Welcome to RSDSA:

The RSDSA is a 35-year old not-for-profit organization. RSDSA’s mission is to provide support, education, and hope to everyone affected by CRPS/RSD while we drive research to develop better treatment and a cure.

We invite you to join our community dedicated to working for you and your future. Being part of our RSDSA community is important. There is power in numbers. We have a community of more than 22,000. But we must increase our community so that Congress, The National Institute of Health, pharmaceutical corporations, and insurers hear our collective voice!

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

Please join us on social medial on Facebook and Twitter #@RSDSA.

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

We also have 161 educational videos on our YouTube channel: RSDSA of America.

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

Sincerely,

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

**Early Diagnosis Is Key**

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

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

**Treating Flare-ups**

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

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

**Treatment Is Straightforward:**

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

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

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

With better understanding of CRPS, emergency physicians will know when and how to intervene. Concern over drug seeking should be allayed, allowing appropriate care to be provided.
The following blog post was written on 11/6/16 by Nancy Sajben, MD for her website. You can visit her website by https://painsandiego.com/2016/11/06/medication-summary-for-intractable-pain-crpsrsd/.

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

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

Below is a brief list.

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

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

Some patients with CRPS combine my medications with ketamine infusions.

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

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

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

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

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

5. Testosterone in either male or female is depleted by opioids, it may be depleted by stress. Low T is a risk for depression, weakness and osteoporosis.
7. Dextromethorphan – reduces hyperexcitable glutamate
8. Oxytocin
9. Memantine – double the Alzheimers dose for CRPS. Like ketamine, it blocks the NMDA receptor.
10. Lamotrigine
11. Palmitoylethanolamide (PEA, PeaPure) a glial modulator, also acts on mast cells. A food supplement. No Rx. Your body makes it. Plants make it. Capsules & cream
12. Ketamine via nasal spray, under tongue combined with IV or not, works on glutamate-NMDA receptor. Not an essential drug. Where ketamine has stopped working, patients have become pain free after years of CRPS.
13. Creams combinations, so many. Most of my CRPS pts very much like Mg++/guai 10% each. You may or may not trial various combinations lido/keto/keta, etc. Numerous. DMSO 50%.
14. Medical Marijuana (CBD, THC, terpenes) [Marijuana saves lives](https://painsandiego.com/2016/11/06/medical-marijuana-proven-to-save-lives-science-november-4-2016/). Entire issue of Science, November 4, 2016, devoted to pain. NAC and alpha lipoic acid are noted by research from the Netherlands.

**Appendicitis**

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

**Disclaimers**

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

By Guest Bloggers Bobby and Lauren Geller

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

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

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

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

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

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

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

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

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

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

With appreciation and gratitude,
Lauren and Bobby Gellert
Outcomes of Children With Complex Regional Pain Syndrome After Intensive Inpatient Rehabilitation

Valerie Brooke, MD, Steven Janseleiwitz, 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;xxx

INTRODUCTION

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

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

The few previous studies of children treated primarily with inpatient or outpatient therapy show rates of long-term full resolution that ranged from 60% to 100% [2,32-34].

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Disclosure Key can be found on the Table of Contents and at www.pmijournal.org

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Bernstein et al [2] reviewed charts of 23 children with RSD who had been treated with intensive outpatient PT of 2 to 3 PT sessions per day. Twelve patients had resolution of their pain, and 20 patients had full functional restoration after a mean follow-up time of 2.4 years. Blau [32] indicated full resolution of pain and function in 10 children with RSD after PT, with no patient spending more than 2 days in the hospital. The mean follow-up time was 1.1 years.

Sherry et al [33] studied children with CRPS-1 with either home-based exercises or inpatient therapy. Outcomes after a mean of 5.25 years showed pain resolution in 98% 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 motting, hyper-sensitivity to light touch, skin temperature changes, altered perspiration, and/or changes in patterns of hair growth. Patients were admitted for treatment based on diagnosis, patient and family willingness to enter treatment, and approval from insurance.

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

Treatment

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

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

RESULTS

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

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

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...
to achieve resolution. Although counseling was recommended for nearly all the children after discharge, only 5 participated, all of whom had eventual resolution of their pain.

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

**DISCUSSION**

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

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

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

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

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

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

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

CONCLUSION

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

UNCITED REFERENCES

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

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Management of Pediatric Patients With Complex Regional Pain Syndrome

Robert T. Wilder, MD, PhD

Abstract: This review summarizes current information about diagnosis and treatment of complex regional pain syndrome (CRPS) in children. Although it has been widely held that CRPS in children is intrinsically different from adults, there appear to be relatively few differences. However, there is a marked preponderance of lower extremity cases in children. Historically, psychological factors have been invoked to explain the genesis and persistence of CRPS in children, but the evidence is not compelling. Treatment outcome studies are limited but indicate that children generally respond to a primary focus on physical therapy. Multidisciplinary treatment reports are particularly encouraging. The general perception that children have a milder course may relate to the potentially greater willingness of children to actively participate in appropriately targeted treatment rather than to innate differences in the disease process itself. Recurrence rates appear higher in adults, but response to reintervention 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. The lower extremity is more commonly affected than the upper, with a ratio of about 5:1. Type 1 CRPS seems to be more common among Caucasian children. I have noted this association in my practice at both Children’s Hospital, Boston, and at the Mayo Clinic, Rochester. To exclude sampling bias, physicians at Children’s Memorial Hospital in Chicago and Children’s Hospital Medical Center in Cincinnati were also polled (personal report from S. Suresh, Children’s Memorial Hospital, Chicago, IL, and K. Goldschneider, Children’s Hospital Medical Center, Cincinnati, OH). Although these hospitals have a substantial proportion of minority patients, the same association was seen there. Bernstein et al 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.

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. 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. 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, Franck, 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. 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.\(^{1,12}\) Sporadic early reports of children with CRPS first appeared in the 1970s. Several of these patients had spontaneous resolution.\(^ {1,6,17}\) This led to the suggestion that no treatment should be performed for children with CRPS. The rationale was that all treatments carry risks and side effects, and for a self-limited disease these should be avoided.\(^ {17}\) Other authors used treatment strategies very similar to those used in adults, including sympathetic blocks, antidepressants, vasodilators, steroids, and so forth, generally with complete resolution of the disease.\(^ {13,17-19}\) Between these two extremes was a group of authors recommending conservative treatment consisting primarily of physical therapy (PT) either with\(^ {8,20}\) or without\(^ {9}\) concomitant use of transcutaneous electrical nerve stimulation (TENS). The overall impression is that CRPS is more easily treated in children than in adults. This impression is challenged by later reports from Wilder et al.\(^ {1}\) Stanton et al,\(^ {3}\) and Greipp\(^ {21,22}\) showing that a percentage of children will have long-term pain and disability even with aggressive therapies such as sympathetic-chain catheters, and antidepressant and anticonvulsant medications.

