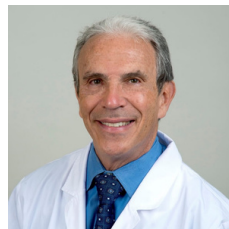


IN RARE FORM

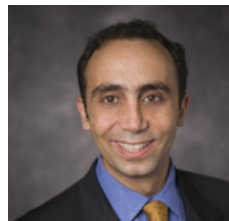
This edition of In Rare Form is sponsored by Abbott



Facebook and YouTube Livestream on Surgery and CRPS - Fri, August 14, 2026



RSDSA is hosting a **free** livestream with Joshua Prager, MD, MS and Salim Hayek MD, PhD on **Friday, August 14 at 7PM Eastern/4PM Pacific** on facebook.com/rsdsa and youtube.com/@RSDSA from your computer, tablet, or phone.



This event will be recorded and available for replay if you can't make it to the livestream!

Our guests will join us to discuss surgery and CRPS. Send the questions you would like them to answer to info@rsds.org.

Dr. Joshua Prager is a distinguished board-certified pain medicine physician at the California Pain Medicine Center in Santa Monica, California.

Dr. Prager's professional activities include chairing and participating in evidence-based medicine guideline projects, leading a best practices project, developing a revised treatment algorithm for CRPS, and serving on the RSDSA Board of Directors. He is analyzing data on managing ketamine infusion side effects for treating CRPS and depression, with his publication in the Journal of Pain Medicine reviewing ketamine infusions for CRPS treatment.

His clinical practice focuses on CRPS, neuromodulation, and precision spinal diagnostics and therapeutics.

Salim Hayek MD, PhD is the Chief of the Division of Pain Medicine and Professor of Anesthesiology at University Hospitals Cleveland Medical Center / Case Western Reserve University. He is also the former president of the North American Neuromodulation Society.

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Participate in RSDSA's Demographic Survey

RSDSA would love to learn more about our community members so we can better serve you. Please take a few minutes to complete our [short survey](#) (and help us spread the word!).

Participation is completely optional, and nothing will change if you choose not to respond to the survey. As a thank you, two participants will be randomly selected to receive a \$50 Visa gift card on August 13.

The information collected will be used for our organization's development and impact reporting.

If you provide any personal information on this form, it will only be shared with RSDSA staff and our Board of Directors. Thank you for being part of the RSDSA community!



Most Recent Topics on the RSDSA Message Board

RSDSA's [message board](#) community is intended to provide a moderated and supportive environment for individuals affected by CRPS, including patients, caregivers, friends, family members, and advocates.

We know many members of the community are not active on social media, but are still looking for online connection and peer-to-peer support. Our new message board aims to achieve those goals while also providing even more assistance and faster response times to your important questions.

Join for free today at messageboard.rsds.org

You must be [signed in](#) to view and contribute to these posts.



[Tennessee-based CRPS Warrior and Chaplain Looking To Connect](#)



[Medical Transportation For Appointments](#)



[Partner has CRPS. I want to learn and do what I can](#)

What's New With CRPS?

As of Monday, August 3rd, Ambros Therapeutics' [neridronate trial](#) now has 19 sites. Please keep an eye on their [study page](#) as new trial sites are rolling out regularly!

- Phoenix, AZ
- Tucson, AZ
- Napa, CA
- Pasadena, CA
- Tustin, CA
- Washington, DC
- Brandon, FL
- Daytona Beach, FL
- Pembroke Pines, FL
- Lawrenceville, GA
- Newnan, GA
- Chicago, IL
- Orland Park, IL
- Reno, NV
- Shrewsbury, NJ
- Charlotte, NC
- Wilmington, NC
- Winston-Salem, NC
- Houston, TX



Current Research Study Opportunities

Below you will find a list of CRPS-focused studies that we are currently aware of:

- Ambros Therapeutics: [Complex Regional Pain Syndrome-Relief and Improvement Study for Efficacy](#)
- Stanford University: [Transcranial Magnetic Stimulation for Complex Regional Pain Syndrome](#)
- Stanford University: [Low-Dose Naltrexone for the Treatment of Complex Regional Pain Syndrome](#)

