

IN RARE FORM



DRG: A Targeted Therapy for CRPS and Causalgia

Sponsored by Abbott.

Your pain is what you feel. No more and no less.

Pain is defined as an unpleasant sensory and emotional experience that could be associated with actual tissue damage¹. Any persistent and or recurrent pain that lasts for more than six months after an injury or surgery is considered chronic pain².

This means your perception is the proof of your condition. There's no definitive test to determine the amount of pain you're feeling, or where it's coming from. So, finding the right chronic pain treatment depends mostly on information from you and how you explain it to your doctor.

What is CRPS?

Complex regional pain syndrome (CRPS) is a specific kind of chronic pain that affects areas such as the groin, leg, pelvis, or foot, usually after an injury or surgical procedure. The event that leads to CRPS can be as simple as stubbing a toe, twisting an ankle, or having a hernia operation.

Previously known as Reflex Sympathetic Dystrophy Syndrome (RSD), CRPS is caused by damage to—or malfunction of—the peripheral and central nervous systems. According to the National Institute of Neurological Disorders and Stroke, CRPS is characterized by prolonged or excessive pain with changes in skin color, temperature, and or swelling in the affected area³. Some doctors still call this syndrome RSD, or use the two terms, CRPS and RSD interchangeably.

IN THIS ISSUE

**CRPS AWARENESS MONTH
SOCIAL RECAP**

**REQUEST A CARD FROM
CAROLYN'S CARDS THIS
HOLIDAY SEASON**

**SUPPORT RSDSA'S END OF
YEAR APPEAL**

**MEDICAL EQUIPMENT
AVAILABLE IN PRINCETON,
NJ**

**RECAP OF THE FOURTH
ANNUAL FLAME OUT WALK
TO EXTINGUISH RSD/CRPS**

**BID IN THE RSDSA
COMMUNITY AUCTION BY
DECEMBER 23RD**

Today, CRPS is divided into two types: CRPS type 1 and CRPS type 2:

CRPS Type 1 is a clinical syndrome with unknown cause—meaning no confirmed nerve injury—that is diagnosed based on symptoms such as chronic pain, swelling, and changes in skin color or temperature⁴.

CRPS Type 2, or causalgia, is associated with a confirmed nerve injury. For example, a patient who had surgery on an ankle then developed CRPS in the same region would be considered type 2. The line between the two types of CRPS is blurry, but the treatment is similar⁴.

DRG Therapy, A Unique Treatment for CRPS

The dorsal root ganglion or DRG, is a cluster of nerve cells along the spine that plays a critical role in the development and maintenance of chronic pain. It contains the primary sensory neurons that transmit sensations such as pain and touch from the body to the brain.

Researchers have found that certain groups of DRG nerves control pain signals from specific areas of the body – such as the pelvis, groin, hip, knee, ankle, and foot – where people experience pain. This makes it an ideal target for intervention to treat specific focal pain.

Proclaim™ DRG Therapy is a novel neurostimulation technology that targets and relieves pain in the lower extremities by stimulating the dorsal root ganglion^{5,6}.

Traditional neurostimulation has been used safely for decades, but it doesn't always work for people with causalgia or CRPS⁵. DRG stimulation can help treat chronic pain associated with CRPS 1 and 2 of the lower body, including areas like the pelvis, groin, hip, knee, ankle, and foot⁶.

How DRG works

Think about hitting your funny bone on a table. As you strike the bundle of nerves located under your elbow, a painful message is sent to your brain, causing your elbow to hurt. After this, your natural reaction is likely to rub your elbow. As you are rubbing your elbow, you are actually confusing the nerves by sending a non-painful message to the brain. Since nerves can only carry a limited amount of information, they will prioritize the non-painful message over the painful one.

Neurostimulation works to block pain in a very similar way but with low electrical pulses. DRG therapy allows us to target pain even more precisely than traditional neurostimulation. By focusing electrical stimulation specifically on the DRG, the Proclaim™ DRG system is able to interrupt pain signals before they reach the spinal cord, so you don't feel pain in the same way. Interrupting these pain signals at the source enables the use of low energy levels on a recharge-free platform and helps eliminate unnecessary stimulation throughout the body⁵.

This leads to more focused therapy than traditional neurostimulation and generally better outcomes for patients with CRPS.

