JUNE 2025 ISSUE 39

IN RARE FORM

IN THIS ISSUE

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

RSDSA's in-person conference is back for CRPS Warriors, caregivers, and professionals that support our community!

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.

Dr. Pradeep Chopra will serve as the keynote for our 2025 conference. He will join us to discuss "Managing CRPS in Adults and Children." More details to follow!

Info and dates to remember

- Early Bird Registration Pricing
  - $40 for CRPS Warriors
  - $40 for Caregivers
  - $100 for Professionals
- **Early bird pricing ends July 15, 2025**
- Registration includes lunch on Saturday
- Our room rate of $154 per night ends on **October 2, 2025**
- **If you're interesting in sponsoring the conference, email us at info@rsds.org.**

Register and read our conference FAQs

Thank You For Supporting RSDSA's 6th Annual Virtual CRPS Awareness Walk!

Thank you to everyone who supported this year's Virtual CRPS Awareness Walk! It was great seeing so many Warriors out and about in their communities in an effort to spread awareness for CRPS as we work towards finding a cure.

We know that some Warriors weren't able to get out and about on Saturday, but we hope you're able to congregate with one another at a later date. **We will announce a new date for Connecticut's CRPS Awareness Roll 'n Stroll once we receive it from the event organizer.**

Remember that it is not too late to donate to our virtual walk. We will accept donations through December 31, 2025.

Thank you to everyone who joined our livestream and to those who sent us photos and videos! See a few of them below and on the next page!


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6th Annual RSDSA Virtual CRPS Awareness Walk
2025


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2025


CRPS
June 7, 2025
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RSDCA '25

Livestream With Dr. Amir Minerbi to Discuss the Breakthrough Discovery That Uses Gut Bacteria and AI to Diagnose Crps

RSDSA is hosting a free livestream with Dr. Amir Minerbi on **Thursday, July 10th at Noon Eastern** on facebook.com/RSDSA and youtube.com/@RSDSA from your computer, tablet, or phone.

In mid-May, we shared an update on McGill University researchers, in collaboration with colleagues in Israel and Ireland, who developed AI technology that can detect patterns in gut bacteria to identify CRPS with remarkable accuracy, potentially transforming how CRPS is diagnosed and treated. Dr. Minerbi was one of the physicians that worked on the study.

Dr. Amir Minerbi is the Director of the Rambam Institute for Pain Medicine and a Senior Lecturer at the Ruth & Bruce Rappaport Faculty of Medicine, Technion–Israel Institute of Technology.

He earned his MD-PhD from Technion's combined program in 2009. Following this, he completed dual residency training in Family Medicine and Pain Medicine at the Rambam Institute for Pain Medicine. From 2017 to 2019, Dr. Minerbi pursued a clinical research fellowship at the Alan Edwards Pain Management Unit, McGill University Health Centre in Montreal, Canada.

Dr. Minerbi's research centers on the role of the gut microbiome in chronic pain. His laboratory investigates the microbial composition associated with various pain conditions, explores the mechanisms through which gut bacteria influence pain pathways, and develops clinical applications for microbiome-based diagnostics and therapeutics. The Minerbi Lab is internationally recognized as a pioneer in clinical research targeting the gut microbiome as a novel therapeutic avenue for chronic pain.

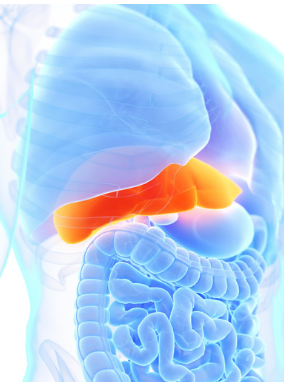
Resources to prepare for the livestream:

- McGill University | Breakthrough discovery uses gut bacteria and AI to diagnose a chronic pain syndrome
- Anesthesiology | Altered Gut Microbiome Composition and Function in Individuals with Complex Regional Pain Syndrome
- Anesthesiology | Bug in the Syndrome: Using the Gut Microbiome to Diagnose Complex Regional Pain Syndrome

We're excited to have the opportunity to speak with Dr. Minerbi about the finding and what's next.

If you have a question for Dr. Minerbi, send us a message on Facebook or email it to us at info@rsds.org. The livestream will be recorded and will be available for replay as soon as it's over.

Retrospective Analysis of Liver Function Post Intravenous Ketamine for Treating Complex Regional Pain Syndrome



One of the big arguments that insurance companies make about IV ketamine and CRPS is that it affects the liver.

Researchers and physicians, including Dr. Pradeep Chopra, Dr. Philip Getson, and Dr. Jay Joshi, analyzed the medical records of 52 patients who received IV ketamine and not one of them had an abnormal liver function test.