Research Study with the University of Bath

Orsolya Szekely is a PhD researcher at the University of Bath working with Dr. Janet Bultitude in the Centre for Pain Research. They are conducting an **online study** examining how people with CRPS observe and interpret movement. The study takes approximately 45 minutes to complete and involves:

- Answering some questions about pain symptoms and background information
- Watching short videos of different movements
- Making simple judgements about the movements shown
- Completing some follow-up questions about participants' experiences

Participants with CRPS who complete the study will receive **£30 compensation (approx \$39 USD)** for their time. Payment will normally be made by bank transfer. They welcome participants from both within and outside the UK; however, where an international bank transfer is not possible, they may provide payment in the form of a gift voucher instead.

If you have already taken part in this study, they will thank you for your interest and offer to pay you for your previous participation without taking part a second time.

Risks and benefits

There are no anticipated risks beyond those encountered in everyday life. However, some participants may find that thinking about their symptoms or observing movement is mildly uncomfortable. Participation is entirely voluntary, and participants may stop the study at any time without giving a reason.

While participants may not receive any direct benefit, the findings will help researchers better understand movement perception in CRPS and may contribute to future research into the condition.

Further information and participation

Anyone interested in learning more about the study or taking part can contact Orsolya Szekely via os386@bath.ac.uk.

Ethics approval

This study was approved by the University of Bath, Biomedical Sciences Research Ethics Committee (Reference: 5029-21378).

Join RSDSA's Adult Weekend Retreat Waitlist

The CRPS Connection - Strategies and Skills for Living with CRPS will take place October 2-5 in Philadelphia! This event is for adults with CRPS who are 36 and over.



The CRPS Connection is a thoughtfully designed, in-person gathering focusing on strengthening practical skills, sharing lived experiences, and building meaningful connections with others who truly understand the day-to-day realities of CRPS.

This event is currently **sold out**. We have started a waitlist for those who are interested in attending. Please send us an email at info@rsds.org to join the waitlist.

Our scholarship winners have been contacted. Thank you to everyone who applied. If a scholarship winner is unable to attend, we will select another winner as soon as possible.

If you have any questions, or if you're interested in sponsoring the weekend, please contact us at slkweiner@rsds.org.

Thanks For Attending RSDSA's Young Adult Weekend Retreat!

We had an awesome (and hot!) time in Scottsdale during last month's Young Adult Weekend Retreat. It was a great few days of networking, workshops, and fun out on the town!

Thank you to everyone who attended and helped to make the weekend possible for our CRPS Warriors between 18 and 35. Stay tuned for details on our 2027 retreat!



A Journey To Relief: Tony's Story

Abbott is an annual sponsor of RSDSA. Join our livestream with Abbott on September 22, 2026.

Living with complex regional pain syndrome (CRPS) can bring daily challenges as individuals navigate life under the weight of persistent, severe pain. For Tony, his journey with severe pain started when he was diagnosed with rheumatoid arthritis at 19. Despite the physical toll, he built a remarkable career as a top chef at restaurants across the country.



"My attitude was always: Keep moving through [the pain]," said Tony. Yet he had numerous surgeries and fusing procedures to try and control his pain. And nothing really worked.

"After I [had fusion surgery on] my ankle in 1991, I was never really that mobile. I dragged my leg around," Tony explained.

"If you want to be mobile, cut it off"

Tony heard this unwelcome advice from a doctor, so at age 40 he made the difficult decision to have his left leg amputated below the knee in the hopes of increasing his mobility.

For a while the amputation helped alleviate Tony's pain. And with physical therapy, he learned how to get around on one leg, even mastering skiing. But 5 years later, he developed severe nerve pain, diagnosed as complex regional pain syndrome (CRPS). That's when his pain specialist told him about DRG therapy.

Finding a life-changing therapy

Tony initially did a trial period with DRG therapy to see if it could provide some relief. The first day of his trial period, he felt so good that he walked 5 miles around New York City.