Physical Therapy

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

A major school of thought is that PT is the treatment modality that offers a chance for resolution of CRPS in either adults or children.\(^ {24}\) All other therapies, when used, should be prescribed with the goal of facilitating the basic PT regimen. From this hypothesis one would predict that more intensive PT would provide faster and more complete resolution of CRPS. Although nonrandomized trials of intensive PT by Sherry et al,\(^ {5}\) Murray et al,\(^ {23}\) and others seem to support this, a recent prospective randomized trial by Lee et al\(^ {27}\) does not. In this study patients were assigned to once-weekly or three-times-weekly outpatient PT along with a baseline of weekly cognitive-behavioral sessions. Results for both groups were good, with pain scores decreasing to near zero and function improving, but no statistically significant difference was found between the two groups. This may have been limited by small sample size (13 per group) or because the actual amount of exercise performed may have been similar between the two groups. Curiously, the trend was for more complete resolution in the once-weekly group.

TENS

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

Biobehavioral and Psychological Treatments

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

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

A case series by Brommel et al\(^ {35}\) also found psychological dysfunction in children with CRPS. They concluded that the despair of the patients about their reflex sympathetic dystrophy expressed unsolved fears of early childhood. Again, no control groups were studied. Stanton et al,\(^ {2}\) in reviewing a series of patients with CRPS, noted that 83% of the patients given psychological evaluations had “significant emotional dysfunction.” This was not further defined, although they also noted a great deal of stress in the lives of the patients. In contrast, Vieyra et al\(^ {36}\) performed a preliminary study comparing
patients with CRPS to children with migraine headaches and 21 normal controls. Contrary to expectations, no differences in family functioning were found among the three groups. Unfortunately, this work was never published in a peer-reviewed journal. A literature review by Lynch 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.38,39

In isolated cases, psychological factors may indeed have a predominant role in the etiology of CRPS. Jaworowski et al reported CRPS in a 12-year-old who developed simultaneously a conversion disorder; her identical twin also developed an identical conversion disorder.40 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.41,42 There are no prospective placebo-controlled trials of cognitive and behavioral therapies in the treatment of CRPS, either in adults or children. Their use is extrapolated from case reports and prospective series for other pain states, notably headache.43,44 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.45 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 invite the diagnosis of CRPS. When sympathetic blocks are used in the treatment of childhood CRPS, several authors have proposed the use of indwelling catheters rather than repeated single injections.1,25,46 There are several reasons to prefer this technique. First, accurate placement of a lumbar sympathetic block is facilitated by use of fluoroscopy. Minimizing radiation exposure is appropriate for children. Second, many children and adolescents require heavy sedation or a brief anesthetic for the placement of these blocks. Minimizing the number of anesthetics required is also useful. Third, the goal of the sympathetic block is not to “treat” the CRPS per se, but rather to provide adequate pain relief that the patient can effectively engage in PT. An indwelling sympathetic-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.3,5,23 They have reported success motivating their patients to participate in PT despite ongoing pain and alldynia. Others,1,25,47 have used blocks to improve compliance in patients unwilling or unable to participate in PT secondary to pain. At present there are no prospective trials directly comparing outcomes in pediatric CRPS with or without sympathetic or epidural blockade.

**Medications**

There are also no prospective randomized clinical trials of any medications in the treatment of CRPS in children. Case reports and case series have reported success with tricyclic and other antidepressants,46 anti-convulsants (particularly gabapentin),48,49 steroids,50,51 (either systemically or as part of an intravenous regional technique),52 nonsteroidal anti-inflammatory agents,53 and opioids, both systemic and neuraxial. A good deal of controversy exists about drug therapy for this condition. Many authors have found steroids to be of no benefit.1,4,57 Those who stress the value of intensive PT suggest that no medications are appropriate.5,23 The rationale is that all medications may have side effects and the potential for morbidity. As they are not necessary in the view of these authors, they should be avoided. Sherry et al stopped all medications at the start of the PT program.1 A direct comparison of intensive PT with or without any of these medications is lacking.
Neurosurgical Techniques

A few children with CRPS fail to respond to multiple treatment approaches, including the stepwise multidisciplinary approach used by Wilder et al. and Lee et al. and the intensive PT approach used by Sherry et al. These children and their parents will often seek multiple medical opinions and undergo increasingly invasive and dangerous procedures in their quest for pain relief. Two types of neurosurgical procedures have been used in these patients: spinal cord stimulation (SCS) and sympathectomy. There is moderate evidence supporting the use of SCS in the treatment of CRPS in adults. Retrospective series by Kumar et al.8 and Kemler et al.9 and a later prospective series by Kemler et al.10 all show efficacy in terms of sustained pain reduction of modest proportions. Pain thresholds are not changed by SCS.11 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 sympathegalgia, 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 Johnson12 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.13 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.14 There are studies showing a surprisingly high acceptance rate for acupuncture therapy among children.15,16 There are also case reports of benefit to this therapy.17 It is rational to think that acupuncture, by its mechanisms of raising endogenous opioids and acting as a counter-stimulant to “close the gate” on spinal cord transmission of pain signals, might be of benefit in this disorder. Well-blinded studies are difficult to design, however, so obtaining definitive proof of efficacy may be slow in coming.

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

CONCLUSIONS

CRPS in children has been widely held to be intrinsically different from that in adults. This has been based on both demographics and a perception that children may have a milder course or a better response to conservative treatments. Other than the marked preponderance of lower extremity CRPS in children and adolescents, the demographics do not seem all that different for children than adults. A female preponderance exists for both groups. Both appear to have Caucasian predominance. Psychological factors are often invoked in pediatric CRPS, including enmeshment of the patient and parents and a degree of overachievement. Although this certainly may play a predominant role in some cases, the available evidence is not compelling that children with CRPS are unique compared with either other children with chronic pain or adults with CRPS. Finally, as regards the perception that children have an easier course than adults do, the evidence is not strong. Certainly, several series have reported children responding to courses of intensive PT alone. Nonetheless, the consensus is that PT is the definitive treatment of adults with CRPS as well as children. I have been unable to locate any series of intensive (5–6 hours per day) PT programs for adult patients analogous to that reported by Sherry et al. Series using less-intense PT, as reported by Wilder et al. or Lee et al., give results similar to a stepwise multidisciplinary treatment plan in adults.17 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.18,19 Recurrence occurred in approximately 30% to 50% of patients, a much higher rate than the rate of 1.8% per patient-year reported for adults.20 Although recurrence is common, it generally seems to respond more readily to physical therapy and related treatments than the initial episode.5,21 A case report by Tong and Nelson22 illustrated that for some children the recurrent bouts of CRPS may be as severe as or even more severe than the original.

