DECEMBER 2025 ISSUE 42

IN RARE FORM

Looking Forward, Together

CRPS is one of the most painful and least understood conditions known to medicine - and because of that, many individuals face their diagnosis feeling isolated, afraid, and unsure where to turn. For thousands of people across the country, RSDSA becomes the first steady source of clarity, community, and hope. It is only through your support we can continue this great work.

This year, supporters like you helped RSDSA:
- Create resources and education for individuals and families living with this rare condition
- Provide guidance and community connections for people navigating their CRPS journey
- Deliver expert-led livestreams, online support, and educational materials to improve understanding and outcomes
- Increase awareness among healthcare providers and advocates
- Strengthen national networks so no one must walk this path alone
- Grow our patient assistance programs

But there is still so much more work to be done.

Because CRPS is rare, individuals often struggle for years searching for clear information, appropriate care, and a supportive community. For more than 40 years, RSDSA has funded research, centralized credible resources, and laid a foundation that many organizations rely on today. As we look toward 2026, we are committed to doing even more - expanding education, strengthening advocacy, and growing our patient assistance programs, to name just a few. None of this is possible without your dedicated support.

Your year-end gift has a direct and meaningful impact.

Please click below to make your year-end contribution today.

DONATE TO RSDSA

RSDSA Had a Busy 2025!

RSDSA had a full year of accomplishments, awareness, and activities. These include:

- Hosting our first in-person conference since 2019
- Working with our scientific advisory committee and the International Research Consortium for CRPS on research opportunities
- Sharing the most recent CRPS research studies with the community (see page 13!)
- Continuing our email newsletter (sign up here!)
- Cleaning up our support group list to only include active and responsive groups
- Working with our advocacy chair on Rare Disease Week activities, and providing additional advocacy/legislative tips and updates to the community
- Sending out six editions of *In Rare From*
- Hosting six webinars on Facebook and YouTube
- Helping CRPS Warriors in need via our Patient Assistance Funds
- Distributing and analyzing a community survey to better understand the CRPS community's wants and needs
- Updating our state physicians lists to only include active and knowledgable physicians that treat CRPS
- Updating our Dental, Hospital/Emergency Room/Urgent Care, and Health Care Aides, Personal Care Assistants, and Certified Nurse Assistant Guidelines
- Providing daily email, social media, and phone support to CRPS Warriors, their physicians, caregivers, and hospitals
- Physically mailing brochures, I Have CRPS Cards, and other CRPS/RSDSA information packages to physicians, hospitals, and Warriors in need
- Regularly updating the RSDSA website, including our news/blog section and resources page
- Leading and coordinating with the community on events such as our Virtual CRPS Awareness Walk, Burning Hope's Walk Strong, The Orange County Survivors and Caregivers Support Group's CRPS/RSD SoCal Friendship Gathering & Stroll, and many more
- Sending kids with CRPS to The Coalition Against Pediatric Pain's (TCAPP) Pediatric Pain Week
- Hosting our annual Young Adult Weekend Retreat for CRPS Warriors between 18 and 31
- Supporting the premiere of the INVISIBLE movie on Amazon Prime Video

Consider donating to RSDSA today via rsds.org/donate


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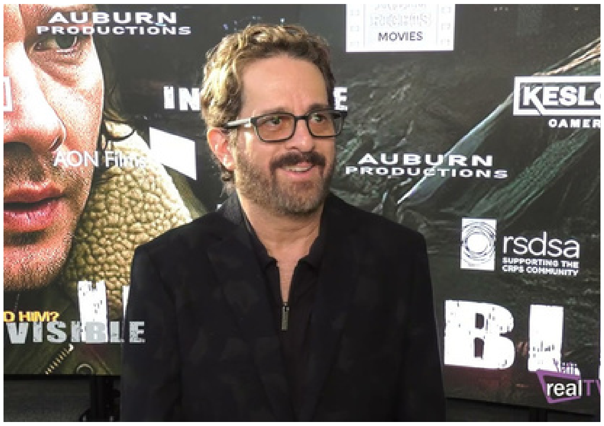
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SR-260

2025 RSDSA Conference Recap - Videos Are Now Available

Thank you to everyone who attended our 2025 Treating The Whole Person: Optimizing Wellness conference in October! It was a great weekend meeting and connecting with CRPS Warriors from across the world (yes we had attendees from Canada, South Korea, and Guam!).

The event opened on Friday evening with a meet and greet and continued into Saturday morning with a keynote address from Dr. Pradeep Chopra. Numerous CRPS, medical, and legal professionals took the conference stage in additional to CRPS Warriors who spoke about hope, advocacy, and their lived experience.

The RSDSA Board of Directors also took the opportunity to meet ahead of the conference to realign on goals for 2026 and beyond.

Watch the full videos from our conference on the RSDSA YouTube Channel.
View photos from the conference on Facebook.
View the resources from our conference on the RSDSA Conference Hub.