"It felt great," he said. "Up to that point, I had not walked that far in about 5 or 6 years." Tony then had a permanent DRG system implanted. And he said he's never felt better. The majority of his nerve pain is relieved, so he's able to hike again—and even able to go back to skiing. He's now a ski instructor for disabled people.

"For me, it's been a life-changing device," Tony said of DRG therapy. "And I found it because I don't give up."

Tony hopes his story can help other people also suffering from CRPS I or Causalgia (CRPS II). "What people need to know is that if you have nerve pain, [DRG therapy] has a huge potential to change the quality of your life," he said. "For me, it has completely changed the quality of my life."

What is Proclaim™ DRG Therapy?

Proclaim DRG Therapy is a novel neurostimulation technology that relieves pain at the source by interrupting pain signals at the dorsal root ganglion (DRG) before they reach the spinal cord. The DRG is a cluster of sensory nerve cells that sit along the levels of the spine that researchers have shown to help modulate pain signals from areas of the body where people experience pain.¹ Differing from traditional tonic spinal cord stimulation that has been used for decades, DRG stimulation may be a better choice for those with CRPS I or causalgia of the lower extremities.²

By focusing electrical stimulation specifically on the DRG pain signals can be interrupted so you don't feel pain in the same way. Proclaim DRG therapy has been clinically proven to provide significant pain relief, improve physical function, and enhance quality of life.^{2*}

Eligible patients can trial the therapy to see if it provides meaningful pain relief before committing to a permanently implanted system.³ To learn more about DRG therapy watch Dr. Kiran Patel's November 2025 [webinar](#) that covers the nature of pain, common pain conditions, and therapeutic options for pain relief. She will also join us for another webinar in September 2026.

ISI

This testimonial relays an account of an individual's response to the treatment. This patient's account is genuine, typical, and documented. However, it does not provide any indication, guide, warranty or guarantee as to the response other persons may have to the treatment. Responses to the treatment discussed can and do vary and are specific to the individual patient.

These materials are not intended to replace your doctor's advice or information. For any questions or concerns you may have regarding the medical procedures, devices and/or your personal health, please discuss these with your physician.

*Quality of life observed in other endpoints in the ACCURATE study

1. Esposito, M., Malayil, R., Hanes, M., & Deer, T. (2019, June). Unique Characteristics of the Dorsal Root Ganglion as a Target for Neuromodulation. U.S. National Library of Medicine. <https://pmc.ncbi.nlm.nih.gov/>

2. 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. doi:10.1097/j.pain.0000000000000814

3. Proclaim™ DRG Neurostimulation System Clinician's Manual. Plano, TX. 2025.

Risk Information: The placement of a neurostimulation system requires surgery, which exposes patients to certain risks. Complications such as infection, swelling, bruising, and possibly the loss of strength or use in an affected limb or muscle group (e.g., paralysis) are possible. Additional risks such as undesirable changes in stimulation may occur over time. Be sure to talk to your doctor about the possible risks associated with neurostimulation.

Rx Only

Brief Summary: Prior to using Abbott devices, please review the User's Manual for a complete listing of indications, contraindications, warnings, precautions, potential adverse events, and directions for use. The system is intended to be used with leads and associated extensions that are compatible with the system.

Indications for Use: Spinal column stimulation via epidural and intra-spinal lead access to the dorsal root ganglion as an aid in the management of moderate to severe chronic intractable* pain of the lower limbs in adult patients with Complex Regional Pain Syndrome (CRPS) types I and II.**

*Study subjects from the ACCURATE clinical study had failed to achieve adequate pain relief from at least two prior pharmacologic treatments from at least two different drug classes and continued their pharmacologic therapy during the clinical study.

