Welcome to RSDSA:

RSDSA is a 36-year old not for profit organization. RSDSA’s mission is to provide support, education and hope to everyone affected by CRPS/RSD while we drive research to develop better treatments 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 empowering. It’s a partnership with a power in numbers. We have a community of more than 39,000. We work to raise our community profile so that Congress, The National Institute of Health, pharmaceutical corporations, and insurers hear our collective voice!

We ask you to sign up for our free electronic eblasts at Join our Membership. When you do you will also receive our RSDSA Community Update Newsletter, information about RSDSA community events, fundraisers and other important information. Please join us on social media at Instagram, RSDSA Facebook, and Twitter.

RSDSA has a state-by-state listing of healthcare professionals interested in treating CRPS. Please call us at (203)877-3790 to obtain a listing for your state.

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

It’s easy to join our community. Just provide is with your email address and/or your telephone number and we will gladly enroll you. You are not alone in your fight against this horrific disorder. Please donate today by using the enclosed envelope or call us at (203)877-3790. If you choose not to join our community, please consider making a good will donation to cover the cost of our mailings. We keep your contact information confidential and do not share or sell.

Sincerely,

James W. Broatch, MSW
Executive Director and Vice President
Helpful links for individuals newly diagnosed CRPS

- [https://www.youtube.com/watch?v=b49DtFigbbw](https://www.youtube.com/watch?v=b49DtFigbbw) (good video for family and friends who may not understand)
- [https://rsds.org/wp-content/uploads/2020/05/Early-Treatment-of-Acute-CRPS.pdf](https://rsds.org/wp-content/uploads/2020/05/Early-Treatment-of-Acute-CRPS.pdf) (steroids are the go-to treatment for early onset CRPS)
- [https://rsds.org/how-crps-is-diagnosed/](https://rsds.org/how-crps-is-diagnosed/)
- [http://rsds.org/joinmembership/](http://rsds.org/joinmembership/) - Individuals can receive the newsletter via postal mail or email
- The Sajben article enclosed in this packet details good non-opiate medications (see attached above) (Medication Summary for Intractable Pain, CRPS/RSD)
- Watch Dr. Chopra’s video: [https://www.youtube.com/watch?v=EFjRv8yw3E4&t=61s](https://www.youtube.com/watch?v=EFjRv8yw3E4&t=61s)  
  [https://www.youtube.com/watch?v=9fTqE-GFy3M](https://www.youtube.com/watch?v=9fTqE-GFy3M) (good non-threatening video on desensitization)
- [https://rsds.org/youve-been-diagnosed-with-crpsrd-now-what/](https://rsds.org/youve-been-diagnosed-with-crpsrd-now-what/) This page is the treasure trove of information. You can download or print our Adult and Pediatric information packets, view some excellent videos, and read an excellent overview article by Steven Bruehl.
- Link to our peer-reviewed journal articles: [https://rsds.org/existing-papers/](https://rsds.org/existing-papers/)
- Link to our YouTube videos of our conferences: [https://www.youtube.com/user/RSDSAofAmerica/](https://www.youtube.com/user/RSDSAofAmerica/)
- Free accredited on-line course for docs & nurses: [https://rsds.org/accredited-course-on-crps-for-mdsand-rns/](https://rsds.org/accredited-course-on-crps-for-mdsand-rns/)
- Other related websites and organizations: [https://rsds.org/related-web-sites/](https://rsds.org/related-web-sites/)
- Our blog: [https://rsds.org/blog/](https://rsds.org/blog/)
- Our patient assistance application-one-time $500 emergency patient financial grant: [https://rsds.org/jenkins-patient-assistance-fund/](https://rsds.org/jenkins-patient-assistance-fund/)
- [https://www.youtube.com/watch?v=wUnwbNslk1c&t=75s](https://www.youtube.com/watch?v=wUnwbNslk1c&t=75s) (warm-water therapy)
- [https://www.youtube.com/watch?v=iiaglUE6kxg&t=5s](https://www.youtube.com/watch?v=iiaglUE6kxg&t=5s) (Brain Retraining)
The Only Pain Disease with Complex in its Name: Learn about it and Treat it Well!

Accredited Course on CRPS for MD’s, and RN’s

RSDSA encourages members of our medical professional community to share this accredited course on CRPS with their colleagues.

Course Presenter: Jay Joshi, DABA, DABA-PM, FABA-PM, CEO/Medical Director, the National Pain Centers, Vernon Hill, IL

Continuing Education (CI) Language Diagnosis and Treatment of CRPS
RSDSA 11/01/2019 – 11/01/21
https://rsds.org/accredited-course-on-crps-for-mds-and-rns/
The Legacy of Jennifer Abramson’s Inspirational Life

All proceeds will be invested in RSDSA's Research Fund

*JEN'S GIFT* is a testimony to Jennifer Abramson’s brief but wonderful life. Jennifer lived only 31 years; yet for her short time she made a big impact. Her spirit lives on in *Jen's Gift*. Her goal was to enlighten, transform people's thinking, and spread faith and hope in the infinite possibilities of this life.

*Jen's gift will inspire you.* Her wisdom, clever humor and insights paired with her beautiful photos will make you laugh, smile, cry and maybe think about things in a new and different light.

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

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Pain and Activity
By: Michele Gargan, Ph.D.

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

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

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

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

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

Complex regional pain syndrome (CRPS), previously known as reflex sympathetic dystrophy (RSD), is a chronic neuropathic pain condition that can arise from trauma of any kind. It can be the result of something as minor as a blood draw that initiates a reaction. The condition arises more frequently than many emergency physicians may realize: roughly 3 percent of patients suffering a Colles fracture develop CRPS. Often the traumatic event cannot be remembered, and CRPS has been associated with trauma happening anywhere from a day to a year after the event. Its most consistent feature, however, is how often physicians fail to make the diagnosis on initial presentation. Furthermore, our lack of understanding about how to manage the severe pain that occurs during acute flare-ups of this chronic condition worsens the suffering that many patients with CRPS endure over decades.

**Early Diagnosis Is Key**

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

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

**Treating Flare-ups**

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

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

**Treatment Is Straightforward:**

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

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

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

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

Published on November 15, 2016 under Guest Blogger for RSDSA

By Nancy Sajben, MD

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

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

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

Below is a brief list.

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

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

Some patients with CRPS combine my medications with ketamine infusions.

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

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

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

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

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

5. Testosterone in either male or female is depleted by opioids, it may be depleted by stress. Low T is a risk for depression, weakness and osteoporosis.
7. Dextromethorphan – reduces hyperexcitable glutamate
8. Oxytocin
9. Memantine – double the Alzheimers dose for CRPS. Like ketamine, it blocks the NMDA receptor.
10. Lamotrigine
11. Palmitoylethanolamide (PEA, PeaPure) a glial modulator, also acts on mast cells. A food supplement. No Rx. Your body makes it. Plants make it. Capsules & cream
12. Ketamine via nasal spray, under tongue combined with IV or not, works on glutamate-NMDA receptor. Not an essential drug. Where ketamine has stopped working, patients have become pain free after years of CRPS.
13. Creams combinations, so many. Most of my CRPS pts very much like Mg++/guai 10% each. You may or may not trial various combinations lido/keto/keta, etc. Numerous. DMSO 50%.
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://rsds.org/find-a-support-group-near-you/) of so many throughout the country. There is so much more. Indeed, at least 36 points discussed on June 2015.

Disclaimer

The material on this site is for informational purposes only.
It is not legal for me to provide medical advice without an examination.
It is not a substitute for medical advice, diagnosis or treatment provided by a qualified health care provider.
Are steroids useful in the treatment of complex regional pain syndrome?

Steroids are one of the oldest treatments for complex regional pain syndrome. They appear to be most effective in the very early stages of the condition, or during acute flares.

How much steroid should be taken, and for how long?

For new onset of symptoms of complex regional pain syndrome, I typically treat patients with either a 12 day or an 18 day course. Methylprednisolone is available in blister packs (commonly referred to as Medrol dosepacks). Each dosepack is a six day treatment course. We will use two dosepacks in an alternating fashion so that the patient will get 24 mg of methylprednisolone on day one and on day two, then 20 mg on day three and four, and continuing to reduce the dose by 4 mg every two days. For more severe symptoms, we may use prednisone, starting at 60 milligrams per day for three days, decreasing the dose every three days until the course of treatment is completed after 18 days. For acute flares of CRPS, I will. Typically the limit usage to a 6 day course of methylprednisolone (a single dose pack).

Are there risks of using steroids?

The use of steroids is associated with multiple side effects and potential complications that is why we are so careful to limit their use to short time periods. Complications include increase blood sugar, increase blood pressure, osteoporosis, thinning of head hair, increased facial or bodily hair, increased weight especially in the face and abdomen, muscle atrophy, easy bruising, thinning of the skin, and effects on mood and cognition. Even this extensive list is not a comprehensive list of all the potential problems with the use of steroids.

Given these risks, should a patient with complex regional pain syndrome still consider the use of steroids as a possible treatment?

In the vast majority of situations steroids are not appropriate for chronic treatment of CRPS. Nevertheless, they are potentially very useful for brief treatment of the acute symptoms that might be seen with new onset or flares. For brief treatment courses, the side effects are usually minimal to mild. For patients who have repetitive flares, I will limit the use of a six-day course of steroids to two to three times per year.

Why do steroids work?

This is far from clear, but steroids have several properties that seem to be helpful. Steroids reduce the abnormal firing of damaged or irritated nerves. In addition, steroids are powerful anti-inflammatory agents and also suppressors of immune function. At least one component of CRPS appears to be an autoimmune disorder: The anti-inflammatory and immunosuppressive properties of steroids appears to be very helpful for acute neuropathic pain conditions, including CRPS.
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
Outcomes of Children With Complex Regional Pain Syndrome After Intensive Inpatient Rehabilitation

Valerie Brooke, MD, Steven Janselelewitz, 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 9 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.

