FEBRUARY 2026 ISSUE 43

IN RARE FORM

IN THIS ISSUE

Join our 7th Annual Walk For CRPS on Saturday, June 6th, 2026

RSDSA's 7th Annual **Walk for CRPS** will take place on Saturday, June 6, 2026. We're excited to bring our national walk and day of awareness to a town near you!

For the last six years you have helped raise awareness for CRPS by providing care, advocacy, research funding, education and hope to the CRPS community via your teams. We invite you to once again come together as we work to educate the world about CRPS.

Although we wish we could see all CRPS Warriors in person, the benefit of our walk is that you can have team members from across the country or even around the globe! This gives your supporters the freedom to walk on their own schedule and still feel involved in such a wonderful experience and cause.

Registration Information

- $25 for adults | $15 for children ages 5-12
- You can register as an individual or create/join a team

Our event is open to participants of all abilities. Whether you walk, roll, or run along with us, we want to see you on June 6th. **Please remember that physically walking is not a requirement to participate.**

REGISTER HERE

For questions and for more information on our Walk for CRPS, contact London Kelley at london@rsds.org or 501-781-1921.

How to Plan for RSDSA’s 7th Annual Walk For CRPS

February	Form a planning team and prepare for the Walk! Outline potential participants, goals, routes, water stations, checkpoints, volunteers, etc. This is a highly individualized step, as each Walk looks different. Lean on RSDSA for ideas and feedback.
March	Begin reaching out to participants and sponsors in order to increase awareness. Aim high and be ambitious! Research permits and insurance requirements. Communicate any needs to RSDSA. Submit any necessary applications by early March as most municipalities need at least 60 days lead time.
April	Promote the Walk using flyers, social media posts, and word of mouth. Use community leaders, including physicians, to get the word out and lean on participants to help promote the Walk as well. Share registration links with everyone you can and encourage registrants to keep the momentum going.
May	Regularly communicate with your sponsors and participants to generate excitement and awareness. Ensure that all details are cemented and contingencies are created. Create a rain plan and day-of task list for volunteers. Final participant counts are due to RSDSA by May 14th to ensure shirts arrive on time!
June	It’s Walk day! There will likely be latecomers who want to register day-of. A quick registration line with 1-2 volunteers should suffice. Ensure all volunteers are well versed on emergency protocols.
July	Now is the time to sit back and reflect. What went well? What could have gone better? Identify wins and losses so you can plan for next year. Take some time to write acknowledgments to each sponsor as a meaningful way to improve your impact, steward relationships, and awareness.

What's New With CRPS?

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

RSDSA and the IRC endorse the excellent review of trial designs and methodology found in **Optimising clinical trial methods for complex regional pain syndrome: a methodological framework (OptiMeth-CRPS)** by our esteemed international colleagues, led by Dr Keith Smart in Dublin.

This paper summarizes recent trial designs and methodology in a very comprehensive 'Delphi' like process.

Livestream with Dr. Norman Harden on Thursday, February 26 at 7PM Eastern

Join our Facebook and YouTube livestream with Norman Harden, MD on Thursday, February 26th at 7PM Eastern. Dr. Harden will join us to discuss CRPS research, a new research registry, and how we're working with professionals across the globe via the International Research Consortium for CRPS.

R. Norman Harden, MD, is Chairman of the Board of the International Research Consortium for CRPS. He is the co-leader of the diagnostic criteria for CRPS (also known as the Budapest Criteria), founder of the RSD treatment program at the Medical University of South Carolina, and later served as the Director of the Center for Pain Studies and founder of the Chronic Pain Care Center at the Rehabilitation Institute of Chicago.

He is a professor of the Department of Physical Medicine and Rehabilitation and the Department of Physical Therapy and Human Movement Sciences at Northwestern University and holds the Addison Chair in Pain. Dr. Harden is also a member of the RSDSA Board of Directors and is the Co-Chair of our Scientific Advisory Committee.

Meet us on Facebook, or join us on YouTube, on 2/26. Come ready with your research questions! **As always, the livestream will be recorded and will be available if you miss it or if you want to rewatch it later.**

Tips for Caregivers of CRPS Warriors

National Caregiver Appreciation Day is March 3rd! RSDSA continues to support our community by providing tips for caregivers and CRPS Warriors alike.

