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
Important Articles & Videos for those are Newly Diagnosed

- https://www.youtube.com/watch?v=b49DtFigbbw (good video for family and friends who may not understand)
- https://www.youtube.com/watch?v=PhE9Z9Uzz0&t=27s (peripheral nerve stimulator for people with CRPS Type II)
- https://rsds.org/educational-presentations (our recent Facebook Live presentations)
- https://rsds.org/existing-papers/#Surgery (peer-reviewed articles on surgery with preexisting CRPS)
  
  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/
- http://rsds.org/joinmembership/ Individuals can receive the newsletter via postal mail or email
- https://www.youtube.com/watch?v=9fTqE-GFy3M (good non-threatening video on desensitization)
- Watch Dr. Chopra's video: https://www.youtube.com/watch?v-wloFDUqHA1g&t-653s (just skip the diagnosis part and go to treatment. His main weapons are LDN & ketamine)
- Dr. Getson discusses the many different faces of CRPS: https://www.youtube.com/watch?v-o9q6ApLysQ8
- https://rsds.org/youve-been-diagnosed-with-crpsrsd-now-what/ the above page is the treasure trove-you can download or print out our introductory information packet etc, view some excellent videos, an excellent overview article by Steven Bruehl.
- Link to our peer-reviewed journal articles: https://rsds.org/existing-papers/
- Link to our YouTube videos of our conferences: https://www.youtube.com/user/RSDSAofAmerica/
- Free accredited on-line course for docs & nurses:
  https://rsds.org/accredited-course-on-crps-for-mds-and-rns/
- Our stories of hope: https://rsds.org/stories-of-hope/
- other related websites and organizations: https://rsds.org/related-web-sites/
- Our weekly blog: https://rsds.org/blog/
- Our patient assistance application-one-time $500 emergency patient financial grant:
  https://rsds.org/jenkins-patient-assistance-fund/
- If individuals are not on opioids, LDN is a good anti-inflammatory compounded medicine
- https://www.youtube.com/watch?v=wUnwbNslk1c&t=75s (warm-water therapy)
- https://www.youtube.com/watch?v=iiaqgU6kxg&t=5s (Brain Retraining)
- Good video on non-medical interventions with Dr. Melanie Levine, a practicing psychologist who also has CRPS:
  https://www.youtube.com/watch?v=Jj4bYhjBO14&t=104s
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/

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The Legacy of Jennifer Abramson’s Inspirational Life

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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 again pain. Also be aware of the amount of energy you are using to accomplish a task as well as the quality of your movement. Replace short, quick intense movements with longer, slower, lighter movements. Elongate the muscles when dusting, scouring, or reaching, and low down to allow a full range of motion.
- Take frequent breaks. Every twenty minutes or so, change positions, change activity, or just rest. It may take you longer to do what you used to do in the blink of an eye. So What? It is important to learn to pace yourself.
- Schedule a rest period in the middle of the morning and the middle of the afternoon. A half-hour is usually effective, but some people take an hour or longer. If you have to nap, go ahead. But many people find that just relaxing, listening to music, taking a bath, daydreaming, or meditating is effective in extending their ability to function throughout the day. Go back to your activity log and find the natural breaks where you can insert rest periods. If you think there is not time to rest, you are trying to accomplish too much.
• Make conscious transitions between tasks. For example, if you are cooking dinner, take a few seconds to breathe and stretch between peeling the potatoes and molding the meat loaf. This allows you to release muscle tension and adjust your posture as well as tune into your physical effort in order to maintain a steady, easy pace.

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

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

If you have a chronic pain condition, you have to accept that much of your life has changed permanently. This does not mean your life is over. It just means that you can’t do things the way you used to before the pain set in. If you set realistic goals, learn to pace yourself, maintain a moderate level of daily activity, and engage in pleasurable pursuit, you will be able to have a full life.
How to Obtain the Best Medical Care for CRPS

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Feinberg Medical Group  
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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 quality treaters enjoy questions and are not threatened by knowledgeable patients. Have you read up about CRPS? Have you made yourself familiar with the usual medications and treatments prescribed for this condition?
Here are some other things to consider when you are evaluating obtaining the best treatment for CRPS.