DRG Therapy: Clinically proven to have superior outcomes

A Clinical study has proven that Abbott's DRG Stimulation successfully provides sustainable pain relief and quality of life improvements for the majority of patients with focal chronic pain. Evidence from the 12-month study shows that DRG therapy:

- Reduces pain an average of 81.4%⁵
- Provides persistent pain relief to 86% of patients⁵
- More than 8 out of 10 experienced significant pain relief with DRG Stimulation⁵

The Proclaim DRG™ neurostimulation system is the only FDA-approved DRG technology for treatment of CRPS Types 1 and 2, in the lower extremities⁶. Ask your doctor or pain specialist about DRG therapy if you are experiencing focal chronic pain.

[Learn more about DRG therapies](#) and [how to find a pain specialist near you](#).

Important Safety Information: Proclaim™ DRG Neurostimulator System (neuromodulation.abbott)

(TM) indicates a trademark of the Abbott group of companies

(C) 2022 Abbott. All rights reserved

MAT-22100077 | Item approved for US use only

Abbott

8701 Bee Cave Road. Building 2 West. Austin, Texas 78746 USA, Tel: 1 651 756 2000

Neuromodulation.Abbott

Rx Only

Brief Summary: Prior to using Abbott devices, please review the Instructions for Use for a complete listing of indications, contraindications, warnings, precautions, potential adverse events and directions for use.

¹ Raja, S. N., Carr, D. B., Cohen, M., Finnerup, N. B., Flor, H., Gibson, S., Keefe, F. J., Mogil, J. S., Ringkamp, M., Sluka, K. A., Song, X. J., Stevens, B., Sullivan, M. D., Tutelman, P. R., Ushida, T., & Vader, K. (2020). The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. *Pain*, 161(9), 1976–1982.

² Treede, R. D., Rief, W., Barke, A., Aziz, Q., Bennett, M. I., Benoliel, R., Cohen, M., Evers, S., Finnerup, N. B., First, M. B., Giamberardino, M. A., Kaasa, S., Kosek, E., Lavand'homme, P., Nicholas, M., Perrot, S., Scholz, J., Schug, S., Smith, B. H., Svensson, P., ... Wang, S. J. (2015). A classification of chronic pain for ICD-11. *Pain*, 156(6), 1003–1007.

³ [Complex Regional Pain Syndrome Fact Sheet | National Institute of Neurological Disorders and Stroke \(nih.gov\)](#)

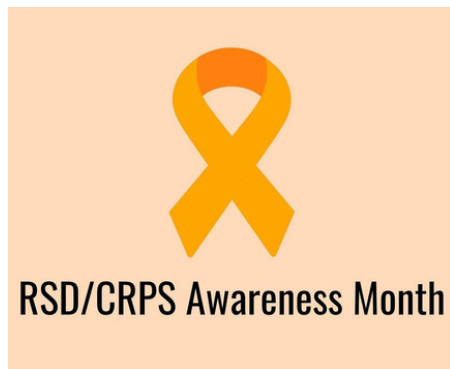
⁴ Harden, R. N., McCabe, C. S., Goebel, A., Massey, M., Suvar, T., Grieve, S., & Bruehl, S. (2022). Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines, 5th Edition. *Pain medicine* (Malden, Mass.), 23(Suppl 1), S1–S53.

⁵ Deer TR, Levy RM, Kramer J, et al. Dorsal root ganglion stimulation yielded higher treatment success rate for complex regional pain syndrome and causalgia at 3 and 12 months: a randomized comparative trial. *Pain*. 2017. 158(4): 669–681. ACCURATE IDE STUDY, St. Jude Medical. (n=152)

⁶ Abbott. Proclaim™ DRG Neurostimulation System Clinician's Manual. Plano, TX. 2018.