- **Continue to Learn About CRPS** - Understanding its symptoms, flares, and unpredictability can help you respond with empathy instead of frustration. This also helps you provide trust and emotional safety to your CRPS Warrior.
- **Ask, Don't Assume** - Instead of guessing what your loved one needs, ask: "What would help right now?" This includes asking before touching affected areas.
- **Help Create a Low-Stress Environment** - Stress can easily intensify CRPS symptoms. Practicing routines and calm communication can make a difference.
- **Assist with Appointments & Advocacy** - Offer to attend medical appointments. Take notes during the appointment and help track symptoms and medications. Be their voice if physicians question the need for new medicines or treatments.
- **Encourage Pacing**, **Not Pushing** - Overdoing it can trigger flares. Help your CRPS Warrior balance activity with rest.
- **Support Mental Health** - CRPS can lead to anxiety, depression, or isolation. Encourage counseling or peer support if needed.
- **Take Care of Yourself, Too** - Caregiver burnout is real. Rest, seek support, and maintain your own health. Practice patience and reach out for assistance when necessary.

View our Resources for Caregivers page on the RSDSA website to view videos filled with information and stories that could be helpful for caregivers and their CRPS Warriors.

Sign up to Connect With Fellow Caregivers

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

If you're interested in Caregiver Connect, email us at info@rsds.org.

Join us at Rare Disease Week in Washington, DC - February 24-26, 2026

Rare Disease Week is a free event hosted by the Rare Disease Legislative Advocates, a program of the EveryLife Foundation for Rare Diseases. It brings together rare disease advocates to make their voices heard with their Members of Congress.

Participants are educated on policy proposals impacting the rare disease community and provided opportunities to advocate directly for policy change.

Lisa Van Allen, chair of the RSDSA Advocacy Committee, attended Rare Disease Week in 2025 and wrote a detailed post about her experience on the RSDSA blog. She will attend Rare Disease Week again this year and is looking forward to connecting with other CRPS Warriors! **Let us know if you're attending!**

CRPS Warrior Presenting in the Rare Artist Gallery

Congratulations to CRPS Warrior Zanny Nicholas for becoming an Award Recipient in the 2025 Rare Artist Program hosted by the EveryLife Foundation for Rare Diseases.

Zanny entered an original song she wrote about the struggles of living with CRPS titled "Alive Again". She was also the *only* CRPS Warrior to be a finalist in this year's competition and we're happy to see that the community voted for her! Zanny will be present at the Rare Artist Gallery during Rare Disease Week later this month.

"ALIVE AGAIN"

by zanny nicholas / age 26 / complex regional pain syndrome

I used to be a lefty but I lost it
I used to be free, but now that's
All packed up in boxes
And it's just dumb
It's just luck and I don't got it
There's a monster in my closet
But I'll feed it and I'll walk it
Until it loves me
Until I'm...

Wanted to be amazing
But now all I wanna be is healthy
Somebody help me

I'd die trying
I would die trying
'Cause the war in me is violent
I would die trying
But I'm healing, I feel it
I'm alive again

I used to be ashamed of all my feelings
Walking in place, but now I'm
Running 'round screaming
That I'm not stuck, I'm just sick
There's a spider on the ceiling
Yeah, it's coming down quick
I hear it when I'm sleeping

I used to be amazing
But now all I wanna be is a
Person not a patient

I'd die trying
I would die trying
'Cause the war in me is violent
I would die trying
But I'm healing, I feel it
I'm alive again
I'm alive again

There's so much more life I wanna live
And there's not much left for me to give
It's not my fault, but sometimes
It feels like it is
But I'm getting better
I promise

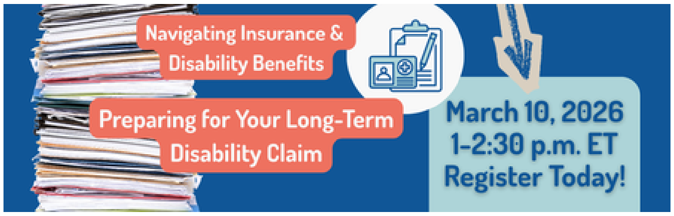
I would die trying
I'm still trying
'Cause the fire in me is blinding
I would die trying
But I'm healing, I feel it
I'm alive again

Virtual: Rare Disease Day at the NIH - Friday, February 27, 2026

Rare Disease Day at the National Institutes of Health (NIH) will take place on Friday, February 27, 2026, from 9AM to 5PM Eastern. The virtual event will be filled with panel discussions, rare diseases stories, and more. Register here for free.

Free Webinars This March: Navigating Insurance & Disability Benefits

US Pain Foundation is hosting a **FREE** two-part webinar series on Zoom focused on navigating the claims process and effectively positioning yourself for successful Long-Term Disability and Social Security (SSA) Disability claims.



