills, and had 30 minutes of self-directed PT on their own in the evenings. Additional services included art therapy, recreational therapy, and child life therapy. A few children were referred for a psychiatric consultation. Weekend therapy included 2.5 hours of PT and occupational therapy on Saturday, plus 45 minutes of self-directed therapy on both weekend days. Family visitation was limited. Each patient was given an individualized home therapy program.
after discharge, with the expectation to perform 45 minutes each weekday, and 90 minutes on each weekend day, until full functional activity was established.

Either before or shortly after admission, the patients were weaned off any medications being taken for CRPS-1. The patients were allowed to take acetaminophen or ibuprofen for headaches or soreness. The patients were discharged once they had reached their best performance on the above activities and demonstrated an ability to perform their home program.

RESULTS

Patient characteristics are depicted in Table 1. The mental health diagnoses at admission included depression (6 children), anxiety (9), attention-deficit/hyperactivity disorder (3), somatization or conversion disorder (2), eating disorder (1), and posttraumatic stress disorder (2). An additional 4 children were seen by a psychiatrist during their inpatient treatment and were diagnosed with general anxiety disorder (3), dysthymia (2), and depression (2). School absences were recorded for 28 children (88%), which ranged from missing several days due to the pain, to being home schooled secondary to pain and immobility. Five children (16%) had a previous diagnosis of chronic headaches or migraines.

Signs and symptoms on the day of admission, location of pain, and previous treatments are listed in Tables 2, 3, and 4, respectively. All the children had at least 1 prior treatment approach, although typically more. Functionally, 8 children (25%) required the use of crutches for ambulation, and 4 (13%) used a wheelchair, and 3 (9%) were non-weight-bearing secondary to pain. The admission median pain rating was 8.5 (range, 5–10). The average length of stay was 19 days, with a range of 8–32 days.

### Table 1. Patient characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Girls</td>
<td>26 (81)</td>
</tr>
<tr>
<td>Boys</td>
<td>6 (19)</td>
</tr>
<tr>
<td>Mean age (range), y</td>
<td>14.3 (8-18)</td>
</tr>
<tr>
<td>Mean duration of symptoms before treatment (range), mo</td>
<td>9 (0.5-48)</td>
</tr>
<tr>
<td>History of injury or trauma, n (%)</td>
<td>17 (53)</td>
</tr>
<tr>
<td>History of psychological diagnosis, n (%)</td>
<td>14 (44)</td>
</tr>
<tr>
<td>Perfectionist or overachiever personality traits, n (%)</td>
<td>16 (50)</td>
</tr>
</tbody>
</table>

### Table 2. Signs and symptoms on day of admission

<table>
<thead>
<tr>
<th>Sign</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Pain</td>
<td>52 (100)</td>
</tr>
<tr>
<td>Hyperesthesia</td>
<td>27 (84)</td>
</tr>
<tr>
<td>Skin color changes</td>
<td>15 (47)</td>
</tr>
<tr>
<td>Temperature changes: hot or cold</td>
<td>13 (40)</td>
</tr>
<tr>
<td>Swelling</td>
<td>5 (16)</td>
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</tbody>
</table>

### Table 3. Pain location

<table>
<thead>
<tr>
<th>Location</th>
<th>n (%)</th>
</tr>
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<tbody>
<tr>
<td>Lower extremity only involved</td>
<td>14 (44)</td>
</tr>
<tr>
<td>Neck, back, abdomen, or torso involvement</td>
<td>10 (31)</td>
</tr>
<tr>
<td>Upper extremity only involved</td>
<td>5 (16)</td>
</tr>
<tr>
<td>Both upper and lower extremity involved</td>
<td>3 (9)</td>
</tr>
</tbody>
</table>

All the children completed inpatient treatment. At discharge, the pain rating dropped to a median of 2 (range, 0-10). Eleven children (34%) had complete resolution of their pain at discharge (Figure 1). No child required the use of crutches or wheelchairs, although 5 (16%) were unable to participate in physical or sports activities. One of these 5 had limitations secondary to focal atrophy, not due to pain, and one had limitations due to hemiplegic cerebral palsy. Nineteen families (59%) were successfully contacted for the follow-up telephone survey. The remaining 13 families were lost to follow-up due to disconnected telephone numbers (3), failure to answer telephone calls (6), or nonresponse to messages (4). The average time to survey follow-up was 21 months, with a range of 6-43 months.

Of the 21 children who continued to have pain on discharge, 14 (67%) had resolution of their pain at a median of 2 months (range, 1–11 months) (Figure 1). Four who had pain on discharge were lost to follow-up. Of the 19 children who participated in the follow-up telephone survey, 3 never had pain resolution, with 2 reported a current pain level of 2, and one reported a level of 6. These ratings were less than their admission ratings, with reductions of 7, 3, and 2. Overall, 25 children had resolution of their pain. This is 78% of admissions and 89% of those with known outcomes.

Relapses occurred in 7 children (37%), including 1 relapse, or flare, in a patient whose pain improved but did not resolve after treatment. Six patients achieved full resolution of the recurrence. Five achieved resolution with home-based exercises learned during their inpatient treatment. One patient required additional outpatient therapy. The child with the flare was admitted for a second intensive therapy program, which resulted in reduction of the pain but still failed.

### Table 4. Previous treatments

<table>
<thead>
<tr>
<th>Treatment</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Nonsteroidal anti-inflammatory drugs</td>
<td>21 (66)</td>
</tr>
<tr>
<td>Outpatient physical therapy</td>
<td>20 (63)</td>
</tr>
<tr>
<td>Opiates</td>
<td>17 (53)</td>
</tr>
<tr>
<td>Antidepressants</td>
<td>16 (50)</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>13 (41)</td>
</tr>
<tr>
<td>Benzo diazepines</td>
<td>10 (31)</td>
</tr>
<tr>
<td>Cast or splint of extremity</td>
<td>5 (16)</td>
</tr>
<tr>
<td>Muscle relaxants</td>
<td>5 (16)</td>
</tr>
<tr>
<td>Oral steroids</td>
<td>3 (9)</td>
</tr>
<tr>
<td>Local injections</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Sympathetic nerve block</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Epidural injection</td>
<td>1 (3)</td>
</tr>
</tbody>
</table>
to achieve resolution. Although counseling was recommended for nearly all the children after discharge, only 5 participated, all of whom had eventual resolution of their pain.

Three children had additional treatment for their CRPS-1 after discharge. One child began with a personal trainer after discharge as well as treatment by a naturopath and an acupuncturist, with eventual full resolution of pain. Two children saw other allopathic physicians after discharge for their pain. One child had full resolution of pain 11 months after discharge and after seeing a pediatric rheumatologist who used the same therapeutic techniques as in this study. The other child saw a pain center physician, attempted biofeedback with no resolution of pain, received a diagnosis of nonepileptic seizures, and never had pain resolution. One child continued with outpatient PT after discharge for focal muscle atrophy. Of the 5 children who reported functional limitations on the day of discharge, 3 children continued to report physical activity limitations on the day of the follow-up survey. However, one was due to hemiplegic cerebral palsy, one to new knee instability, and one to CRPS-1.

**DISCUSSION**

CRPS-1 occurs in both the adult and pediatric populations, but it differs in several respects. Pediatric CRPS has a 6-7:1 female:male ratio, whereas adults have a female predominance of 2-4:1 [14,35]. Children also tend to have symptoms in the lower extremities 3-6 times more frequently than in the upper limbs, whereas adults more frequently have upper extremity involvement [14,35]. In addition, children tend to have less-pronounced neurologic or sympathetic symptoms [35]. In our experience, children have not developed nail or hair growth changes. Adults have quite variable rates of recovery and frequently have long-term disability, whereas children are more likely to have complete resolution.

Many of our pediatric patient characteristics follow the pattern of previous reports and studies of children with complex regional pain syndrome, including the female predominance of patients [2,4,6,13,15,16,19,20,23,31-34,36-38], lower extremity involvement greater than upper extremity [2,5,8,13,15,18-20,23,33,34,36,37,39], and not always having an inciting event or trauma [2,3,5,6,15-17,20,23,31,33,34,36,38,39]. Previous reports showed an average age of 10.7 years at onset of CRPS-1 symptoms, whereas others reported median ages of 12, 13, or 14 years [4,23,33,38]. Previous reviews also reported an average duration of CRPS-1 before treatment of 6.3 months, or medians of 2, 4, 5, and 12 months [4,17,20,33,38]. In our sample population, the average age of onset of CRPS-1 was 13.3 years, and the median number of months before inpatient treatment was 9 months, both of which were higher than most previous published reports. The higher duration of symptoms before inpatient treatment could be explained by a delay in diagnosis, attempts at other treatments, or a delay in getting approval for inpatient treatment.