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

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

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

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

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

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

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

Tips for Managing Complex Regional Pain Syndrome

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

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

Early Diagnosis Is Key

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

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

**Treating Flare-ups**

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

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

**Treatment Is Straightforward:**

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

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

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

With better understanding of CRPS, emergency physicians will know when and how to intervene. Concern over drug seeking should be allayed, allowing appropriate care to be provided.
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 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. 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 until you see the category or tag when I first posted on that. Or simply plow through 7.5 years of detail with references. You do the work to check the side columns as I have no time to embed links below, taken from throughout this site.

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

Some patients with CRPS combine my medications with ketamine infusions.

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

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

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

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

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

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

Appendicitis

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

Medications target 3 main systems, as discussed at the conference

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

The glutamate NMDA receptor – ketamine, memantine.

Glia, the innate immune system – glial modulators.

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

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

MOVEMENT

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

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

Disclaimer

The material on this site is for informational purposes only. It is not legal for me to provide medical advice without an examination. It is not a substitute for medical advice, diagnosis or treatment provided by a qualified health care provider.
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 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 Janelewitz, MD

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

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

Setting: A tertiary care hospital.


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

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

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

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

PM R 2012;xxxx

INTRODUCTION

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

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

The few previous studies of children treated primarily with inpatient or outpatient therapy show rates of long-term full resolution that ranged from 60% to 100% [2,32-34].
Bernstein et al [2] reviewed charts of 23 children with RSD who had been treated with intensive outpatient PT of 2 to 3 PT sessions per day. Twelve patients had resolution of their pain, and 20 patients had full functional restoration after a mean follow-up time of 2.4 years. Blau [32] indicated full resolution of pain and function in 10 children with RSD after PT, with no patient spending more than 2 days in the hospital. The mean follow-up time was 1.1 years. Sherry et al [33] studied children with CRPS-1 with either home-based exercises or inpatient therapy. Outcomes after a mean of 5.25 years showed pain resolution in 88% and functional restoration in 98%. Sherry did not elaborate on how many patients received inpatient versus outpatient therapy and drew no conclusion as to whether one was better than the other. A later study by Sherry [10] also included children with more diffuse musculoskeletal pain as well as patients with CRPS-1. Treatment consisted of an average of 2 weeks of intensive inpatient or outpatient PT, followed by a 1-hour daily home program performed for another 2-8 weeks. He reported that 80% of children had no pain and were fully functional after 1 month of treatment, with 15% having some pain but full function, and 5% with no improvement at all. At the 5-year follow-up, 90% of patients were free of pain and fully functional.

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

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

**METHODS**

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

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

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

**Treatment**

Inpatient lengths of stay varied depending upon the needs of the child and response to treatment, but all children participated in 5 hours of therapy per day, 5 days per week. The 3 hours of daily PT included timed, high-intensity aerobic activities, lower and upper extremity strengthening, core strengthening, stretching or yoga, and balance or coordination activities. Aerobic activities included the treadmill, stationary bike, step-ups on a bench, sprints, and various nontraditional mobility activities. The patients were required to beat the previous day's timed aerobic activities by 1 second before moving to the next activity. Daily occupational therapy included 2 hours of exercises such as push-ups, sit-ups, plank exercises, or using an upper extremity bike. Desensitization exercises, such as brushing, towelling, 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.

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 1. Patient characteristics

<table>
<thead>
<tr>
<th>Category</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>Category</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>

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>
complex regional pain syndrome, including the female pre-
mandine of patients [2,4-6,13,15,16,19,20,23,31-34,36-38],
lower extremity involvement greater than upper extremity
[2,5,8,13,15,18,20,22,33,34,36-37,39], 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 diagnos-
sis, attempts at other treatments, or a delay in getting ap-
proval 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 percent-
age 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 in a new location. Regardless, the skills
learned in inpatient rehabilitation were effective in resolving
pain and dysfunction in 5 recurrences and kept these chil-
dren 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 substi-
tuated, for several reasons. As noted by Bruhl and Carlson
[43] and Lynch [44], the previous studies were not prospecti-
ve 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 re-
gional 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 depres-
sion can lead to chronic pain or that the distress of a chronic
pain syndrome can lead to depression. The high prevalence

**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 predomi-
nance 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

