Welcome to RSDSA:

The RSDSA is a 36-year old not-for-profit organization. RSDSA’s mission is to provide support, education, and hope to everyone affected by CRPS/RSD while we drive research to develop better treatment and a cure.

We invite you to join our community dedicated to working for you and your future. Being part of our RSDSA community is important. There is power in numbers. We have a community of more than 39,000. But we must increase our community so that Congress, The National Institute of Health, pharmaceutical corporations, and insurers hear our collective voice!

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

Please join RSDSA on social media on Instagram @rsdsa_official, RSDSA Facebook and, Twitter #@RSDSA.

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

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

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

Sincerely,

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

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

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

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

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 knowledgably patients. Have you read up about CRPS? Have you made yourself familiar with the usual medications and treatments prescribed for this condition?
Here are some other things to consider when you are evaluating obtaining the best treatment for CRPS.

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

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

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

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

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

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

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

Tips for Managing Complex Regional Pain Syndrome

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

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

Early Diagnosis Is Key

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

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

**Treating Flare-ups**

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

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

**Treatment Is Straightforward:**

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

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

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

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

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

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

Below is a brief list.

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

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

Some patients with CRPS combine my medications with ketamine infusions.

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

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

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

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

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

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

Appendicitis

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

Medications target 3 main systems, as discussed at the conference

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

The glutamate NMDA receptor – ketamine, memantine.

Glia, the innate immune system – glial modulators.

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

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

MOVEMENT

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

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

Disclaimer

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

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

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

Setting: A tertiary care hospital.


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

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

Results: All the children had failed various prior treatment approaches: 34% had resolution at the time of discharge; 78% of admissions and 89% of those with follow-up had eventual resolution of pain; and 95% had full restoration of physical function at a median time from start of treatment of 2 months. Seven had recurrence and 9 were able to resolve the recurrence without further intervention from the medical community.

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

INTRODUCTION

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

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

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

Sherry et al [33] studied children with CRPS-I 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-I. 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-I was made by 1 of 3 pediatric physiatrists working at the clinic and hospital with experience in diagnosing and treating children with CRPS-I. 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-I 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.
Table 1. Patient characteristics

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

Table 2. Signs and symptoms on day of admission

<table>
<thead>
<tr>
<th>Symptom</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>32 (100)</td>
</tr>
<tr>
<td>Hyperesthesia</td>
<td>27 (84)</td>
</tr>
<tr>
<td>Skin color changes</td>
<td>15 (47)</td>
</tr>
<tr>
<td>Temperature changes: hot</td>
<td>13 (40)</td>
</tr>
<tr>
<td>or cold</td>
<td></td>
</tr>
<tr>
<td>Swelling</td>
<td>5 (16)</td>
</tr>
</tbody>
</table>

Table 3. Pain location

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

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

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

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

Table 4. Previous treatments

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

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

**DISCUSSION**

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

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

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

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

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

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

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

CONCLUSION

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

UNCITED REFERENCES

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

ACKNOWLEDGMENTS

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

REFERENCES


Management of Pediatric Patients With Complex Regional Pain Syndrome

Robert T. Wilder, MD, PhD

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

Key Words: complex regional pain syndrome, pediatric


DEMOGRAPHICS

In children less than 18 years of age, complex regional pain syndrome (CRPS) type 1 develops most commonly in girls, with the incidence rising at or just before puberty. 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,10 Franx,11 Chappel, and others has argued that disturbed vascular scintigraphy with increased pooling in the initial phase and hyperfixation on bone scintigraphy is necessary on bone scan to make the diagnosis of CRPS. In contrast, most other authors find that bone scans are quite nonspecific for the diagnosis of CRPS. Multiple authors have found that in patients meeting the clinical diagnosis, bone scan may show either hypofixation or hyperfixation or may be normal.5,12,13 This is not to say that bone scans are not useful in working up the patient with signs and symptoms of CRPS; however, the primary utility is in ruling out some underlying orthopaedic abnormality that might be triggering the neurovascular changes rather than diagnosing CRPS.