Our pain resolution rate is similar to prior studies on outpatient and inpatient therapy intervention, which ranged from 60%-100% [2,32-34]. Our high functional restoration rate is also similar to these studies but lacks a validated and thorough measure. We found a median time to resolution of pain of 2 months (range, 1-11 months) (Figure 1). For studies that reported time to resolution, the range was 2 weeks to 2.5 years [16,17,20,21,25-29,31,36,40,41,42]. Recurrences of CRPS-1 symptoms occurred in 7 of the 19 children contacted for follow-up in this study. This percentage of recurrences (37%) is not uncommon, and falls within a similar percentage range reported in previous studies [2,3,5,6,10,17,20,26,30,33,36-38,41,42]. Recurrences were found to occur either in the original area or the limb, or occasionally occurred in a new location. Regardless, the skills learned in inpatient rehabilitation were effective in resolving pain and dysfunction in 5 recurrences and kept these children from having to seek out further medical interventions.

Many researchers in previous studies have suggested that there is a strong psychological association in children who have complex regional pain syndrome [2,4,20,23,30,32,37-39]. Despite this association, causality cannot be substantiated, for several reasons. As noted by Bruhl and Carlson [43] and Lynch [44], the previous studies were not prospective trials, and they lacked control groups, had small sample sizes, and did not always have valid Diagnostic and Statistical Manual of Mental Disorders—II (DSM-II) diagnoses, which relied instead on statements of personality characteristics. Our study found the same associations but also had the same limitations. It also was difficult to make any assumptions regarding the relationship of mental health to complex regional pain syndrome, because depression and anxiety can occur as a result of chronic pain. Sherry et al [38] notes this in their reviews, with understanding that a preceding depression can lead to chronic pain or that the distress of a chronic pain syndrome can lead to depression. The high prevalence...
of psychological diagnoses in children with CRPS-1 require skilled professionals to treat the mental issues at the same time the therapy is working to decrease pain and increase function.

Three children in our study with known outcomes did not resolve their pain, which limits the ability to compare them with the children who did resolve their pain. However, it is interesting to note the characteristics of the 3 children who seemed to have failed our inpatient treatment program. First, these children had unusual pain distributions. The first one with diffuse pain covering the face, chest, back, and bilateral legs, as well as complaints of chronic fatigue. She had no initiating injury, no known history of a psychiatric diagnosis but did have a history of hyperflexibility. At discharge, the child reported a change in pain rating from 5 to 2, and, at follow-up, a pain rating of 2, which suggests at least an initial response to treatment. At follow-up, she also continued to report functional limitations, including an inability to sit or move for long periods of time.

The second child had right upper quadrant abdominal pain after a resection of a local nodular hepatic hyperplasia. In addition, this child also had autonomic changes in her feet, as well as numbness on her abdomen. She went on to receive treatment at another clinic and was subsequently found to have nonepileptic seizures. Unlike the first patient, she did not report any immediate decrease in her pain; she reported both an admission and discharge pain rating of 8. At long-term follow-up, her pain rating had decreased to 6, although she continued to miss school and participated in very limited physical activities. The third child had back and bilateral posterior leg pain with significant headaches. His back and leg pain, but not his headaches, improved after treatment, with a reported change from 9 to 2. However, his pain did not resolve, and he was readmitted for a second inpatient stay after injury resulted in worsened CRPS-1. His pain improved after the second stay but did not fully resolve.

The limitations of our study are similar to those in earlier studies on children with CRPS-1. The number of study participants is small; there are no control groups for comparison; and not all children participated in the follow-up survey. Even though our rates of resolution of pain and restoration of full function are encouraging, further study is required to determine whether outpatient therapy is more or less effective than intensive inpatient therapy or other treatment approaches.

**CONCLUSION**

The results of our study suggest that intensive inpatient rehabilitation, which consists of physical, occupational, and psychological therapy, without the use of other medical intervention and followed by a home program, is effective for children with complex regional pain syndrome even when other approaches have failed. Additional studies are necessary to compare this treatment with other approaches.

**UNCITED REFERENCES**

This section consists of references that are included in the reference list but are not cited in the article text. Please either cite each of these references in the text or, alternatively, delete it from the reference list. If you do not provide further instruction for this reference, we will retain it in its current form and publish it as an “un-cited reference” with your article [40].

**ACKNOWLEDGMENTS**

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**REFERENCES**


Management of Pediatric Patients With Complex Regional Pain Syndrome

Robert T. Wilder, MD, PhD

Abstract: This review summarizes current information about diagnosis and treatment of complex regional pain syndrome (CRPS) in children. Although it has been widely held that CRPS in children is intrinsically different from adults, there appear to be relatively few differences. However, there is a marked preponderance of lower extremity cases in children. Historically, psychological factors have been invoked to explain the genesis and persistence of CRPS in children, but the evidence is not compelling. Treatment outcome studies are limited but indicate that children generally respond to a primary focus on physical therapy. Multidisciplinary treatment reports are particularly encouraging. The general perception that children have a milder course may relate to the potentially greater willingness of children to actively participate in appropriately targeted treatment rather than to innate differences in the disease process itself. Recurrence rates appear higher in adults, but response to reinstitution of treatment seems to proceed efficiently. Clinical judgment dictates the extent of medication or interventional therapy added to the treatment to facilitate rehabilitation. In many ways, the approach to the treatment of children mirrors that of adults, with perhaps greater restraint in the use of medications and invasive procedures. The rehabilitation of children with CRPS, like that of adults with CRPS, needs further rigorous investigation.

Key Words: complex regional pain syndrome, pediatric


DEMgunakange

In children less than 18 years of age, complex regional pain syndrome (CRPS) type 1 develops most commonly in girls, with the incidence rising at or just before puberty.3–5 The lower extremity is more commonly affected than the upper, with a ratio of about 5:1. Type 1 CRPS seems to be more common among Caucasian children. I have noted this association in my practice at both Children’s Hospital, Boston, and at the Mayo Clinic, Rochester. To exclude sampling bias, physicians at Children’s Memorial Hospital in Chicago and Children’s Hospital Medical Center in Cincinnati were also polled (personal report from S. Suresh, Children’s Memorial Hospital, Chicago, IL, and K. Goldschneider, Children’s Hospital Medical Center, Cincinnati, OH). Although these hospitals have a substantial proportion of minority patients, the same association was seen there. Bernstein et al.6 also reported this association: 18 of 23 patients in their report were Caucasian, 4 Hispanic, and 1 black. This may not be unique to children, however as Allen et al reported a similar distribution in adult patients: 91% (107 of 118) of their population was Caucasian.6

CRPS type 2 is found with roughly equal incidence in both boys and girls and has been noted in children as young as 3 years of age.7,8 Interestingly, however, even though brachial plexus injury during delivery is common and can lead to longstanding motor weakness, neonates with Erb’s palsy do not generally develop pain in the extremity.

DIAGNOSIS

The diagnosis of CRPS remains a clinical one based on appropriate findings in the history and physical examination. Pain, particularly with allodynia, and signs of autonomic instability either historically or on examination are required to make this diagnosis. The pain should be out of proportion to the inciting event, if any, and is usually distally generalized in the extremity.9 Pathologic processes that might explain the pain must be excluded. There are no laboratory tests that can absolutely confirm or exclude this diagnosis.