**Please note that in 1994, a consensus group of pain medicine experts gathered by the International Association for the Study of Pain (IASP) reviewed diagnostic criteria and agreed to rename reflex sympathetic dystrophy (RSD) and causalgia, as complex regional pain syndrome (CRPS) types I and II, respectively. CRPS II (causalgia) is defined as a painful condition arising from damage to a nerve. Nerve damage may result from traumatic or surgical nerve injury. Changes secondary to neuropathic pain seen in CRPS I (RSD) may be present, but are not a diagnostic requirement for CRPS II (causalgia).

Contraindications: Patients who are unable to operate the system, who are poor surgical risks. Patients who have failed to receive effective pain relief during trial stimulation.

Warnings/Precautions: Diathermy therapy, implanted cardiac systems or other active implantable devices, magnetic resonance imaging (MRI), computed tomography (CT), electrosurgery devices, ultrasonic scanning equipment, therapeutic radiation, explosive and flammable gases, theft detectors and metal screening devices, lead movement, operation of machinery, equipment and vehicles, pediatric use, pregnancy, and case damage.

Adverse Effects: Unpleasant sensations, changes in stimulation, stimulation in unwanted places, lead or implant migration, epidural hemorrhage, hematoma, infection, spinal cord compression, or paralysis from placement of a lead in the epidural space, cerebrospinal fluid leakage, tissue damage or nerve damage, paralysis, weakness, clumsiness, numbness, sensory loss, or pain below the level of the implant, pain where needle was inserted or at the electrode site or at IPG site, seroma at implant site, headache, allergic or rejection response, battery failure and/or leakage. User's Guide must be reviewed for detailed disclosure.

Participate and Donate to the 6th Annual Picklin' for a Cure

The 6th annual [Picklin' for a Cure Awareness and Fundraising Pickleball Tournament](#) will take place at Udall Park from October 16-18, 2026.

They will continue to support RSD/CRS through RSDSA. They will also continue to support Lewy Body Dementia organizations both at the national and Tucson-level as well as the Amyotrophic Lateral Sclerosis (ALS) Therapy Institute.



“Picklin’ for a Cure” 501c3 has donated over \$160,000 to these charities as well as Tucson Area Pickleball, All in Youth Pickleball and Bhutan Cultural Exchange.

On behalf of All in Youth Pickleball, Tucson Area Pickleball and Picklin’ for a Cure, we thank you for your past support and look forward to your support this year.

If you're interested in being a sponsor, please contact Kevin Warfield @ 480-603-7332 or Tom Warfield @ 520-331-4418. If you're interested in playing in the tournament, [register here](#).

Thank you,
Kevin Warfield and Tom Warfield
Founders and Managing Directors of Picklin’ for a Cure

Host An Event with RSDSA

We pride ourselves in hosting in-person awareness and fundraising events across the country in addition to our stellar virtual events.

We would love to collaborate on additional events and are seeking your assistance to make them a resounding success.

If you are interested in hosting an event (like a walk, expo, sports tournament, etc!), please send London Kelley, our special events coordinator, an email at london@rsds.org.



A Hope Beyond the Pain

Written by CRPS Warrior Diana Jordan

I am a CRPS warrior. My story is one of pain, suffering, anxiety, depression, loss, grief, fear, and barriers. But my story is also one of hope, indescribable joy, community, restoration, peace, acceptance, and boundless love. Both of these things can be true because of Jesus.

I had a great childhood. I have a loving family who raised me in the church. I was baptized as a baby, confirmed as a teenager, and was president of the Methodist ministry at Virginia Commonwealth University. I excelled academically and was a successful gymnast and dancer.

Despite all that, my relationship with the Lord was shallow and immature. As a young adult, my main sense of identity came from my profession and hobbies - I felt that what I was able to do defined who I was. I stayed busy to try to tamp down the feelings of purposelessness that crept in. I valued my independence and tried to operate out of my own strength.

On Valentine's Day of 2018, I had surgery on my left foot for a misaligned bone. It was a relatively short and simple procedure where they broke the 5th foot bone, moved it into proper alignment, and screwed it into place. I had successfully had the same procedure done on my right foot the year before, so I felt like I knew what to expect and was happy that after this, I'd have no more feet left to correct. The procedure itself went smoothly, but pretty soon after surgery, I could tell something was different. The pain was far worse and was not improving in the weeks following surgery as it had on my right foot. By June of that year, my surgeon told me he suspected I had something called Complex Regional Pain Syndrome. He referred me to a pain management specialist, who officially diagnosed me with this obscure neurological disorder that I had never even heard of.