PM R 2012;xxx

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].

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Disclosure: nothing to disclose

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Disclosure: nothing to disclose

Disclosure Key can be found on the Table of Contents and at www.pmrjournal.org
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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 made 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 allosthenia, 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 nontypical 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, toweling, 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 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>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Girls, n (%)</td>
<td>26 (81)</td>
</tr>
<tr>
<td>Boys, n (%)</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>Symptom</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>32 (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>
</tr>
</tbody>
</table>

**Table 3. Pain location**

<table>
<thead>
<tr>
<th>Location</th>
<th>n (%)</th>
</tr>
</thead>
<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>
</tr>
</thead>
<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>Benzodiazepines</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—III (DSM-III) 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, this 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

We thank Dr Janice Cockrell and Dr Mark Shih for providing valuable input into the creation of this article, and we thank our rehabilitation team for the excellent care of these patients.

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 reinitiation 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


DEMOGRAPHICS

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.3,4 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 Cincinnati 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 al5 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 alldynia, 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.7 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,9 Francx,10 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.3,5,12,13 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 (or reflex sympathetic dystrophy, as it was known at the time) suggested that the syndrome was extremely rare in children. Sporadic early reports of children with CRPS first appeared in the 1970s. Several of these patients had spontaneous resolution. 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. Other authors used treatment strategies very similar to those used in adults, including sympathetic blocks, antidepressants, vasodilators, steroids, and so forth, generally with complete resolution of the disease. Between these two extremes was a group of authors recommending conservative treatment consisting primarily of physical therapy (PT) either with or without 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 Wilder et al, Stanton et al, and Greipp showing that a percentage of children will have long-term pain and disability even with aggressive therapies such as sympathetic-nerve catheterization, and antidepresants and anticonvulsant medications.

Physical Therapy

A recent report by Sherry et al 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 reported for PT alone two decades earlier. Murray et al 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. 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, Murray et al, and others would seem to support this, a recent prospective randomized trial by Lee et al 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. 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." Some authors have even presumed that CRPS is entirely a psychological or psychosomatic disease process. 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 of purely psychological origin.

There is scarce evidence that children with CRPS are psychologically unique. Sherry and Weisman 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 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, 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 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 in 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. 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 1980s. 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. Wilder et al. reported that 57% of their patients who received such training benefited from it and continued to use this treatment modality. Stanton et al., however, found that psychological interventions were not consistently effective. This was felt to be the short time for interactions with the therapist during the patient’s inpatient admission. Lee et al. 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. 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. 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 revoke 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. 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-chain 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. They have reported success motivating their patients to participate in PT despite ongoing pain and allodynia. Others 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, anti-convulsants (particularly gabapentin), steroids, nonsteroidal anti-inflammatory agents, 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. Those who stress the value of intensive PT suggest that no medications are appropriate. 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. 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.1 and Lee et al.2 and the intensive PT approach used by Sherry et al.3 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.8 and Kemler et al.9 and a later prospective series by Kemler et al.10 all show efficacy in terms of sustained pain reduction of modest proportions. Pain thresholds are not changed by SCS.51 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 algia, 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.11 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.,25 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%25 of patients, a much higher rate than the rate of 1.8% per patient-year reported for adults.58 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 Nelson68 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 multi-disciplinary 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.

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

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 “has a physical or mental impairment that substantially limits one or more major life activities.”

US Department of Education, Office of Civil Rights
Protecting Students With Disabilities: http://www.ed.gov/about/offices/list/ocr/504faq.html

National Dissemination Center for Children with Disabilities (NICHCY)

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

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

“Helping Youth with CRPS Succeed School”

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.

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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 Swiatlinski

“I 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 Richards, age 11
What is CRPS?
CRPS is a neuroinflammatory syndrome characterized by pain in one or more limbs and/or ankles, feet, abdomen, or hands, even virtually any part of the body can be affected. The pain, described as burning or sharp, typically appears after a traumatic event, such 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, overuse 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 several diagnostic studies.

CRPS is not life-threatening, but it can become chronic and extremely painful. The pain may be severe, disabling, and interfere with daily activity, leading to as many as 25% of school days missed. Early diagnosis and treatment, with an emphasis on movement, behavioral approaches, and rehabilitation, offer the highest probability of remission, which may be achieved in almost 92% of those treated.

Treatment options
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 “overachieve” behaviors, over-scheduling, apathy and reduced motivation and/or initiation, and anxiety, depressed mood, and/or inflexibility.

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. Because the slightest bump can cause lasting flare-ups of this very painful syndrome, every effort should be made to see that the child is not exposed to the bumping and jostling of school hallways. The student’s desk in each classroom should be positioned away from traffic patterns to avoid inadvertent bumping.
2. Determine whether the student needs ergonomic seating/adjustable desk.
3. Designate another student as a helper who can carry the student’s books/belongings during the day, help at lunch, and during the changing of classes.
4. Because students with CRPS in their upper extremity may have difficulty writing, allow the student to record lectures, use a keyboard, or portable word processor, or use another student’s notes.
5. Given that CRPS symptoms can be exacerbated by the cold, allow the student to bring a heating pad. Also, guidelines should be developed regarding whether the child should go outside for recess when it is excessively cold; care must be taken to see that the patient has adequate warm clothing, and is kept out of drafts.

Limiting Stress
Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:
1. Schedule all classes on one level or provide student with key to the elevator
2. Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
3. If a student is unable to write, modify normal test taking, and allow additional time for tests.
4. 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).

“Your life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”

— You’re

My parents and I were visiting our family friends out in East Hampton the week before I left for college. All summer my dad, who also doubles as my training partner, and I had been finishing our runs just as the sun was setting. On this day, we began our 70-minute run around 7:15pm. Before starting, we asked two bikers leaving the woods how much light they thought we had left. They said 45 minutes tops and we thought, “we’ve been fine all summer, what could go wrong?”

The first half of the run felt great. I was happy, fit, chatting away with my dad. However, the conversation quickly turned into an argument about my wanting to leave East Hampton a day early so I could say goodbye to my friends. The argument was soon curtailed by cries of pain as I lit up the face of my watch to see what had happened. I had turned my ankle on a rock and that was the end of that run. Thank goodness for my dad, who carried me through the pitch-black woods to the first house we could find. Once we showed them my ankle, they immediately called an ambulance. As we waited, the children at this house were determined to cheer me up. This is a moment that still brings a smile to my face. Five hours later, I was in bed with three torn ligaments and enough Vicodin in me to fall asleep.

This newsletter was sponsored by R. Steven Shisler, Esquire is an attorney whose practice concentrates on representing people who suffer from CRPS caused by the negligence of others. He is a member of, and secretary of, the board of directors of RSDSA. He has suffered from reflex sympathetic dystrophy/complex regional pain syndrome and the partial paralysis of his left arm for 47 years as the result of a motorcycle accident. Steve can be reached at 215-564-4080.
CALL FOR AUTHORS & IDEAS

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

SPECIAL THANKS

We would like to acknowledge our Corporate Partners whose generosity helps to underwrite issues of the RSDSA Community Update. Our Corporate Partners include Abbott, Baker Family Charitable Trust, Grünenthal, Vitalitus and Michael & Lynn Coatney.
Working Virtually During a Pandemic

Since the start of the pandemic, RSDSA staff have been working virtually. We are retrieving telephone calls, answering emails, monitoring our social media platforms, providing crisis interventions, mailing masks and information packets, conducting staff meetings via Zoom and much more. We were so disappointed to cancel many educational, awareness, and fundraising events.

We’ll be conducting a fall virtual “Treating the Whole Person: Optimizing Wellness” conference over the course of a week. Next month, we’re conducting an inaugural virtual walk on August 22. To register, please visit https://secure.qgiv.com/event/rsdsa-crps-walk.

RSDSA, like other not-for-profits, has been adversely financially impacted by the COVID-19 pandemic, yet we are still accomplishing our mission of supporting, educating and providing hope to the CRPS community. Please consider making a donation, no matter what size, to help us serve the CRPS community. Please visit https://rsds.org/donate/ to donate now or to start donating monthly.

Facebook BeLive Presentations

During the pandemic, RSDSA has been hosting BeLive presentations for the CRPS community. With each subsequent presentation, our attendance has soared. The first BeLive with Dr. Melanie Levine had 1,148 unique viewers. The top audience members were women aged 55-64 and the top viewing location was New York. Our second BeLive with Dr. Peter Abaci attracted 1,556 unique viewers and the top audience members were women aged 55-64 and the top viewing location was California. Our third BeLive with Dr. Scott, Dr. Fass, and Brendan Pitcairn had 1,990 unique viewers. The top audience members were women 55-64 and the top viewing location was Pennsylvania.

The presentations are archived on our website: https://rsds.org/educational-presentations/

All of our recent conference videos are archived on this page too.

Sponsorship of this Electronic Issue of the RSDSA Community Update

This issue is sponsored by R. Steven Shisler, Esquire, an attorney whose practice concentrates on representing people who suffer from CRPS caused by the negligence of others. He is secretary and a member of the board of directors of RSDSA. He has suffered from Reflex Sympathetic Dystrophy/Complex Regional Pain Syndrome and the partial paralysis of his left arm for 47 years as the result of a motorcycle accident. Steve can be reached at 215-564-4080.

If you are interested in sponsoring an upcoming issue, please contact me at 203-623-4415.