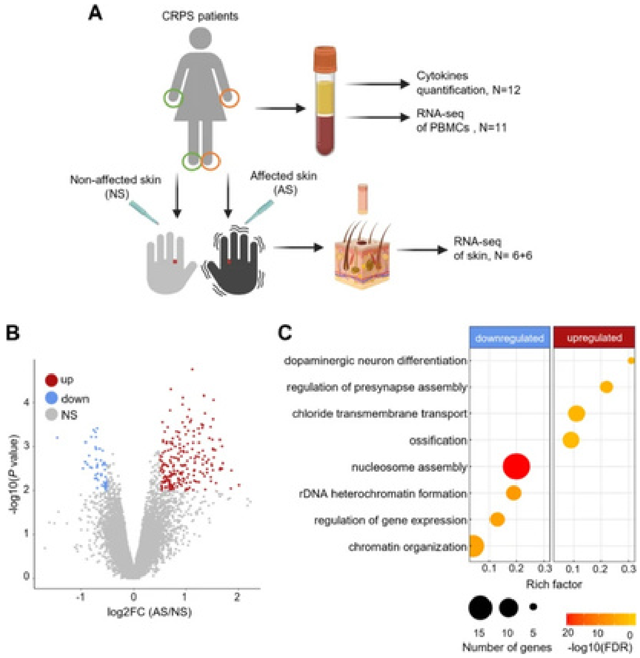
Read the full study here.

Identification of two biological subgroups of complex regional pain syndrome type 1 by transcriptomic profiling of skin and blood in women

In a recent RSDSA-supported study published in BMC Molecular Medicine, scientists describe, for the first time, two biological subtypes of CRPS type 1 that are consistent across both skin and blood.

This study identified two potential biological subgroups of CRPS type 1 in women through skin and blood transcriptomic profiling, advancing the understanding of CRPS. This could facilitate the development of targeted treatments for CRPS type 1.

Learn more and read the full study here.



Sensory Processing Patterns + The Association of Pain, Sleep, and Occupational Engagement on Quality of Life in CRPS Warriors

In 2022, Dr. Gretchen Bachman came to RSDSA as the Principal Investigator of a study titled "Complex Regional Pain Syndrome, Sensory Integration, and Sensory Processing: Is There a Relationship?". We shared a link to her study and we thank everyone who was able to participate.

Portions of the results/manuscript can be found in the Occupational Therapy Journal of Research.

A second study focused on quality of life with CRPS was shared with the RSDSA community 2024. Dr. Bachman's corresponding dissertation abstract can be found here.

Pain Research and Treatment Missing From 2026 HHS Budget

60 million Americans may suffer from chronic pain, but you'd never know it by reading the proposed $94.7 billion budget for the Department of Health and Human Services. Not a single word or dollar is devoted to pain research, treatment, or how to help those 60 million Americans. Learn more.

Top Tips to Reduce Pain While Flying + TSA Toll Free Helpline for Travelers With Disabilities and Medical Needs

If you’re planning to travel this summer (or to our conference this fall!) be sure to keep these links handy as they have tips for traveling with CRPS:

- TSA has a hotline and resources that are made to assist travelers with disabilities and medical conditions, prior to getting to the airport. Alerting TSA of your needs before your travel will help you once you arrive at your local airport:
  - Call the TSA Cares hotline at (855) 787-2227 on weekdays, 8 a.m. to 11 p.m. Eastern and weekends/holidays, 9 a.m. to 8 p.m. Eastern
  - Request TSA Cares Assistance
  - Traveling with Medication
  - Disabilities and Medical Conditions
  - RSDSA’s blog on the TSA Cares Hotline

CRPS Warrior Kristi Oen wrote a post for the the RSDSA blog back in 2019 that talks about her top tips to reduce pain while flying. Fellow Warriors still talk about how helpful her blog is!

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Five Reasons Giving Hope for CRPS Patients: A Future Filled with Promise

Written by James Doulgeris for In Rare Form

Complex Regional Pain Syndrome (CRPS) is one of the most misunderstood and misdiagnosed conditions in modern medicine. It is a chronic, debilitating neurological condition that can transform even the smallest injury into a lifetime of relentless pain, often spreading beyond the original site of trauma. But for those living with CRPS—those who fight daily to move, to sleep, to live—there is real and growing reason for hope.

Here are five powerful reasons why CRPS patients, and I am one, can look to the future with renewed optimism.