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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.\textsuperscript{14,15} Sporadic early reports of children with CRPS first appeared in the 1970s. Several of these patients had spontaneous resolution.\textsuperscript{16,17,19} 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.\textsuperscript{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.\textsuperscript{15,17-19} Between these two extremes was a group of authors recommending conservative treatment consisting primarily of physical therapy (PT) either with\textsuperscript{20} or without\textsuperscript{19} 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.\textsuperscript{1} Stanton et al.\textsuperscript{3} and Greipp\textsuperscript{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.\textsuperscript{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.\textsuperscript{4} reported for PT alone two decades earlier. Murray et al.\textsuperscript{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.\textsuperscript{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.,\textsuperscript{3} Murray et al.,\textsuperscript{23} and others would seem to support this, a recent prospective randomized trial by Lee et al.\textsuperscript{25} does not. In this study patients were assigned to once-weekly or three-times-weekly outpatient PT along with a baseline of weekly cognitive-behavioral sessions. Results for both groups were good, with pain scores decreasing to near zero and function improving, but no statistically significant difference was found between the two groups. This may have been limited by small sample size (13 per group) or because the actual amount of exercise performed may have been similar between the two groups. Curiously, the trend was for more complete resolution in the once-weekly group.

TENS

TENS is a noninvasive physical modality that may provide excellent analgesia for some patients. It has been described in several case reports and series.\textsuperscript{1,2,6-32} 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.”\textsuperscript{15} Some authors have even presumed that CRPS is entirely a psychological or psychosomatic disease process.\textsuperscript{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\textsuperscript{34} studied 21 families of children with CRPS. These were generally high-achieving, compliant children. They found that in virtually all cases there was significant parental enmeshment with the patient. Beyond that, they found that multiple different stressors were present in these children, including marital conflict between the parents (n = 12), significant school problems (n = 13), and sexual abuse (n = 4). Testing revealed no major psychopathology, except for one child who scored high on 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.\textsuperscript{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.,\textsuperscript{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.\textsuperscript{36} performed a preliminary study comparing
patients with CRPS to children with migraine headaches and 21 normal controls. Contrary to expectations, no differences in family functioning were found among the three groups. Unfortunately, this work was never published in a peer-reviewed journal. A literature review by Lynch et al. in 1992 and recent prospective psychological studies of CRPS in adults also support that these patients are not psychologically unique from others with chronic pain.

In isolated cases, psychological factors may indeed have a predominant role in the etiology of CRPS. Jaworowski et al. reported CRPS in a 12-year-old who developed simultaneously a conversion disorder; her identical twin also developed an identical conversion disorder.

Whether or not psychological dysfunction exists prior to the onset of CRPS, psychological, cognitive, and behavioral strategies are often used as part of the treatment of children with CRPS. Case reports of successful treatment of CRPS with cognitive and behavioral strategies began to appear in the 1980s. There are no prospective placebo-controlled trials of cognitive and behavioral therapies in the treatment of CRPS, either in adults or children. Their use is extrapolated from case reports and prospective series for other pain states, notably headache. Wilder et al. reported that 57% of their patients who received such treatment benefited from it and continued to use this treatment modality. Stanton et al., however, found that psychological interventions were not consistently effective. This was felt to be due to the short time for interactions with the therapist during the patient’s inpatient admission. Lee et al. used cognitive and behavioral therapy as part of their baseline treatment of CRPS patients who were randomized to receive one or three sessions per week of PT. Compliance with attending the sessions was good and overall results were good, but the specific effect of the cognitive and behavioral treatments was not broken out. Sherry et al. did not use formal cognitive or behavioral treatments in his series of 103 patients treated with intensive PT, but they did refer 77% for psychological counseling, either individual or family. The results from the counseling were not measured or studied.