CRPS Awareness Month Social Recap

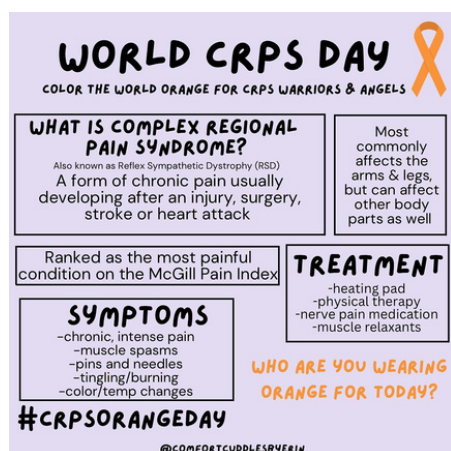
Here's a quick recap of some of the social posts we saw online during CRPS Awareness Month!



via [@cardiocamerascOFFEE](#) on Instagram



via [@_audreybates](#) on Instagram



via [@comfortcuddlesbyerin](#) on Instagram



via [Sheryl Selena](#) on Facebook



via [@CRPSOrangeDay](#) on Twitter

Support RSDSA's End of Year Appeal

2022 has been the third challenging year in a row for non-profit organizations like RSDSA. We are all still feeling the impact of the pandemic as businesses close their doors and consumers are affected by inflation.

Throughout the year, we have been able to continue serving those who suffer from unimaginable pain by providing numerous resources that CRPS Warriors have been able to access from the comfort of their homes. Your generosity made that possible.

RSDSA hopes to continue being a trusted source for those with CRPS. With your [help](#), we can provide information and support to our community.

You help provide a place where one can search for information on the latest research and treatments. Your contribution enables the community to share experiences and connect with others. Please consider making a gift to our end of the year appeal by visiting rds.org/donate.



Subscribe to the RSDSA YouTube Channel

Missed one of our Facebook Live sessions this year? What about a Virtual Conference Session?

No worries, as we have them all on-demand on the RSDSA YouTube Channel.

Take a moment to browse through our library of RSD/CRPS content from over the past decade. And don't forget to subscribe to our channel while you're there!



Song of Our Scars: The Untold Story of Pain

by Kelly Considine

I had the honor and privilege of interviewing Dr. Haider Warraich at RSDSA's "2022 Optimizing the Whole Person" Conference.

I have to start out by thanking Jim for reigniting my love of reading with the books "An Untethered Truth: A

Medical Journey" by Tracy Coval, who we were lucky enough to hear from at the conference, and "The Song of Our Scars" by Dr. Warraich.

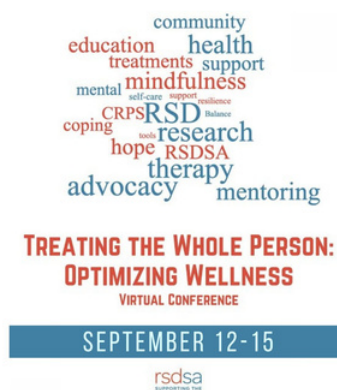
Speaking with Dr. Warraich was such a pleasure because he has seen pain from both sides of the medical field. He is a researcher, physician, and a fellow pain warrior like more than 1.5 million people in the world, who shared invaluable insights into the evolution of acute pain to chronic pain.

At one point in his book he says, "In my darkest days I didn't even know if I could practice medicine at all." Thankfully, that was not the case because we need more pain warriors in the medical field who are willing to go to bat for us and investigate the poorly understood pain conditions such as CRPS.

He also said, "physicians are imperfect creatures", and we discussed what made a "good doctor." The key to being a good doctor is sympathy. Having someone sit with you, listen to your symptoms, and then show concern and understanding is all that we want. We know doctors are human and can't know everything, but I always appreciated the doctors who said, "I don't know, let me look into this further." The doctor's honesty and dedication to look for an answer is everything a patient could ask for.

Unfortunately, many of us have heard the term "it's all in your head" at some point in our rare disease journey. This is both invalidating yet true. No one wants to hear that the pain is in their heads because it implies we have control over our situation, however, Dr. Warraich is working to destigmatize this by making it less of an accusation. Instead, he explained that it means our pain has been centralized and there are pain pathways in the brain.

Furthermore, Dr. Apkarian has completed functional MRIs on animal and human models to see what areas of the brain are involved in pain, so it is true that pain is in our head, but it is not consciously caused.



HAIDER WARRAICH
SONG OF OUR SCARS: THE UNTOLD STORY OF PAIN

If you have yet to read the book, I highly recommend it. There were many excellent points that Dr. Warraich makes throughout the book that we didn't even get to touch on. He discusses the treatment of pain dependent on race and gender.