![Figure 1. Resolution of pain over time. Bars indicate number of
patients with unresolved pain at each time interval.](Image)
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 “uncited 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 than 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.1–3 The lower extremity is more commonly affected than the upper, with a ratio of about 5:1. Type 1 CRPS seems to be more common among Caucasian children. I have noted this association in my practice at both Children’s Hospital, Boston, and at the Mayo Clinic, Rochester. To exclude sampling bias, physicians at Children’s Memorial Hospital in Chicago and Children’s Hospital Medical Center in Cincinnati were also polled (personal report from S. Suresh, Children’s Memorial Hospital, Chicago, IL, and K. Goldschneider, Children’s Hospital Medical Center, Cincinnati, OH). Although these hospitals have a substantial proportion of minority patients, the same association was seen there. Bernstein et al4 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.5

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

DIAGNOSIS

The diagnosis of CRPS remains a clinical one based on appropriate findings in the history and physical examination. Pain, particularly with allodynia, and signs of autonomic instability either historically or on examination are required to make this diagnosis. The pain should be out of proportion to the inciting event, if any, and is usually distally generalized in the extremity.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.5,11,12,13 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 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 Mandy et al, Stanton et al, and Greipp et al showing that a percentage of children will have long-term pain and disability even with aggressive therapies such as sympathetic-chain catheters, and antidepressant and anticonvulsant medications.

Physical Therapy

A recent report by Sherry et al 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). 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 "unusual 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, 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, Vierya 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 et al. 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. Jaworski 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 studies 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 due to 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, anticonvulsants (particularly gabapentin), steroids (either systemically or as part of an intravenous regional technique), 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.\textsuperscript{1} and Lee et al.,\textsuperscript{25} and the intensive PT approach used by Sherry et al.\textsuperscript{5} These children and their parents will often seek multiple medical opinions and undergo increasingly invasive and dangerous procedures in their quest for pain relief. Two types of neurosurgical procedures have been used in these patients: spinal cord stimulation (SCS) and sympathectomy. There is moderate evidence supporting the use of SCS in the treatment of CRPS in adults. Retrospective series by Kumar et al,\textsuperscript{18} and Kemler et al.,\textsuperscript{19} and a later prospective series by Kemler et al.,\textsuperscript{60} all show efficacy in terms of sustained pain reduction of modest proportions. Pain thresholds are not changed by SCS.\textsuperscript{61} No series of children undergoing SCS have been reported, although I know of at least a half-dozen children who have undergone SCS for CRPS. Results have been mixed, ranging from modest improvement in pain and function to a worsening of pain, with explantation of the system. SCS has an advantage over sympathectomy in that it is nondestructive and completely reversible.

Sympathectomy, either chemical or surgical, has been reported in children with CRPS. Disadvantages of this procedure include the fact that it is appropriate only for the sympathetically mediated portion of the patient’s pain, that it is irreversible and may cause sympathetic ganglionitis 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 Johnson\textsuperscript{62} 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.\textsuperscript{1} reserved the use of sympathectomy for patients with impending loss of function from cellulitis complicating massive peripheral edema. The three patients undergoing these procedures did not have improvement in pain scores despite improvement in circulation and edema.

Complementary and Alternative Medicine
Randomized, blinded trials showing the efficacy of acupuncture are also lacking in CRPS. One such study has been performed, but there was improvement in both groups, with no statistical difference between groups.\textsuperscript{63} There are studies showing a surprisingly high acceptance rate for acupuncture therapy among children.\textsuperscript{64,65} There are also case reports of benefit to this therapy.\textsuperscript{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 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.\textsuperscript{5} Series using less-intense PT, as reported by Wilder et al.\textsuperscript{1} or Lee et al.,\textsuperscript{25} give results similar to a stepwise multidisciplinary treatment plan in adults.\textsuperscript{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.\textsuperscript{2,25} Recurrence occurred in approximately 30% to 50% \textsuperscript{2,25} of patients, a much higher rate than the rate of 1.8% per patient-year reported for adults.\textsuperscript{68} Although recurrence is common, it generally seems to respond more readily to physical therapy and related treatments than the initial episode.\textsuperscript{5,25} A case report by Tong and Nelson\textsuperscript{69} 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
twistwise, 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 truck record in
neuropathic pain management can be added, such as
the tricyclic antidepressants (nortriptyline or amitripty-
line) or anticonvulsants (gabapentin and others). Chi-
ldren taking these medications need to be monitored
carefully for side effects to optimize the risk/benefit ratio.
Sympathetic 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.