Publication of the 5th Edition of Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines

RSDSA is funding the publication of the fifth edition of the Treatment Guidelines, last updated in 2013. Dr. R. Norman Harden is our editor and we hope to complete the project this year. The Guidelines have been cited in 55 subsequent peer-reviewed journal articles.

James W. Broatch
Dermoneuromodulating

BY DIANE JACOBS, PT • DFJPT2009@GMAIL.COM

Introduction

It is my pleasure to provide the RSDSA some information about the hands-on work I call dermoneuromodulating, or DNM. Done well, physical contact by a practitioner should feel good, relieving. The hands of a practitioner should be clean, slow, steady, light, warm, sensitive, responsive, kind, intelligent, effective, and above all, never uncomfortable.

The human brain has been described as the most complex object in the known universe, with its 86 billion neurons (plus another couple hundred million for the peripheral nervous system), each having up to 10,000 connections to other neurons, the sum total of which amount to as many possible nodes of connection as there are stars in the sky, or some astronomical number like that. I like to argue that the only thing that might be able to help such a complex human nervous system is another equally complex human nervous system, a person who has good boundaries, focused attention and rapport with the person who has hired him or her to help with a pain problem.

If you are the person with pain:

Assume control of any hands-on session by being the translator. You have hired this person to help you and, therefore, you have control. You know your own nervous system and that it has been freaked out about … something, even though your doctor told you they can’t find any cause. Pain itself can feel so overwhelming and…. just plain wrong. You know how you feel – you can feel what’s going on inside yourself way better than somebody else can, so don’t be timid about offering feedback. By that I mean, communicate with your therapist – if they are touching you in some way that hurts, say so. The therapist should immediately stop whatever they are doing that feels uncomfortable and try from another angle. This is called keeping “locus of control.” Remember, they DO NOT have to hurt you to help you. Far from it!

You should always feel that you can relax and allow the touch to be whatever it is and do whatever it does. To get that far, you will need to establish trust with said practitioner first. If you do not fully trust him or her, there will be some part of your nervous system, conscious or

WANTED

Individuals to:

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

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

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

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

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

☐ Write an article for the RSDSA Community Update.

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

☐ Share your story of hope. Inspire others who are struggling as you have.
unconscious, that will hold back and won’t be able to permit change. So, take control of the relationship.

Nervous systems cannot be changed by any outside person or force in a physical therapy setting. Nervous systems can change themselves however, for the better.

Nervous systems will change themselves only when they are darn good and ready to change, not before.

Much of the nervous system operates well below your own level of awareness. It will self-correct at that level as well. When it does, it can feel kind of amazing. Then you will think your therapist is a magician. But know that they aren’t - it was you all along, and your amazing nervous system.

**If you are the therapist:**

Explain to your patient that only they can get themselves better, but you will help as much as possible. Set up communication so that the patient feels they can tell you anything and you’ll be there to help them. There may well be tears, so keep a box of tissues handy. Listen, listen, listen.

Don’t say very much. Especially, don’t burden your patient with any comments that could well be noceboic. Noceboic means harmful or threatening to their ears, like any talk about degenerating discs in the spine, or degenerating joints, or ANY orthopaedic situations commonly seen on visual imaging. Bennedetti showed that with noceboic input, cholecystokinin is released in the brain, which is antagonistic to endogenous opioids. We want our people with chronic pain to make all the endogenous opioids they possibly can. So instead, if a patient coming to see you is convinced that something somebody found on an MRI is the cause of their pain, you can simply remark how it has been found that those sorts of things commonly appear on MRIs in completely asymptomatic people too, like grey hair and wrinkles on the inside of the body. Then move on.

Several visits may ensue before you even get around to suggesting any hands-on work. They may tell you that unsuccessful attempts have been made in the past by well-meaning practitioners or even that their pain has been made worse. You will have to have earned their trust before you propose another try. Heraclitus said, you never stand in the same river twice. This time things could turn out different.

Before you ever touch someone, it is very good manners to make eye contact and ask out loud for permission. Assume nothing. Tell your patient you will not hurt them, and if you do, by mistake, immediately change whatever you are doing and thank them for telling you.

As a therapist, you are not responsible for any changes that do or do not occur in another person’s brain. You do not have magic hands. You are a catalyst only. Like any catalyst, for example in a chemical reaction, you will help to speed up a reaction but precipitate out, leaving nothing of yourself behind in the process except a fond memory perhaps (we all hope).

You are important in that you and your desire to help, evident through your words, body language and interaction, are providing a person in pain with a containment system, a context within which they can feel safe and trust you to not hurt them more.

But they, and their own nervous system, are creating the desired change, not you. When you touch them, you are merging your nervous system with theirs for awhile. A non-verbal kinesthetic conversation will take place, and both parties will gain much more insight into the problem facing the person with pain. Both of your attentions will drift back and forth between exteroception and interoception. Some verbal conversation may occur, but a lot of time, changes take place in sort of quiet, non-verbal interaction zone.

Take advantage of a couple built-in features that nervous systems have, called temporal and spatial summation. This means that your innocuous input signal will build over time. Some parts of the nervous system will get excited and nervous and check you out for any threat you may pose. Just don’t hurt it, and you’ll be fine. Eventually it will come over, wag its tail like a puppy, and want to play. The signal will reach deep into the brain and the person’s cortex will check it out, then exploit it, if possible. That is what predictive brains do.

**Pain**

A revolutionary idea about pain emerged in 1965 with the publication of Ronald Melzack and Patrick Wall’s paper, Pain Mechanisms: A New Theory. This
new idea was that the central nervous system had opinions about, and options for interacting with, even for dampening down, spinal cord mechanisms for transmitting nociceptive input to our conscious awareness. This new idea overturned 400 years of dogma that in essence had created a belief system that pain was something that traveled to the brain along nerves from the body. A great deal of neuroscience research has been done since then. Some of it has to do with understanding pain, but most of it has been to try to solve the mysteries of how the brain works, period.

Currently a popular notion is that the brain is predictive, constantly referring to what it already knows, and projecting that outwards onto the rest of the world. This is important for DNM practitioners to consider. It means that if you can supply a carefully prepared person’s brain with just a tiny bit of unexpected, carefully titrated novel sensory input, the whole pain experience may turn on a dime, dissolve, even if that pain has been around for a very long time.

Another feature that people have known about for a long time that has to do with sensory systems is the Weber-Fechner law. It was first worked out with the visual system, but it is important for DNM practitioners to consider. It means that if you can supply a carefully prepared person’s brain with just a tiny bit of unexpected, carefully titrated novel sensory input, the whole pain experience may turn on a dime, dissolve, even if that pain has been around for a very long time.

It is important to realize that a human nervous system has no idea that we use different names for different parts of it. It thinks it is a seamless whole, from skin cell to sense of self.

So, what is the nervous system? It is a highly excitable communication system comprised of brain, spinal cord, and about 45 miles, or 72 kilometers of peripheral neural tree in the body, much of which is in the skin organ. Really, this system is more of a verb than a noun. It is always busy, impulses racing around at speeds of up to 200 miles per hour. If something is amiss in one part of it, the entire system will know about it within milliseconds. Same with when something self-corrects. Even though human brains are large compared to other primate brains (about three times larger than our closet cousin, the chimp, and five times larger than most other mammals our size and weight) it is still pretty small. The entire human nervous system is only about two percent of our body, but it’s the boss of us. It runs us. It runs the entire show because it is so excitable and communicative. It is constantly working, day and night, 24/7, keeping us alive. When we are asleep, it keeps our lungs breathing and our hearts beating. It rolls us over without waking us up (hopefully). In the morning it wakes us up, because it wants us to go void its bladder and get it something to eat or drink. There is an interesting relationship between the brain and the spinal cord. Both are the central nervous system.

The nervous system

It needs for things to be able to change inside the entire nervous system. This novel input may be visual, as with mirror boxes or graded motor imagery, or somatosensory as in movement therapy or manual therapy like DNM.

Spinal cord

The spinal cord is the oldest part of the central nervous system. I like to think that because it is the oldest, the spinal cord thinks it should have seniority. One of its main jobs is to move motor information from the brain out into the body. The brain constantly modulates motor output to make it refined and smooth and just the right amount so that we don’t knock over our coffee cup all the time. What happens when this pathway from brain to body is interrupted, as in a spinal cord injury for example, is that there will no longer be control by an individual over their movement. Their legs will still move in spasmodic contractions, which will be spinal cord behaviour, but the person won’t be able to stop it – it will have to stop all by itself.

My point in bringing this up is to say it seems that as the brain evolved at the front end of the spinal cord, one of its main jobs was to inhibit and smooth out unwanted and unnecessary motor output generated by the spinal cord itself. Even in people without spinal cord injuries, the spinal cord can take over the body with its withdrawal reflex. This is an extremely protective mechanism which can make your hand fly up off a hot stove before your brain can even register that it felt hot. It operates completely independent from the brain, in response to any phasic burst of nociceptive
input. The spinal cord is like a first responder. Then what happens? If the burst of nociception is coming from inside the body somewhere, the spinal cord won’t know the difference and will tighten up the body somewhere in response. What will that do? Probably the tightening will squeeze peripheral nerves somewhere, which may well increase nociceptive input, producing an amplification of “danger signal” to the brain. Like we really need more threat signals, right?

Again, the brain’s job seems to be to inhibit most of somatosensory information from coming in usually. You put your clothes on in the morning and you feel them, then later you don’t feel them anymore. Same with nociceptive input, or danger signalling from the body. Nociceptive input is happening all the time, but generally, we aren’t aware of it. We have what is called “descending modulation” by the brain. This is a wonderful intrinsic automatic system of dampening, mostly to do with inhibition substances the brain makes and puts into the synapses in the spinal cord to dampen the crossover and ascent of nociceptive information up the cord to the brain. Good system. Works really well. Until for some reason it doesn’t.