In the book Dr. Warraich said that Dr. Cartwright "propagated the idea that enslaved Black people were oblivious to pain." I was shocked to read about the 2016 study at the University of Virginia where "58% of the general population and more than 40% of 1st and 2nd year medical students believed that Black people had thicker skin [and in] senior medical students and residents, almost one in four retained this belief." Between 1993 and 2010 there was a skyrocketing of white opioid deaths, but deaths from opioids in the Black population were largely unchanged. During the pandemic, however there was a rise in the number of opioid deaths from Black individuals

The book discusses the physician Dr. Carol Warfield who cared about helping people, "We never talked about money or how much a procedure paid. We just did what was best for the patient," she said. That changed as the desire for reimbursement overwhelmed medicine's moral prerogative. 'Physicians in pain medicine went towards procedures because they were more lucrative'. Dr. Warraich said that "A healthcare system that prioritizes health over profit can transform how the person in extremis is treated. What the treatment of pain might look like in a less ravenous healthcare environment is far from hypothetical, for such an example exists right here in the United States: the Veterans Affairs Health System (VA)." Unfortunately, it is all too often that we see the medical field being treated as a business and less as a system of care for the patient. We need to get back to the prioritization of health over wealth.

I was shocked to read that even though women face more pain they are at a "disadvantage when it comes to seeking that care: while women represent half of medical students and a third of anesthesiology residents, only 18% of pain physicians are women." In a field that needs empathy, it lacks a woman's presence and women are known to be more empathetic.

This was very alarming to read..."Americans constitute only 5% of the world's population but consume 30% of the world's opioids." Our medical system is quick to put band-aids on things and not spend the time and energy to truly treat the patient. I think that all of us with CRPS have felt that way at one point or another. If we are in pain we are given a script for pain medication, but in other countries that is not always the case which is why the United States has had to deal with the opioid crisis epidemic.

I first heard about the "Acceptance and Commitment Therapy" in "The Song of Our Scars", and it was a very new and interesting concept to me. In essence, we have to stay present in the moment, accept our thoughts and feelings and commit to move forward and not dwell on the negative. This was the first time I ever thought to look at my pain in that regard.

It is far from the “no pain, no gain” mentality that was beat into my head in the early days of my physical therapy when I didn’t have a clear diagnosis and when I finally did get the diagnosis of RSD, now CRPS, the physical therapists didn’t know how to treat it any differently than they would a typical sprained or injured ankle. I was grateful when I finally found physical therapists who saw the pain as real and realized that pushing through it was not the answer. The Acceptance and Commitment Therapy really caught my attention, and I agree that we must accept our chronic pain if we ever hope to move forward and move in the direction of the goals we committed to.

This is a great read! I hope you pick up a copy, if you haven’t done so already, and enjoy it as much as I did! I hope you all take away a newfound knowledge about chronic pain and its implications to not only ourselves but to society and the diverse group of individuals experiencing pain.

Thank you again Dr. Warraich.

Watch the full video of Dr. Warraich's session from our virtual conference on the RSDSA YouTube Channel [here](#).

Medical Equipment Available in Princeton, NJ

A CRPS Warrior is selling the three mobility items pictured below. They will accept the best offer and donate the proceeds to RSDSA. However, you must be able to pick them up in Princeton, NJ.

Photo 1 (Blue and Black): Drive 4 Wheel Rollator with removable back support

Photo 2 (Red): New portable wheelchair that was purchased 2 years ago from Walgreens

Photo 3 (Black and Blue): Pride Victory 9 with Walker Bracket and basket (includes charger and manual). Originally purchased June 2019.

Please email us at info@rdsd.org if you are interested.



Recap of the Fourth Annual Flame Out Walk to Extinguish RSD/CRPS

The day dawned bright, with moderate temperatures and humidity, typical of late summer. Sunday, September 18, was a perfect day for the Fourth Annual Flame Out Walk to Extinguish RSD/CRPS. The event was held at Joe Palaia Park in Ocean Township, N.J.

This year's walk was dedicated to Stephanie Theresa Smith, who succumbed to the ravages of this disease on October 4, 2021, at age 46. Her parents, Diana and Peter, offered to match up to \$10,000 in donations, in her memory.