**Sympathetic Blocks**

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

**Medications**

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

A few children with CRPS fail to respond to multiple treatment approaches, including the stepwise multidisciplinary approach used by Wilder et al1 and Lee et al2, and the intensive PT approach used by Sherry et al.3 These children and their parents will often seek multiple medical opinions and undergo increasingly invasive and dangerous procedures in their quest for pain relief. Two types of neurosurgical procedures have been used in these patients: spinal cord stimulation (SCS) and sympathectomy. There is moderate evidence supporting the use of SCS in the treatment of CRPS in adults. Retrospective series by Kumar et al8 and Kemler et al9, and a later prospective series by Kemler et al9, 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 sympathetic paralysis, 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 Johnson10 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 al1 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.12 There are studies showing a surprisingly high acceptance rate for acupuncture therapy among children.64,65 There are also case reports of benefit to this therapy.66 It is rational to think that acupuncture, by its mechanisms of raising endogenous opioids and acting as a counter-stimulant to "close the gate" on spinal cord transmission of pain signals, might be of benefit in this disorder. Well-blinded studies are difficult to design, however, so obtaining definitive proof of efficacy may be slow in coming.

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

CONCLUSIONS

CRPS in children has been widely held to be intrinsically different from that in adults. This has been based on both demographics and a perception that children may have a milder course or a better response to conservative treatments. Other than the marked preponderance of lower extremity CRPS in children and adolescents, the demographics do not seem all that different for children than adults. A female preponderance exists for both groups. Both appear to have Caucasian predominance. Psychological factors are often invoked in pediatric CRPS, including enmeshment of the patient and parents and a degree of overachievement. Although this certainly may play a predominant role in some cases, the available evidence is not compelling that children with CRPS are unique compared with either other children with chronic pain or adults with CRPS. Finally, as regards the perception that children have an easier course than adults do, the evidence is not strong. Certainly, several series have reported children responding to courses of intensive PT alone. Nonetheless, the consensus is that PT is the definitive treatment of adults with CRPS as well as children. I have been unable to locate any series of intensive (5–6 hours per day) PT programs for adult patients analogous to that reported by Sherry et al.5 Series using less-intense PT, as reported by Wilder et al1 or Lee et al,25 give results similar to a stepwise multidisciplinary treatment plan in adults.67 The apparent mildness of pediatric CRPS may be due to a greater willingness of children to actively participate in appropriate PT more than to an innate difference in the disease process itself.

The potential for recurrence of CRPS is often of great concern to children with this syndrome and 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.3,25 Recurrence occurred in approximately 30% to 50% of patients, a much higher rate than the rate of 1.8% per patient-year reported for adults.68 Although recurrence is common, it generally seems to respond more readily to physical therapy and related treatments than the initial episode.5,25 A case report by Tong and Nelson51 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 part of a multi-disciplinary program stressing exercise and rehabilitation.

REFERENCES


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

If you visit the RSDSA website, there are several stories from young women who, in spite of the terrible pain caused by CRPS, are achieving their goals and living fulfilling lives. Yvonne writes, “My life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.” We want to help you understand how you can help children who have CRPS, either by simply being supportive or helping make accommodations and modifications in the school environment. Your support and understanding can determine whether our children succeed or fail.

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

More Information
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)

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

“Arranging 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.”

Section 504

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

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“I hate CRPS. I hate the pain. I get from it. But, I am done letting it run my life. From now on, it is not in charge. I am. Life is to be lived.”
-Karen Richards, age 11

Helping Youth with CRPS Succeed School

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

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

Although the cause of CRPS is unknown, overuse injuries, trauma, psychological stress, nutritional factors, and hormones are possible contributing factors. 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, which may be achieved in about 92% of those treated.

