AUGUST/SEPTEMBER 2025 ISSUE 40

IN RARE FORM

IN THIS ISSUE

Our Treating the Whole Person: Optimizing Wellness Conference is October 24-25 in Dallas!

Learn more about our speakers, how to register, FAQs, and more!

RSDSA's in-person conference is two months away! We are looking forward to coming together at the Sheraton DFW Airport Hotel in Irving, Texas (Dallas) to discuss the latest updates on CRPS, hear from experts, and to network with others who truly understand from Friday, October 24th to Saturday, October 25th.

We'll kick the weekend off by hosting a meet and greet on Friday evening. Our conference sessions will take place on Saturday beginning at 9:30 AM. All speakers and sessions will focus on a number of CRPS-related topics including research, advocacy, mindset motivation, legal challenges, caregiving, and more.

Info and dates to remember

- Registration pricing:
  - $50 for CRPS Warriors
  - $50 for Caregivers
  - $100 for Professionals
  - Registration includes lunch on Saturday
- Our room rate of $154 per night ends on **October 2, 2025**
- If you're interested in sponsoring the conference or hosting an exhibit table, email us at info@rsds.org.

Visit our conference hub at rsds.org

Conference Speakers and Sessions

Details are subject to change. A complete agenda with times will be provided to conference registrants.

Managing CRPS in Adults and Children
Pradeep Chopra, MD

Treating the Whole Person Begins with Trust
Peter A. Moskovitz, MD

Advocacy Breakout Session
Lisa Van Allen

Caregiver Connect Breakout Session
Sue Pinkham

From Hurt to Hope: The Path to Joy
Amberly Lago

CRPS Research Updates
Stephen Bruehl, PhD

CRPS Research Updates
Norman Harden, MD

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SUPPORTING THE CRPS COMMUNITY

Understanding the Impact of Upcoming Medicaid Changes

CRPS: Things You Wish Someone Had Told You
Joshua Prager, MD

Can the Legal System Help Me?
Bryan Pope, Esq.

Advocacy and Events Breakout Sesssion
Miller Kerr

CRPS Internationally
Dr. Choi Jongbum

Conference Sponsors and Exhibitors

Sponsors and exhibitors are subject to change. If you're interested in sponsoring the conference or hosting an exhibit table, email us at info@rsds.org.

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DOG TRAINING & CONSULTING LLC

What's New With CRPS?

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

CRPS Warrior Ed Mowery was recently featured in the *New York Times* in an article titled "Treating Chronic Pain Is Hard. An Experimental Approach Shows Promise" as well as a segment on CBS News Sunday Morning.

Ed joined a research study that uses deep brain stimulation to control his CRPS pain. The results of his brain implant have resulted in "maybe one bad day a week."

Livestream with Dr. Anita Davis - September 16, 2025

RSDSA is hosting a free livestream with Anita Davis, PT, DPT, FNCP on Tuesday, September 16th at 7PM Eastern on facebook.com/RSDSA and youtube.com/@RSDSA from your computer, tablet, or phone.

Dr. Davis recently spoke to USA Today about how conditions like CRPS are often misdiagnosed as mental health disorders. Many CRPS Warriors are told that "it's all in your head" and they do not get the care that they need in a timely manner.

We're welcoming Dr. Anita back to our livestream series for **Pain Awareness Month** to talk about how to deal with dismissive physicians.

Dr. Anita Davis has focused her career on treating people with chronic pain conditions. She developed and managed the rehabilitation program for the Brooks Rehabilitation Comprehensive Pain Rehabilitation Program for 30 years. Dr. Davis is also part of an interdisciplinary team at Nemours Jacksonville assessing and treating pediatrics with chronic pain. She has presented at local and national conferences on issues related to chronic pain evaluation and treatment and psychologically informed practice. Academically, she graduated from the Medical College of Georgia in 1985 and completed a transitional doctorate in 2009. She also serves on the Florida Department of Health Rare Disease Advisory Council and manages a support group for individuals with CRPS.

Please Urge Congress to Protect Pain Research

The House and Senate Appropriations Committees are working on the FY2026 budget bills now. The President has proposed a 40% cut to NIH's budget.

Pain research at the NIH has long had a tiny budget relative to other diseases and conditions with lesser burdens affecting lesser numbers of Americans. But all that changed dramatically in 2018 when it was clear that the lack of effective treatments for pain had meant relying on opioids for pain management.