1. Neuromodulation Advancements Are Rewriting the Rules

Just a decade ago, options for managing severe CRPS were limited and often ineffective. Today, we are witnessing a transformation. Breakthroughs in neuromodulation—including dorsal root ganglion (DRG) stimulation, peripheral nerve stimulation, and even non-invasive vagus nerve therapies—are changing lives.

Unlike traditional spinal cord stimulation, DRG therapy targets precise nerve clusters responsible for localized CRPS pain. Patients who once found little relief in medications or standard devices are now experiencing measurable improvements in both function and quality of life.

In the coming years, closed-loop stimulation systems and AI-powered pain pattern recognition are expected to personalize these interventions even further. This is no longer science fiction. It is happening now, and the future holds even greater precision and promise.

2. The Science of CRPS Is Catching Up to Suffering

CRPS is still regarded by a rapidly decreasing number of physicians as a psychological condition or, worse, dismissed as “all in the patient’s head.” That era is ending.

The current scientific consensus recognizes CRPS as a neuroinflammatory disorder involving central and peripheral nervous system dysfunction, immune dysregulation, and even mitochondrial dysfunction in some cases like mine. This deeper understanding is fueling new diagnostic criteria, targeted research, and biologically relevant treatment pathways.

Moreover, advanced imaging techniques like functional MRI and quantitative sensory testing are validating what patients have long known: their pain is real, and it is measurable.

Recognition is the first step to progress, and CRPS is finally getting the scientific respect it deserves.

3. Emerging Drug Therapies Are Expanding the Arsenal

Standard CRPS medications—such as opioids, anti-inflammatories, and antidepressants—often provide little more than partial relief. But the therapeutic horizon is broadening.

Ketamine infusions, low-dose naltrexone (LDN), intravenous immunoglobulin (IVIG), and monoclonal antibody therapies are among the innovative treatments under active investigation and, in some cases, compassionate use. What's more, CRPS patients are increasingly benefiting from treatments developed for adjacent conditions, such as neuropathic pain, fibromyalgia, and autoimmune disorders.

Clinical trials are also beginning to reflect the heterogeneity of CRPS—meaning treatments may soon be tailored not just to the disease, but to your version of it.

This is the dawn of personalized pain medicine.

4. Awareness and Recognition Are Fueling Systemic Change
CRPS is no longer invisible. Awareness campaigns, documentaries, and viral patient advocacy have brought the condition into the public eye, shifting perception among healthcare providers and insurers alike.

Medical schools and continuing education programs are integrating pain science and rare disease training into their curricula. Pain specialists are learning to ask the right questions earlier, improving diagnostic accuracy and treatment timelines.

Insurance companies are increasingly approving advanced therapies and covering diagnostics that once required exhausting appeals. Policymakers, too, are beginning to understand the enormous human and financial toll of untreated CRPS, unlocking the potential for future legislation that prioritizes access and affordability. HHS Director Kennedy is reportedly a strong advocate of this legislation.

The system is imperfect—but it is changing.

5. Patient Advocacy and Community Are Stronger Than Ever
In the darkest hours of chronic illness, community is often the brightest light. The CRPS community—fueled by patients, caregivers, advocates, clinicians, and researchers—is growing stronger, louder, and more unified than ever.

Online networks now serve as critical hubs for education, support, and empowerment. Organizations like the RSDSA (Reflex Sympathetic Dystrophy Syndrome Association), Burning Nights CRPS Support, and others are raising funds, supporting research, and advocating for better care at every level of the healthcare system.

Perhaps most importantly, patients are finding one another. They are organizing, collaborating, and sharing their stories—not just to survive, but to thrive. In doing so, they are rewriting what it means to live with CRPS.

The Future Is No Longer a Question Mark
For far too long, CRPS has been a condition defined by despair and neglect, relegated to the dark corners of medicine. But the tide is turning.

Innovative technologies, emerging therapeutics, scientific breakthroughs, systemic change, and the fierce will of patients and advocates are converging into a new era of hope.

The future is no longer a question mark. For CRPS patients, it is a road worth walking—a future worth fighting for.

You are not alone. And you are not without hope.

James Doulgeris has been a contributor to RSDSA. New drugs and therapies have allowed him to be more productive. He is chairman of RSDSA's Ketamine Project.

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.

Young Adult Weekend Retreat - Now For Warriors 18 to 35 | Deadline June 13th

RSDSA's Young Adult Weekend Retreat is June 27th - June 30th in Nashville and we are inviting young adults with CRPS between the ages of 18 to 35 to spend the weekend with people who fully understand what they are going through.

Our host hotel is the Holiday Inn Express Downtown Broadway (920 Broadway Nashville, TN 37203 - 615-244-0150). The cost to attend is $250.