March 10 at 1PM Eastern
Navigating Insurance and Disability Benefits: Preparing for Your Long-Term Disability Claim
Register Here

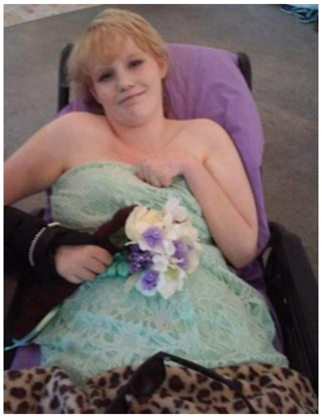
March 12 at 1PM Eastern
Navigating Insurance and Disability Benefits: Preparing for Your Social Security Disability Claim
Register Here

In this series, you'll:

- Discover how to build a compelling medical record with objective documentation, functional assessments, and specialist opinions that insurers cannot ignore.
- Learn to avoid the most common pitfalls and reasons for denied claims when chronic pain is the issue.
- Understand the psychology of insurer and SSA communication, hear helpful communication tips, and learn what NOT to disclose.
- Explore how to obtain and review common disability policy provisions and qualification documents.
- Consider various strategies around employment timing and severance.
- Discover next steps after approval and as benefits continue.

Whether you're currently working, considering exit strategies, or unable to work due to disability and already navigating the claims process, these presentations provide actionable guidance on employment considerations, medical positioning, and early legal strategy to help you secure the disability benefits you deserve. The panelists will address potential real-world scenarios and answer your questions relating to claims and processes.

Apply for the Hannah Bernard Memorial Scholarship by Thursday, April 30, 2026



The Coalition Against Pediatric Pain has announced that the Hannah Bernard Memorial Scholarship is available to anyone fighting complex pain conditions and pursuing their education, including high school, college, trade schools and online courses.

Four $4,000 scholarships will be awarded to the winners in memory of Hannah Bernard in May/June 2026.

Learn more and apply here.

Dr. Alissa Wolfe's Scholarship Program Winners Contacted

Back in December we announced that Maria's Fund was offering a scholarship for a free course of training by Dr. Alissa Wolfe, a DPT and chronic pain specialist.

We are thrilled to share that through the generous support of Maria's Fund, in partnership with RSDSA, seven individuals were awarded tuition to participate in The Chronic Pain Breakup Method, a specialized program led by Dr. Wolfe helping those with CRPS.

One main award was granted, along with secondary awards to six additional recipients, all aimed at helping them move forward on their healing journey.

We are incredibly encouraged by the potential impact of these awards and are optimistic about the outcomes ahead. Maria's Fund remains committed to expanding access to care and continuing future funding opportunities to help more individuals affected by complex pain conditions.

Walk Strong 2026 is Saturday, April 4 in Dallas, Texas!

Join Burning Hope in walking a 3k in support of the CRPS community on Saturday, April 4, 2026 in Dallas, Texas. *Proceeds will aid research and treatment options for those with CRPS through* RSDSA.

Register as an individual or grab your friends, family, coworkers, or organization and create a team to participate and raise funds!

If you can’t make it to Dallas, participate from your hometown and register under On-Location. But don’t walk alone! Start your own On-Location team and have your team members walk with you!

- **Date and Time**: Saturday, April 4, 2026 at 10 AM (Pre-registration begins at 9:15 AM)
- **Location**: Northaven Trail and Inwood Parking Lot, Dallas, TX 75229 (Across the street from Grace Bible Church)
- **Registration Cost**: $25 for Adults, $15 for Children 12 and under
    - *Online registration closes on March 30; May still register at event*

Burning Hope is a nonprofit that's mission is to give hope to those affected by CRPS, raise awareness of CRPS among all people, and support research and treatment opportunities through events and fundraising.

About the founder, Miller Kerr

At 10 years old, Miller’s journey with CRPS started after a playground basketball injury.

After many pain-filled months of trying to find a doctor that could help, hours of therapy, and many different hospitals, Miller finally found the Cleveland Clinic. Through their pain management program, they helped Miller learn how to walk again and cope with the pain. Miller has lived with the pain for the past 12 years showing her just how STRONG she can be!

Current Research Study Opportunities

Below you will find a list of 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

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.

The New Front Line of Patient Advocacy: PDABs and the Trouble with QALYs

If you live with CRPS, you are likely an expert at navigating pharmacy counters and insurance appeals. But there is a new acronym in the healthcare landscape that might determine whether you can access your medication at all: **PDABs**.