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

Students with CRPS and School
For those students who are able, we recommend the following:

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

Other interventions that can be practiced as needed include:

- Psychological intervention for child and family to assist with adjustment to home and community, behavioral interventions, and emotional support
- Relaxation techniques and cognitive-behavioral exercises/strategies
- Monitoring for “overset” behaviors, overscheduling, apathy and reduced motivation and/or initiation, and anxiety, depressed mood, and/or inflexibility

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

1. Because the slightest bump can cause lasting flare-ups of this very painful syndrome, every effort should be made to see that the child is not exposed to the bumping and jostling of school hallways. The student’s desk in each classroom should be positioned away from traffic patterns to avoid inadvertent bumping.

2. Determine whether the student needs ergonomic seating/adjustable desk.

3. Designate another student as a helper who can carry the student’s books/belongings during the day, help at lunch, and during the changing of classes.

4. Because students with CRPS in their upper extremity may have difficulty writing, allow the student to record lectures, use a keyboard with a portable word processor, or use another student’s notes.

5. Given that CRPS symptoms can be exacerbated by the cold, allow the student to bring a heating pad. Also, guidelines should be developed regarding whether the student should go outside for recess when it is excessively cold, care must be taken to see that the patient has adequate warm clothing, and it is kept out of drafts.

6. Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:

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

Limiting Stress
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“Life is going to be full of adjusting and changing, but I will never let CRPS stop me from living my life.”
—Yevonne
4th Annual Long Island CRPS Awareness Walk & Expo

BY JERI KRASSNER • RSDSA SPECIAL EVENTS COORDINATOR

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

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

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

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

Continued on pg. 4
INSIDE THIS ISSUE

4th Annual Long Island CRPS Awareness Walk & Expo Proves You Are Not Alone .................. Cover

Director’s Report .................................................................................................................. 3

Fun Meets Fundraising ....................................................................................................... 5

Opportunity .......................................................................................................................... 6

CRPS Changes Lives ............................................................................................................ 8

Role of Physical Therapy in an Interdisciplinary Team for Chronic Pain Management .......... 10

RSDSA Approves New Grant Application for Research Study ......................................... 12

Spotlight On Support: A Newsletter Addition .............. 13

The Longest Day of Golf..................................................................................................... 13

Ride for Warriors Recap - An Interview with Eric Moyal .............................................. 15

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

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

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Director’s Report

BY JAMES W. BROATCH, MSW • RSDSA EXECUTIVE VICE PRESIDENT, DIRECTOR

American Society of Pain Management Nursing (ASPMN)

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

Reaccreditation of Adult CRPS Course for Physicians and Nurses

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

I don’t have the words to thank you enough for your amazing help at the perfect time. I didn’t know I was going to be rushed into emergency surgery after almost dying of my ketamine troches more than ever and your gift of helping me get them by working with me was wonderful and so appreciated! I have a long recovery ahead of me (sorry for delay in sending my thanks) I’ve been in the hospital & then a long term care center but it has been made easier by your help, I can’t say thank you enough. I want all my friends & family to know this disease & the torture I suffered it brought to our lives as it steals our lives from us it isn’t often you find people who understand or are willing to help a in your time, I was blessed with both as am forever grateful. Thank for being angels & helping me get my medication I would not have been able to get my ketamine troches without your help. I have always been the giver & cared as a mental health therapist so thank you also for giving me the experience of knowing what it’s like to receive roles & be on the other side to get the gift. You guys are amazing. I’m much love & gratitude.

Danelle Chase

Thanks!
4th Annual Long Island CRPS Awareness Walk & Expo Proves You Are Not Alone

(continued)

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

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

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

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

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

Cross-Country Bike Ride in 2020

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

Patient Assistance Program in Honor of Brad Jenkins

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

EASY WAYS TO GIVE

- Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.
- Use AmazonSmile.com and make RSDSA your charity of choice while shopping online.
- If you’re selling things on eBay, you can give a portion of the profits straight to RSDSA.
- Set up a collection canister in your local grocery store.
- Plan an event with the help of RSDSA by emailing us at jjkrassner@rsds.org
One of the most effective ways to bring the CRPS community together and raise awareness in your hometown is to host an event. These may come in various shapes and sizes, and some may serve gumbo, but it all comes back to the RSDSA’s mission of providing support, education, and hope to all affected by the pain and disability of CRPS/RSD, while also driving research to develop better treatments and a cure.