In summary, although not definitively proven, PT leading to active normal use of the involved extremity is generally held to be the single most effective therapy in the treatment of CRPS. Children may be willing to participate in PT, despite the associated pain, with proper motivation. In general, however, the clinician’s job is to
help provide adequate analgesia to speed progress in PT. A stepwise, multidisciplinary approach is generally in the patient’s best interest, starting with minimally invasive modalities such as TENS and biobehavioral pain management techniques. Acupuncture may be useful at this point, too, if there is a practitioner available in the community who has experience working with children. If needed, medications with a proven track record in neuropathic pain management can be added, such as the tricyclic antidepressants (nortriptyline or amitriptyline) or anticonvulsants (gabapentin and others). Children taking these medications need to be monitored carefully for side effects to optimize the risk/benefit ratio.

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 multidisciplinary program stressing exercise and rehabilitation.

REFERENCES


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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.

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

For older students, provide a designated handicapped parking space.

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

**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 “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 (a) 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


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

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*Children and adolescents who have CRPS, either by simply being supportive or helping make accommodations and modifications in the school environment. Your support and understanding can determine whether our children succeed or fail.*

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What is CRPS?
CRPS is a neuroinflammatory syndrome characterized by pain in one or more limbs and/or ankles, feet, abdomen, or hands that is virtually any part of the body that can be affected. The pain, described as burning or sharp, typically appears after a traumatic event, such as a broken bone, sprain, sports injury, automobile accident, or bad fall. There is often coldness and swelling in the affected limbs as well as allodynia (a painful response to a normally innocuous stimulus). The pain is disproportionate to the original injury and is present long after the original trauma has healed. CRPS is more common among pre- and adolescent girls than boys by about 5 to 1. It is usually seen in girls who engage in sports, dancing, or gymnastics.

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

CRPS is not life-threatening, but it can become chronic and even spread to other parts 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, with an emphasis on movement, behavioral approaches, and rehabilitation, offer the highest probability of remission.

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

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

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

When Students Require Special Accommodations
Some students may not be able to resume activities as normal. Some accommodations that have helped students with CRPS are listed below:
1. Because the slightest bump can cause lasting flare-ups of this very painful syndrome, every effort should be made to see that the child is not exposed to the bumping and jostling of school hallways. The student’s desk in each classroom should be positioned away from traffic patterns to avoid inadvertent bumping. Determine whether the student needs ergonomic seating/adjustable desk.
2. 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.
3. 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.
4. 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.
5. Because CRPS is not life-threaten, academic schedules and curricula may have to be modified, including:
   - Schedule all classes on one level or provide student with key to the elevator.
   - Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
   - If a student is unable to write, modify normal test taking, and allow additional time for tests.
   - Reduce school time if necessary (students may be late due to pain flare-ups) and supplement with home-based instruction and tutoring.
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).

Limiting Stress
Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:
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“ar’s Life in going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”
—You’re
INSIDE THIS ISSUE: READ ABOUT ERIC’S 1,700 MILE “RIDE FOR WARRIORS” ON PAGE 12
CALL FOR AUTHORS & IDEAS
Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? Is there a special topic you would like to see included in the RSDSA Community Update? We would love to hear from you. Please email your thoughts to info@rsds.org.

SPECIAL THANKS
We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Arkansas Pain Center, LTD, Baker Family Charitable Trust, Center for Pain Management, Edelman, Krasin & Jaye PLLC, Grüenthal, Law Office of Scott Callahan, MCARE Pharmacy, Sutliff and Stout Neurologic Relief Center, NoPainHanna, Oska, Pope/Taylor National CRPS/RSD Lawyers, Shirley Ryan Ability Lab, Vitalitus.
Three years after the Center for Disease Control (CDC) released its Guidelines for Prescribing Opioids for Chronic Pain, intended for primary care providers (PCPs), three of the Guideline authors recently wrote an article in the April 24 issue of New England Journal of Medicine acknowledging untoward consequences related to the misapplication of the Guidelines. For the past three years, RSDSA staff, the Board of Directors and I have struggled to help individuals with Complex Regional Pain Syndrome (CRPS) and other chronic pain syndromes deal with the misapplication of this Guideline. Individuals on long-standing high-dose opioid therapy reported being abandoned by their PCPs or pain specialists, were forced abruptly to taper to a much less efficacious dosage (90 Morphine milligram equivalents or below) or were forcefully tapered from stable medical regimes without regard to withdrawal symptoms. According to Thomas Kline, MD, PhD, at least 40 individuals have died by suicide due to physician abandonment, being forcefully tapered without patient consent and then being unable to find an alternative efficacious intervention or medication to treat their unrelenting pain. Furthermore, insurance companies, state legislatures, pharmacy boards and chain stores have also created obstacles for access for opioid therapy for people with chronic pain.

If you are having difficulty with your physician regarding your ongoing opioid therapy, RSDSA can provide you with the NEJM article by calling 877-662-7737 or by emailing info@rsds.org.

If you are on Twitter, consider following @bethdarnall; @ThomasKlineMD; @CIAAG-Lauren; @RSDSA; or follow Lynn Webster, MD: http://www.lynnwebstermd.com/

RSDSA ENDS ITS 20-YEAR STUDY
RSDSA has ended its 20-year study of the long-term health impact of CRPS on individuals diagnosed with it. We thank everyone who participated. We have begun the analysis of the almost ten years of data and hope to publish as soon as possible. We are very grateful for the Brodsky Foundation’s underwriting of this ground-breaking study.

We’re seeking sponsors for this newsletter for those who need it most. Earlier this month, we mailed a special appeal to our RSDSA community to ask for their help in sponsoring the newsletter for those who are housebound or don’t have Internet access. For the past several years, RSDSA has published the newsletter in both electronic and print version at no charge. Other organizations have chosen to publish only an electronic version because of increased printing and postage costs, but we have not.
Instead, we’re reaching out to our readers for help. Please become a sponsor of your newsletter so those who need it most can continue to receive in the mail. Please make a gift in the enclosed envelope to help RSDSA serve as an instrument of hope and information to those struggling with CRPS. Thank you.

As a CRPS patient, many different parts of your life have been affected by pain. The list may include day-to-day pain management and relief, sleep trouble, balancing relationships, and so on.