Back to the whole nervous system in general
In order to do its job of keeping us alive and keeping our physiology functioning properly, the nervous system uses a staggeringly huge amount of energy compared to its proportional size, as a body system. This amazing system that amounts to only two percent of the body uses up to 25 percent of all available oxygen and glucose ALL THE TIME. Day and night, 24/7. These two substances are delivered to the nervous system by blood flow.

If any part of a nervous system doesn’t get what it needs, it will complain to you, the person within your own nervous system. A lot of pain seems to have something to do with what I affectionately call “crabby nerve syndrome.” Remember there are 45 miles of nerves in there. That is a lot of nerve length to keep fed, oxygenated, and drained by the vascular system.

Nerves are long sensitive physical noodles that can’t move by themselves – they depend on you to move the containment system around them, within which they can slide a bit. Peripheral nerve entrapment literature is extensive, and at this point in my life, I figure most pain might boil down to some nerve somewhere feeling oppressed within its containment tunnel. I say most, not all. Obviously, there are some types of chronic pain that are more mysterious. For example, Phantom Limb Pain can occur in a person with, say, amputation of a leg, where there really aren’t any nerves to be entrapped, yet the person can feel pain in a foot that is no longer there. But where there are nerves, a person can often physically affect them somewhat for the better.

Michael Shacklock has done extensive work and research with what he calls “neurodynamics.” The term refers both to the way nerves move within the body as we move about in life, and the treatment approaches he and others have devised as ways to treat people with pain. These involve special movements to slide nerves back and forth within the body, by say, extending the arm out, bending the head to the side while bending the hand at the same time. Most physiotherapists have learned how to teach these moves to people with pain. The idea is “feed the nerve.” By sliding a nerve within its tunnel by a small amount frequently, you are “feeding” it by activating mechanically sensitive blood flow into and out of the nerve. Imagine the crabby nerve is a sick puppy. It’s too weak to eat by itself, but you know it must be hungry and without food, it could die. So, you give the puppy an eyedropper of food every couple of hours. Not too much, because you want that food to stay down. But you know it needs help to recover, and that means adequate nourishment.

Neurons have things called receptors all along the length of their membranes. These are proteins that the neuron makes that initiate an impulse to move along the neuron. They are constantly turning over, taken out and replaced. The idea is that by doing small neural glides or slides, feeding the sick puppy little by little, the neurons will get better. They will make fewer receptors and the new receptors will be receptive to more appropriate stuff. They will become less sensitive, in other words. The puppy recovers, starts to run around and wag its tail again. Nerve slides or glides could be thought of as “move better pills.” You take a set dose, without missing any doses, and complete the entire prescription. It takes about 72 hours for receptors to completely turn over in nerve membranes. By day four,
there should be some sort of improvement in perception of one’s pain.

The skin organ

This is my favorite organ right after the nervous system. It has different layers and tissue types in it and lots of different glands, blood vessels and neurons, which makes it very complex. The outermost layer of it, the epidermis, is comprised of cells derived from the exact same layer in an embryo that turns into the entire nervous system. It is as if the skin is the outside of the brain!

The skin organ is actually quite thick: on the back of the hand, it may only be a few millimeters thick, but around the trunk, hips and upper thighs, it can be inches thick. It is also heavy, weighing as much as the skeleton.

We don’t usually notice how heavy our skin organ is though, because it is held onto the body by thousands of small skin ligaments, which distribute its weight.

Some of those skin ligaments are tubular, and through them pass nerves and vessels that supply the skin organ itself.

Nerves that pass into the skin organ are called cutaneous nerves. They contain autonomic motor neurons that control its blood vessels, smooth muscle cells that make your hair stand up and sweat glands. These nerves also contain a lot of sensory neurons that report to the central nervous system everything that is happening at and within this remarkable interface between you and the world. When you let a practitioner touch you, a lot of neurons will be activated. Most of them will remark, “I was touched.” And that’s it. They stop firing. There are some however, that will continue to fire as long as someone continues to touch you, especially if they are stretching your skin a little bit. These are the ones I suspect help the brain change itself. They say, “I am being continuously touched… still being touched… still being touched…” and they keep going, keep firing and transmitting data until the person takes away their hands.

Here is a hot tip: you can do this by yourself. It takes a bit of time to figure out how, but the way I do it for occasional crabby back pain, for example, is to line up a piece of dycem (although any sticky material that comes in a sheet you can cut to size will work. A piece of yoga mat is a good example) four or five inches square between my sore bit, and a wall or door jam. Then I move a bit this way or that way until I find the right direction to hold in. Meanwhile my skin organ is being tugged appropriately and some crabby cutaneous nerve in my back is getting what it needs to stop complaining.

If you are a practitioner, it behooves you to be gentle. If you do mild skin stretch on skin surface that is not allodynic (sore to touch), you do not need to worry because the nervous system is going to register your input everywhere anyway. So, begin your touch somewhere that isn’t sore, nearby, or in the same place on the other side of the body. And then sit back and let the person’s nervous system do all its own heavy lifting and changing.

Furthermore, you will somewhat be moving cutaneous nerves. If you know where they are likely to come out into the skin organ through their little aponeurotic rings, you can even target them by pulling the skin organ itself (into which they firmly embed) and thereby pulling the cutaneous nerve a bit further through its ring. You can find the rings by carefully palpating for spots that may feel somewhat, or a lot, tender. So be careful– don’t prod. Be kind. Then pull the skin organ in a way that relieves tenderness.

Conclusion

In the end, if you are the person who has pain, know that movement is good. You may have avoided moving for a long time because of pain but think about the health of that 45-mile neural tree inside your body and how much it depends on movement to get healthy and then stay healthy. “Motion is lotion,” as we say. Consider how you inhabit your body. Notice, then change up what I like to call default resting positions: always crossing the same leg, never the other. Always leaning on the same elbow, never the other. Always falling asleep on one side, never the other. Nothing we do in our body is “wrong,” but we are built with two sides, and both sides should receive about the same amount of exposure to resting behaviours, or something might start to hurt one day out of the blue. Find a therapist you like and trust. Stay in charge of your own wellbeing, even as you take on their suggestions and oversight. Work together with them and don’t give up, ever.
It Takes a Village
BY JENNY PICCIOTTO

Complex pain requires a multidisciplinary approach, according to S. Shar Hashemi, M.D., F.A.C.S., a board certified surgeon who has completed fellowships in orthopedic hand surgery and peripheral nerve surgery. We met on a video call to discuss the extraordinary surgery his team recently performed for a patient who had undergone amputation of his leg below the knee and was unable to use his prosthetic due to severe CRPS Type II nerve pain.

The team includes specialists with expertise in physical medicine and rehabilitation, hand and nerve surgery, neurology, specialized peripheral nerve imaging, orthopedics, and cell based therapy. Their website describes the scope of their practice:

At Nerve, Bone and Joint Institute, we utilize our multidisciplinary training complemented by state-of-the-art medical devices to diagnose and treat neuro-musculoskeletal conditions. We evaluate patient conditions on a case-by-case basis and provide a personalized management plan for each individual patient condition. In creating the patient management plan, NBJI physicians consider a full-spectrum of treatment modalities encompassing restorative, regenerative, and reconstructive options.

Dr Hashemi explained that “Our goal is to solve complex neuro-musculoskeletal problems. I look at the problem-set as a team approach. It takes a village to evaluate a CRPS patient. From the biological, psychological, and social aspects, we engage a team of experts to analyze the patient’s concerns, perform a detailed physical exam, create a plan of care and execute the plan.”

The first step is to establish a specific diagnosis by analyzing data and test results, and getting first hand data from the patient. “We use a few different ocular lenses when we look at these problem-sets; orthopedic, neurosurgical and reconstructive,” Dr. Hashemi says. “We start with a detailed history, then complete a detailed physical exam including a peripheral nerve exam, and correlate our findings with the diagnostic tests performed.”

The essential task, he explains, is to “get to the root cause” of the problem. Additional testing may be needed to determine whether the problem is soft tissue, muscular, tendon, joint, neurologic, or vascular. This specific and detailed diagnosis then drives their analysis to determine the best course of treatment.

Approximately sixty percent of the patients at NBJI have a nerve injury. Of those about twenty-five percent have a diagnosis of CRPS II, which differs from CRPS I in that there is a known peripheral nerve injury. CRPS patients, he notes, are often dismissed or not thoroughly worked up by a multidisciplinary team. “Etiologies of pain can be multifactorial; biomechanical and peripheral nerve sources need to be evaluated. I have seen some patients with spinal cord stimulators who achieve great relief and others who remain symptomatic. It is these symptomatic, challenging cases that our NBJI team enjoys seeing.”

Dr. Hashemi told me about his patient and the delicate surgery they performed. While working alongside a highway, the man’s foot was run over by a vehicle, resulting in extensive damage to his bones and soft tissue. His surgical team in Ohio attempted reconstruction to preserve the foot, but insufficient blood flow led to infection, and he ultimately underwent a series of amputations resulting in the loss of the leg below the knee. He suffered intense pain at the stump and was unable to wear the liner for his prosthesis, much less put it on to walk. This once active man in his prime was no longer able to enjoy his relationship with his wife, work, or take part in community activities he once enjoyed.

“He was basically bed-bound,” Dr. Hashemi said, “a motivated gentleman, a previously active member of society.” He noted that “In America there are about a million amputees and twenty percent of them have chronic
pain. The pain could be from CRPS II, Phantom Limb Syndrome, or painful neuromas.”