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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.

**Special Services for Those Who Can’t Go to School**

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

**Section 504**

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

**Individual Education Plan**

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

**More Information**

US Department of Education, Office of Civil Rights

Protecting Students With Disabilities:

http://www.ed.gov/about/offices/list/ocr/504faq.html

National Dissemination Center for Children with Disabilities (NICHCY)

Individuals with Disabilities Education Act (IDEA)

http://www.nichcy.org/Laws/IDEA/

Disabilities:

http://www.nichcy.org/Disabilities/Laws:

http://www.nichcy.org/Laws/

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

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**Helping Youth with CRPS Succeed School**

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“Hate what you have to do, but do it well. You have to be part of the organization’s success.”

—Karen Richards, age 11

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

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

—Dorothy Switalski

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What is CRPS?
CRPS is a neuroinflammatory syndrome characterized by pain in one or more limbs and/or ankles, feet, abdomen, or hands, and often involves a lack of predictable recovery. The pain is disproportionate to the original injury and is present long after the original trauma has healed. CRPS is most 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 numerous tests to rule out other serious conditions.

CRPS is not a life-threatening, but it can become chronic and even spread to the rest of the body. It can be highly disruptive 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.

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 patients 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 with a 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.
6. 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.
6. 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).
WHEN YOUR CHILD’S PAIN WON’T GO AWAY

It could be Complex Regional Pain Syndrome

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

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

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

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

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

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

RSDS 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.rsd.org, if you are in need or have questions.

If you think you or someone you know has CRPS/RSD, please visit your physician and provide him or her with educational information about the disease. Much more can be accessed through our website. You may also contact us at 877-662-7737.

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

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

CRPS is a 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.

THE FACTS

What is CRPS/RSD?
CRPS/RSD is a rare neurological disorder that causes severe inflammation in the sympathetic nervous system.

What Causes It?
It occurs after a trauma, such as a musculoskeletal or nerve injury, surgery or broken bone. Sometimes there isn’t an initiating event.

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

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

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

SIGNS & COMMON SYMPTOMS

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

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

WHAT TO TELL YOUR PHYSICIAN

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

JUST BECAUSE YOU CAN’T SEE IT, DOESN’T MEAN IT DOESN’T EXIST. BUT TO RECEIVE HELP, YOUR CHILD MUST BE HEARD.
Mirror Therapy and Other Brain Retraining Treatments

By Sarah M. Whitman, MD

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

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

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

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

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

What People with CRPS Should Expect from Therapy

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

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

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

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

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

Home Exercise Programs

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

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

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

Treating Complex Regional Pain Syndrome

A Guide for Therapy

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

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

What Does CRPS Look Like?

CRPS pain is often described as deep, aching, cold, and/or burning and is frequently associated with increased skin sensitivity. Pain is generally rated moderate to severe and is disproportionate to any inciting event. Symptoms of CRPS can include abnormal swelling, altered sweating, 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 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 decongestive therapy. Manual decongestive therapy (MDT) 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 in multiple small areas in increasing intensity in the skin. Stimulation can be graded from light touch to deep pressure and contact from a variety of materials. 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 positioning.

Stress Loading consists of two principles: scrubbing and carrying. A stress loading program promotes active movement and compression of the affected joints for a minimum of 3-5 consecutive minutes, three or more times each day. Though stress loading may initially produce increased swelling and pain, which peak a few days after the starting of the therapy, they subside. The affected extremity, after several days a decrease in symptoms will begin to be evident. Use of the affected extremity in daily tasks is encouraged throughout rehabilitation to inhibit muscle guarding and disuse atrophy.2