As a result, Congress increased the overall funding of pain research across the NIH and started the HEAL (The Helping to End Addiction Long-term®) Initiative. A little less than half of the HEAL funding goes to pain research and the other half to Substance Use Disorders (SUD) research.

Since 2018, great progress has been made in conducting research to better understand pain, determine the best way to make appropriate use of the treatments we have and find new treatments.

Now is not the time to stop that funding, just when we are beginning to see the fruits of that investment emerge. Please use your voice to tell Congress to protect the NIH Pain Research budget and the HEAL Initiative.

The US Pain Foundation has a simple online form you can use to send a message to your congressional representatives.

RSDSA Support Group Corner

We're excited to announce that we have updated the support group listing on the RSDSA website to only reflect active groups. Check them out and reach out if you have any questions!

We also want to thank our RSDCA support group as they hosted a fundraiser for RSDSA in the community this summer!

If your group has upcoming events, please let us know via info@rsds.org so we can highlight them on social media, our weekly newsletter, and the next edition of *In Rare Form.*

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RSDSA - REFLEX SYMPATHETIC DYSTROPHY ASSOCIATION

Show this flyer or simply mention the fundraiser to your server to have your sales counted.

FUNDRAISER DETAILS

5461 Katella Ave, Cypress, CA 90630

July 23, 2025*

If ordering online, please follow these instructions:

1. Start your order at **redrobin.com/order** and select the restaurant above.
2. In the menu, go to the category labeled "Fundraisers (To-Go Only)" and click on that item.
3. Click the "add" button, and then "add to bag."
4. Add your meal items and check out.
5. Arrive at Red Robin, come in, say hi, grab your food and be on your way! If your location has curbside pick-up, we can bring it to your car too!

*Fundraiser during restaurant operating hours. Visit redrobin.com and find this location to view hours. Donation based on all eligible net dine-in and to-go food sales only. Excludes sales from catering (at select locations), 3rd party ordering and delivery sites, alcohol, gift cards, retail, tax and gratuity. Offer void if flyer is distributed in or near the restaurant during fundraiser day & hours.

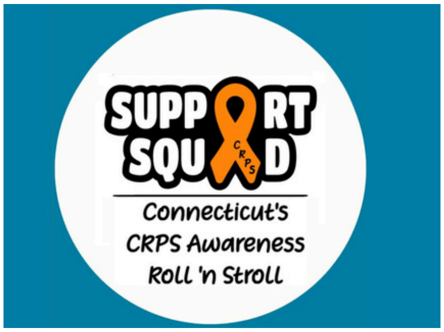
D-Shee by the Sea - Walk & Stroll to Support CRPS Awareness - September 14th

Attention New Jersey Warriors! D-Shee by the Sea - Walk & Stroll to Support CRPS Awareness is happening Sunday, September 14th at 11:00 AM.

CRPS Warrior Daniel Sheehan (D-Shee) was diagnosed with CRPS in June 2020. He is now partnering with RSDSA to help raise awareness, support groundbreaking research, and ensure that others facing this illness don't feel alone, dismissed, or hopeless.

If you are in the northeast, join us on the Ocean City, NJ Boardwalk on September 14th for a walk and stroll with fellow Warriors and members of the community.

Connecticut's CRPS Awareness Roll 'n Stroll - September 20th



Join RSDSA and Kelly's Crusaders for Connecticut's CRPS Awareness Roll 'n Stroll in support of the CRPS community on September 20th at 3:00 PM. All proceeds will benefit RSDSA, helping to advance care and bring hope to those in need.

We are inviting people from the Northeast region to join us! We are looking forward to an exciting day where CRPS Warriors and their loved ones can come together. Register as an individual or create a team with your family, friends, co-workers, and support system to raise money for our Roll 'n Stroll.

5th Annual Picklin' for a Cure - October 17-19

The 5th Annual Picklin' for a Cure from October 17-19, 2025 at Udall Pickleball Facility in Tucson, Arizona will raise awareness and funds for RSDSA, Lewy Body Dementia Association, Banner Health Alzheimer's Institute, J. Orin Edson Family Lewy Body Dementia Center of Tucson, and ALS-Therapy Development Institute. We are excited for another great tournament and success in raising money for these worthy non-profit organizations.