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

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

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

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

Plan on attending next year on February 1, 2020.
Opportunity
BY LAURA HINKLE • JUST41KH@OUTLOOK.COM

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

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

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

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

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

Forward to August 12, 2019... at 8:00 in the morning, I was warming up for two swimming competitions at the Michigan Senior Olympics. It was all just blowing my mind. I dove in about 9:15 AM for the 50-meter breaststroke. I dove in again about 11:15 for the 200-meter breaststroke. I was high on adrenaline and competing in my very first athletic competition. Yes, I hurt like crazy. My RSD wasn’t happy with me. And yet, I was still doing it. I was swimming in the Senior Olympics. Much to my surprise I received a silver medal in the 50 and a gold medal in the 200! I had won 2 Michigan Senior Olympic medals! I was blown away.

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

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

ABOUT THE AUTHOR
Laura Hinkle is a 25-year warrior who is also a frequent RSDSA donor.
On the morning of May 15th in 1973, Steve Shisler was enjoying the second week of summer after his sophomore year of college. He said goodbye to his Grandmother and hopped on his motorcycle to head to his summer job. When a car pulled into the intersection he was crossing, he swerved to the right and tried to lay the bike down to get out of the way, but the car just kept coming. He woke up in the hospital five days later. That morning would change his life forever.

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

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

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

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

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

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

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

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

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

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

Through clients and friends with CRPS, he became aware of the RSDSA and became a supporting member in 1996. He has written articles about Worker’s Compensation and retaining legal advice for the community¹, and been a speaker at RSDSA conferences. In 2013 he was elected to the Board of Directors and currently serves as Secretary.

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

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

You can learn more about Steve at his website: www.shislerlaw.com


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.
Role of Physical Therapy in an Interdisciplinary Team for Chronic Pain Management

BY WENDY WURTZEL PT, DPT • SHIRLEY RYAN ABILITY LAB

Physical therapy is a first-line intervention for individuals with pain. However, when it comes to chronic pain, particularly Complex Regional Pain Syndrome (CRPS), working with an interdisciplinary team of healthcare providers can be a more effective treatment approach. Often, the responses to physical therapy as a stand-alone intervention can vary. Physical therapy alone may have no effect on pain and functioning, or result in triggering flare-ups, leading to increased debility.

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

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

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

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

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

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

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

**WANTED**

Individuals to:

- Set up a collection canister in your local grocery/convenience store.
- Plan an event with the help of RSDSA by emailing us at info@rsds.org.
- Fill up a Penny Pig with your spare change to help RSDSA sponsor children in pain at summer camp.
- Help educate health care professionals by promoting the availability of our accredited courses on adult and pediatric CRPS.
- Blog for our weekly Tuesday’s Burn. Do you have a story or experience to share?
- Write an article for the RSDSA Community Update.
- Promote awareness of CRPS by sharing your story with TV or newspapers (we can help you).
- Share your story of hope. Inspire others who are struggling as you have.
- Join our peer-to-peer program (see our back cover).

**ABOUT THE AUTHOR**

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

BY JASON HALE, MD • HALEJ3@CCF.ORG

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

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

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

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

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

HAVE YOU THOUGHT ABOUT YOUR LEGACY?

Are you looking for a long-term way to make a meaningful difference in the lives of people with CRPS? Please consider making a planned gift to RSDSA today. Planned giving options include:

• Gifts of Stocks and bonds.
• Including RSDSA as a beneficiary in your life insurance policy.
• Including RSDSA as a beneficiary in your will.

Tax benefits apply to each of these options.