Despite a regime of medications and a spinal cord stimulator, the man continued to experience severe pain. After twelve years and multiple dozens of doctors, he eventually met one who was familiar with Dr. Hashemi’s work at NBJI and suggested it would be worth the trip to Washington D.C. for an evaluation. After a tug of war with insurance approvals, denials, and reversals, the patient decided to make arrangements to pay for his own treatment. Dr. Hashemi explained that “NBJI worked closely with him to make his dream come true by offering a dual risk agreement where our team would provide expertise care at an efficient cost. We believe in service excellence.”

A thorough diagnostic workup was completed before proceeding to surgery. “We completed an orthopedic and peripheral nerve exam and learned there were several nerves adhered to the amputation site that precluded him from wearing the liner or the prosthetic. We performed selected image guided diagnostic blocks and demonstrated that he had significant relief in the region of pain. We know that he was on morphine for twelve years. This may not be able to get you off morphine, we told him, but our goal is to transfer the nerves that are damaged and supercharge the nerves that are working to maintain your ability to flex your knee but remove the pain at the stump site.”

In the procedure, called Targeted Muscle Reinnervation, “The goal is to preserve motor function while removing sensory pain that was overwhelming the system. We relocated the critical sciatic nerve and its branches. The tibial and peroneal branches were transferred to those motor branches needed to preserve his ability to flex his knee.”

Dr. Hashemi described the microsurgery in deeper detail: “We proceeded to surgery after cardiac clearance, preoperative labs and lumbar spine imaging, and electro-diagnostic testing to a four hour surgery under anesthesia where we exposed the sciatic nerve, high up on the thigh — not where the amputation is. With our intra-operative nerve monitoring team and the use of a microscope and microsurgical technique, we identified which branches (of the sciatic nerve) are going to the area of pain, (and) which branches are innervating the muscle that needs to be preserved. We excised the branches that were going downstream but at a higher level (than the painful stump), and connected them as nerve transfers to the motor branches of the biceps femoris and the semitendinosas. So what that did was allowed us to move nerves that were previously causing him severe pain, not allowing him to wear the liner, and prosthetic, to the point that our goal would be for him to immediately be able to wear the liner, and then within a month to start wearing the prosthetic.”

In the post operative period, the patient was amazed that he was able to touch the area without pain, but Dr. Hashemi was and remains cautious. It would take time to assess the outcome of the surgery, he told the patient. “Initially the indwelling catheter masks the pain, then the nociceptive medications mask the pain; then we can examine the outcome of the surgery.” As a surgeon, he wants to see great results, but working with the team back home and gathering objective data is necessary.

“We don’t jump to a conclusion,” he says, “Alodynia, color changes, and lack of use have all improved. Manually putting pressure on the stump site has improved even though there was no incision there. At this stage he did not have a flare up. Narcotic and all other medication requirements have gone down, and his satisfaction and hope for life continued to go up. He has been able to wear his liner every day and is preparing to try wearing the prosthetic. After weaning off the morphine he took for twelve years, he even cancelled his appointment with pain management because the time can be utilized to work with physical therapy.”

I asked Dr. Hashemi whether or not they took any precautions to prevent a spread of CRPS for this patient, given the precautions we often hear that surgery for a patient with active CRPS is contraindicated.

“Yes,” he said, “there are a couple things we need to do. First we need to make sure this is CRPS II with a peripheral nerve injury. The patient must meet the Budapest Criteria. Literature states that surgery is an aggressive move in CRPS patients. We feel that the literature is misspeaking and misrepresenting the entire spectrum. We understand that applies to CRPS I, but don’t think it applies to CRPS II.”

In addition, precautions are taken during the procedure. “In the
Operating room, these patients already have a neuropathic agent, a nociceptive agent, a muscle spasm agent on board, and they are given IV ketamine through the surgery to calm down the NMDA receptors. The surgery itself is delicate tissue handling and an infusion pain catheter is in place to make sure that this stays localized and the patient doesn’t have an overwhelming response."

(This case) “is an example of an active treatment of a nerve condition where there is nerve injury and we create a function for the peripheral nerve. We create a function for it so it doesn’t sit there in a mechanosensitive area and constantly send substance P and neuro-hormones to the spine through the dorsal root ganglion and communicating through the brain.”

Dr. Hashemi told me that the patient is recovering not only from the surgery, but has recovered hope that his quality of life is improving, allowing him to engage more meaningfully with his family and community.

As the founder of NBJI, Dr. Hashemi places great value on a genuine connection with his patients. His practice, which started with a single patient nine years ago, has grown organically. Since then he and his team have helped 4,000 people. He is interested in building bridges with patients and insurance carriers so he can deliver treatments to patients earlier. He knows that research and data collection are necessary to show insurers that this type of treatment can be successful and cost effective.

“Ongoing research in peripheral nerve is required to continue to provide patients with the advanced treatment options and design more accurate diagnostics. We work with human problems, using expert analysis, one case at a time. Our success starts with one patient and builds from there. We need more patient education and big data collection to advance our field in peripheral nerve surgery. I believe artificial intelligence and machine learning can facilitate this process dramatically.”

His mission for the future is to offer nerve surgery Fellowships to groom future doctors to help patients around the world with these problems.

“I believe,” he says, “that in life everyone is here for a reason and my reason for being here is to solve complex problems. I feel we have the skill set to at least attempt to solve these problems.”

1https://nerveboneandjoint.squarespace.com/about
2nerveboneandjoint.squarespace.com

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Neuro-acupuncture: Hope for CRPS?

By Jenny Picciotto

At the end of April in the midst of COVID-19 stay at home orders, I had the pleasure of talking with Jason Hao, a Doctor of Oriental Medicine, who practices and teaches a special type of acupuncture to treat central nervous system disorders including Complex Regional Pain Syndrome (CRPS). Despite the lockdown, we were able to connect face to face on Zoom. Cheerful and accessible, he showed me models of the human skull, explained how neuro-acupuncture differs from traditional acupuncture, and described the remarkable way this treatment has transformed lives. Derived from traditional Chinese Scalp Acupuncture, neuro-acupuncture incorporates Western medical models such as neuro-anatomy, the mapping of areas of brain function. (Note: Quotations have been lightly edited for clarity and flow)

“My treatment, neuro-acupuncture, is a contemporary acupuncture technique, integrating Traditional needling methods with Western medical knowledge of neuro-anatomy, neurology, and neuroscience. It is a new type of acupuncture. It is a very effective technique to treat neurological disorders of the central and peripheral nervous system such as stroke, Multiple Sclerosis, Parkinson’s, Traumatic Brain Injury, PTSD, Phantom pain and CRPS, as well as Cerebral Palsy and Autism. My new technique often produces remarkable results with just a few needles, much faster than other acupuncture traditional methods.”

He explained that the brain controls all of the body’s activities including sight, smell, taste, speech, balance and the experience of pain. By accessing projections of the sensory and functional areas of the brain at the level of the scalp, neuro-acupuncture stimulates the brain, blood vessels, nerves, and dopamine system deep inside. According to the article “Review of Clinical Applications of Scalp Acupuncture,” co-authored with his wife Dr. Linda L. Hao, DOM, PhD:

“Unlike traditional acupuncture, where one needle is inserted into a single point, in scalp acupuncture needles are subcutaneously inserted into whole sections of various zones. These zones are the specific areas through which the functions of the central nervous system, endocrine system, and channels are transported to and from the surface of the scalp. From a Western perspective, these zones correspond to the cortical areas of the cerebrum and cerebellum responsible for central nervous system functions such as motor activity, sensory input, vision, speech, hearing, and balance.”

Dr. Hao studied Traditional Chinese Medicine at Heilongjiang University in Harbin, China before immigrating to the United States in 1989 to teach at Texas College of Traditional Chinese Medicine. He was the first Chinese teacher in the Southwest Acupuncture College. He and his wife Linda Hao, DOM, PhD, who graduated from the same University, co-authored the book Chinese Scalp Acupuncture. They founded the Neuro-acupuncture Institute (NAI) in Santa Fe in 2015 and have since graduated over 150 students from the program. They travel across the globe teaching and lecturing about this hybrid technique. “We only have two hands,” he says, “so want to share this life changing therapy with as many people as possible.”

The Mayor of Santa Fe honored the Haos for their service to the community in 2018 by declaring February 16th, 2018, (Chinese New Year) “Drs. Jason & Linda Hao Day”. The Proclamation recognized their contributions to the community, their professional excellence, and the spirit of compassion and dedication they devote to helping people suffering from neurological disorders.

We discussed many conditions Dr. Hao treats with this technique, but honed in on CRPS. “Traditional acupuncture to the limbs,” he said, “doesn’t work with CRPS because the body is over stimulated and very sensitive. Instead of stimulating the area of pain, the diagnosis for treatment is based
on which part of brain function is awry.”

“For CRPS we focus on the sensory and motor areas. Stimulating those areas improves nerve and brain functions, makes circulation better, nerve synapses connect better. When they communicate and balance, the pain will go away. We have treated many patients who were paralyzed or in a wheelchair who were able to get up and walk after treatment. Working with CRPS kids who have painful swelling and color change, after putting the needle in pre-motor areas, the color change and swelling goes down immediately.”

He has treated between seventy to eighty CRPS patients. The results, he says, are mostly positive, although three to ten percent of patients do not respond.

“If the CRPS is long established there are likely to be more complications. Instead of local focused pain, other parts of the body have pain. It affects emotion, like anxiety, or depression. They may have other complications like neuralgia, or fibromyalgia. Patients are in shock, tense, and after many medications, injections, they have tried so many things, there is a loss of hope. The whole system is affected. The limbs may be rigid, or have muscular atrophy, with one leg stronger than others. Any movement hurts. For those kinds of patients we may need to treat more areas of the brain, so they would probably need more than four treatments.”