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

The Coalition Against Pediatric Pain's Pediatric Pain Week at Great Wolf Lodge

by RSDSA Board Member Sue Pinkham

The Coalition Against Pediatric Pain's (TCAPP) Great Wolf Lodge Event was a huge success for our children who live in chronic pain and their families. Great Wolf Lodge provided handicapped rooms for every family who needed them, and addressed all our children's allergy needs (of which there were many!). This event brought together old friends and created new friendships very quickly. As I watched the new families enter the ballroom, I noticed a slight hesitancy and nervousness. But within 30 minutes, children were hugging each other and comforting each other as they built LEGO sets together and chatted. It was amazing to watch the friendships grow so quickly between children and parents.

The connections these families made were quick, and new families learning that these people "get it". It's incredible to meet another child/parent who understands what your child/family is going through – you don't need to explain the struggles, the medical challenges, school challenges, etc. They understand all of it because they live with it too.

By the end of the week, children were exchanging phone numbers, gaming names to connect online and promising to keep in touch with each other, all with tears in their eyes. As we say, it's not goodbye, it's "see you next time!"

We could not have offered this camp without the financial support of the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) and our anonymous donor. We are so grateful for all the support and confidence we receive as an organization. Here are some of the parents' testimonials from the week:

"Thank you so much for including our family on this wonderful summer adventure. We had such a great time and made some awesome memories! I'll probably never have the opportunity to go down a waterslide with my family again (because I probably shouldn't have done it in the first place, lol), so that for one will be a permanent special memory for us!"

"This trip was amazing. It allowed Kyleigh to meet new kids and to enjoy life, something we can't always do for many reasons. Great Wolf was great and I felt very accommodated. The activities were good and the children enjoyed them. All in all, I thought the entire experience was amazing and awesome for families to not only meet other, but to have fun and family time that we cannot typically have for various reasons. Thank you to everyone in your organization for this opportunity."

“TCAPP Camp gave our family a rare and much-needed break from the isolation and logistics that so often make travel impossible with chronic illness. Most trips leave us struggling to keep up, but here we were met with kindness, flexibility, and activities designed so everyone could participate at their own pace. We made lasting friendships the very first night, and the central, low-pressure crafts and games created an easy way to connect throughout the week. Our 9-year-old not only had fun but also experienced a level of acceptance and understanding about their chronic pain that we’ve been trying to nurture for years—lessons that unfolded naturally through play and friendship.” - Paula

“This was our first time attending a TCAPP event. For us, it was amazing to be with families who experience the same struggles as us. If we were not up for an event, there was no judgment from the group. We did not feel the need to "keep up" with anyone. Our daughter could go at her own pace and didn't feel peer pressure to overexert herself. The tasks and events did not revolve around athletic abilities and gave the kids a chance to bond. It was also very nice to have allergy-friendly food available to us. Usually we need to pack a ton of gluten-free food (which we still did, but it was a novelty to have GF cookies around!).

Watch the INVISIBLE Movie on September 2, 2025!

INVISIBLE, a poignant suspense drama from filmmaker Matthew Michael Ross, explores the often-misunderstood realms of invisible diseases, addiction, and mental illness. One of the actors plays a CRPS Warrior.

The film, which has already won seven festival awards, is set to release on all digital platforms via Indie Rights Films distribution on Amazon, YouTube, and Google Play on September 2nd, 2025. Learn more about the movie here.

Short RSDSA Community Survey - We want to hear from you!

RSDSA would like to hear from the community about what they would like to see us accomplish in the near future.

Please take a moment to fill out our short survey at your earliest convenience.

Click here to take the survey.

How to Complete an In Memoriam Donation to RSDSA

Many individuals reach out to RSDSA in order to complete an “In Honor/In Memory” gift for a loved one with CRPS.

We have included detailed answers to frequently asked questions on our website so you can donate via check or complete an online donation with PayPal or a debit/credit card.

Thank You For Attending the 2025 Young Adult Weekend Retreat

We appreciate everyone who was able to attend our June 2025 Young Adult Weekend Retreat in Nashville. It was a great time!

Keep an eye on our new Young Adult Weekend Retreat page on the RSDSA website for details on our 2026 location and dates!

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!

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