Please note that all room fees are based on double occupancy. A $50.00 non-refundable deposit is required to reserve your spot.

Final payment of outstanding balance is due Friday, June 13, 2025 with all information and emergency forms. With help from sponsors and donations, RSDSA will cover the additional costs for rooms, meals, and speakers.

If you have any questions or concerns, please contact RSDSA's Young Adult Retreat Committee at rsdsa.nashville2025@gmail.com.

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

CRPS Warrior Deborah Robbins is the 2025 Ms. Wheelchair Kentucky!

Congratulations to CRPS Warrior Deborah Robbins for being named the 2025 Ms. Wheelchair Kentucky! Deborah has had CRPS for 30 years and is looking forward to teaching others about CRPS when she travels to Grand Rapids, Michigan this summer to compete in the 2026 Ms. Wheelchair America pageant from August 18-24, 2025.

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Extension Ofc. Events

The following is a listing of upcoming Morgan County Extension Office events and programs:

- March 13 – Healthy Relationships, 5 p.m.; West Liberty Homemakers, 7 p.m.
- March 17 – Healthy Relationships Workshop, 5 p.m.
- March 18 – 4-H Sewing Group, 4 p.m.
- March 19 – District Board, 5 p.m.; Peace by Piece- Sewing
- March 20 – Healthy Relationships Workshop, 5 p.m.
- March 26 – LRA Skills Day, 10 a.m. @ Fleming Co. Ext.
- March 27 – Camp Meeting 10 a.m.
- March 28 – Plant Disbursement Day
- April 15 – Farmers Market Meeting, 5 p.m.
- April 16 – District Board, 5 p.m.
- April 28 – CEC, 12 p.m.
- May 2 – Deadline to sign up for 4-H Camp (June 3-6).
- May 13 – Farmers Market

Local woman is crowned Ms. Wheelchair Kentucky

Deborah Robbins will travel to Grand Rapids, Mich., for natl. event

By Miranda M. Cantrell

Local resident Deborah Robbins was recently named Ms. Wheelchair Kentucky 2025 following the annual pageant held on Saturday, March 1, in Louisville.

The state-level program was hosted by the Ms. Wheelchair America organization, which seeks to provide an opportunity of achievement for female wheelchair users as per event literature.

***

"Ms. Wheelchair Kentucky advocates for Kentucky women who have disabilities, showing that women with disabilities have the same hopes and dreams as those without disabilities -they just accomplish their goals with wheels for mobility!"

***

Robbins, 44, has been con-

Local historian and noted skeptic Joe Nickell passes at 80

W. Liberty native wrote "Historical Sketches" column for many years

West Liberty native Joe Nickell, historian and long-time friend (and columnist) of The Licking Valley Courier, died last week in Amherst, New York. He was 80 years old.

Joe Nickell was an authority on Morgan County history and his popular column, "Historical Sketches," was a regular feature in The Courier for many years until 2024, when his health began to fail.

Following a fire which destroyed The Courier's office and printing plant n 1985, Joe Nickell, with the help of the late Lynn Nickell, Woodrow Stamper and other friends, voluntarily took on the task of salvaging the paper's back files, laboriously sorting and drying each page dating back to 1910 and assisting with getting them microfilmed — a valuable

Joe Nickell, "Historical Sketches" Columnist

the University of Kentucky.

As a member of the Center for Inquiry, he was internationally recognized as an investigator and was a frequent contributor to "The Skeptical Inquirer," a magazine devoted to the investigation of historical, paranormal, and forensic

Free Event: Living Rare, Living Stronger in Atlanta, Georgia

Registration for the National Organization for Rare Disorders (NORD®)'s Living Rare, Living Stronger® event in Atlanta, Georgia is now open. It is free for patients, families, and caregivers.

NORD encourages those living with a rare disease and their families to join them on June 27, 2025, for a special day of candid conversations, education, and community building. Register here.

Rare Artist 2025 is Now Open for Submissions

Enter through July 9th at RareArtist.org.

The Rare Artist program, powered by the EveryLife Foundation for Rare Diseases, was established in 2010 to showcase the talents of those impacted by rare diseases. The annual contest provides a national platform for artists to advocate through music, poetry, and visual artwork.

This year they are introducing a new medium: MUSIC! Music has the power to move hearts and activate change. Now, it's another way to raise your voice for rare disease advocacy. Whether it's a song about your personal journey or an anthem for our community, your music can help others feel seen, heard, and understood.

The contest is open to anyone in the U.S. who has a rare disease or is connected to someone who does. For a full list of guidelines, visit RareArtist.org.

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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