A group from Belgium including Herregods,10 Francx,11 Chappel, and others has argued that disturbed vascular scintigraphy with increased pooling in the initial phase and hyperfixation on bone scintigraphy is necessary on bone scan to make the diagnosis of CRPS. In contrast, most other authors find that bone scans are quite nonspecific for the diagnosis of CRPS. Multiple authors have found that in patients meeting the clinical diagnosis, bone scan may show either hypofixation or hyperfixation or may be normal.5,12,13 This is not to say that bone scans are not useful in working up the patient with signs and symptoms of CRPS; however, the primary utility is in ruling out some underlying orthopaedic abnormality that might be triggering the neurovascular changes rather than diagnosing CRPS.
**TREATMENT**

CRPS in pediatric patients has always been considered different from CRPS in adults. Early large series of CRPS (reflex sympathetic dystrophy, as it was known at the time) suggested that the syndrome was extremely rare in children.\(^{14,15}\) Sporadic early reports of children with CRPS first appeared in the 1970s. Several of these patients had spontaneous resolution.\(^{16,17}\) This led to the suggestion that no treatment should be performed for children with CRPS. The rationale was that all treatments carry risks and side effects, and for a self-limited disease these should be avoided.\(^{17}\) Other authors used treatment strategies very similar to those used in adults, including sympathetic blocks, antidepressants, vasodilators, steroids, and so forth, generally with incomplete resolution of the disease.\(^{15,17-19}\) Between these two extremes was a group of authors recommending conservative treatment consisting primarily of physical therapy (PT) either with\(^{8,20}\) or without\(^{8}\) concomitant use of transcutaneous electrical nerve stimulation (TENS). The overall impression is that CRPS is more easily treated in children than in adults. This impression is challenged by later reports from Wider et al.\(^1\) Stanton et al.\(^3\) and Greipp\(^21,22\) showing that a percentage of children will have long-term pain and disability even with aggressive therapies such as sympathetic-chain catheters, and antidepressant and anticonvulsant medications.

**Physical Therapy**

A recent report by Sherry et al\(^5\) contradicts this pessimistic viewpoint. Using a program consisting exclusively of PT up to 6 hours per day, without any blocks or medications, they reported a cure rate of over 90%. These impressive results are similar to those Bernstein et al\(^4\) reported for PT alone two decades earlier. Murray et al.\(^23\) also reported similar results using PT as the primary treatment modality: 40 of 46 patients resolved with intensive PT alone.

A major school of thought is that PT is the treatment modality that offers a chance for resolution of CRPS in either adults or children.\(^24\) All other therapies, when used, should be prescribed with the goal of facilitating the basic PT regimen. From this hypothesis one would predict that more intensive PT would provide faster and more complete resolution of CRPS. Although nonrandomized trials of intensive PT by Sherry et al.,\(^5\) Murray et al.,\(^23\) and others would seem to support this, a recent prospective randomized trial by Lee et al.\(^25\) does not. In this study patients were assigned to once-weekly or three-times-weekly outpatient PT along with a baseline of weekly cognitive-behavioral sessions. Results for both groups were good, with pain scores decreasing to near zero and function improving, but no statistically significant difference was found between the two groups. This may have been limited by small sample size (13 per group) or because the actual amount of exercise performed may have been similar between the two groups. Curiously, the trend was for more complete resolution in the once-weekly group.

**TENS**

TENS is a noninvasive physical modality that may provide excellent analgesia for some patients. It has been described in several case reports and series.\(^1,26-32\) None of these series describe TENS as universally effective, and there are no prospective, blinded trials of efficacy. In view of the modest cost, generally high acceptance by children, and remarkable safety of this device, it is almost always worthwhile giving a trial of TENS as part of a multidisciplinary approach to CRPS.

**Biobehavioral and Psychological Treatments**

Much has been written about psychological aspects of children with CRPS. Authors have invoked psychological contributions to the disease since the earliest case reports of CRPS in children appeared. Carron and McCue, in their 1972 description of a child with CRPS, stated that they made “the usual referral to psychiatry and for sympathetic blocks.”\(^15\) Some authors have even presumed that CRPS is entirely a psychological or psychosomatic disease process.\(^33\) Presumably they are confused because CRPS crosses dermatomes and areas of innervation by single nerves to form a distally generalized stocking-and-glove distribution. The marked allodynia and pain far out of proportion to the original inciting injury, if any, have also caused many practitioners to question whether CRPS has an organic basis or is purely psychological origin.

There is scarce evidence that children with CRPS are psychologically unique. Sherry and Weisman\(^34\) studied 21 families of children with CRPS. These were generally high-achieving, compliant children. They found that in virtually all cases there was significant parental enmeshment with the patient. Beyond that, they found that multiple different stressors were present in these children, including marital conflict between the parents (\(n = 12\)), significant school problems (\(n = 13\)), and sexual abuse (\(n = 4\)). Testing revealed no major psychopathology, except for one child who scored high in somatization. Sherry and Weisman suggested that CRPS is frequently a stress-related disease, and the therapeutic approach must take these psychosocial factors into account. One difficulty with this study is that appropriate control groups were not tested with equal thoroughness. Children with new-onset arthritis were compared in terms of global assessment, but the other psychological tests were not reported for this control group. A healthy control group was not included.

A case series by Brommel et al.\(^35\) also found psychological dysfunction in children with CRPS. They concluded that the despair of the patients about their reflex sympathetic dystrophy expressed unsolved fears of early childhood. Again, no control groups were studied. Stanton et al.\(^2\) in reviewing a series of patients with CRPS, noted that 83% of the patients given psychological evaluations had “significant emotional dysfunction.” This was not further defined, although they also noted a great deal of stress in the lives of the patients. In contrast, Vieyra et al.\(^36\) performed a preliminary study comparing
patients with CRPS to children with migraine headaches and 21 normal controls. Contrary to expectations, no differences in family functioning were found among the three groups. Unfortunately, this work was never published in a peer-reviewed journal. A literature review by Lynch et al 1992 and recent prospective psychological studies of CRPS in adults also support that these patients are not psychologically unique from others with chronic pain. In isolated cases, psychological factors may indeed have a predominant role in the etiology of CRPS. Jaworowski et al 11 reported CRPS in a 12-year-old who developed simultaneously a conversion disorder; her identical twin also developed an identical conversion disorder. Whether or not psychological dysfunction exists prior to the onset of CRPS, psychological, cognitive, and behavioral strategies are often used as part of the treatment of children with CRPS. Case reports of successful treatment of CRPS with cognitive and behavioral strategies began to appear in the 1980.40,41 There are no prospective placebo-controlled trials of cognitive and behavioral therapies in the treatment of CRPS, either in adults or children. Their use is extrapolated from case reports and prospective series for other pain states, notably headache.42,43 Wilder et al 1 reported that 57% of their patients who received such training benefited from it and continued to use this treatment modality. Stanton et al,3 however, found that psychological interventions were not consistently effective. This was felt to be due to the short time for interactions with the therapist during the patient’s inpatient admission. Lee et al 23 used cognitive and behavioral therapy as part of their baseline treatment of CRPS patients who were randomized to receive one or three sessions per week of PT. Compliance with attending the sessions was good and overall results were good, but the specific effect of the cognitive and behavioral treatments was not broken out. Sherry et al 1 did not use formal cognitive or behavioral treatments in his series of 103 patients treated with intensive PT, but they did refer 77% for psychological counseling, either individual or family. The results from the counseling were not measured or studied.

Sympathetic Blocks

In previous years many authors have equated sympathetically mediated pain with CRPS. During the 1993 consensus conference that eventually led to the new taxonomy of CRPS, there was widespread agreement that the pain of CRPS could be sympathetically maintained, sympathetically independent, or some combination of both that could change over time.43 Sympathetic blocks may help define the proportion of pain that is sympathetically mediated at that time and may be of therapeutic benefit, but they do not confirm or refute the diagnosis of CRPS. When sympathetic blocks are used in the treatment of childhood CRPS, several authors have proposed the use of indwelling catheters rather than repeated single injections.1,23,46 There are several reasons to prefer this technique. First, accurate placement of a lumbar sympathetic block is facilitated by use of fluoroscopy. Minimizing radiation exposure is appropriate for children. Second, many children and adolescents require heavy sedation or a brief anesthetic for the placement of these blocks. Minimizing the number of anesthetics required is also useful. Third, the goal of the sympathetic block is not to “treat” the CRPS per se, but rather to provide adequate pain relief that the patient can effectively engage in PT. An indwelling sympathetic-catheter, when effective, provides continuous pain relief without motor or sensory dysfunction and can be highly effective in allowing PT to proceed. These patients are generally hospitalized. Indeed, one advantage of the indwelling catheter is that it mandates hospitalization, which may allow more intensive PT than is available on an outpatient basis. Single-shot sympathetic blocks need to be coordinated with the PT sessions so that the patient is pain-free during the sessions. Indwelling epidural catheters, although often effective in relieving the pain, cause sufficient motor and/or sensory block that the patient cannot effectively participate in PT. This may be counterproductive, as any immobilization of the limb appears to worsen CRPS. Use of clonidine or opioids along with low concentrations of local anesthetic in the epidural catheters may avoid this problem, but this may not provide adequate analgesia. Several authors who emphasize intensive PT as the sole treatment modality for childhood CRPS actually recommend against the use of sympathetic blocks.3,5,23 They have reported success motivating their patients to participate in PT despite ongoing pain and allodynia. Others,1,25,47 have used blocks to improve compliance in patients unwilling or unable to participate in PT secondary to pain. At present there are no prospective trials directly comparing outcomes in pediatric CRPS with or without sympathetic or epidural blockade.