Scrubbing consists of affected extremity in a back/forth motion while weight bearing through the extremity.3 The patient scrubs a wide surface, keeping the bristles of the brush in constant contact with the surface, while maintaining constant pressure on the brush. The amount of weight placed through the affected extremity and the duration of the activity are gradually increased. Scrubbing is performed with the patient in quadruped for upper extremity involvement and in seated sitting or standing for lower extremity involvement. For upper extremity involvement, the therapist scrubs one hand with the affected hand. For lower extremity involvement, a long Veleros® 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 with the patient seated at a table or counter. Persons with limited wrist extension may benefit from using a handled brush.2 The Dystrophil® 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 each day, whichever the patient is standing or walking.5,6

The lower extremity can be loaded in a variety of ways. Walking is an important loading technique if care is taken to ensure weight bearing through the affected leg during gait, especially when an assistive device is used. Increased weight bearing can be accomplished with verbal/physical cueing or by having the patient carry a weighted object or bag on the affected side. Loading can also be facilitated by engaging the patient in activities that promote weight shifting and balance (i.e., transferring load) or by placing the unaffected foot onto a small foot stool during static standing tasks.

Mind-Body Interventions include stress reduction, desensitization of the nervous system and provide coping tools for dealing with pain. They include relaxation, meditation, guided imagery, biofeedback, hypnosis, and mind-body-based stress reduction (MBSR) which is a form of meditation practices that is commonly used to help treat chronic pain. The practice of these interventions should be considered immediately.

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

Splitting/Splitting or bracing may be used to promote increased movement and provide support to the extremity and to increase functional ability. 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 begins to reintegrate joint activities in AROM, coordination, dexterity, and strengthening tasks. Proprioceptive neuromuscular facilitation (PNF) patterns are often well tolerated during treatment.

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistive exercises or gait training. The patient should be encouraged to gradually return to daily life activities. These treatments and activities can be very painful and the therapist must understand and be able to explain the differences between pain and damage to alleviate the fear of the patient. While these treatments should be done within the patient’s tolerance, the patient must understand that they will have to push through pain to achieve their goals. Care must be taken to ensure safety of the anatomical structures in 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 maximize functional use of the extremity. As CRPS varies greatly in severity and duration, it is very important for the therapist to demonstrate enthusiasm, support and encouragement of the patient during the treatment process.

The patient, in turn, must be actively involved in integration of treatment techniques into 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).

THE DIAGNOSIS

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

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

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

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

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

Reflex Sympathetic Dystrophy Syndrome Association 99 Cherry Street PO Box 502 Milford, CT 06460 Tel: 203.877.3790 Toll Free: 877.662.7737 Fax: 203.882.8362 Email: info@rsds.org Website: http://rsds.org

Raising awareness of CRPS since 1984

COMPLEX REGIONAL PAIN SYNDROME

LIVING WITH CHRONIC PAIN MORE SEVERE THAN A CONSTANT JELLYFISH STING
HOW CRPS CHANGED A CHILD’S LIFE

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

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

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

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

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

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

To receive help, they must be heard.

THE FACTS

WHAT IS CRPS/RSD?

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

WHAT CAUSES IT?

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

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

WHAT ARE THE EFFECTS?

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

WHO CAN DEVELOP CRPS/RSD?

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

WORKING FOR A CURE

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

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

COMMON SYMPTOMS

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

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.

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.

99 Cherry Street
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FAX: 203.882.8362
www.rds.org

PLEASE CONSIDER MAKING A DONATION
Treating the Whole Person: Optimizing Wellness Recap

RSDSA hosted its first Treating the Whole Person: Optimizing Wellness virtual conference last month and it was an amazing experience!

We thank each of our speakers for attending and for providing attendees with valuable information on CRPS. Our speakers included:

- Dr. Corey Hunter
- Dr. Sherri Haas
- Dr. Andreas Goebel
- Dr. R. Norman Harden
- Elisa Friedlander, LMFT
- Lindsey Kolb
- Jeffrey Rabin, Esq.
- Dr. Jonathan Fass
- Dr. Traci Patterson
- Dr. Katinka van der Merwe
- Dr. Hannelie van der Merwe

We also loved how many CRPS Warriors enjoyed the one-on-one networking session that allowed them to meet one another via an audio and/or visual conversation. Due to the positive feedback on that portion of the conference, we will be hosting a similar event to allow Warriors to network with one another later this month. Keep an eye on the RSDSA Facebook Page for more information!

