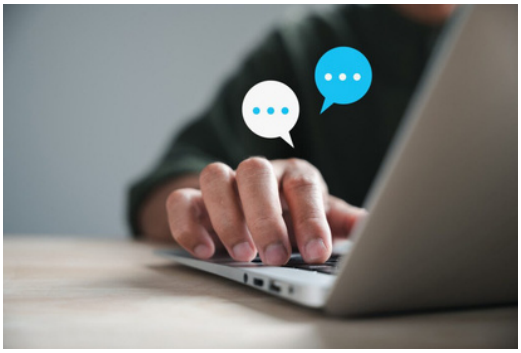
JUNE 2026 ISSUE 45

IN RARE FORM



IN THIS ISSUE

Join The New RSDSA Message Board Community!

RSDSA is proud to announce a new message board community at messageboard.rsds.org!

The 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.

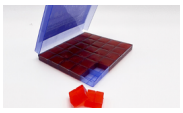
Join for free today at messageboard.rsds.org

Most Recent Topics on the RSDSA Message Board

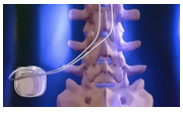
You must be signed in to view and contribute to these posts.

Advice needed for upcoming Mohs procedure for skin cancer

CRPS newbie looking for advice



Where can I find ketamine troches?



Advice on Spinal Cord Stimulator

Thank You for Making RSDSA's 7th Annual Walk for CRPS A Success!

You did it! Our 7th Annual Walk for CRPS took place last Saturday, June 6, 2026. We loved seeing everyone out in their communities spreading awareness for CRPS while also helping RSDSA provide advocacy, research, education and hope to the community. Thank you to everyone who registered, donated, and participated.

A special thank you goes to Kelly Considine, the chair of our 7th Annual Walk for CRPS, and London Kelley, RSDSA's special events coordinator who truly led this event and made it happen!

Thank you to Ambros Therapeutics for serving as a **Gold Sponsor** of the 7th Annual Walk for CRPS.

We did want to call out a great news segment from WMBF News out of Myrtle Beach! Kira Kordiak, who leads the Conway Riverwalk, SC walk team and the Myrtle Beach-area support group, secured this amazing TV coverage to help further spread the word about CRPS.

What's New With CRPS?

Ambros Therapeutics, Inc. recently announced that the first patient has been dosed in its pivotal CRPS-RISE Phase 3 clinical trial evaluating neridronate versus placebo for the treatment of Complex Regional Pain Syndrome Type 1 (CRPS-1).

As of Wednesday, June 17th, Ambros Therapeutics' neridronate trial now has 14 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
- Pembroke Pines, FL
- Newnan, GA
- Orland Park, IL
- Charlotte, NC
- Wilmington, NC
- Winston-Salem, NC
- Houston, TX

Apply for the Karen "Lexi" Alexandra Richards Uslu Scholarship by June 30th

The application for TCAPP's Karen "Lexi" Alexandra Richards Uslu Scholarship is open through June 30th.

This $2000 scholarship is for:

- A person with a chronic complicated illness that has impacted their daily life
- Someone who shows an interest in writing, journalism, advocacy, photography, health related policy or health related field
- Can be for undergraduate or graduate education.

Apply here by June 30th.

Register for RSDSA's Adult Weekend Retreat and Apply for One of Two Scholarships

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.

REGISTER HERE

SCHOLARSHIP

- **Location**: Holiday Inn Express Philadelphia-Midtown by IHG (1305 Walnut St, Philadelphia, PA 19107) | 215-735-9300
- **Cost**: $275 - Includes complimentary hotel breakfast, a **single** occupancy hotel room, all meals and workshops
  - 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 **September 18, 2026** with all information and emergency forms.
- During registration we will ask if a caregiver is attending with you. They will *not* be charged a registration fee as they will not participate in our sessions, but they will receive the complimentary hotel breakfast.
- Thanks to the generosity of an anonymous donor, we are offering two $275 scholarships for the 2026 Adult Weekend Retreat.
- *This is not a conference! Stay tuned for details on our 2027 conference!*

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

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
- 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

June is National Safety Month! Be Prepared for Natural Disasters

Some local governments have resources to help assist with medical needs (electricity for a medical device during an emergency, evacuation assistance, etc.) but they cannot help if they don't know who (and where!) you are.

Does your county have a "Special Needs Program" that can assist you during a natural disaster?

Contact your county to learn more about resources. Start by researching your local Office of Emergency Management, Department of Health or call your town/city hall. Please note that the name of this office may vary depending on where you live.

TJ Whalen Memorial Foundation Announces Expanded Partnership with RSDSA

The TJ Whalen Memorial Foundation is announcing an extended collaboration with RSDSA. We have provided a large transfer of our financial resources to RSDSA to not only fund general research applications, but to also specifically help individuals with CRPS who are in need of financial assistance for treatments not covered by insurance, e.g. physical therapy, wheelchairs, service dogs, transportation, and other daily needs.