Medications

There are also no prospective randomized clinical trials of any medications in the treatment of CRPS in children. Case reports and case series have reported success with tricyclic and other antidepressants,1 anticonvulsants (particularly gabapentin),48,49 steroids,50–54 (either systemically or as part of an intravenous regional technique),55 nonsteroidal anti-inflammatory agents,56 and opioids, both systemic and neuraxial. A good deal of controversy exists about drug therapy for this condition. Many authors have found steroids to be of no benefit.1,4,57 Those who stress the value of intensive PT suggest that no medications are appropriate.5,23 The rationale is that all medications may have side effects and the potential for morbidity. As they are not necessary in the view of these authors, they should be avoided. Sherry et al stopped all medications at the start of the PT program.5 A direct comparison of intensive PT with or without any of these medications is lacking.
Neurosurgical Techniques

A few children with CRPS fail to respond to multiple treatment approaches, including the stepwise multidisciplinary approach used by Wilder et al. and Lee et al.25 and the intensive PT approach used by Sherry et al.5 These children and their parents will often seek multiple medical opinions and undergo increasingly invasive and dangerous procedures in their quest for pain relief. Two types of neurosurgical procedures have been used in these patients: spinal cord stimulation (SCS) and sympathectomy. There is moderate evidence supporting the use of SCS in the treatment of CRPS in adults. Retrospective series by Kumar et al.58 and Kemler et al.26 and a later prospective series by Kemler et al.60 all show efficacy in terms of sustained pain reduction of modest proportions. Pain thresholds are not changed by SCS.61 No series of children undergoing SCS have been reported, although I know of at least a half-dozen children who have undergone SCS for CRPS. Results have been mixed, ranging from modest improvement in pain and function to a worsening of pain, with explantation of the system. SCS has an advantage over sympathectomy in that it is nondestructive and completely reversible.

Sympathectomy, either chemical or surgical, has been reported in children with CRPS. Disadvantages of this procedure include the fact that it is appropriate only for the sympathetically mediated portion of the patient’s pain, that it is irreversible and may cause sympathetic and that long-term physiologic effects of lumbar sympathectomy on adolescent girls are not well characterized. In a mixed series of adults and children, Bandyk and Johnson62 reported an initial 10% failure rate. With 30-month follow-up, long-term results showed a reduction in pain relief overall to 25% excellent relief (pain scores < 3 of 10), and 50% with pain that was moderately reduced from before the block. Wilder et al.1 reserved the use of sympathectomy for patients with impending loss of function from cellulitis complicating massive peripheral edema. The three patients undergoing these procedures did not have improvement in pain scores despite improvement in circulation and edema.

Complementary and Alternative Medicine

Randomized, blinded trials showing the efficacy of acupuncture are also lacking in CRPS. One such study has been performed, but there was improvement in both groups, with no statistical difference between groups.63 There are studies showing a surprisingly high acceptance rate for acupuncture therapy among children.64,65 There are also case reports of benefit to this therapy.66 It is rational to think that acupuncture, by its mechanisms of raising endogenous opioids and acting as a counter-stimulant to “close the gate” on spinal cord transmission of pain signals, might be of benefit in this disorder. Well-blinded studies are difficult to design, however, so obtaining definitive proof of efficacy may be slow in coming.

Although many patients may have used herbal remedies and nutritional supplements, there are no studies or even case reports of their efficacy. Most herbal remedies contain active biochemicals. They may indeed benefit some patients, but they may also have significant interactions with any medications that might be prescribed, and may have toxicity in their own right.

CONCLUSIONS

CRPS in children has been widely held to be intrinsically different from that in adults. This has been based on both demographics and a perception that children may have a milder course or a better response to conservative treatments. Other than the marked preponderance of lower extremity CRPS in children and adolescents, the demographics do not seem all that different for children than adults. A female preponderance exists for both groups. Both appear to have Caucasian predominance. Psychological factors are often invoked in pediatric CRPS, including enmeshment of the patient and parents and a degree of overachievement. Although this certainly may play a predominant role in some cases, the available evidence is not compelling that children with CRPS are unique compared with either other children with chronic pain or adults with CRPS. Finally, as regards the perception that children have an easier course than adults do, the evidence is not strong. Certainly, several series have reported children responding to courses of intensive PT alone. Nonetheless, the consensus is that PT is the definitive treatment of adults with CRPS as well as children. I have been unable to locate any series of intensive (5–6 hours per day) PT programs for adult patients analogous to that reported by Sherry et al.5 Series using less-intense PT, as reported by Wilder et al.1 or Lee et al., give results similar to a stepwise multidisciplinary treatment plan in adults.67 The apparent mildness of pediatric CRPS may be due to a greater willingness of children to actively participate in appropriate PT more than to an innate difference in the disease process itself.

The potential for recurrence of CRPS is often of great concern to children with this syndrome and to their parents. Studies have shown a fairly high rate of recurrence in the same limb after successful treatment or spread to another limb concurrent with the initial diagnosis.2,25 Recurrence occurred in approximately 30% to 50% of patients, a much higher rate than the rate of 1.8% per patient-year reported for adults.68 Although recurrence is common, it generally seems to respond more readily to physical therapy and related treatments than the initial episode.5,25 A case report by Tong and Nelson69 illustrated that for some children the recurrent bouts of CRPS may be as severe as or even more severe than the original.

In summary, although not definitively proven, PT leading to active normal use of the involved extremity is generally held to be the single most effective therapy in the treatment of CRPS. Children may be willing to participate in PT, despite the associated pain, with proper motivation. In general, however, the clinician’s job is to
help provide adequate analgesia to speed progress in PT. A stepwise, multidisciplinary approach is generally in the patient’s best interest, starting with minimally invasive modalities such as TENS and biobehavioral pain management techniques. Acupuncture may be useful at this point, too, if there is a practitioner available in the community who has experience working with children. If needed, medications with a proven track record in neuropathic pain management can be added, such as the tricyclic antidepressants (nortriptyline or amitriptyline) or anticonvulsants (gabapentin and others). Children taking these medications need to be monitored carefully for side effects to optimize the risk/benefit ratio. Symptomatic blocks can be useful to accelerate recovery, they are unlikely to be effective monotherapy for CRPS, but they do play a role as a way to help a patient work more actively in an ongoing PT program. Using the above approach, most patients will have an excellent response. For those who cannot sustain improvement despite an ongoing exercise program, neurosurgical techniques such as SCS or, in highly selected cases, sympathectomy may be useful. These techniques are not guarantees of success, and they should be used only as a part of a multidisciplinary program stressing exercise and rehabilitation.

REFERENCES


Children and adolescents suffering from complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD), need understanding and support to maintain a sense of normalcy. A student’s condition may vary from day to day, and the persistent pain associated with CRPS is invisible, so many health care professionals and school personnel may assume the child is faking and may doubt his or her pain.

If you visit the RSDSA website, there are several stories from young women who, in spite of the terrible pain caused by CRPS, are achieving their goals and living fulfilling lives. Yvonne writes, “My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”

We want to help you understand how you can help children who have CRPS, either by simply being supportive or helping make accommodations and modifications in the school environment. Your support and understanding can determine whether our children succeed or fail.

Arrange special transportation if traveling on a crowded, bumpy school bus is too difficult.

For older students, provide a designated handicapped parking space.

Arrange for the student to meet with the school counselor on a regular basis.

Students with CRPS may qualify for special services, such as a 504 plan or an Individual Education Plan (IEP).