Please contact your attorney or a financial advisor. For more info, contact RSDSA at info@rsds.org or go to https://rsds.org/donate/.
Spotlight On Support: A Newsletter Addition

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

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

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

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

This Edition’s Spotlight: The Northeast Philadelphia RSDSA Support Group, a newly formed group, recently welcomed Stephen Shisler Esq. to speak at one of their meetings. He discussed the critical need for medical teams to use the precise language of the “Budapest’s Criteria” in medical records for CRPS patients to increase their chances for success when winning legal challenges presented by both Workman’s Compensation and Social Security Disability cases.

“Many of the patients attending our support group meeting and especially our newly diagnosed members have never heard of the “Budapest Criteria” much less knew the importance of using this very specific diagnostic language,” says support group founder and facilitator, Kimberly Russo.

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

The Longest Day of Golf

BY JERI KRASSNER • JKRASSNER@RSDS.ORG

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

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

Josh had a slow start toward his goal to birdie every hole. He missed the green on a short approach shot on the first hole, then hit two balls in the water on the second hole. Despite his inauspicious start, Josh quickly got back on pace with a par and two birdies on the next three holes. Josh kept going and going.

It’s his ability to stay undaunted and persevere that makes him the perfect representative for our community. And thanks to Jim he can now tell the difference between an Osprey and a Hawk.

The RSDSA Board set an ambitious goal of $50,000 and we are 1/3 of the way to goal. However, it is not over and there is still time to contribute to this fundraiser. LDOG campaign is open and we accept donations to the end of the year. You can still be our best hope and help fulfill our mission by making a donation to https://www.firstgiving.com/event/rsds/2019-Longest-Day-of-Golf.
Driving from Medford, Massachusetts to Miami, Florida takes approximately 23 hours and 47 minutes. Hop on a flight at Medford’s nearest airport and you’ll land in Miami in just a few hours. So, how long does it take on a bike? Two and a half weeks. That’s the amount of time it takes to bike the seventeen thousand miles between Medford and Miami.

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

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

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

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

“I loved talking and hearing people’s stories with CRPS,” says Eric. “It was amazing to hear how people are still doing incredible things in their lives despite this debilitating condition.” While biking through New Jersey, Eric was invited by board members Hank & Mary Beth Ludington to have lunch at their home. Mary Beth was 21 when she first experienced symptoms of CRPS, but was not diagnosed for many years. With support from her family, she was able to get

“\textit{If there is one thing Eric has learned during the Ride for Warriors, it is that CRPS Warriors are doing amazing things. “Do not undermine your accomplishments!” he says.}
married, have 3 girls, 4 grandkids and go to grad school. However, Mary Beth did have a fear that she was holding her family back from different experiences because of her physical limitations. This is a fear that many people living with chronic illness have faced with loved ones. When Mary Beth apologized for feeling as though she was holding her family back on a vacation, her family’s response was “are you kidding me?!” Mary Beth’s children felt this statement could not be farther from the truth. In fact, they expressed gratitude and love for the experiences and memories she provided her children.

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

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

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

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

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

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

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

- Jessica Kennedy Dutkiewicz who drove for an hour with her husband just to meet Eric in Georgia. She shared her story and treated him to dinner.
- Linda Horan who housed Eric and his mother, made them dinner and shared her story.
- Mary Beth and Hank Ludington who met Eric and Anat for lunch, shared her story and helped sponsor the ride.
THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

RSDSA UPCOMING EVENTS

<table>
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<th>OCTOBER</th>
<th><a href="http://WWW.RSDSA.ORG">WWW.RSDSA.ORG</a></th>
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<tr>
<td>10/19</td>
<td>3rd Annual Tame the Pain Golf Event, Galena, OH - Sharon &amp; Matt Weiner</td>
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<td>10/26</td>
<td>Treating the Whole Person: Optimizing Wellness - Denver, RSDSA</td>
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<td>NOVEMBER</td>
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<td>Fight the Flame 5K - Cleveland, OH</td>
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<td>11/4</td>
<td>Color the World Orange - Worldwide</td>
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<td>11/16</td>
<td>RSDSA Funny Fundraiser - Philadelphia, PA</td>
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Don’t see an event near you?
Contact Jeri Krassner jkkrassner@rsds.org to discuss planning an event in your area!