He told me about some of the CRPS patients he has worked with. The editor of Chinese Scalp Acupuncture was his patient twenty years ago. His method cured her of CRPS, he says, and they have remained good friends ever since. Another case involved a young gymnast who fractured the growth plate in her leg and developed CRPS.

“Zoe was a gymnast who had injured her leg, had full body pain, and was disabled. During treatment the color change on her feet went away, swelling went down and she was able to get up and run. She was cured after one treatment.”

The idea that a single treatment of anything could alleviate long standing severe CRPS is astonishing, but Dr. Hao says his success with pediatric patients continued. “Her mother knew many others through a support group and sent other nine to twelve year olds - twenty-eight children with CRPS – and after between one to four treatments with only four needles on the head Zoe’s mother reported we had 100% recovery rate.”

He put me in contact with Sue Rempel, one of his patients, who developed CRPS in her left knee following surgery. After seven years, numerous medications and interventions, the CRPS had spread and Sue was confined to bed and a wheelchair. Wiped out by the medications, she held on to the little hope she had left, when her doctor at the Cleveland Clinic told her the she would soon need a morphine pump. When her friend, a physical therapist whose patient had been cured of paralysis by Dr. Hao, suggested he might be able to help her, she knew she had to try.

“By the fourth or fifth treatment I could stand and bear weight,” she says, “but I was flying back and forth for end-of-life care for my mother.” She tells me that the trauma of the CRPS was re-triggered by activities she associated with the pain. Although the excruciating disabling pain never returned after those initial treatments, it took about twenty treatments over the course of a year to completely recover. “My pain level is now zero. He gave me my life back.”

Neurologists have told her it is impossible, but she is off all pain medications and fully functional. She is back at work as a volunteer hospice nurse, sits on three company boards, and volunteers at the Neuro-acupuncture Institute. “In my experience as a patient many people have complex health issues that can require more treatments. For younger patients who have not had CRPS long, four visits can work. But many of us have had it for a long time; our body has a strong memory of the pain and can hold onto it longer.”

Last fall she went to Ecuador on a medical mission and hiked a 6,000 foot volcano, then went on to realize her dream of climbing Machu Picchu. As an RN with a Masters in Nursing, she says that it is easy to dismiss the effectiveness of Oriental medicine because we don’t understand it, but there are many treatments in Western medicine that we also don’t understand.

There are no clinical studies of Dr. Hao’s technique, which has been developed and refined over decades of clinical experience. He is working on securing funding for research with Autism, Cerebral Palsy, CRPS, and Muscular Sclerosis. In his experience between 5-10% of patients don’t respond to treatment. “We need to figure out what kind of patient it works for, at
Spotlight on Support Groups: Treating CRPS & Chronic Pain with Functional Medicine and Calmare Therapy

BY MELISSA WARDLAW

Hello, fellow CRPS Warriors! I would like to introduce you to the CRPS/RSD, Chronic Illness & Pain Support/Empowerment Group of Metro Atlanta, Georgia. I started this local, in-person group about six years ago and we later added a corresponding private Facebook Group that has approximately 65 members and counting. Our members consist of patients and their spouses/caregivers, both men and women, with multiple different ethnicities and ages ranging from teens to the 70s! This is more proof that CRPS, chronic illnesses & pain do not discriminate.

Because our meetings and group activities take place in person, we have had to adapt and find new ways of connecting and offering support to members, as most groups have had to do during the COVID-19 lockdown. In April 2020, we held a virtual ZOOM meeting which was successful, having a little over twelve members in attendance. Despite the ZOOM app cutting us off after 40 minutes and having to start over a few times, it was helpful to check in and share our concerns about COVID-19 as well as the stress that comes along with it. The quarantine has had a devastating effect on many of our members, resulting in additional flares of pain & symptoms.

We also just recently had our first Facebook Live with a very special guest, Rabia Vaughns (PA-C), titled “Treating CRPS & Chronic Pain with Functional Medicine and Calmare Therapy.” We also touched on strategies to more effectively prepare for the COVID-19 crisis. Rabia owns and operates a Functional Medicine practice and has recently opened the first clinic in Georgia that offers Calmare “Scrambler” Therapy. Rabia is unique in that her husband has suffered with CRPS for four years, which is one of the many reasons that motivated her to bring Calmare Therapy to Georgia!

Despite having some technical difficulties in the Facebook Live (mainly on my end), we modified so members were able to hear Rabia loud and clear! Below are the highlights of Rabia’s presentation.

**Functional Medicine**

Functional medicine is a framework that looks at the whole person as an individual instead of just the patient’s diagnosis or symptoms. It asks the question of “why” the illness appears. What factors drive illness and what factors drive health? The goal is to reduce things that make people sick and increase things that make people well. It is less about treating symptoms and more about getting to the root of problems. The overall goal with CRPS and chronic pain is to calm down an already inflamed nervous system!

Functional medical practitioners partner with patients as individuals who are part of a comprehensive medical team. They also spend A LOT of time with each patient. Rabia believes every CRPS patient is an expert and, in turn, has to become their own advocate.

In terms of where she starts with a new Functional Medicine patient, Rabia said that because each patient is different, there is no “one size fits all” process. However, she will usually start with a comprehensive history and medical history. This includes gathering information on genetics, testing, childhood trauma, symptoms, stress, personality type, hormones, triggering events (injuries, accidents, stressful happenings), etc. Testing will vary depending on the individual patient’s symptoms and needs. Some of the types of testing that are available include measuring hormones, cortisol, thyroid, antibodies, TSH, digestive function, allergies, food sensitivities and many more.

She then determines mediating factors such as lifestyle, diet and exercise, hormones, endocrine system, nervous system, etc. and works from there to determine an individual plan for using the mind and body’s own healing powers to obtain further wellness.

For additional information, please visit Rabia’s website at [www.newlifewellness.net](http://www.newlifewellness.net).

**Calmare Therapy**

Calmare Therapy, otherwise known as “Scrambler Therapy,” helps by interfering with the constant pain signal, “scrambling” the brain’s constant pain message.
and correcting it to the normal “no pain here” message. This can help relieve pain and restore function. It goes straight to the root cause of CRPS, as opposed to just treating or masking symptoms of pain.

It works by placing small electrodes on the skin around (not on) the affected extremity or areas of pain. With CRPS, our brains get constant messages of pain. Calmare Therapy works to override that signal and instead delivers synthetic “no pain” information to the brain which, in essence, tells the brain that we don’t have pain.

According to Rabia, if it will work, one should notice a difference within the initial session to a few sessions. Usually it takes approximately 10 sessions, typically having five sessions per week.

Calmare is non-invasive and has no side effects. Contrary to popular belief, it CAN be done in conjunction with taking opioids and Ketamine, but NOT with anticonvulsants or other medications, such as Lyrica or Gabapentin. CBD/THC can also interfere with its effectiveness. Ideally, patients will be off as many medications as possible to have the best chance of success. Rabia prefers to work with the patient’s pain management physician to wean off any medications prior to treatment.

In Rabia’s opinion, Calmare Therapy is a great treatment to try FIRST, before any medications or invasive treatments and before CRPS has had a chance to spread. Booster treatments are common from a few months to a few years.

Calmare Therapy works well in conjunction with Functional Medicine. This way, patients are retraining their brain AND body at the same time - hence, the “mind/body” approach.

**Member Q & A**

**What is the difference between a TENS unit and Calmare Therapy?**

A TENS unit treats symptoms - when the TENS unit is not in use the symptoms and pain will still be present. Calmare delivers NEW information to the brain of “no pain” which then sends this message to the body ultimately breaking that feedback loop. In short, Calmare treats the source; TENS treats the symptoms.

**Is Calmare Therapy effective for Full-Body/Systemic CRPS?**

For full-body CRPS (or fibromyalgia for example), Calmare can definitely work but it will likely take longer than the 10 standard treatment sessions. With Calmare, you can treat five different sections of the body at a time.

Rabia believes it makes so much sense to try Calmare in the beginning of a CRPS diagnosis; however, it also makes sense to try it no matter how long you have had CRPS or where you have it since it’s non-invasive and there are no side effects.

**Can Calmare Therapy be used with a Spinal Cord Stimulator (SCS)?**

Using Calmare with a SCS or DRG is a contraindication. However, some doctors are doing it, but the device just needs to be turned off. Also, similar to a TENS unit, a SCS doesn’t send “no pain” signals like Calmare does.

**What is the cost of Calmare Therapy? Does insurance cover it?**

Calmare Therapy is usually less than Ketamine infusions as well as many other therapies. It is also covered by some insurances. Please check with your provider. Rabia also provides a superbill which makes filing easier.

Rabia has had very good success to date using Calmare Therapy. She is in amazement and doesn’t want to call it a miracle treatment, but she has been very impressed with the results thus far. For more information, please visit her website at www.georgiacalmaretherapy.com.