**Section 504**

Section 504 of the Rehabilitation Act of 1973 is a civil rights law that prevents discrimination against individuals with disabilities from any institution that receives federal funds from the U.S. Department of Education. Some private schools that do not receive federal funding may be exempt from Section 504. According to the United States Department of Education, a student qualifies for Section 504 protection if he or she has “a physical or mental impairment that substantially limits one or more major life activities.”

**Individual Education Plan**

An Individualized Education Plan (IEP) is developed in accordance with the Individuals with Disabilities Education Act (IDEA), which governs special education. IDEA has a number of eligible categories, including Otherwise Health Impaired (OHI). The criteria for an OHI designation is “limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (a) is due to chronic or acute health problems… and (b) adversely affects a child’s educational performance.”

**More Information**

[US Department of Education, Office of Civil Rights](http://www.ed.gov/about/offices/list/ocr/504faq.html)

[Protecting Students With Disabilities](http://www.ed.gov/about/offices/list/ocr/504faq.html)

[Section 504 of the Rehabilitation Act of 1973](http://www2.ed.gov/about/offices/list/ocr/504faq.html#protected)

[Individual Education Plan](http://www2.ed.gov/legislation/FedRegister/finalrule/1999-1/031299a.pdf)


3 http://www2.ed.gov/about/offices/list/ocr/504faq.html#protected


Reflex Sympathetic Dystrophy Syndrome Association, 99 Cherry Street, Milford, CT 06460, www.rsdia.org, Tel: (203) 877-3790 Toll free: (877) 662-7737 Email: info@rsdia.org

“Hate CRPS. I hate the pain. I get from it. But, I am done letting it run my life. From now on, it is not in charge. I am. Life is to be lived.”

—Karen Richens, age 11

“Children and adolescents suffering from complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD), need understanding and support to maintain a sense of normalcy. A student’s condition may vary from day to day, and the persistent pain associated with CRPS is invisible, so many health care professionals and school personnel may assume the child is faking and may doubt his or her pain. If you visit the RSDSA website, there are several stories from young women who, in spite of the terrible pain caused by CRPS, are achieving their goals and living fulfilling lives. Yvonne writes, “My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”

We want to help you understand how you can help children who have CRPS, either by simply being supportive or helping make accommodations and modifications in the school environment. Your support and understanding can determine whether our children succeed or fail.

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“At the evaluation meeting, one of your questions should be “What are WE going to do to help my child?””

—Dorothy Switalski

""
CRPS is a neuroinflammatory syndrome characterized by pain in one or more limbs and/or ankles, feet, abdomen, or hands, even after a traumatic event, as a broken bone, sprain, sports injury, automobile accident, or bad fall. There is often coldness and swelling in the affected limb(s), as well as allodynia (a painful response to a normally innocuous stimulus). The pain is disproportionate to the original injury and is present long after the original trauma has healed. CRPS is more common among pre- and adolescent girls than boys by about 5 to 1. It is usually seen in girls who engage in sports, dancing, or gymnastics.

Although the cause of CRPS is unknown, overseen injuries, trauma, psychological stress, nutritional factors, and hormones are possible contributors. CRPS is thought to reflect overreaction of the autonomic nervous system, leading to transmission of pain signals after the initial injury. As there is no single test for CRPS, the diagnosis is made clinically by patient history, thorough examination, and the results of numerous tests to rule out other serious conditions.

CRPS is not life-threatening, but it can become chronic and spread to other parts of the body. It can be highly painful, over-scheduling, apathy and reduced motivation and/or initiation, and anxiety, depressed mood, and/or inflexibility.1

Physical/exercise therapy of the affected body part is the most effective treatment for pediatric CRPS. This therapy desensitizes and restores function—strength, endurance, and range of motion. Mind-body techniques, such as relaxation, biofeedback, and self-hypnosis, are helpful for pain management and can alleviate the fear of movement often seen in people with CRPS. Psychological interventions to help with coping and emotional responses, and family therapy to promote adaptive parental/familial responses, can also be valuable. Medications, nerve blocks, and interventional measures, such as a tunneled epidural catheter or spinal cord stimulator, can also be used to facilitate and accelerate progress in physical therapy. A comprehensive coordinated interdisciplinary approach for CRPS management will provide the best results in the majority of children.

### Students with CRPS and School

For those students who are able, we recommend the following:
- Attend school daily whenever possible
- Permit the student to go to the nurse when needed (may be experiencing a pain flare-up)
- Limit the use of over-the-counter medications
- Be allowed to walk in the back of the classroom or in the hallway periodically without disruption to others to stretch and move for pain reduction
- Establish routines and schedules for learning and extracurricular activities
- Be as independent as possible in completing assignments
- Be encouraged to practice normal activities

Other interventions that can be practiced as needed include:
- Psychological intervention for child and family to assist with adjustment to home and community, behavioral interventions, and emotional support
- Relaxation techniques and cognitive-behavioral exercises/strategies
- Monitoring for “overschercher” behaviors, over-scheduling, apathy and reduced motivation and/or initiation, and anxiety, depressed mood, and/or inflexibility.1

## When Students Require Special Accommodations

Some students may not be able to resume activities as normal. Some accommodations that have helped students with CRPS are listed below:

1. Permission to leave school during class to avoid congested hallways.
2. Permission to leave school during tests.
3. Permission to leave school during lunch, and during the changing of classes.
4. Permission to leave school during assemblies or other events.

Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:
- Schedule all classes on one level or provide student with key to the elevator.
- Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
- If a student is unable to write, modify normal test taking, and allow additional time for tests.
- Reduce school time if necessary (students may be late due to pain flare-ups) and supplement with home-based instruction and tutoring.
- Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:
- Schedule all classes on one level or provide student with key to the elevator.
- Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
- If a student is unable to write, modify normal test taking, and allow additional time for tests.
- Reduce school time if necessary (students may be late due to pain flare-ups) and supplement with home-based instruction and tutoring.
- If mobility is impaired, credit the student’s physical/occupational therapy as the requirement for gym (if the school has a pool, allow the student to use the pool during gym).
Then

RSDSA cosponsors CCK Pediatric Pain Week for third year.

Now

This issue was sponsored by Relax Release Relief (learn about this new technique on page 3)

Moving Forward
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CALL FOR AUTHORS & IDEAS

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

SPECIAL THANKS

Ketamine Treatment Centers Partnership.

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

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

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

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

First Observation of Relief
Our story begins with a girl who is only 14 years old. She was diagnosed with CRPS after a softball injury to her left leg and suffered without relief for four years. A small selection of the techniques used in Relax Release Relief was applied for 20 minutes and immediately resulted in complete pain relief which has lasted for over six and a half years. Since then, observations have shown that such an immediate remission with a single session is extremely rare but in this one case the word “cure” does apply. Again, this is just an observation. If remission does occur from pain, it is usually after the fourth or fifth session.

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

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

The results:
• Four had no effect
• Four had over 50% improvement, each lasting a different amount of time
• Three experienced a period of complete relief

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

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

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

The vast majority of participants achieved relief or remission from their pain for varying lengths of time. All except one had
significant improvement. Some experienced complete relief for several months and continue to experience relief. Hope is reborn.

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

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

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

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

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

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

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

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

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

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

Begin: www.RRRTV.net

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

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

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

RSDSA Co-Sponsors Pediatric Pain Week in Kentucky Again

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


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

RSDSA’s Patient Assistance Fund in honor of Brad Jenkins

For the past three years, RSDSA in conjunction with Andrea Jenkins and her family, has helped many people experiencing a financial emergency. Brad Jenkins was a young man with CRPS who died tragically from an accidental opiate overdose.

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

Most recently, we paid a bill of $343.61 for a woman who needed that money to resolve an outstanding debt at a local hospital before being allowed to have surgery to insert Spinal Cord Stimulator (SCS). She has been fighting for assistance from the Social Security Administration...
for five years, and had written to both her governor and senator to help resolve her plight. RSDSA was her last resort. We provided another patient with funds to travel to the Hasbro Children’s Hospital in Rhode Island. Finally, the Patience Assistant Fund was able to help a single mom with CRPS who had been hospitalized. She has a disabled daughter and was having difficulty paying her $501.00 electric bill, which was so high because they live in an all-electric apartment.

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

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

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

Corporate Sponsorship of the RSDSA Community Update
Years ago, the RSDSA Board of Directors voted to eliminate its membership dues to subscribe to our quarterly newsletter because some individuals with CRPS could not afford that expense. In a subsequent cost-saving measure, RSDSA began to publish the newsletter electronically with an occasional “paper newsletter.” So many individuals of our community without Internet access felt abandoned. We have heard you. At our June meeting, the RSDSA Board of Directors voted to publish the newsletter four times a year, two electronically and two via postal mail.