From personal experience, we know how hard life can be when dealing with persistent pain. It does not have to be this way. Pain patients need and deserve more. Because of that, we created the Pathways pain relief app: a self-help program that equips you with strategies and techniques to turn the volume down on persistent pain. These are designed to help calm your pain system and improve well-being.

Let’s go through some specific ways in which the Pathways program may help you as a CRPS patient:

1. REDUCING FEAR OF PAIN
   It is widely acknowledged that fear of pain leads to increased pain intensity, and CRPS patients are no exception.

   As a first step, we help you to let go of this fear. Once we are able to do that, your pain system will be able to calm and reduce the intensity of pain.

2. ON-DEMAND PAIN RELIEF TECHNIQUES
   When a painful episode comes on, you will often find yourself white-knuckling the pain. This can make a painful episode even worse.

   We empower you with proactive techniques that help shorten, or even break the pain cycle. From mindfulness and meditation exercises, to follow-along breathing exercises, and guided visualizations, which brings me to the next point.

3. GRADED MOTOR IMAGERY AND VISUALIZATION PRACTICE
   When dealing with CRPS, your perception on the affected parts of your body can become altered. The affected limb(s) may start feeling detached from your body, you may perceive it as larger, heavier or even a different temperature compared to objective assessment.

Pathways Pain Relief App
BY SANDIP SEKHON • FOUNDER OF THE PATHWAYS APP
HELLO@PATHWAYS.HEALTH

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THE SIXTH-ANNUAL COLOR THE WORLD ORANGE™ is NOVEMBER 4, 2019

Get your orange ready! The sixth-annual Color The World Orange™ for CRPS/RSD Awareness on November 4, 2019 will be here before you know it! Here are some ideas on how to get involved:

• The easiest way to participate is to wear orange on November 4 and post a picture to social media with the hashtag: #CRPSORANGEDAY™

• Plan a Color The World Orange™ party! We love receiving the amazing photos from Color The World Orange™ events from across the globe. Serve orange food and orange drinks, decorated with orange flowers, spread a lot of awareness and have a lot of fun!

• Change your Facebook page background to advertise November 4 as Color The World Orange™.

• Reach out to friends and family, encourage them to wear orange and learn more about CRPS/RSD.

• Ask local businesses to hang a sign advertising Color the World Orange™. You can find signs and pamphlets on our website: www.colortheworldorange.com

Instead, we’re reaching out to our readers for help. Please become a sponsor of your newsletter so those who need it most can continue to receive in the mail. Please make a gift in the enclosed envelope to help RSDSA serve as an instrument of hope and information to those struggling with CRPS. Thank you.

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Guided imagery, such as visualizing movements, can help to correct this. Did you know that just imagining a painful part of your body moving helps to recalibrate the brain’s perception of that body part, often without the associated pain?

In other words, just thinking of a painful movement activates the same neural pathways associated with actual practice, but without the associated pain. You can think of it like sneaking under the pain radar. The more we do this, the more we desensitize your pain system.

As an example, we had a patient who was unable to move his left arm without feeling severe pain. So to start, he began imagining a painful movement - lifting a cup of coffee. After a week, he began watching his partner perform this movement, while continuing to imagine that he was moving his arm.

Two weeks later, he was able to perform the actual movement with 30% less pain, and he continues to improve.

4. GRaded PHYSICAL ACTIVITY

Moving safely is key to overcoming persistent pain and improving health. We want to do enough to feel the benefits of physical activity, but not too much as to risk a flare up and freak out your pain system. We guide you through this, and offer a growing number of physical activity sessions.

5. WELL-BEING

Chronic pain conditions including CRPS can sap the joy from life. But stay strong and have hope. There’s no reason why you cannot still love life. We guide you on how to improve well-being in every part of life, whatever your level of pain.

From getting a good restorative sleep, to nutrition, working on your relationships, and more.

You can find the Pathways app on both the Apple AppStore and Google Play. It is free to download and one fifth of our pain relief program and meditations are free. You can then choose to subscribe with a money-back guarantee if you practice our techniques, and do not find pain relief.

A program like Pathways would have saved me years of debilitating RSI pain. That is why I created it, and I hope it helps you find relief.

To your health,
Sandip - Founder

______________________________

Take a look at how the Pathways Pain Relief App has helped fellow CRPS Warrior, Robert Hicks

The Pathways Pain Relief App has helped me in so many ways.

I was diagnosed with CRPS three years ago and, as many of us have done, I saw doctor after doctor. In hindsight, some doctors contributed to the pain by instilling fear of movement while others offered tidbits of help, but nothing substantial.

With the app, it took into account every aspect of my life that had been affected by CRPS. The sleep therapy section helped massively. My body perception, especially on my left arm, was out of whack. The visualization process and graded imagery the program took me through seemed to have helped reduce pain by at least thirty percent.

The skin on that same arm was very sensitive. I heard about the desensitization process before but the way Pathways presented it was much more useful. I practiced skin desensitization and have seen a big improvement (although it is not completely better yet).

The program helped me understand how fear, fear-avoidance and pain-anxiety was a direct cause of my body’s pain response. I was given techniques to combat these things, which again has helped.

I have never been into meditation or mindfulness. However, since that is an integral part of the program, I gave it a shot. It has become another tool that has really changed my perspective on my condition.

I cannot begin to give this enough credit. There’s so many more ways this app has helped, such as understanding my hypervigilance, how pain works, getting me back into safe, graded movements.

For the first time in years, I’m hopeful about my future. I never normally write reviews and that sort of thing, but this changed my life, so the Pathways Pain Relief app deserves it. I can see this helping many people with persistent pain.

Best,
Robert
RSDSA Collaborating with Partners

BY ELIZABETH A. SEICKEL (RN, BSN) • AKA “NURSE BETH” • BSEICKEL145@GMAIL.COM

RSDSA has been a grassroots organization since 1984, and continues to create relationships with diverse groups, organizations, and medical communities to support the CRPS community.

This makes the partnership between RSDSA and American Society for Pain Management Nursing (ASPMN) so vital. RSDSA has expanded from a local partnership with ASPMN-Long Island Chapter, which began in 2016, to a national level, serving as an exhibitor at their ASPMN 28th National Conference, “The Changing Tides of Pain Management” in 2018.

The ASPMN mission is to advance and promote optimal nursing care for people affected by pain by promoting best nursing practices. This is accomplished through education, standards, advocacy and research, making nurses indispensable members of the healthcare team.