All sessions were recorded and will be available on the RSDSA YouTube Channel once they are edited! Please subscribe to our channel so you will be the first to know when they are available.
November is CRPS Awareness Month

Monday, November 2nd was the seventh annual Color The World Orange™ for CRPS/RSD Awareness, but we want to see you in your orange all month since it is CRPS Awareness Month! Be sure to sport your favorite orange all month and tag Color The World Orange and RSDSA so we can also support and repost!

Watch as Eric Moyal of Ride For Warriors delivers a TEDx Talk about his sister's journey with Thoracic Outlet Syndrome and Complex Regional Pain Syndrome.

CRPS Awareness Month Resource Page

Also tag us in photos from proclamations and special congressional recognitions you may receive in your area such as this one from the Town of Smithtown, NY. Thanks again to Stacey Udell for her leadership!

Need assistance explaining what CRPS is to those who want to learn more? Share this handy resource page with your network this month!
Rare Disease Legislative Advocates
by Nancy Shurtleff

This year, I began my participation with the organization Rare Disease Legislative Advocates (RDLA). RDLA “is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collectively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers.”

Intrigued, I visited their website at rareadvocates.org. I first learned of Rare Disease Legislative Week in Washington, DC and read some great stories about the impact individuals with rare diseases can make. I believe everyone in the rare disease community has a voice and I was interested in becoming involved in the patient advocacy community.

My opportunity came on August 14, 2020. RDLA helped organize a phone call with my U.S. Representative for California’s 45th congressional district, Katie Porter. Due to Covid-19 restrictions, we were not able to meet in person. Along with two others, we presented Representative Porter with our written and verbal request that she join the Congressional Rare Disease Caucus which is a bipartisan Congressional Caucus open to all members of the United States House and Senate. By definition, this Caucus is a forum for Members of Congress to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases. Representative Porter agreed and within a month had officially joined the Caucus!

Advocacy is easier than you may think. Advocacy is simply public support for a particular cause. Your cause! When you talk to your medical providers, pharmacist, co-worker(s), family and friends about CRPS, you are using your advocacy skills. As an advocate, you can also be an important part of the legislative and policy making process. You can make your voice heard by writing or calling your Senators and Representatives (view the sample letter on the next page!). RDLA’s website is a wealth of information! Included are advocacy tools and tip sheets, along with information on how to foster a relationship with your Member of Congress, Schedule a Meeting with your Legislator and Lobbying for Rare Disease non-profit organizations.

Last year during Rare Disease Legislative Week on Capitol Hill, with the help of RDLA, 900 Rare Disease Advocates attended, 393 meetings with Members of Congress were held, involving 227 patient organizations. In 2021, Rare Disease Legislative Week is July 19-22. Please visit the RDLA website at rareadvocates.org for information on how you can be a part of this amazing week. Together, we can make a difference.
Sample CRPS Advocacy Letter

[Date]

The Honorable [First & Last Name]

Dear Representative/Senator/Congress[wo]man,

My name is _______ and I am a resident in your district residing at __________. I am writing you today as a member of the rare disease community. I suffer from a disease called Complex Regional Pain Syndrome (CRPS), formerly known as Reflex Sympathetic Dystrophy (RSD). CRPS is a rare neuropathic debilitating, painful condition. It is associated with sensory, motor, autonomic, skin and bone abnormalities. During these trying times it is important not to lose sight that the rare disease community, a population already underserved, has borne a disproportionate amount of sacrifice in the face of Covid-19 as compared to the greater population. We have lost access to our doctors, been cut off from treatments and watched as our medications were diverted. Now, we are asking for your help.

Many people living with rare diseases are immunocompromised. This puts them at greater risk when they travel. Additionally, there are few experts specializing in rare disease conditions. This leaves patients and their families no choice but to take time and expense to see their provider, no matter how great a risk it is. In fact, a recent survey done by the National Organization for Rare Disorders (NORD) found that 39% of patients have traveled at least 60 miles to receive medical care, while 17% found the burden of travel so great that they had to move closer to treatment.