Combined with a controversial metric called the **QALY**, these boards are changing the way the value of your life—and your relief—is calculated.

Read the full post on the RSDSA blog.

Submit Your Question For Our "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.

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.

Young Adult Weekend Retreat 2026 - June 26-29 in Scottsdale, Arizona | Scholarships are available!

RSDSA's next Young Adult Weekend Retreat will take place June 26-29, in Scottsdale!

Young adults with CRPS between the ages of 18 to 35 will spend the weekend with people who fully understand what they are going through. Our Young Adult Weekend Retreats have been a great success as they offer young adults with CRPS the opportunity to network, attend workshops, learn to advocate for themselves, and build a support system all while leaving time to sightsee and have unique experiences.

- **Location**: Hilton Garden Inn Scottsdale Old Town (7324 E. Indian School Rd, Scottsdale, AZ 85251) | 480-481-0400
- **Cost**: $250
    - A **$50.00** non-refundable deposit is required to reserve your spot. You can also choose to pay in full at the time of registration.
    - Final payment of outstanding balance is due **June 11, 2026** with all information and emergency forms.

Please note that all room fees are based on double occupancy. With help from sponsors and donations, RSDSA will cover the additional costs for rooms, meals, and speakers.

For the first time ever, our friends at Living With RSDS, Inc., a non-profit founded by those living with CRPS, **is covering the $250 registration fee for two attendees**. If you're interested in obtaining one of the two scholarships, fill out the application before Tuesday, March 31, 2026.

If you have any questions, or if you're interested in sponsoring the weekend, please contact RSDSA's Young Adult Retreat Committee at youngadult.crps@gmail.com.

RSDSA Support Group Corner

Beth Stillitano, leader of the Fight the Flame CRPS Support Group, is hosting the 2026 Fight the Flame CRPS Conference on Saturday, March 21 in **Charlotte, North Carolina**. Registration is open!

Join patients, caregivers, and experts for a day of knowledge, healing, and connection. *Please direct all conference questions to Fight The Flame.*

Additionally, Fight the Flame will host their support group meeting on **Saturday, February 14, 2026 at 1PM Eastern**. The meeting will focus on “Hope Through Dog Training” and attendees will hear from Sally Fowler of Disabled Advantage.

To RSVP and receive the meeting link, email Beth@FightTheFlame.org

2026

FIGHT THE FLAME

CONFERENCE

21 March, 2026
8 AM - 5 PM

Courtyard by Marriott
Charlotte Waverly
6319 Providence Farm Lane
Charlotte, NC

LIVING WITH CRPS

Insights, treatments and healing

A day of education, support and hope

For CRPS patients, caregivers and healthcare professionals

REGISTER NOW

FightTheFlame.org

OUTSTANDING SPEAKERS

Pradeep Chopra, MD
Center for Complex Conditions

Amber Tolbert, LCSW, LISW-CP
Owner and Founder
The Healing Collective

Karen “Duff” Duffy
Author, Pain Advocate

Jonathan Leake, MD
Derive Health

Chase Teagarden, PT, DPT, TPS, CLT
The Window Pain

Caryn Fidalgo, OTD, OTRL/L
Green Light Mobility

Aashish Jay Kumar, MD, D.ABA
Spine & Pain Specialists of the Carolinas

Attend the new **CRPS Warriors of Florida** support group!

A new Tampa Bay-area support group, led by Beth Wegner, will meet on **Sunday March 1, 2026 at 11 AM Eastern** at Just Love Coffee Cafe (2020 W Brandon Blvd Suite 105, Brandon, Florida 33511).

Come and meet up with other CRPS Warriors in the Tampa area. No one understands what you go through better than another Warrior. Come and trade ideas of things that help, learn from others, and hopefully meet a new friend.

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@rsds.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.

Tuesday, February 24 - Thursday, February 26 - Rare Disease Week in Washington, D.C.
Thursday, February 26 - Livestream with Norman Harden, MD
Saturday, March 21 - Fight the Flame®'s CRPS Conference in Charlotte, NC
Tuesday, March 31 - Young Adult Weekend Retreat Scholarship Application Deadline
Saturday, April 4 - Walk Strong in Dallas, TX
Thursday, April 30 - Hannah Bernard Memorial Scholarship Application Deadline
Saturday, June 6 - RSDSA's 7th Annual Walk for CRPS
Friday, June 26 - Monday, June 29 - Young Adult Weekend Retreat: Scottsdale

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