Jim Broatch, RSDSA Executive Director, VP and Nurse Beth had the pleasure of networking with a diverse group of nurses, advanced practice nurses, nursing administrators, CNOs, staff nurses, clinical nurse specialists, clinical educators, academic educators, NP and researchers who participated from across the country. For many, it was the first time hearing about the non-profit organization RSDSA and the CRPS community it serves.

On the flip side, Jim and I were pleasantly surprised to speak with practitioners who ARE actively treating CRPS patients across the country. Discussing the clinical treatment options in their communities will help RSDSA update our patient resource list. Throughout the conference, hundreds of nurses inundated the exhibit wanting to digest posters of “What is CRPS?” “Signs and symptoms,” “Pediatric accredited CRPS course,” “What is Ketamine and LDN?” (low dose naltrexone) and to obtain RSDSA’s patient educational resources to utilize in their communities.


It was a testament to the power nurses bring to their institutions and practices and the absolute importance of RSDSA in creating these relationships.

Did you know ASPMN has local chapters? Could this be the connection you and your medical practitioners network with to bring RSDSA and CRPS information to your community and support group?

http://www.aspmn.org/chapters/Pages/localchapters.aspx

Since nurses are the gateway to engaging communities and their workplaces with energy and knowledge about national issues and trends, RSDSA is moving forward in 2019 by expanding its role at ASPMN 29th National Conference in Portland, Oregon where this year’s theme “Bridging the Gaps in Pain Management” enables RSDSA to continue its mission. RSDSA is grateful for this unique partnership.

Another unique partnership RSDSA has fostered is with the New York Chiropractic College (NYCC). With the support of Ms. Melissa Murphy, the Levittown health Center Administrator, RSDSA was able to exhibit at their November 17, 2018 event “A Women’s Health Symposium on Natural Health Care.” Meeting staff, students and community members, Nurse Beth was able
to share resources about RSDSA as well as CRPS education. In fact, NYCC has supported the RSDSA Annual Long Island CRPS Awareness Walk & Expo since it’s inception in 2016 through the donation of a raffle basket along with plans to continue CRPS education for staff and students, including student volunteer opportunities at future RSDSA walks. RSDSA appreciates this continued relationship.

RSDSA had another opportunity in 2018 to extend CRPS education with Zucker Medical Students at Hofstra University at the medical school as well as volunteer opportunities at “RSDSA 3rd Annual Long Island CRPS Awareness Walk.” In addition to the students volunteering at the medical tent, they were provided unique opportunity to speak one on one with CRPS patients to hear their stories. This provided students first hand experience and insight into the complexities CRPS patients face, while having the opportunity to meet with diverse health professionals in the “education and exhibit” tent. All of which supplements the lack of pain education in medical school curriculums. On average, there are only five to seven hours of mandatory pain education in medical schools versus over 75 hours in veterinary school.

RSDSA followed up with a presentation to the neurology club students and its professor titled “Your Patient has CRPS: Now What?” provided by Jim Broatch, Nurse Beth and Nurse Amanda, both of whom have CRPS. Interesting to note, one of the students shared that there was a question about CRPS on a state board’s exam. RSDSA outreach is making a difference!

Finally, RSDSA appreciates all the media outreach in 2018 thanks in part to Stacey Udell, PR counsel volunteer for “RSDSA Annual Long Island CRPS Awareness Walk & Expo.”

To hear a sample of this, please visit [https://rds.org/rdsa-news-room/](https://rds.org/rdsa-news-room/)

*WBAB (102.3FM); “Plugged into Long Island” with radio host: Ted Lindner aired August, 26 2018

*NLI News Radio,(102.3FM) Non-Profit Voice, WLI radio host: Al- lison Brecher August 4, 2018 LIVE

*WHRU Hofstra Student Producer Emily Sauchelli and Kimberly Donahue, WRHU News Director


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*Newsday reporter Janelle Griffith

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Advocating for the Chronic Pain Community

BY JENNY PICCIOTTO

Lauren Deluca is the founding member of the nonprofit Chronic Illness Advocacy and Awareness Group (CIAAG) which advocates and lobbies for the chronically ill. The organization is dedicated to patient education and empowerment. According to their website:

The Chronic Illness Advocacy & Awareness Group (CIAAG) envisions a world where those with disabilities and chronic illnesses are guaranteed palliative care and access to prescription life sustaining medications without stigma, fear or push-back, particularly from the medical community. We shape social narratives to promote inclusion of disabled rights and individualized patient-centered care. We lobby against political agendas and misinformation campaigns that interfere with patient’s access to vital medications and palliative care.

In this time of healthcare policy change, a complex array of factors is contributing to a loss of adequate medical care for pain patients. The overreach of CDC Opioid prescribing guidelines has left many people with intractable pain suffering without adequate treatment, leading to an increase in suicides.

Healthcare policy is also subject to economic factors such as the influence of special interest groups, drug manufacturers, corporate profit, and the financial incentives for insurers to reduce the cost of pain care, estimated at $650 billion/year. The business of healthcare has dehumanized real people, reducing them to statics.

Lauren’s own experience at the hands of the healthcare system compelled her to create the organization. After her condition was mishandled, misdiagnosed, and left untreated, she faced a life threatening medical emergency. Yet she was perceived as a person seeking drugs, not a person in a medical emergency. “If I wasn’t living it, I wouldn’t believe it,” she says.

She explained what happened to her at a session of the UN General Assembly Special Session (GASS) on Drugs in Vienna, Austria, in September of 2018. GASS is tasked with developing a plan to address the global drug problem and CIAAG, as a nongovernmental organization, was invited to speak on behalf of the chronic pain community. Lauren presented the policy solutions CIAAG has developed to address the needs of the chronic pain community while balancing the issues of world drug abuse. Her compelling address is shared below.

“Thank you for the floor, Chair, honored delegates, ladies and gentlemen. I would also like to thank the Vienna NGO Committee on Drugs and the International Association for Hospice and Palliative Care for their encouragement and support for my statement on behalf of patients who need internationally controlled essential medicines for the relief of pain.

My name is Lauren Deluca and I am the Founding President of Chronic Illness Advocacy & Awareness Group, a national non-profit working in the United States to raise awareness of the crisis of untreated pain in our country.

Our organization was formed as a result of my personal healthcare struggles in 2017 when I suffered from a pancreatic attack and was denied access to appropriate care.

I have, quite literally, been fighting for my life since May of 2017 and I am only standing here today due to the extreme measures I took to get myself and fellow patients the help we need to manage our pain and severe symptoms. For nearly a year I was bounced doctor to doctor and turned
away, One doctor told me he had taken all their patients off opioids rather than risk losing his license for anyone.