Thank You to Our Conference Sponsors and Exhibitors

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Tonko, Miller-Meeks Introduce Resolution on Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy Awareness Month

Bipartisan resolution recognizes rare, painful condition

Washington, November 21, 2025

WASHINGTON, DC—Representatives Paul D. Tonko (D-NY) and Representative Mariannette Miller-Meeks (R-IA) today announced the introduction of a bipartisan resolution designating November as Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy Awareness Month to raise awareness about this rare neuro-inflammatory syndrome and ensure individuals living with this condition have access to early detection as well as safe and effective treatments.

Complex Regional Pain Syndrome also known as Reflex Sympathetic Dystrophy is characterized by persistent, regional pain that is disproportionate to any known trauma or lesion, and is accompanied by sensory, motor, vasomotor, and/or trophic changes in the affected limb.

Rep. Tonko successfully championed the push in Congress to improve visibility and access to treatments for the millions of individuals impacted by a rare disease with his Helping Experts Accelerate Rare Treatments (HEART) Act, which was signed into law in December 2022.

“For the millions of Americans living with a rare or ultra-rare disease, reliable information is scarce and treatment options are even more limited, leaving patients and their families with few paths forward and even fewer reasons for hope.” Rep. Tonko said. “That’s why I am incredibly proud of my work alongside advocates to have passed the HEART Act. This law amplifies the voices of those living with a rare disease as well as healthcare professional who care for them, while also accelerating the development and approval of new treatments. But my work to uplift the needs of those living with these rare conditions is far from over. Today, I’m honored to introduce a new resolution on Complex Regional Pain Syndrome alongside Representative Miller-Meeks and am deeply grateful to all those who have helped raise awareness on this often-overlooked condition. I pledge to continue working to ensure Congress meets the needs of those living with a rare disease.”

“As a physician, I know how devastating Complex Regional Pain Syndrome can be for patients who often spend years searching for answers,” Rep. Miller-Meeks said. “Early detection and access to effective treatment are critical, yet too many Americans face delays, misdiagnosis, or a lack of awareness. I’m proud to join Rep. Tonko in leading this bipartisan effort to shine a light on CRPS and ensure that patients, families, and providers have the tools and support they need.”

The text of the resolution can be viewed HERE.

In a statement, the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) said, “Reflex Sympathetic Dystrophy Syndrome Association (RSDS.org) supports CRPS Awareness as a great step forward in giving comfort and hope to all those afflicted with CRPS. We are deeply grateful to Representative Tonko and Representative Miller-Meeks for their continued commitment to raising awareness. The nature, and even the existence of CRPS, is too little known. Increasing awareness of CRPS will motivate wider education about this painful disease among healthcare professionals as well as among the lay public. It will promote support for those who suffer with CRPS, and it will encourage research into the mechanisms of the disease of CRPS, which will lead to better treatments, and, ultimately, for a cure for CRPS.”

A Journey To Relief: Tony's Story

Abbott is an annual sponsor of RSDSA.

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 webinar that covers the nature of pain, common pain conditions, and therapeutic options for pain relief.

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 pharma- cologic 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.

What's New With CRPS?

In this new section, we'll share the latest news and updates about CRPS.

A PhD candidate at the University of Bath is inviting CRPS Warriors to take part in research on how CRPS affects movement perception.

This survey must be completed on a laptop or desktop computer.

Click here to take the survey. Please wait until the download bar has finished loading. Once it is complete, you will see "all resources downloaded." and you'll be able to click the "Ok" button to begin the 45 minute study. **Please do not change the numbers in the participant or session boxes.**

Submit Your Question For Our New "Dear Abby" Column

We heard you loud and clear! Many of you requested that we add a "Dear Abby" column to future editions of *In Rare Form*. Please submit your questions to info@rsds.org using the subject line **Dear Abby**.

Please note that the "Dear Abby" column will not be used as a diagnostic tool. We will take questions on a rolling basis.

Add Your Loved One To our CRPS Warriors Memorial

RSDSA has highlighted CRPS Warriors we have lost over the years thanks to approved submissions made by their loved ones.

If you have a loved one you would like added to this memorial, please send us an email at info@rsds.org.

Share Your Stories of Hope With the Community

RSDSA is looking to feature more Stories of Hope on our blog and future editions of *In Rare Form*. If you are in remission, or if you've found a treatment that works for you, the CRPS community wants to hear about it!

Please reach out to us via info@rsds.org.

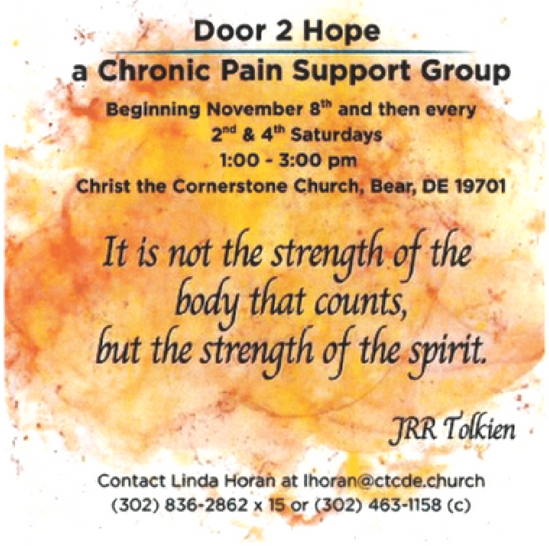
RSDSA Support Group Corner

There's a new support group in Delaware! Linda Horan's Door 2 Hope Support Group will meet every 2nd & 4th Saturday from 1-3 PM at Christ the Cornerstone Church Room 105 (lower level). The church is located at **3135 Summit Bridge Road, Bear, DE 19701**.