**COVID-19 Strategies**

Rabia says that many of the strategies we can use to boost our immune systems and reduce inflammation to aid with COVID-19, we can use in general for CRPS and Chronic Pain. Rabia’s top three tips to reduce inflammation are the following:

1) Focus on nutrition - eat nutrient dense foods
2) Focus on healing the gut
3) Work on calming the nervous system to bring down stimulation and stress (this is a challenge when we are always dealing with chronic pain and our nervous systems are always on high alert)

**Nutrition - “Food as Medicine”**

- Start with one meal at a time!
- Try boosting color (think of the rainbow)
- Eat foods with high doses of Vitamins C and A (colors include oranges and reds)
- Eat lots of vegetables (non-starchy, like leafy greens) and fruit
- Eat stuff that grows from the earth
- Eat organic as much as possible
- Increase protein intake that has zinc and amino acids which are important for building new things in the body (i.e., meat, nuts, seeds, eggs, shitaki mushrooms, etc.); minimum 60 grams/day for women; men 70+
- Increase “good” fats that reduce inflammation and have omega 3 and 6 such as fish, salmon, halibut, cod, nuts, seeds, avocados, etc.; stay away from “bad” fats such as dairy and red meat that increase inflammation
- Omega 3 supplement - “just because you don’t eat it doesn’t mean you don’t need it” good for brain and heart health; need it for every cell in the body
- Stay away from processed foods, especially sugar (ideally only 20-30 grams/day)
- Swaps are good, such as coconut, berries, paleo brownies (google for substitutes)
- Give your body more of what it needs and less of what it doesn’t to help prevent viruses
- Do your best; some is better than none
**Email Rabia for “Phytonutrient Spectrum Food” and “Detox Food Plan” documents

Healing the Gut
- Your brain is tied to your gut; what happens in your gut impacts your brain
- 90% of serotonin is made in your gut which impacts stress, anxiety and depression
- Inflammation in the gut impacts inflammation in the rest of the body
- You have bacteria in your gut; by adding more plant based and fermented foods (Kimchi, sauerkraut, yogurt, etc.) that have live bacteria you will reduce inflammation
- Greater than 50% of our immune system is located in the gut.
- Processed foods (sugar, and other foods that shouldn’t be there) can override good foods (fiber, etc.) and you will have “bad growth.” You will then start having digestive symptoms and GI issues.
- Eat more prebiotic foods such as bananas, apples and artichokes
- Stress also affects the gut
**Email Rabia for “The 5R Framework for Gut Restoration” document

Calming the Nervous System
- Manage physical and emotional stress
- Hydration is very important for pain but also for staying well in general
- Focus on what you CAN control, not on what you can’t. For example: Did I social distance? Did I wear a mask?
- Take a walk outside; turn off the news; call loved ones; try yoga classes on YouTube; meditate and do breath work; get enough rest
- Now is the time to try new things
- Supplements/Vitamins: High potency multivitamin, Omega 3, prebiotic and probiotic (multivitamin of the gut)
- Ask yourself three things everyday:
  1) What real food did I eat today?
  2) How did I care for my gut today?
  3) How did I manage my stress today?
**Email Rabia for a probiotic supplement recommendation link

Rabia also provided our group with the following link of additional tips for boosting immunity during the COVID-19 outbreak.

To find out more information about Rabia Vaughns (PAC), Functional Medicine and Calmare Therapy in Georgia, or to email her for the additional resources mentioned in this article, her business contact information is below:

New Life Wellness: www.newlifewellness.net Georgia Calmare Therapy: www.georgiacalmaretherapy.com Phone: 706-688-9355

Bio:
Melissa Wardlaw was diagnosed with CRPS/RSD as a result of a spinal cord injury (non-paralyzing) suffered during a routine medical procedure. She also suffers from fibromyalgia, lumbar and cervical degenerative disc disease, migraines and additional chronic medical issues. Formerly a Business Executive/Consultant with an MBA in Entrepreneurship, she is also a Certified Career Coach and Certified Professional Resume Writer, and now spends her time career coaching and offering peer counseling/advocacy (pro bono) to those dealing with similar medical struggles. As a fierce advocate, she also runs both in-person and online support/empowerment groups for CRPS/RSD and chronic illnesses/pain in the Metro Atlanta area. A “fur mom” to two cats, Melissa is an avid volunteer and supports multiple organizations committed to rescuing animals and helping those with chronic illnesses/pain. She can be reached at crpsatl@gmail.com.
What is the Relationship of a Differential in the COL11A1 Gene to CRPS?

BY STEVEN BRUEHL, PH.D. • PROFESSOR OF ANESTHESIOLOGY • VANDERBILT UNIVERSITY OF MEDICINE

In our DNA methylation study that was supported by RSDSA (Bruehl S et al. DNA methylation profiles are associated with complex regional pain syndrome after traumatic injury. Pain. 2019; 160: 2328-2337), we found that differential methylation in the COL11A1 gene was the ONLY gene location (out of 450,000 sites examined across the genome) that showed true genome-wide significance for a link to CRPS development after traumatic injury. DNA methylation (in which gene activity is turned off or on by environmental or genetic factors) is not exactly the same as showing links between genetic mutations and CRPS, but our findings are certainly suggestive of possible links between genetically-determined collagen-formation variants and CRPS.

Here is a relevant section of the article discussion regarding COL11A1 for what it’s worth:

“The largest differential methylation effect in the current work was for the COL11A1 gene. COL11A1 is involved in collagen formation, and notably, the only prior gene expression work in CRPS found that one of the top differentially expressed genes was also a collagen-related gene, MMP9.37 There is no prior evidence of a specific role for collagen-related factors in CRPS, although we might speculate that given the role of collagen in skin formation,54 altered expression of genes such as COL11A1 and MMP9 might contribute to altered skin growth often characteristic of CRPS.7,8 In addition, it may be relevant that both the COL11A1 gene and the KRT16 gene are part of the TFAP2A gene regulatory network.77 The protein expressed by the KRT16 gene has been shown to be a target for autoantibody responses in a preclinical CRPS model.61

Here are the other relevant references cited above:


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Barriers to research include funding and having a large patient population for testing. Dr. Hao says he would like to collaborate with neuro-medical professionals and use Functional MRI studies to understand exactly how this treatment affects the brain. The documentary film “A Return to Life,” which follows his patients before, during, and after treatment is in post production and the trailer can be viewed at the NAI website. During my hour-long talk with Dr. Hao I was struck by his enthusiasm and relaxed, genuine attitude. He described many patients and conditions he has treated, including several at Walter Reed Medical Center who had Phantom Limb pain and CRPS. Interviews and testimonials on the Institute’s web site and articles about him in the media offer tributes to unexpectedly swift and amazing cures.

With a smile he tells me, “Now our son is grown up, I have more free time. I’d like to give something back to society, help more people change their life, and return to a new life.”

1https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3833481/
2https://www.youtube.com/watch%3Ftime_continue=141%26v=Zo5M4Kuly70&feature=emb_logo
3https://www.youtube.com/watch?v=rAGEdh5bNA
5https://www.acupuncturetoday.com/mpacms/at/article.php?id=30431

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1https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3833481/
2https://www.youtube.com/watch%3Ftime_continue=141%26v=Zo5M4Kuly70&feature=emb_logo
3https://www.youtube.com/watch?v=rAGEdh5bNA
5https://www.acupuncturetoday.com/mpacms/at/article.php?id=30431
I showed up to the athletic training room at Princeton on September 1 in a large boot and on crutches, unable to bear any weight on my ankle. Luckily, I recovered quickly and was back to running in three weeks. By mid-October I was back to fully training for indoor track. Little did I know, I had just awakened a beast in my shin that did not fully unveil itself until January 18, 2011.

I began experiencing pain in the middle of my tibia at the end of October and stopped running right before Thanksgiving 2010. Several scans and inconclusive test results later, I began treatment for a mid-tibia stress fracture. Shortly before Christmas I was put on crutches. For the next three weeks, I was completely non-weightbearing, so when I returned to campus on January 4th (my birthday), off crutches, I felt great...for a total of 10 minutes. That’s when I knew something wasn’t right. The burning sensation worsened under sheets and while wearing pants, to the point where I was back home studying for finals crawling three feet from my room to the bathroom.

It was not until a Saturday night in the middle of January, when I called Dr. Lisa Callahan complaining of a constant and horrific burning sensation on my shin, that we realized what we were dealing with. On Monday morning, I was in the office of Dr. Dan Richman, a renowned pain management doctor whose specializes in RSD/CRPS. By Tuesday I received my first of eight Lumbar Sympathetic Nerve blocks.

From January to March, I was a full-time student who was barely at school. Each Monday afternoon, I would travel over an hour to the Hospital for Special Surgery in New York City (HSS) to receive the blocks. Afterwards, I would be very loopy from the Ativan given before the procedure so I would stay home, and my mom would drive me to school at 6:30am on Tuesday, a 70-minute drive, making it just in time for 9 am Psychology lab. Both of my parents were (and still are) absolute saints throughout this time.

Although it was suggested by the Dean of my residential college, my parents, and my doctors that I take a year off, I refused. Being on campus with my friends and teammates, going to class and to the training room was the normalcy I needed to get me through this mentally and physically painful time. Even though my concentration and memory temporarily declined due to the Lyrica, a medicine used to normalize overactive pathways, and my grades suffered, I still do not regret my decision to stay. My doctor began to immediately wean me off the Lyrica but kept me on the Ketamine cream to continue to reduce the amount of pain and inflammation in my shin. Of all the treatments, the topical Ketamine, physical therapy exercises, and therapy sessions were the most beneficial in defeating this disease. Aside from my family, staying at Princeton was the only thing keeping me going. If it wasn’t for such a strong support system, I would have felt like there wasn’t much point in being alive.

The road to my first race began in the Fall of 2012 but to say it was smooth sailing would be an enormous lie. I had taken the better part of two years off but was finally able to run five days a week that fall and begin workouts by the end of October. However, I began to let my mind get the best of me by convincing myself that I needed to lose weight. I felt great in workouts until my body could no longer handle being under-fueled.