The venue, set in a 240-acre park, with well laid out trails, paved to accommodate wheelchairs and bikes, wound through open fields and forested settings. The walk route was one- and three-quarter miles.

The sign in area was set-up by the Vietnam Veterans of America, primary sponsor. Coffee, tea, water, snacks, rolls and pastries greeted the participants, donated by local businesses. Ice cream pops, also donated, came at the end of the walk.

A total of 83 people signed in for the walk including including RSDSA's co-presidents Hank & Mary Beth Ludington.

Five RSD/CRPS Pain Warriors took part in the walk, leading the assembled after brief introductions and welcoming speeches by the Hopkins and Smith families. Prior to the walk, Dr. Michael Cooney of Calmare Therapy NJ/USA, a sponsor of the event, provided information on treatment options.

The walk was a success, both financially and in raising awareness of this insidious disease. It also provided a venue for networking and support services. At last count, over \$37,000 had been collected, easily topping the \$30,000 goal and more than doubling last year's amount. Plans for next year's walk are already underway.

If you would like to volunteer to be part of the planning committee for the next walk, contact Linda or Bob Hopkins at 732-531-2574.

Thank you to our Sponsors: Diana & Peter Smith, Vietnam Veterans of America, Chapter 12, [Asbury Park Wall Elks Lodge #128](#), [Assistive Choices](#), [Calmare Therapy NJ](#), [Green Leaf Pet Resort](#), [Jag-One](#), O'Dowd Transportation, [VWF Post #2179](#), [VWF Post #2226](#)

Bid in the RSDSA Community Auction by December 23rd

Start your holiday shopping at the [RSDSA Community Auction](#). We may have the gift you are looking for! Browse the auction on Galabid to see the many wonderful items we have available for bidding. There are a variety of items special to the CRPS community! Don't forget that bidding ends on Friday, December 23rd.



New CRPS Diagnostic Subtype to be included in ICD-11 Version of CRPS Criteria

CRPS researchers at a scientific conference in Valencia, Spain have proposed a new CRPS subtype to capture individuals with CRPS who had previously been diagnosed with CRPS, then improved sufficiently to no longer meet the full CRPS criteria but suffered from continued symptoms requiring ongoing care.

The new subtype will be CRPS with Remission of some Features. It will be applied to individuals who were documented to meet full CRPS criteria at an earlier point in time. Individuals in this new category are not necessarily improved with regards to pain intensity nor are they free of all symptoms and they may relapse.

Especially noted are the occasional individuals who may fully meet diagnostic criteria one day and not the next. It is critical for legal and insurance reasons that temporarily not meeting criteria, for whatever reason, is not considered equal to a “cure” of the condition, particularly given the known variability of CRPS features.

A link to the report of the Valencia conference can be found [here](#).



Request a Card From Carolyn's Cards this Holiday Season

Carolyn's Cards is a program led by Carolyn McNoldy that sends cards and other small surprises through the mail to individuals with CRPS and to their caregivers. Carolyn wants to help those feeling isolated or down to not feel alone, and to ensure they feel encouraged, supported, and part of a community. Most importantly, she wants to give them a smile.



The program was inspired by Carolyn's mother who would send her cards when she was down, in a lot of pain, or recovering from surgery as they would help to brighten Carolyn's day. She thought it would be great if she could reciprocate that feeling for others. She started sending cards to the attendees of the first Young Adult Weekend as a way to stay connected to them and show support. Carolyn was surprised to hear how much they genuinely enjoyed the cards. She has continued to add names to her list after each Young Adult Weekend.

If you would like to send a card to a Warrior this holiday season, please send the person's name and address to carolyns.cards2@gmail.com.

Happy Holidays from RSDSA!

We're wishing you and your loved ones a safe and joyous holiday season. See you in 2023!

We want your feedback!

Please send any suggestions or upcoming events of interest to our community to info@rsds.org and please consider donating at rsds.org/donate.

Thank you to our Title Sponsors

Our title sponsors make RSDSA events and awareness activities possible. Please join us in thanking and supporting them!

[Abbott](#) | [The Baker Family Charitable Fund](#) | Diana and Peter Smith in memory of Stephanie Theresa Smith | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager
Lynn & Michael Coatney | [The Cochran Firm, National CRPS/RSD Lawyers](#)