I immediately began pursuing medications, treatments, and procedures. While my pain did have some temporary response to these things, my overall condition declined. Within the first two years, it had gone from being just in my left foot to my shin, knee, leg, and hip. And as is common with those with CRPS, I developed anxiety and depression. And while, praise God, I have never attempted suicide, I have struggled with suicidal ideation: fantasizing about ways I could make the pain end.





During this time, I also had an identity crisis. I could no longer physically do my job processing crime scenes or participate in many of my daily activities. Instead of being fit and active, I was disabled, and I did not like it. I felt confused about who I was and like a burden to those around me. But the Lord did not see me this way. He slowly and lovingly began to show me that my identity was not in what I can do but is in who I am as His daughter through the blood of my Lord and Savior Jesus. He helped me

believe that I was still an important part of His body. He showed me how to grieve all I had lost and lament. I saw my pain reflected in Psalm 6: “Be gracious to me, O Lord, for I am languishing; heal me, O Lord, for my bones are troubled. My soul also is greatly troubled. But you, O Lord—how long?...I am weary with my moaning; every night I flood my bed with tears; I drench my couch with my weeping.”

He drew near to me and surrounded me with encouraging and supportive people. And he gave me a joy that the pain could not destroy. “For the Lord has heard the sound of my weeping. The Lord has heard my plea; the Lord accepts my prayer.” Even though the pain remains, He has blessed me in so many other ways. An amazing husband who doesn’t complain about the days he has to be my caretaker. Supportive and loving family and friends: there have been many rides given when I couldn’t drive, meal trains during periods of intense treatment, and more prayers than I can count. I was able to get training in adult education and instructional design and transfer careers. He’s provided me with a job with the flexibility I need to be able to attend the continuing doctor visits, procedures and treatments. He has provided the financial means to pursue treatments and medications not covered by insurance. He has given me ways to continue to serve my neighbors within the bounds of my physical limitations. He has protected me from addiction to the many potentially addictive substances that I take as a part of my daily medication routine. But most importantly, He’s brought me deeper into relationship with Him and a peace that surpasses understanding. He is teaching me how to depend on Him in all things, and it is only through His strength that I am here today.

The life of a CRPS Warrior is not easy. The pain we experience is something most people cannot even fathom. But my ultimate hope is not in myself; it’s not in doctors and medications; it’s not even in the possibility of a cure. My hope is in the promises of the One who has proven Himself to be faithful and trustworthy. I still pray and ask the Lord to remove this thorn in my flesh. But until that happens, I know His grace is sufficient for me. And while I don’t know if I will ever have another pain-free moment on this side of heaven, I cling to the promise of Revelation 21:4: “He will wipe every tear from their eyes. There will be no more death or mourning or crying or **pain**, for the old order of things has passed away.” 10

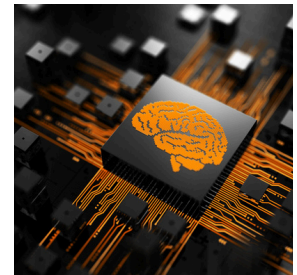
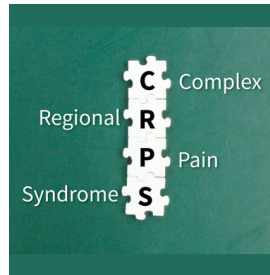
Catch Up On Our Livestreams and Blog Content

Behind on our livestream series? Head over to the [RSDSA YouTube Channel](#) to catch up on our latest videos focused on living with CRPS. We host a livestream every other month on months that *In Rare Form* is not published.



Send potential livestream topics and guests to us at info@rdsd.org!

The latest posts on the RSDSA blog feature insights on living with CRPS, using AI safely when researching CRPS, and much more.