I celebrated my 21st birthday over the toilet with the Norovirus, losing even more weight. When I returned to campus a few days later, my roommate was horrified by how skinny I looked. My teammates and coach voiced their concerns as well, but I was able to hide behind having had the Norovirus. It wasn’t until I was in the hospital with a Kidney Infection (from a UTI) looking at my back in the mirror, bones sticking out more than usual, that I realized I was too skinny. That realization allowed me to see that it wouldn’t be the CRPS stopping me from competing but instead, the games I was playing in my head.

Three weeks after I got out of the hospital, I finally had a breakthrough in practice. It was time to ask my coach if I could race. On February 16, 2013, I stepped onto the start line in the 800 meters for the first time in almost three years. The best part about that day wasn’t the race but the people who were there to cheer me on. My support system helped me to believe I would run competitively again, even when it felt unlikely.

Even though I did not accomplish anywhere close to what I had hoped to during my time in the NCAA, I can say this experience taught me the importance of resiliency. It is the reason, along with my doctors, parents, family, friends and physical therapist, that I haven’t had a serious CRPS-related setback in over nine years. For that, I couldn’t be more grateful.
A Poem for RSDSA Helpers

By George Brugliera

Morning came early today;  
Now showered and clean,  
Felt my icy cold steering wheel,  
The traffic scene.

The sun arrived right around lunch,  
But my job took it back,  
Left my nerves in a bunch.

The studying I do,  
For work and my job,  
Leaves welts on my eyelids,  
And stress that pulls hard.

Driving from work  
The song soothes my soul,  
Or silent meditation  
From all that life pulls.

Believe or not,  
I’m sitting at home,  
Just wondering how you’re doing  
As I make up this poem.

Sometimes I can’t see the sun,  
Even though the sky is clear:  
But I feel the warmth,  
From all of you,  
The ones that care.
RSDSA BOOK QUIZ GIVEAWAY  WWW.RSDSA.ORG

The first ten respondents who answer all of the following questions correctly will receive a free copy of the *The Dyodyne Experiment* by CRPS Warrior James Doulgeris and V. Michael Santoro.

In *The Dyodyne Experiment* the novel’s heroine, Sarah Randall, contracts CRPS because of injuries. Imagine the first DNA tracking device delivered using a Genetically Engineered Virus. Available on Amazon in paperback and via Kindle.

*The action is fast and furious, and many readers will stay up late, desperate to read just one more chapter...*” - Sandra Iler Kirkland, Vine Voice

1. In what year was RSDSA incorporated as a 501(c)3 non-profit?
   a. 1984
   b. 1960
   c. 1977
   d. 2000

2. How many branded items does RSDSA sell in its store?
   a. 5
   b. 10
   c. 12
   d. 9

3. How many research projects is RSDSA currently funding?
   a. 7
   b. 5
   c. 3
   d. 1

4. True or False
   Since 1992, RSDSA has funded more than 2.2 million dollars in CRPS-related research.

5. True or False
   There are 184 videos on the RSDSA YouTube channel.

6. How many states & territories have RSDSA Support groups?
   a. 50 plus Puerto Rico & Washington DC
   b. 45 plus Puerto Rico & Washington DC
   c. 47 plus Puerto Rico & Washington DC
   d. 38 plus Puerto Rico

7. To date, how many Facebook Live presentations has RSDSA hosted?
   a. 6
   b. 5
   c. 3
   d. 4

Please email Jeri Krassner, RSDSA Special Events Coordinator with your answers. I will reply to all contestants. Thank you, Jeri, jkrassner@rsds.org
WHEN YOUR CHILD’S PAIN WON’T GO AWAY

It could be Complex Regional Pain Syndrome

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.rsds.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.

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.
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 neurologic 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.

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

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.
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.norigroup.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 to 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 putting 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. This is not a task that you can do in a single session; rather, it is a process that takes time. The goal is to help you regain your strength and mobility, and to reduce your pain. There will be days when you would rather not follow the home program or go to therapy, and moments when your pain increases and you question the reason for putting yourself hurt even worse. In those moments, let your hope of recovery and the support of close ones cheer you to continue.

Home Exercise Programs

A home exercise program is a set 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.
What is Complex Regional Pain Syndrome

Complex Regional Pain Syndrome (CRPS) is a chronic pain syndrome. CRPS generally involves a dysfunctional response of the nervous system and may develop after a traumatic injury or a period of immobilization. CRPS is divided into two categories: Type I (formerly known as Reflex Sympathetic Dystrophy) and Type II (formerly known as Causalgia).

What Does CRPS Look Like?

CRPS pain is often described as deep, aching, cold, and/or burning and is frequently associated with increased skin sensitivity. Pain is generally rated moderate to severe and is disproportionate to any inciting event.

Symptoms of CRPS can include abnormal swelling, abnormal hair or nail growth, abnormal skin color or temperature changes, abnormal sweating, limited range of motion, and movement disorders.

Evaluation of CRPS for Functional Rehabilitation

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

Treatment Protocols

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

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

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

Contrast baths that gradually broaden the temperature difference between the two can work toward tolerance of heat or cold.1

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

Stress Loading consists of two principles: 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 or swelling, the amount of the extremity, after several days a decrease in symptoms will begin to be evident. Use of the affected extremity in daily tasks is encouraged throughout rehabilitation to inhibit muscle guarding and disuse atrophy.2

Scrubbing consists ofagents ofwasting resistance in a back/forth movement while weight bearing through the extremity.3 The patient scrubs against a hard surface, keeping the brushes in constant contact with the surface, while maintaining constant pressure on the brush. The amount of weight placed though the affected extremity and the duration of the activity are gradually increased.

Scrubbing is performed with the patient in quadruped for upper extremity involvement and in elevated sitting or standing for lower extremity involvement.4 For upper extremity involvement it is important to use a scrub brush with the affected hand. For lower extremity involvement, a long Velerol® 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 using a standing table or counter. Patients with limited wrist extension may benefit from using a handled brush.2 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 for 5-10 minutes a day, whenever the patient is standing or walking.5,6 The lower extremity can be loaded in a variety of ways.7 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. standing on the unaffected foot) and the affected foot during daily 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/or mindfulness based stress reduction (MBSR). Mindfulness is a form of meditation practice that is commonly used to help treat chronic pain. The practice of these interventions should begin immediately.

Bracing/Positioning 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 sequentally or individually. This type of treatment is done over a long period of time and fast results should not always be expected.

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

Functional Training begins once the patient is actively engaged in an edema management and stress-loading program. As the pain and edema decrease, the patient becomes more able to tolerate and participate in AROM, coordination, dexterity, and strengthening tasks. Proprioceptive neuromuscular facilitation (PNF) patterns are often well tolerated during treatment.8

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistive exercises or gait training. The patient should be encouraged to gradually return to daily life activities. These treatments and activities can be very painful and the therapist must understand and be able to explain the differences between pain and damage to alleviate the fear of the patient. While these treatments should be done within the patient's tolerance, the patient must understand that they will have to push through pain to achieve their goals. Care must be taken to ensure safety of the anatomical structures in insensitive situations (as after a nerve block). Pacing and pain management techniques, such as appropriate rest breaks, alternating tasks, thermal or cold therapy, 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 promote functional use of the extremity. As CRPS varies greatly in severity and duration, it is very important for the therapist to demonstrate enthusiasm, support and encouragement of the patient during the treatment process.

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

References

**THE RIGHT TREATMENT**

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).

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**THE DIAGNOSIS**

There is no single diagnostic test for CRPS. Only a careful exam can produce the proper diagnosis.

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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.

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**WE ARE HERE TO SUPPORT YOU**

- **YOU ARE NOT ALONE** -

Reflex Sympathetic Dystrophy Syndrome Association

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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.

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**THE FACTS**

**WHAT IS CRPS/RSD?**

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

**WHAT CAUSES IT?**

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

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

**WHAT ARE THE EFFECTS?**

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

**WHO CAN DEVELOP CRPS/RSD?**

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

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**WORKING FOR A CURE**

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

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

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**COMMON SYMPTOMS**

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

What is CRPS?

- Physicians do not know why CRPS develops or what causes it, but CRPS is a nerve disorder that usually occurs after a traumatic injury, surgery, sprain, fracture, or a period of immobilization. The principal symptom is chronic pain that is dramatically disproportionate to the original injury.

- More than 150 years ago, Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.

- CRPS can lead to depression for those who can no longer work or participate in life the way they did before the onset of CRPS.

- CRPS can lead to disability. CRPS can spread to other body parts that were not originally affected.

- I may look “healthy,” but I often suffer unbearable, unrelenting, and burning nerve pain. The McGill pain scale rates the pain of people with CRPS higher than that of people with cancer, amputation, kidney stones, and childbirth.

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

- For some, lights, noise, or vibrations can cause disproportionate pain.

Here’s How You Can Help Us

- My pain is real even though it is sometimes invisible and may not be readily apparent in my demeanor or activities.

- I am learning various coping mechanisms to get through the day, but the chronic pain is always there. I have good and bad days; my pain may even change hourly, and I cannot predict how I will feel each day.

- Sometimes it hurts to be touched anywhere so please ask before you touch me.

It is OK to ask me about CRPS.

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

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

Pain Scale

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

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PLEASE CONSIDER MAKING A DONATION
Thank you for considering a donation to RSDSA. Contributions like yours are the pillars supporting our financial foundation. By making an unrestricted gift, you enable RSDSA to host conferences for adults, sponsor Young Adult Weekends, and support research. Our conferences empower patients with current information to help them make better decisions for their health and optimize their wellness as they deal with CRPS. Thus, inspiring them with positivity and strength to take control of their illness and their life. RSDSA strives to make a difference in the lives of people affected by CRPS. We also provide emergency financial assistance for those that need help with medical expenses, as many people with CRPS/RSD are unable to work.

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 35 years. We are grateful for your support!