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

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

Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rsds.org
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
YOU ARE YOUR CHILD’S BEST ADVOCATE

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

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

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

THE FACTS

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

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

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

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

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

SIGNS & COMMON SYMPTOMS

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

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

WHAT TO TELL YOUR PHYSICIAN

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

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

By Sarah M. Whitman, MD

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

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

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

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

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

What People with CRPS Should Expect from Therapy

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

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

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

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

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

Home Exercise Programs

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

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

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

Treating Complex Regional Pain Syndrome

A Guide for Therapy

Reflex Sympathetic Dystrophy Syndrome Association
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Raising awareness of complex regional pain syndrome since 1984
What is Complex Regional Pain Syndrome

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

What Does CRPS Look Like?

CRPS pain is often described as deep, aching, cold, and/or burning and is frequently associated with increased skin sensitivity. Pain is generally rated moderate to severe and is disproportionate to any inciting event. Symptoms of CRPS can include abnormal swelling, abnormal hair growth, abnormal skin color or temperature changes, abnormal sweating, limited range of motion, and movement disorders.

Evaluation of CRPS for Functional Rehabilitation

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

Treatment Protocols

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

Edema is managed using specialized garments (Jobst® garments, Isotoner® gloves, Coban®) and manual lymphatic drainage and AROM (active range of motion) activities are also fundamental in managing edema. Elevation of the extremity can be effective; however it can sometimes become part of a cycle of guarding and 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 internal to external per material. Wearing jewelry, clothes and shoes on the affected areas are also ways to normalize sensation.

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

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

Stress Loading consists of two principles: scrubbng and carrying. A stress loading program promotes active movement and compression of the affected joints for a minimum of 3-5 consecutive minutes, three or more times each day. Though stress loading may initially produce pain, tolerance can be achieved. Conditions based stress reduction (MBSR) is a form of meditation practice that is commonly used to help treat chronic pain. The practice of these interventions should begin immediately.

Bracing/Bracing is a set of rehabilitation procedures 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 improved positioning. A custom made cast or a custom made orthotic is used to facilitate normal tissue length, and improve functional positioning.

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

The therapist can help the patient to gradually improve AROM and flexibility through gentle progression of active and active-resistant exercises or gait training. The patient should be encouraged to gradually return to daily life activities. These activities and treatments can be very painful and the therapist must understand and be able to explain the differences between pain and damage to alleviate the fear of the patient. While these treatments should be done within the patient’s tolerance, the patient must understand that they will have to push through pain to achieve their goals. Care must be taken to ensure safety of the anatomical structures in insensitive situations (as after a nerve block). Pacing and pain management techniques, such as appropriate rest breaks, alternating tasks, thermal or cold application, diaphragmatic breathing, and relaxation techniques, can assist the patient in minimizing pain flares while participating in intensive rehabilitation.

Treatment Summary

The overall role of the therapist during rehabilitation of CRPS is to guide the patient through a program designed to minimize pain and edema and maximize functional use of the extremity. As CRPS varies greatly in severity and duration, it is very important for the therapist to demonstrate enthusiasm, support and encouragement of the patient during the treatment process.

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

References

**THE RIGHT TREATMENT**

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

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

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

**THE DIAGNOSIS**

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

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

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

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

**WE ARE HERE TO SUPPORT YOU**

- YOU ARE NOT ALONE -

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

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

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

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

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

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

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

*To receive help, they must be heard.*

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**THE FACTS**

**WHAT IS CRPS/RSD?**

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

**WHAT CAUSES IT?**

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

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

**WHAT ARE THE EFFECTS?**

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

**WHO CAN DEVELOP CRPS/RSD?**

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

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**WORKING FOR A CURE**

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

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

**COMMON SYMPTOMS**

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

Pain Scale

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

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

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

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