Legitimate pain patients such as myself have been slandered by care teams when we attempt to advocate for pain control as our right. Several pain management clinics have told us they no longer take new patients as the US Drug Enforcement Agency has advised them they would be shut down and their licenses withdrawn if they prescribed to any new patients.

I recently had a feeding tube put in as I can now, no longer eat solid foods due to the damage I incurred; all stemming from a denial of care based on wholly on physicians’ fear of law-enforcement and the legislative changes taking place to address the overdose crisis. Let me be clear. These measures are not addressing the current opioid overdose crisis. The tragedy of people using illicit opioids and dying from overdoses, should not impact pain or palliative care patients such as myself. Our lives matter as much as theirs, yet we are being punished by bureaucrats, regulators, and law enforcement agencies with no medical training.

Sadly, what I went through, and many others are going through in the US is becoming the “new normal” for patients suffering with chronic illness, disease and incurable conditions. Law enforcement targeting of physicians and patients increased, and there is no relief in sight, either for families suffering from the opioid epidemic, or for patients and physicians. This is why I paid my own way to come from the US to speak to you today.

If the current direction continues, all individuals will be cut off from rational access to essential opioids except for patients suffering from end-stage cancer. And even some cancer patients are coming under scrutiny, as regulators question whether their cancer is “painful enough” to warrant an opioid prescription, rather than Tylenol.

Chronic Illness Advocacy & Awareness Group is working with elected officials and the patient community to help restore balance between protecting the public health from drug abuse and the safe, essential access to opioid analgesics for the chronically ill, older persons, and persons with disabilities.

CIAAG is proposing a practical solution: we have recommended a Palliative Care Model to properly enable those with known painful conditions and illnesses to receive the appropriate care they need using a coordinated care team approach. Individuals would receive treatment for the various symptoms of their illness or condition, including appropriate pain relief, to promote quality of life for the patient and their family.

In addition, we have devised a tracking method via the ICB-10 codes to categorized the data by the illnesses type rather than number of opioid doses. This tracking mechanism will permit law enforcement to ensure proper controls are in place to alleviate diversion of controlled substances, while maintaining the ability to develop data on “best practices” for opioid prescribing.

While we recognize the importance of having controls on scheduled medications, we must not lose sight of the fact that opioids are life-sustaining, essential medications. The United States’ approach to combatting the overdose crisis is fatally aggravating it, as reflected in the record breaking number of deaths in 2017 and 2018, despite prescribing being at a 25 year low.

Failure to protect patients’ rights to access essential medications and healthcare will result in the loss of innocent lives through suicide, and inflate an already deadly statistic to a human rights crisis. And, we as a nation and a community, deserve better.

The INCB and CND have been helping the world become aware of the crisis of access to controlled medicines in more than 75% of the world. The US opioid crisis must not be allowed to derail the progress made during the UNGASS, at the Human Rights Council, and at the World Health Organisation.

I thank you.”

In the course of advocating for herself, Lauren realized two important things. First, that the State and Federal legislators she reached out to for help had no interest in meeting with her as an individual. By reframing her message and becoming a corporation, her voice gained legitimacy and she could get meetings with policy makers. Second, she realized how wide spread the problem of inadequate health care is.

Through the Facebook group she launched in fall of 2017, she met many people who shared similar stories. “Learning this
was happening to people all over the country was a wake-up call. It wasn’t just my problem, it was society’s problem. I felt compelled to fight for all these people who had no special interest group to speak for them.”

CIAAG was formed to be a resource for patient advocacy education and a platform for lobbying on behalf of patient interests. Through their partnerships with other pain organizations, they can collaborate, monitor, and speak out, giving a voice to the chronic pain community. RSDSA was the first member of the coalition, which includes the National Pancreas Foundation, Chronic Disease Coalition, and the Endometriosis Research Center, among others.

“The biggest problem,” Lauren explains, “is the lack of communication between independent disease groups. When we collaborate, we realize we have shared needs across different communities. Together we have a lot more strength to be heard in Washington, D.C.”

Taking on topics like affordable drug prices, big pharmacy interests, and the effects of the CDC Opioid Guidelines, members of CIAAG meet with governors, legislators, and international organizations. Their efforts include sending a Joint-Letter to House health care representatives in support of Medicare negotiated prices, ending monopoly abuses, and requiring transparency from drug manufactures and pharmacy benefit managers. They meet with leaders and present information at seminars educating both the public and policymakers about how “the current approach to the Opioid Epidemic is in fact now creating a crisis of untreated pain leading to increases in patient abandonment, abuse and a drastic rise in suicides in America.”

CIAAG invites you to join their efforts by becoming a member of the community through their website. Membership provides you access to their library of materials, advocacy training, tools for reaching out to your legislators, and email updates. You can also volunteer to take local action by becoming a member of the state leadership program. State leaders work together to monitor the progress of local healthcare legislation, make calls, write letters, and attend local meetings or hearings so patient’s concerns can be weighed alongside the other factors driving the legislation of new laws.

“We want to develop a panel in each state to follow legislation,” Lauren says. “We need to know what hearings are taking place, what bills are being written now. We need to be there or our rights will be taken away.”

According to their website: We all deserve compassionate, patient centered care that improves quality of life. CIAAG provides personal empowerment & education in our local communities. Learn about how you can get involved locally to help effect real time policy change to ensure access to medicine. This affects all of us: We are all one accident away from this becoming your life.

Reflecting on her journey, Lauren says that since getting her feeding tube, she has gained weight and gotten stronger, both physically and mentally. “I was bed bound and hated being alive,” she says. “I am still mostly homebound, with nerve damage and gastric episodes, but I’m learning how to deal with my limitations. I am relearning how to live my life, accepting what is, and adjusting my activities around my body. Having a focus – advocacy – keeps me sane. I was just an individual, but I learned how to engage legislative power. I want to teach others that their voices can be heard too, without even leaving the house.”

1 http://www.unodc.org/documents/commissions/CND/2019/Contributions/Thematic_Debate/26_Sep/Lauren_De_Luca_NGO.pdf
2 https://www.ciaag.net/uploads/1/1/6/5/116509489/membership_tier_flyer.png
3 https://www.ciaag.net/uploads/1/1/6/5/116509489/why_become_a_member_of_ciaags_advocate_army__1_.pdf

ABOUT THE AUTHOR

Jenny Picciotto is a writer and CRPS patient who enjoys reading and playing the piano. She was a yoga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.
If you are currently a young adult or remember what it is like to be a young adult, you understand that it can be a uniquely confusing time. You are not a child anymore but do not quite feel like an adult yet. There are so many life decisions to make about friends, dating and marriage, having children, college, careers, finances, where to live, etc. Throwing RSD/CRPS into the mix of young adulthood makes these life decisions even harder and more complicated.