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

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

For more information please visit www.colortheworld.com
DOES CRPS SPREAD?

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

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

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

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

The one common denominator in these articles is that they discuss the spread from one limb to another. It seems to be the consensus that when the disease spreads it does so horizontally or vertically (left arm to left leg, left arm to right arm, etc.) 95 percent of the time with a contralateral spread (left arm to right leg) about five percent of the time.

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

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

A recent article from a Scandinavian journal suggests that patients with CRPS are at risk for spread following a second traumatic event including surgeries or injury to a previously unaffected limb. Although there is some credibility to this report, more often than not, the spread is spontaneous and not secondary to such a traumatic event. Further, the term “traumatic event” needs to be classified downward to include such seemingly innocuous occurrences such as a venipuncture, blood pressure cuff that is too tight, etc.

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

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

• Otorhinolaryngologic symptoms occur. These include otophobia, intermittent and transient hoarseness which comes from the effect of CRPS on the branchial plexus and an increase of hypersensitivity to sound, especially bass. I have seen one patient who began to stutter uncontrollably as a consequence of his Complex Regional Pain Syndrome.

• Dental issues are rampant. Part of this stems from dietary indiscretion, part from immune system compromise, and part from disruption of the dental nerve roots. However, poor oral hygiene, poor nutrition, and a loss of saliva due to dry mouth results in decay, periodontal disease, and ultimately tooth loss.

• Dermatologic issues can occur in the form of neurodermatitis, excessively dry skin or hyperhidrosis. A dermatologic condition that is little understood and rare in its presentation is Dercum’s disease. This is manifested by multiple painful lipomas occurring mostly on the trunk, upper arms, and upper legs. The etiology is unclear. Yet another dermatologic manifestation is that of livedo reticularis.

• Gastroenterologic manifestations occur in better than half of the patients. Most commonly this takes the form of gastroparesis with its associated side effects of nausea and vomiting. Acid peptic disease and irritable bowel syndrome are common as well. Dysphagia, indigestion, biliary dyskinesia, and diarrhea and constipation (the latter exacerbated by the use of opioids for control of pain) have also been seen.

• Urinary spread of Complex Regional Pain Syndrome takes the form of symptoms that mimic interstitial cystitis. These include urinary incontinence, dysuria, or the inability/difficulty to void. Bladder pacemakers have been used for this purpose. Botox injections into the pelvic floor have helped. This misdiagnosis of interstitial cystitis can be complicating and prolong the treatment. If the patient does not respond to common modalities of treatment to I.C., a spread of Complex Regional Pain Syndrome to the urinary bladder should be considered.

• Gynecologic manifestations include polymenorrhea, dysmenorrhea, secondary amenorrhea, and menometrorrhagia.

• Neurologic symptomatology such as vertigo, syncope, seizures, and pseudo-seizures can be seen as well. Other neurologic manifestations include cognitive issues, most often short-term memory loss, word retrieval, and difficulty with expression. Some believe that this is due to medication while others believe it is due to the diminished use of brain function caused by the isolation that is sometimes experienced by patients who are no longer a part of the workforce and have a reduced role in society because of their Complex Regional Pain Syndrome.

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

There is an article that elaborates further on the internal organ involvement of Complex Regional Pain Syndrome titled “Systemic Complications of Complex Regional Pain Syndrome” by Dr. Schwartzman in 2012.

There is great concern as to what can be done to minimize the likelihood of spread. A concurrent article discusses the issue of spread from a patient perspective. It is important to understand that in elective surgical procedures there is something that can and should be done! In 2012, an article titled “Ketamine as Adjunctive Anesthesia and Refractory Complex Regional Pain Syndrome Patients: A Case Series,” authored by Dr. Schwartzman and myself, provided details with regard to a study of a limited number of patients who had undergone various surgical procedures using adjunctive Ketamine intraoperatively. In my portion of that study, as well as in patients treated in a similar fashion subsequent to the publication of that paper, no episodes of spread of CRPS following elective procedures, ranging from dental extractions to podiatric procedures, have been reported. The use of Ketamine intraoperatively (with any adjunctive agent that the
anesthesiologist chooses) seems to have the effect of blocking the spread, or at least up to and inclusive of this point in time, has worked in that fashion. It is therefore recommended that in cases of surgery, regardless of how innocuous that procedure may be, Ketamine be used during the course of the procedure in a dosage ranging from 80-150 mg of the drug. The dosage depends upon body weight, length of procedure, and involvement of the nervous system in the proposed surgery.

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

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

Finally, in an interesting observation, I have noted patients who have presented for a full body thermography due to the presence of Complex Regional Pain Syndrome in a single limb. Thermographic images clearly portray sympathetic dysfunction in a second limb while the patient manifests no clinical symptomatology. It would be ideal if interventional blockade could be given before symptoms presented themselves in the second limb. This, of course, is precluded by insurance denial of treatment in an asymptomatic body part.

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

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

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

For more information please refer to www.drgetson.com
WordUp!
BY JULI WORDGIRL

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

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

William Shakespeare wrote, “That which we call a rose by any other word would smell as sweet” (2.1: 85-86). But is pain by any other name anything other than painful? According to the McGill Pain Index, Complex Regional Pain Index (CRPS) is the most painful known pain on Earth. It also has a very a confusing name change history.

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

McGill Pain Index
http://www.rsdhope.org/what-is-crps1.html
(https://www.pinterest.com/pin/573364596281759931)
CRPS is truly complex. There are many different body systems affected by this disease: central and peripheral nervous systems, limbic system, vascular system, immune system, cerebral cortex, spinal glia, and who knows what else will be found.

In 1946, James Evans from Boston changed Causalgia to the more familiar name Reflex Sympathetic Dystrophy (RSD). Evans was describing what he felt was a disorder that involved patients “who had no discernable nerve damage,” and was not complete damage to the nervous system. A lot of confusion followed for the next few decades. With little understanding of a complicated disease and several names, including the name “Sudeck’s Atrophy” (a related branch of CRPS), the International Association of Pain introduced Complex Regional Pain Syndrome as a name to represent the whole disease in 1994. According to Canada’s version of the RSDSA, called PARC (“It’s not a walk in the P.A.R.C.”), the name change from RSD to CRPS was made “to unify the 30 or so confusing terms into one appropriate label for worldwide research purposes.” At that time it was thought that there were two types of CRPS. Type 1: no nerve damage and called RSD; Type 2: with nerve damage and called Causalgia or CRPS. Later, Anne Louise Oaklander, of Harvard Medical School, said in “the distinction between the two types of CRPS is artificial . . . a single neurological disease.”

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

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

WORD UP! SOURCES


https://www.rsdcanada.org/parc/english/RSD-CRPS/whatis.html
RESEARCH & MEDICAL

Moving Forward

BY JENNY PICCIOTTO

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

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

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

Lynn’s commitment to service developed early in life. “The experience of helping others is a wonderful feeling, to know that you can make someone’s world a little better.” It’s important to find something you are passionate about, she told me, and then find a way to make a difference, whether donating money, service or time.

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

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

As we shared our stories, I felt a deep connection with Lynn and her daughter. I related with them on several levels. As a mom, I empathize with the fears and hopes she has for her daughter. Laura’s experience as a patient closely resembles my own. I was reminded how much people living with CRPS have in common, yet how each of our stories is unique.

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

Laura’s doctors inserted a tunneled epidural catheter, a thin tube that delivers pain medication directly to the spinal nerves. The goal of this was to get enough pain relief to participate in physical therapy, but the catheter became infected and had to be removed. Laura then tried a spinal cord stimulator, which increased her pain levels. After trying several treatments, they learned about a program in Australia that uses Graded Motor Imagery (GMI) to treat CRPS. GMI is a combination of techniques that retrain the brain through mirror box therapy, sensory
discrimination, visualization, and left/right body awareness. Stimulating motor and sensory brain activity, this therapy helps the brain reintegrate the body and reduce pain signals. After finding and working with a specialist who was trained in this technique, Laura began to make progress.