The CARES Act removed many barriers to telehealth services solving these problems. At the beginning of the pandemic, use of telehealth services went from 13,000 to 1.7 million visits per week among Medicare recipients. Under Medicare, at the height of the national lockdown, over 9 million telehealth visits were conducted. 88% of rare disease patients who were offered telehealth visits during Covid-19 accepted and 92% of them said it was a positive experience. 70% said that they would like the option of telehealth for future medical appointments.

Currently, Congress and state governments are trying to decide which changes to telehealth should be made permanent. I urge you to protect expansion of telehealth services, especially as it pertains to the rare disease community. Additionally, I ask that you re-examine the National Pain Strategy. As a patient who suffers from CRPS, one of the most painful conditions, I feel the National Pain Strategy is biased against the prescribing of scheduled pain medication for chronic pain. While it expressly provides for “responsible and reasonable use of opioids for individuals who can’t be helped by other modalities,” there are no protections for providers to prescribe at what they deem as therapeutic doses, nor is there a clear definition of what “responsible and reasonable” means. Overall, the National Pain Strategy narrative supports a false belief seen from policy makers that if non-pharmacological treatments are made more accessible, the need for pain medications will become obsolete.

Therefore, I ask that you protect the expansion of telehealth services and re-examine the National Pain Strategy.

Thank you for your time. I look forward to meeting you in your local office in the future.

Respectfully,
Angi Blake's Comfort Bears

by Kelly Hodgkins

Lying alone in the hospital waiting for surgery, Angi Blake felt helpless and hopeless. Her teddy bears of comfort are her response and her way of encouraging other Warriors suffering from CRPS by letting them know they are seen and that they aren’t in it alone.

Angi’s story of CRPS started 27 years ago when her hand was crushed between two iron microphone stand bases. It took six years for her to receive the correct diagnosis after being told it wasn’t real and that it was all in her head. It was a long, painful and lonely journey. She now has CRPS throughout her shoulders and into her intestines.

No longer able to cope with the pain, she connected with a great pain doctor who worked through various therapies with her including 12 surgeries in a four year span as well as four failed spinal cord stimulators. Angi is now on a pain pump with supplementary painkillers as well as a ketamine nasal spray and monthly infusions.

Once she had recovered enough from her surgeries, she began her comfort teddy bear project. She carefully crafts each teddy bear including the necklace and bow tie. The teddy wears a Warrior team t-shirt with a number on his back (she’s on bear 39 now!) to make each recipient feel a part of something beyond themselves and let them know someone cares. Along with the teddy bear, Angi writes a card of encouragement and sends a CPRS alert bracelet and flash drive of information pamphlets as well as a medical history document to complete and take with you to any doctor or emergency room so you don’t have to cope with remembering important information in pain and have brain fog. In return for her kindness, she asks only that each teddy bear be named on arrival and the name sent back to her to be captured in her teddy bear library. Angi says, “Most people take their bear with them to the hospital. One friend travels for a living and her bear, Phil, goes with her all over.”

Every three months, Angi reaches out to each teddy bear recipient with a card to keep in touch and remind them they are not alone.

Her teddies have been sent throughout the United States and Canada and have crossed oceans to North Wales in the United Kingdom, all at her cost. Her generosity to and empathy for those living with CRPS is immense and this project is incredibly important to her. She comments, “I never want others to feel how I did. CRPS can be a very lonely diagnosis. It is my mission to help others with it.”
Join the #CRPSChat on the First Tuesday of Each Month on Twitter

On Tuesday, November 10th, there will be a #CRPSchat at 5:00PM Pacific for all individuals impacted by CRPS.

The chat is intended to help the CRPS community meet and connect with each other. It is to share information, learn about treatments and coping strategies, make friends, and of course, to check in and support one another.

Each chat will have a different topic and the chat leader, @KateandCRPS is open to topic submissions. If you have a topic idea, please direct message the @CRPSChat account or email kateandcrps@gmail.com.

Facebook Live on Thursday, November 12th

Join our next Facebook Live with Richard Rauck, MD on Thursday, November 12th at 7p Eastern.

Dr. Richard Rauck graduated from Wake Forest University Bowman Gray School of Medicine in 1982. He received his bachelor’s degree from Davidson College in Davidson, N.C., and graduated magna cum laude. He completed his residency in anesthesiology in 1985 at the University Of Cincinnati College Of Medicine in Cincinnati, Ohio. In 1986 he completed a fellowship in pain medicine at University of Cincinnati College of Medicine.