Her group's mission is to provide support, education, and hope to all those in pain so they can get to a point where their pain is "manageable" and help others realize they are not alone.

The group is open to all those who experience chronic pain & their caregivers. Contact Linda Horan at lhoran@ctcde.church, (302) 836-2862 Extension 15 or on her cell at
(302) 463-1158

If your group has upcoming events, please let us know via info@rsds.org. If you're interested in starting your own group, email us at slkweiner@rsds.org.



Door 2 Hope

a Chronic Pain Support Group

Beginning November 8th and then every
2nd & 4th Saturdays
1:00 - 3:00 pm
Christ the Cornerstone Church, Bear, DE 19701

It is not the strength of the
body that counts,
but the strength of the spirit.

JRR Tolkien

Contact Linda Horan at lhoran@ctcde.church
(302) 836-2862 x 15 or (302) 463-1158 (c)

This group is open to all those who experience chronic pain and their caregivers.

Everyone's pain is different, no one feels the pain of another.

Our mission is to provide support, education, and hope to all those in pain so they can get to a point where their pain is "manageable" and help others to realize *you are not alone!*

Christ the Cornerstone Church
3135 Summit Bridge Rd.
Bear, DE

Cheers to the Season With Carolyn's Cards

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.

If you would like to request a card for a loved one ahead of the holiday season, email Carolyn at carolyns.cards2@gmail.com.

Host A CRPS Awareness Event in 2026

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 new special events coordinator, an email at london@rsds.org.

Sign up to Volunteer and/or Connect With Fellow Caregivers

RSDSA is looking for volunteers who can assist us with fulfilling our mission! We are in need of volunteers who can help with data entry, minor local travel, and peer support.

We are also always looking for caregivers who are interested in connecting with one another. RSDSA wants to ensure our community's caregivers can find strength and comfort in this journey.

If you're interested in becoming more involved, email us at info@rsds.org.

Childhood Experiences of People with EDS, CRPS, and/or POTS


Oregon State University

Childhood Experiences of People with EDS, CRPS, and/or POTS

We are a new research team consisting of researchers and students with and without disabilities who are interested in the experiences of people living with Ehlers-Danlos Syndrome, Complex Regional Pain Syndrome, and/or Postural Orthostatic Tachycardia Syndrome. The head researcher is Dr. Nina Slota.

What is the study about?

This is Phase One of a multi-phase and multi-year study. Each phase will explore a different facet of life with these disorders. Phase One will collect information about your demographics, your childhood, your identity, and your pain. Whether or not you participate in Phase One, you can choose whether or not to join future studies.

To be eligible for this study you must:

✓ Be 18 years or older

✓ Currently live in the United States

How to participate? Scan the QR Code

https://oregonstate.qualtrics.com/jfe/form/SV_e3ZgrrS0lccOLbw

Learn More: Contact Nina Slota

nina.slota@oregonstate.edu

This study has been approved by the Oregon State University Institutional Review Board, Project # HE-2025-1530.

Research participants are needed for an online questionnaire about “Childhood Experiences of People with EDS, CRPS, and/or POTS.” This study will be Phase 1 of a multi-phase, multi-year study.

If you are 18 or older, have at least one of these syndromes, live in the United States, and want to participate, please click here to participate. Please feel free to share this study.

This project has been approved by the Oregon State University Institutional Review Board, Project # HE-2025-1530.

For any questions, please email Dr. Nina Slota at nina.slota@oregonstate.edu.

Current Research Study Opportunities

In addition to the study listed above, below is a list of additional CRPS-focused studies that we are currently aware of:

- Stanford University: Transcranial Magnetic Stimulation for Complex Regional Pain Syndrome
- Stanford University: Low-Dose Naltrexone for the Treatment of Complex Regional Pain Syndrome
- UC San Diego: The Effects and Mechanisms of a High CBD Cannabis Extract (BRC-002) for the Treatment of Pain and Health in Complex Regional Pain Syndrome
    - Watch the replay of the May 2025 livestream with the lead researchers of the UC San Diego study

Apply for Dr. Alissa Wolfe's Scholarship from December 8-14, 2025

Maria's Fund is offering one scholarship for a free course of training by Alissa Wolfe, a DPT and chronic pain specialist. Several members of the RSDSA community have completed her 14-week online Chronic Pain Breakup Method program which focuses on the neuroscience of pain.

The application will be available beginning December 8th and will close on December 14th via alissawolfe.fillout.com/crps.

You can learn more about the program on Alissa's YouTube Channel.

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SUPPORTING THE
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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 Title Sponsors

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

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