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

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

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

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

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

RSDSA is grateful to the Coatney family for their generous contribution to CRPS research, education, and emergency support for patients facing financial crises. The RSDSA is an international leader in providing resources to CRPS patients, and funding research for better treatment options and a cure for this devastating condition. Our mission statement is to:

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

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

**ABOUT THE AUTHOR**

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

Commonly referred to as Complex Regional Pain Syndrome (CRPS), we now recognize that this injury phenotype results from a complex cascade of reactions involving not only the injury sites, but reactive changes in the sensory ganglion of the injured afferents and spinal cord. Let us consider some of the potential mechanisms that we have come to appreciate.

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

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

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

**Innate and Adaptive immune signaling** - A very exciting area of research is the developing hypothesis that innate and
adaptive immunity play a major role in the development of the nerve injury-CRPS phenotype. The defining property of innate immunity is the existence of families of receptors, toll like receptors (TLR), with which we are endowed at birth and which recognize foreign protein (bacterial cell walls). These receptors are classically found on inflammatory cells and allow them to target pathogens for destruction. We now know that these TLRs are not just on inflammatory cells, but on sensory neurons where the TLRs are activated by pathogens and products released in the body as a consequence of tissue injury and inflammation. Research conducted by the University of California San Diego has shown that spinal TLR activation results in the conversion of a “simple” inflammatory pain state to a neuropathic condition. Linda Watkins at the University of Colorado has suggested that TLRs sensitize the nervous system to worsen the consequence of moderate nerve injury. Adaptive immunity is a process that permits the body to develop antibodies to novel targets. These antibodies bind and mark those cells expressing this target for destruction. In some cases, the system may inappropriately target protein that is expressed on our own nervous tissue, leading to neuronal damage as in neurodegenerative disorders or activating neural systems that lead to pain. Work by Camilla Svensson and her colleagues at the Karolinska Institute has shown that antibodies released prior to the onset of arthritis can affect bone cells leading to bone loss and, in turn, release a pain inducing cytokine. The possible relevance of this scenario to CRPS is an exciting possibility. In short, CRPS represents a true pathology yielding trophic changes in tissue and an enduring pain state. The advances in our understanding of the biology of nerve injury has generated considerable hope that these advances will lead not just to the development of approaches to block the pain, but to be disease-modifying and prevent the changes that lead to the pain state.

ABOUT THE AUTHOR

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

POETRY CORNER

Always
BY DEBBIE ONEAL

Wherever we go, whatever we do
There is this pain that’s stuck within you
Sometimes it’s nagging and keeping slow
Most times it’s raging, and it won’t let go
There are times we cry just getting out of a chair
or from taking a shower and brushing our hair.
We hide behind our smile, We don’t want it to show
We want to get ready We want to go
RSD doesn’t care it’s always there,
Reflex sympathetic dystrophy or as you have come to be known,
complex regional pain syndrome won’t leave us alone.

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

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

Janet & Sami’s Story

BY SAMI SMITH

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

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

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

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

For those reading this story who have been diagnosed with RSD, you know all too well the relentless, never-ending 24/7 physical and emotional pain caused by this disease. Janet tried to explain her painful symptoms to me. “A sheet feels like it’s ripping my skin off; I feel like red-hot coals are being placed all over my flesh; I have an onslaught of incessant burning/stabbing pain in my head, eyes, neck, back, arms, legs, feet, ribs, sciatika, and scapula; I have some sort of bone crushing pain in those areas, as well as a deep bone coldness throughout my body.” With tears in her eyes, she said the list could go on ad infinitum: balance issues, eyesight issues, feet issues, dystonia, thought process and speech issues. It was difficult for Janet to accept the neurological and speech issues because she was a member of Mensa and she knew her brain had turned against her. I became even angrier with God! I was scared. We were both scared. I couldn’t even hold or hug Janet to comfort her because it was too painful for her body. Janet couldn’t get stressed or angry because those emotions would trigger a flare that could last for days or even weeks. As members of the RSDSA community, we all know RSD invades the lives of the warrior as well as family members and caregivers. With an RSD diagnosis comes the baggage of pain levels greater than cancer or childbirth, grief, guilt, shame, frustration, anxiety, confusion and, of course, anger.

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

Miraculously I somehow stumbled across a support group for those who suffered with RSD. It was after speaking with Nancy Cotterman that a glimpse of hope presented itself. She informed me that there was a doctor in Clearwater, Florida who performed Ketamine infusions a mere four hours from our home in Ft. Lauderdale. I was ecstatic! I remember running into Janet’s bedroom beaming with the...
news. She underwent the infusion and when she woke she was asymptomatic! She raised her arms straight up in the air and hollered loudly “no pain!” Coincidentally, Nancy was there to witness Janet’s results. We were elated and ever so grateful to Dr. Hanna and Nancy for steering us in this direction. My anger at God began to diminish and was slowly being replaced with gratitude in lieu of fear.

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

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

One day out of the blue, Janet repeatedly told me how much she loved me. She thanked me for not abandoning her during all these years and for taking such good care of her. She continued saying that I did everything I knew to do and that I should never think I didn’t do enough or could have done more. I just stood there baffled at what she was saying to me. The words echoed in my brain. She smiled at me like it was the first time she had seen me. She was jovial. She wanted to watch movies together and sleep side by side holding hands in the recliners with our dog lying in her lap. This went on for three days and three nights. The fourth night I fed her an ice cream sandwich and kissed her on the cheek whispering my never-ending love and that I would see her in the morning.

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

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

For those of you who are caregivers, loved ones or family of an RSD Warrior, please believe them when they take a risk to voice their pain to you whether it’s emotional, physical, or both. Their pain is real. They are suffering more than you can even begin to comprehend. Presently, there is no cure, but there are Ketamine infusions and that in and of itself is a miracle. Many Warriors go into remission at times for years while others find relief for only several months. Unfortunately, the number of warriors like Janet who take matters into their own hands is astronomical. The suicide rate from this disease is alarmingly high and needs to be addressed in depth. Please heed my words and do not miss the signs. They are called warriors for a reason. They endure pain levels none of us can begin to fathom but they are also human. You never know what the dawn may bring so treat them with love, patience and understanding.

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

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

ABOUT THE AUTHOR

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

My life as a parent with CRPS

BY PAM BENTLEY

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

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

The pain was unbearable. My bed sheets could not touch my foot, leg or lower back and buttock. A gentle breeze or walk through the grass caused me pain. It felt like someone was continually stabbing my leg and holding it over an open flame. After several visits to the neurosurgeon, pain management doctor and physical therapy and no obvious explanation for my pain, it was thought that the nerves needed time to heal, so I continued taking the pain medicine. On one occasion, I went to the emergency room on the advice of my doctor, who thought that my pain may be caused by a blood clot. No, I did not have a blood clot and once again, no one could explain why I was having so much pain.

At my six-month post-operative appointment, the doctor suggested that I see a neurologist at Drexel College of Medicine, Dr. Robert Schwartzman, who specialized in treating a pain disorder known as RSD/CRPS. Not expecting much, I made an appointment. After months of shuffling from doctor to doctor, a lot of pain medication and feeling like I was going to have a major breakdown, I finally had a diagnosis. Dr. Schwartzman told me I had CRPS. What a relief to have a diagnosis- so I thought! He immediately began a course of treatment, telling me the sooner treatment is started, the better the outcome would be. By this time, it had been almost a year since my surgery.

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

ABOUT THE AUTHOR

Pam lives in Pennsylvania with her husband of 28 years. She began her journey with CRPS in 2006 and continues to strive to feel as normal as possible and fight through the pain. She has two grown children who are 22 and 24 years old. Pam enjoys spending time with family, volunteering, reading and visiting the beach.
reading so many articles about the positive results Ketamine has had on chronic pain, my husband and I thought the FDA would approve the treatment any day. To this date, this treatment has not been approved for RSD/CRPS.

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

- Get up every day - shower and try to accomplish something. This can be as simple as making a meal, food shopping or house cleaning.
- Talk to Your Kids – Sit down as a family and explain to your children that you are not able to do everything that you used to do. Everyone needs to work as a team.
- Appearances can be deceiving - Explain to your friends and family that even if you appear ok, you may just be trying to feel “normal.”
- Plan Ahead – If you know you have a busy day of running errands or volunteering at the kids’ school, make dinner ahead of time. Chances are that being on your feet all day will make your pain even worse. If you have something prepped ahead of time that you can easily pop in the oven, it will allow you more time to rest.
- Take Help When You Can Get It – Learn how to let others lend you a hand. Let your neighbor pick the kids up from school or run them to karate practice. Allow someone from church to drop a meal off to your house.
- Give Yourself a Break – Spent your Saturday taking the kids to the beach? Allow yourself to take Sunday off. Have a family movie day complete with PJs and take-out.