During the last RSDSA Young Adult Weekend in November, attendees discussed how there is a lack of a young adult centered support groups online. No other support group page seemed to be what we were seeking out. We discussed starting a new online young adult support groups to fill the void and continue the peer support we experienced during the weekend. In April, the discussed page became a reality.

The goal of this page is to create a positive environment for young adults with RSD/CRPS to support each other and share information. If you are a young adult between the ages of 18-31 and are interested in joining the closed Facebook group, please visit the link (https://www.facebook.com/groups/332916620662853/?fref=mentions&__tn__=K-R) and answer the questions as prompted. We promise you will be among some awesome fellow warriors and you will not be disappointed!

ON THURSDAY, FEBRUARY 28, 2019 THE EMPIRE STATE BUILDING WAS LIT GREEN, PINK, LIGHT BLUE AND PURPLE IN HONOR OF ROCKET PHARM & RARE DISEASE DAY
Ride For Warriors: An Interview with Eric Moyal

BY LAUREN BENTLEY • LAURENBENTLEY93@GMAIL.COM

As the editor of the RSDSA Newsletter, there are many aspects of the job that I love: reading about the latest research studies, promoting community awareness events, learning about alternative methods for coping with pain; but perhaps my favorite part is making connections with other members of the RSDSA community and listening to their stories.

I recently had the privilege to interview Eric Moyal, an energetic, enthusiastic young adult who recently earned his masters’ degree and works in fundraising for Brandeis University. He is also the brother of a CRPS Warrior.

Throughout our conversation, there seemed to be one theme that prevailed above everything else: Eric really loves his sister – so much so that he is biking 1,700 miles to raise awareness and research funding for CRPS. No, 1,700 miles is not a typo. Eric will bike from Medford, Massachusetts, where he currently resides, to his hometown of Bay Harbor Islands, Florida. Along the way, he plans to stop in various cities and meet with those who have CRPS, along with their families. This biking fundraiser is fondly named the “Ride for Warriors.”

Eric first became aware of “the most painful disease known to man” when his younger sister, Anais, was diagnosed with CRPS approximately five years ago. Anais was riding her bike one November day when she was suddenly hit by a car. She was fifteen years old at the time of her accident. Although the initial trauma of Anais’s accident began to heal, she still felt incredible pain – and that something was still incredibly wrong. It took doctors two years to finally diagnosis Anais with CRPS and, by that time, the disease had already taken a tremendous toll on her body.

When asked what inspired him to create the Ride For Warriors, Eric said “I really love my sister, we’re like best friends. We talked a lot over the past few years about what she is going through and how hard it is. Part of the struggle isn’t just about getting a diagnosis, it’s convincing yourself that your pain is real when everyone else is telling you nothing is wrong.” He added, “it’s crazy to go through something like this and have nobody believe you. I want to make sure people are aware that CRPS exists.”
As somebody who has watched her mother battle CRPS for over a decade, I understand feeling pure helplessness and frustration when there is nothing you can do to take away their pain. During our conversation, we bonded over shared stories of misdiagnosis, doctors’ disbelief of our loved ones’ pain, and the protectiveness felt every time we heard somebody say “but you don’t look sick.” It can be hard to figure out how you can help your loved one when the disease is still relatively unknown to the medical community. Nevertheless, Eric has a simple, yet tremendously impactful way to support our Warriors – be a source of understanding. We will never be able to comprehend the level of their pain but we can offer our understanding when they endure frustrating conversations with doctors, experience the judgement of others or just need to go to bed. Anais, now 20 years old, is quite busy being a college student. Although she spends a lot of her free time raising awareness and supporting other college-aged students with CRPS through an organization called Ferocious Fighters, Anais still often experiences a lack of understanding from her peers. Understanding, Eric believes, is something every CRPS Warrior deserves.

The Ride for Warriors is set to kick off on Saturday, June 29th and conclude on July 14th. There are several ways to offer support. Follow and share the campaign on Facebook and Instagram. As mentioned, Eric will be stopping in various cities along the way and would love to speak with fellow members of the CRPS community. Reach out and arrange a time to meet Eric along his ride. If you have the means, consider offering your home as a place for him to stay (Bike route included below, for reference). There are also financial ways to support this cause – all of which go to furthering research. Pledge 10 cents for every mile that is peddled, have your local spin studio host a fundraising event or ask business or governmental organizations to serve as sponsors. Any donation, no matter the size, can be made by visiting the Ride for Warriors Giving Page, which can be found here:
https://www.firstgiving.com/event/rsds/RIDE-FOR-WARRIORS

Aside from supporting this bike ride specifically, Eric also encourages everyone to share the information they have about CRPS with others, whether that is swapping treatment stories with another Warrior or educating a family member about the disease.

The RSDSA is excited to wish Eric, and everyone else working with the Ride for Warriors, the best of luck. But, before Eric hits the road, he has one message for each and every CRPS Warrior: “There IS support and there ARE people out there fighting for you. Keep on being Warriors!”

Social Media Links:
https://www.instagram.com/ericmoyal/
https://www.facebook.com/Ride4Warriors/

Ride for Warriors Giving Page
https://www.firstgiving.com/event/rsds/RIDE-FOR-WARRIORS

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RSDSA YOUNG ADULT WEEKEND

Friday, August 9 – Monday, August 12, 2019

RSDSA is excited to announce that the second Young Adult Weekend of 2019 is coming to the west coast and will be held in San Diego, CA.

After the success of the previous events and the expressed need we will continue to schedule these events across the country!

This event is for young people 21-31 with CRPS. You are invited to attend a weekend of workshops, free time to sightsee, group excursions and spending time with people who truly understand what you are going through to the fullest extent.

Date: Friday, August 9 – Monday, August 12, 2019
Time: Starts Friday at 3:00 PM and ends Monday 12:00 PM
Hotels details to follow.

Fee: $250.00 with a $50.00 non-refundable deposit which will hold your spot. Final payment is due by July 26, 2019.

To register or for more information please contact RSDSA YAW Committee at rsdsayawknd@gmail.com

Easy Ways to Give

- Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.

- Use AmazonSmile.com and make RSDSA your charity of choice while shopping online.

- If you’re selling things on eBay, you can give a portion of the profits straight to RSDSA.

- Set up a collection canister in your local grocery store.