Dr. Rauck is board certified in pain medicine and anesthesiology. He has been actively engaged in clinical research in pain medicine, speaks frequently at many national and international professional meetings, and has an active clinical practice in pain management. Currently, Dr. Rauck is practicing pain management at Carolinas Pain Institute and is the medical director for The Center for Clinical Research.
Yoga Resources

During our Treating the Whole Person: Optimizing Wellness virtual conference we had a guided Yoga session with Lindsey Kolb. Lindsey provided the following resources for those who are interested in continuing with yoga.

If you are a CRPS Warrior looking to work with a yogi, be sure to look for someone who is a yoga therapist, someone who works with clients who have chronic pain, or someone who has a PT background as well as a yoga background.

Books specifically for yoga and chronic pain:

- **Yoga for Pain Relief**
  - This book is more practice focused
- **Yoga and Science in Pain Care**
  - This book is more theory focused
- **The Yoga of Breath: A step by step guide to Pranayama**
  - Perfect if you are looking for breathing practices
- **Sun Chair Yoga, Yoga for Everyone**
  - For those looking for information on chair yoga

Video resources:

- [Accessible Yoga Class](#) [18-minute video]
- [Mini Adaptive Chair Yoga Class for People in Wheelchairs](#) [8-minute video]
- [The YogaJP YouTube Channel](#)
  - This channel features great chair yoga videos
Word Up

**Neuro-autoantibodies** [nūr-əw ə-tōw-ən-tee-bā-deez]

Neuro-autoantibodies are immune proteins that inappropriately target a person’s own nerve cells and cause pain and other symptoms.

The binding of a neuro-autoantibody to a nerve cell can cause dysfunction, damage or cell death.

Such antibodies are responsible for a broad range of neurological diseases.

Neuro-autoantibodies can contribute directly to a disease, serve as biomarkers of that disease or do both.

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**Disability Grants for Home Improvements & Repairs**

Check out and (bookmark!) this list of federal and state disability grants for home improvements and repairs from Best Mobility Aids [here](#).
Home Sharing for People with Disabilities, By People with Disabilities

Who We Are

Dwellability started as an idea between two friends with disabilities over a cup of coffee. Why did it have to be so hard to find a safe, appropriate place to live or visit? We dreamed about creating a way to connect people across the full spectrum of disability because as a community, we know we are a powerful force, but society simply isn’t meeting our housing needs.

So, we started working on Dwellability as a solution for connecting people who need a home with those who have space to share. Pretty simple, right? We hope you will join our community and let us know what we can do to make the site do its absolute best for you!

Our Founders

Dwellability is a passion project for Elizabeth Kenney and Jeff Hinz (partners in business and marriage), as Kenney has an invisible disability that affects her ability to travel and stay in hotels. Kenney is the creative soul behind Dwellability, given her textile design career and a recent graduate degree in social work from NYU. Hinz is the operations expert with 30 years of experience in advertising and startups.

What We Do

Dwellability is an online community that connects people with disabilities who are looking for accommodations, whether it be finding a roommate or a vacation rental. Dwellability caters to all disabilities: Mobility, Deaf, Blind, Cognitive, and Environmental, all in the hopes of helping meet housing and accommodation needs. People with disabilities who have a place to share or are looking for a place can become Dwellability members and find what they need. In addition, people who have spare rooms to rent can benefit by renting either short-term or long-term to people with disabilities.

Please visit www.dwellability.com to search listings, post accommodations, and read our newsletter!
Breakthrough research shows hope for reversing damage in neurological disease

Scientists say they found an immune cell that can reverse damage and restore function.

The nervous system is challenging. Once nerve cells die, particularly in the brain and spinal cord, they don’t regenerate in adults.

It’s been Dr Benjamin Segal’s life’s work.

Read the full article here.

New in the RSDSA Store: Laminated CRPS Medical Reference Cards

Purchase one of our reference cards for $2 so you can keep information about CRPS handy in your wallet at all times!

Click here to purchase.

Please send us feedback!

Please send any suggestions or upcoming events of interest to our community to info@rstds.org and please consider a donation to rstds.org/donate.
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!