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

HOW GIVING BACK, GIVES BACK

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

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

“...it can happen to anyone, including me.”

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

Thank you & congratulations, Grace!

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

ABOUT THE AUTHOR

Jennifer Brien is a CRPS patient living in Seattle. She works in marketing and passionate about wine, dogs, and helping those with CRPS.
THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

EVENTS CALENDAR

SEPTEMBER

September 9: 2nd Annual Long Island CRPS/RSD Awareness Walk - East Meadow, NY
September 16: 2017 CRPS/RSD Awareness Walk - Pennsauken, NJ
September 17: Knock Out Pain 5K and 1 Mile Family Roll & Stroll - Easton, PA

NOVEMBER - CRPS AWARENESS MONTH

November 4: 4th Annual Central New Jersey RSD/CRPS Walk for Hope - Lincroft, NJ
November 5: 5th Annual Fight the Flame 5K - Charlotte, NC and Mentor-on-the-Lake, OH
November 6: Color the World Orange - Worldwide

PEER-TO-PEER CONVERSATIONS

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

VOLUNTEERS:
If you wish to volunteer, please do the following.
• Please contact LindaLang@rsds.org
• Please tell Linda something about yourself and your experience with RSDS.
• Please include your email and a phone number where you may be contacted.
• We especially need teens and parents of children with CRPS to volunteer.

THOSE IN NEED OF SUPPORT:
If you wish to take advantage of this program, please do the following.
• Please contact LindaLang@rsds.org
• Please provide your email, phone number and a little bit about yourself.

Don’t see an event near you?
Contact Samantha Barrett (sbarrett@rsds.org) to discuss planning an event in your area!
WHEN YOUR CHILD’S PAIN WON’T GO AWAY

It could be Complex Regional Pain Syndrome

TREATMENT OPTIONS
Ultimately your physician will prescribe the best program to meet your child’s needs, but research has shown that physical therapy can be one of the most effective treatments for CRPS.

Other treatments, such as psychological support or medication may be needed, so consult your family physician as to the best course of action.

ADDITIONAL RESOURCES
CRPS is not life-threatening, but it can be highly disruptive and lead to excessive school absences if left untreated. Early diagnosis is key.

Once diagnosed, some students may require special school accommodations, such as ergonomic assessments, additional travel time between classes, revised schedules and possibly a helper’s aide.

Students who find their CRPS too painful to allow them to attend school may qualify for special services, such as a 504 plan or Individual Education Plan (IEP). For more information on available accommodations, contact your school’s health services coordinator.

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. We can also provide referrals to pediatric rehabilitation programs.

Please visit our website, www.rsdso.org, if you are in need or have questions.

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 can be accessed through our website. You may also contact us at 877-662-7737.

Stay connected with us by subscribing to our bimonthly newsletter, joining our community email news blasts, or visiting our Facebook page.
YOU ARE YOUR CHILD’S BEST ADVOCATE

Your child frequently experiences severe pain following an accident, injury or other trauma. It may be accompanied by swelling, changes in skin color, temperature, or limited mobility. He or she is suffering, and other treatments have been ineffective. Worst of all, he or she may not be able to tell you what’s wrong. Your child could have CRPS (Complex Regional Pain Syndrome) which is also referred to as RSD (Reflex Sympathetic Dystrophy).

CRPS is a neurological syndrome characterized by severe and often burning pain. While it affects nearly 200,000 people in the U.S., it is rarely mentioned in an initial diagnosis.

There is no gold standard for diagnosing CRPS. Only a careful and thorough exam and review of medical history by your physician can produce the proper diagnosis and recommended treatment. Pediatric CRPS is typically under-recognized and misdiagnosed by physicians, and you may have to advocate for proper testing.

THE FACTS

What is CRPS/RSD?
CRPS/RSD is a rare neurological 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. Sometimes there isn’t an initiating event.

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

What Are the Affects?
CRPS is devastating. It causes severe pain, swelling and sensitivity. Many people are unable to walk, work, go to school, or wear clothes.

Who Can Develop CRPS?
Anyone can develop CRPS, regardless of race, age or gender. However, research shows that it is most common in women.

SIGNS & COMMON SYMPTOMS

This is not an exhaustive list, but symptoms may include:

- Constant pain described as deep, aching, burning or stinging
- If the pain is getting worse, not better, and if the pain is more severe than one would expect from the original injury it may be CRPS
- A prior trauma (fracture, sprain, surgery, etc.)
- Abnormal swelling
- Excessive sweating in the affected area
- Changes in skin color
- Noticeably altered skin temperature in the affected limb
- Weakness in affected limb
- Limited range of motion
- Paralysis or dystopia (muscle contractions resulting in abnormal positions)
- Allodynia (pain from stimuli that is not normally painful, such as the touch of fabric or wind blowing across skin)
- Hyperalgesia (excessive sensitivity to pain)
- Hair growth changes (coarser, darker, rapid growth, loss of hair)

WHAT TO TELL YOUR PHYSICIAN

During your child’s exam, ask your physician if he or she is familiar with CRPS. Also tell your doctor or clinician about any sprains, falls, surgery or other trauma your child has had recently. Provide them with information on timing, severity of pain and any other triggers you may notice.

JUST BECAUSE YOU CAN’T SEE IT, DOESN’T MEAN IT DOESN’T EXIST. BUT TO RECEIVE HELP, YOUR CHILD MUST BE HEARD.
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 lastly actual guided movement.

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

What People with CRPS Should Expect from Therapy

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

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

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

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

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

Home Exercise Programs

A home exercise program is a select group of exercises or activities that a therapist designs. Frequency/participation in therapy sessions may vary from one week to the next, but what is done outside of therapy can have a significant impact on the patient’s overall progress. Following an individualized home exercise program can be an important component of treatment as it helps the patient continue to make progress in strength, endurance, movement and function in between therapy sessions.

Home exercise programs vary depending on your individual needs. Often home exercise programs will initially focus on scrubbing/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://rsdsa.org

Raising awareness of complex regional pain syndrome since 1984
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 continuous materials to intermittent pressure 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.

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

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

**Scrubbing** consists of affected extremity in a back and forth motion while weight bearing through the extremity. 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 against the affected extremity and the duration of the activity are gradually increased. Scrubbing is performed with the patient in quadruped for upper extremity involvement and in elevated sitting or standing for lower extremity involvement. For upper extremity involvement, the patient should stand or sit with the affected upper extremity braced against a 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 be performed while standing at a table or counter. Persons with limited wrist extension may benefit from using a handled brush. The Dystrophile® can be used to gauge reliable performance. It is a device designed to facilitate consistent weight bearing and compliance during scrubbing by activating a light when the patient has reached the preset load.

**Carrying** or loading, is the second component in the stress-loading protocol. Small objects are carried in the hand on the affected side, progressing to a handled bag loaded with increasingly heavier weight. Carrying should be performed a minimum of four days each week, whenever the patient is standing or walking. The lower extremity can be loaded in a variety of ways. Walking is an important loading technique if care is taken to ensure weight bearing through the affected leg during gait, especially when an assistive device is used. Increased weight bearing can be accomplished with verbal/physical cueing or by having the patient carry a weighted object or bag on the affected side. Loading can also be facilitated by engaging the patient in activities that promote weight shifting and balance (i.e. walking on the toes) or by placing the unloaded 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 mindfulness-based stress reduction (MBSR) which is a form of meditation practices that is commonly used to help treat chronic pain. The practice of these interventions should begin immediately.

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

**Splinting/Bracing** is used in severe cases of CRPS. Splinting or bracing may be utilized to incorporate movement into the intervention. Splints 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 able to tolerate and participate in AROM, coordination, dexterity, and strengthening tasks. Proprioceptive neuromuscular facilitation (PNF) patterns are often well tolerated during treatment.

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistive exercises or gait training. The patient should be encouraged to gradually return to daily life activities. These treatments and activities can be very painful and the patient 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 focal 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 and maximize 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 all 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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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.rsdso.org and learn all you can.

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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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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!