- Plan an event with the help of RSDSA by emailing us at jjkrassner@rds.org
Carolyn’s Cards

Carolyn’s Cards is a program that sends cards and other small surprises through the mail to individuals with Complex Regional Pain Syndrome (CRPS) and to their caregivers. The purpose is to help those feeling isolated or down because of CRPS by sending them a card to help them feel less alone, provide encouragement and support, help them feel part of a community, and most importantly to give them a smile. I received the inspiration from my Mother who would send me cards when I was down, in a lot of pain, or recovering from surgery. These cards would help to brighten my day. I thought it would be great if I could reciprocate that feeling for others. I started sending cards to the attendees of the first Young Adult Weekend as a way to stay connected to them and show support. I was surprised to hear how much they genuinely enjoy the cards. I have continued to add names to my list after each Young Adult Weekend.

The cards can be sent for birthdays, holidays, other celebrations, after medical procedures, or when we receive notification that someone is having a difficult time. Carolyn’s Cards will receive names and addresses via recommendations provided by RSDSA or directly emailed to carolyns.cards2@gmail.com.

Poetry Corner

The Breeze
by Sheryl Freed

Like panning for gold from the sky
I stand beneath the breeze
tossed trees
Hands spread wide
and eyes a shimmer
Reaching for the leaves
One last monarch flutters on by
I rest amid the amber drop
Breathing deeply,
my cheeks a glow
Drinking in the warmth
Snuggle close the chill is near
I hold inside my soul the blaze
Arms spread wide
and hearts a fire
Lean in for a kiss
Joy is found but in the moment
I will push aside the sorrow
The burning is pain,
the fear is real
Careful not to touch

Please consider purchasing a magnetic awareness ribbon for your car for only $5. Please send your check to: RSDSA. PO Box 502, Milford, CT 06460 or call us at 877-662-7737.
THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

RSDSA 2019 EVENTS CALENDAR TO DATE

**JUNE**
- 6/29 - 07/16 Ride for Warriors - Eric Moral

**JULY**
- 7/27 Charity Ride for Pain Survivors (CRPS). Derry, PA - Jason L. Caldwell, Sr.

**AUGUST**
- 08/8 - 08/12 Young Adults Weekend, San Diego, CA - RSDSA Sue Pinkham and Sharon Weiner

**SEPTEMBER**
- 9/7 4th Annual Long Island Awareness Walk Eisenhower Park, Long Island, East Meadow, NY
- 9/22 1st Annual Walk in Ocean Township New Jersey - Judy and Bob Hopkins
- 9/29 6th Annual Fight the Flame 5k, Charlotte, NC - Beth and Steven Stilittano
- 9/29 4th Annual Knock Out Pain 5k - Easton, PA - Sarah O'Steen

**OCTOBER**
- TBD 3rd Annual Tame the Pain Golf Event, Galena, OH - Sharon & Matt Weiner
- 10/26 Treating the Whole Person: Optimizing Wellness, Denver, RSDSA

**NOVEMBER**
- 11/3 Fight the Flames, Mentor, OH
- 11/4 Color the World Orange, Worldwide
- TBD RSDSA Swimming Fundraiser, Salt Lake City, UT - Konnie Parke

**PEER TO PEER**

If you wish to take advantage of this program, please do the following.

- Please contact LindaLang@rsds.org
- Please provide your email, phone number and a little bit about yourself.

*Don’t see an event near you?*

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

Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rsds.org
WHEN YOUR CHILD’S PAIN WON’T GO AWAY

It could be Complex Regional Pain Syndrome

TREATMENT OPTIONS

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

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

ADDITIONAL RESOURCES

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

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

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

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

RSDSA offers emotional, financial and medical support to people suffering with CRPS. We can also provide referrals to pediatric rehabilitation programs.

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

If you think you or someone you know has CRPS/RSD, please visit your physician and provide him or her with educational information about the disease.

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

Stay connected with us by subscribing to our bimonthly newsletter, joining our community email news blasts, or visiting our Facebook page.

RSDS.ORG
877-662-7737

RSDSA SUPPORTING THE CRPS COMMUNITY
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.
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 neurostimulator--and, by the way, now you need to start physical therapy.

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

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

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

Home Exercise Programs

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

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

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

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

Reflex Sympathetic Dystrophy Syndrome Association

99 Cherry Street
Luxembourg, CT 06405
Tel: 203.877.3790
Toll Free: 877.662.7737
Fax: 203.882.8362
Email: info@rdsd.org
Web: http://rdsd.org

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

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

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

What Causes CRPS?

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

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

Evaluation of CRPS for Functional Rehabilitation

Principal areas to evaluate are range of motion, strength, edema, dexterity, skin/vasomotor changes, pain/sensation, the presence of abnormal guarding or protection postures/movements and active use of the extremity during the 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 lymphatic drainage (MLD) 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 diuse.

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

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

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

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

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

Scrubbing is performed with the patient in quadruped for upper extremity involvement and in elevated sitting or standing for lower extremity involvement. For upper extremity involvement, the affected extremity is placed on a table or chair. Person with limited wrist extension may benefit from using a handled brush. The Dystrophie® can be used on several locations in order to have a greater range of motion.

Modifications can be made to enhance performance or compliance. For example, upper extremity scrubbing may require an additional table or chair. Lower extremity scrubbing can be performed using a handheld handle. The Dystrophie® can be used on several locations to improve the range of motion.

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 three times a day, whichever the patient is standing or walking.

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

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

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

Splinting/Bracing is used in severe cases of CRPS. Splinting or bracing may be utilized to promote immobilization, minimize inflammation, reduce pain or by placing the unaffected side of the body or limb. Paper presented at Midwest Pain Society. Seattle, Washington: AOTA National Conference; 2000.


References


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

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

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

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

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

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

**WE ARE HERE TO SUPPORT YOU**

- **YOU ARE NOT ALONE** -

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Raising awareness of CRPS since 1984
HOW CRPS CHANGED A CHILD’S LIFE

Once a successful swimmer and a student council member, fourteen-year-old Natalia is now trapped in her body. After a mild wrist sprain, Natalia’s fingers swelled into blood-red sausages. The pain prevented her from even holding a pencil. Exactly a week after her thirteenth birthday, a neurologist finally diagnosed her with CRPS after many ER visits. In the following months, she was hospitalized more than a dozen times.

Just as she began to show improvement, a car collided with her school bus, and her CRPS spread. Pain covered every inch of her body; Natalia has not walked since. Her parents have been unable to hold her hand or hug her for over a year.

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

To receive help, they must be heard.

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)

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

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

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

- CRPS can lead to disability. CRPS can spread.

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

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

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

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

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

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

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

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

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

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

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

- It is OK to ask me about CRPS. Better yet, visit www.rsdso.org and learn all you can.

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Pain Scale

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

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

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

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