Catch up today at rdsd.org/blog

Ilona Thomassen Retires From RSDSA Board After 20 Years

RSDSA Board Member Ilona Thomassen has retired from the Board after 20 years of service.

As a fellow CRPS Warrior, she also served as the president of the Dutch Patient Society, a patient advocacy committee in the Netherlands. She has been involved in national and international research groups and participated in writing and developing the Evidence Based Guidelines for CRPS (2006 and 2014) and the Care Standard for Chronic Pain (2017).

She's been involved in numerous other organizations including the European Pain Federation and has completed numerous scientific contributions and talks focused on CRPS across the globe.



We thank her for spending decades fighting for fellow CRPS Warriors.

RSDSA Support Group Corner

The [Horry/Brunswick Counties & Surrounding Areas CRPS/RSD Support Group](#) is hosting a [fundraiser](#) with the Myrtle Beach Pelicans in support of RSDSA! A portion of each sale through this link will be donated to help those in need with CRPS and RSD.

Myrtle Beach Pelicans vs. Fayetteville Woodpeckers Game

- Sunday, August 23, 2026 at 6:35 PM Eastern
- Location: Pelicans Ballpark at [1251 21st Avenue North, Myrtle Beach, SC 29577](#)
- Ticket Details: Tickets are \$23.77. \$5 from each ticket will be donated to RSDSA.
- To contact the support group/event organizer, email Kira Kordiak at k.l.k.2.00.c.k@gmail.com



The [Fight The Flame Support Group](#) is hosting the [2026 Fight the Flame 5k and 1k Family Roll & Stroll](#) in Charlotte next month!

Fight the Flame 5k and 1k Family Roll & Stroll

- Sunday, September 27, 2026 at 9:00 AM Eastern
- Location: McAlpine Creek Park at [8711 Monroe Rd Charlotte, NC 28212](#)
- Registration Details: 5K tickets are \$30 | 1K Family Roll & Stroll tickets are \$25 | Virtual Walker tickets are \$20
- To register or contact the event organizer, visit runsignup.com/fighttheflame



[View our full list of support groups here on the RSDSA website.](#) If we're missing a support group, or if you want to [start your own](#), please contact Sharon Weiner at slkweiner@rds.org.

CRPS Community Event Calendar

Add the following events to your calendar! **RSDSA sponsored/affiliated events are highlighted in orange**, while additional community events are **highlighted in blue**.

- Friday, August 14 - [Facebook and YouTube Livestream on Surgery and CRPS](#)
- Sunday, August 23 - [Myrtle Beach Pelicans vs. Fayetteville Woodpeckers Game Fundraiser in Myrtle Beach, SC](#)
- September - [Pain Awareness Month](#)
- Tuesday, September 22 - [Livestream with Abbott on the difference between Dorsal Root Ganglion \(DRG\) Therapy and Spinal Cord Stimulation \(SCS\)](#)
- Sunday, September 27 - [Fight the Flame 5k and 1k Family Roll & Stroll in Charlotte, NC](#)
- Friday, October 2 - Monday, October 5 - [The CRPS Connection: Adult Weekend Retreat in Philadelphia, PA \(Join The Waitlist\)](#)
- Friday, October 16 - Sunday, October 18 - [6th Annual Picklin' for a Cure in Tucson, AZ](#)
- Monday, November 2 - [Color The World Orange™ Day](#)

Donate to RSDSA

Please consider donating to RSDSA at rsds.org/donate.

We Want Your Feedback!

Please send any suggestions or upcoming events of interest to our community to info@rsds.org.

Thank You to Our Sponsors

Our sponsors make everything we do possible. Please join us in thanking and supporting them!

[Abbott](#) | [The Baker Family Charitable Fund](#) | Brodsky Family Foundation | [The CRPS Law Firm](#)

Diana and Peter Smith in memory of Stephanie Theresa Smith

Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager

Mike & Lynn Coatney Family Foundation Fund

TJ Whalen Foundation | [Vitalitus](#)