The assistance program we funded within RSDSA is designated as the TJ and MaryJo Whalen Assistance Fund. It was created in memory of TJ, who was a CRPS Warrior from 2010 - 2019, and his loving mother MaryJo, who was his principal caregiver. MaryJo passed away in February 2026 from a highly virulent form of multiple myeloma. She was one of the principal founders of the TJ Whalen Memorial Foundation and was an integral part of the organization as CFO.

As a result, we will be turning over our assets and information to RSDSA. We have had an ongoing collaboration with them for the past four years and have always admired their dedication and compassionate approach to the CRPS community. Donations to the TJ Whalen Memorial Fund are no longer being accepted but instead donations can be made directly to RSDSA.

In loving memory of MaryJo,

Rob Whalen
Founder, TJ Whalen Memorial Foundation

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.

Thank You For Supporing Walk Strong!

Burning Hope hosted a 3k in support of the CRPS community on Saturday, April 25, 2026 in Dallas! This year, Walk Strong supported RSDSA as well as the Pediatric Pain Management Center at Children's Health Dallas.

We thank Miller, Holly, and Todd Kerr for all of their support and leadership!

RSDSA Board Member Bryan Pope was in attendance at Walk Strong to represent the organization.

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.

What CRPS Terms Would You Like Defined?

There are so many medical terms, acronyms, abbreviations, and treatments related to CRPS and sometimes it's hard to keep up with what everything means, especially if you're newly diagnosed.

RSDSA is working on a glossary to help CRPS Warriors have a one-stop-shop for all of the common CRPS terms with accurate definitions. If you have specific terms that you want to ensure make it into the glossary, send us an email at info@rsds.org.

Surviving CRPS/RSD By Faith, Hope, and Prayers

Written by CRPS Warrior Suzy Holcomb

On a crisp late Wednesday afternoon around 5:45 p.m. on the night before Thanksgiving, we were readying to enter our last seventh grade science class of the day in middle school. We were on split-session in our hometown sharing the high school with the high school students because a fellow in town attempted to set fire to the chemistry lab nearly destroying the entire high school building. We only had a few more days to wait until the following Monday morning when WE would be the FIRST class to move into the brand new middle school! Boy, were we excited. Hot shots we would be!

As we approached our next class, in a circular fashion around the hall monitors, we were only a few short feet away from the doorway of our classroom, when this one boy who sat behind me in alphabetical order, and who constantly irritated me, decided he would irritate me one more time. He decided tonight that he would stab me in the right forearm with a wooden pencil! What the heck just happened!? Pain soared and blood spouted as we stood right outside the principal's office. To say the least, I never made it to class as my friends, teacher, and principal rushed me to the nurse's office. The pencil and lead now had broken inside my arm. The nurse did her best to clean the wound, removing what she could and called my mom and dad.

We all headed directly to the doctor's office where he, in turn, entered the arm with his scalpel extricating the rest or most all the pencil and lead as possible. We were able to stop the bleeding. The pain was to beat the band. The swelling, redness, spasms, pins and needles, daggers, and burning were the worst I ever felt. Due to my age, "light" pain medication and an ice pack on my arm to reduce the swelling treated my discomfort and pain. The ice hurt like Hell---o-----!

We were to attend a high school football game the next day and, of course, it was very cold outside. My pain levels soared through the roof. I found out as days went by that holding anything with my hand for any length of time made it distorted, deformed, and quite discolored. So starts the beginning of a new life for me, which stayed undiagnosed for a very long time.

The boy that stabbed me with this pencil received his "fill" from me that first Monday into our new building. I waited patiently for him to arrive that morning. My friends entered inquiring about my ordeal and condition; but my eyes focused totally for my attacker's

arrival. Once he walked in, I grabbed him, even with all the pain I had, and threw him across the room, tossing the new desks and chairs throughout the room. This tore down the new blinds from the windows and I continued to beat the living daylights out of him. Our homeroom teacher, who was our principal, happened to hear the commotion as well as our history teacher who resembled a NFL fullback bruiser. He also came in response to pull us apart. Once separated and our parents contacted, we collectively marched to the principal's office for the big "Why?" I wish today that I could continue that story to have him eat the words WHY!

As years proceeded, I continued to experience lack of usage in my right hand when I went to pick up a teacup or something intricate or if I did something like sewing. I continued to have spasms and distortion in my hands and pain in my arm, but it always seemed omitted and unnecessary by doctors during our visits. The burning, swelling, pins and needles remained a reminder that something definitely was not right inside my arm and hand.

One evening when I went outside to put our pool ladder up for the night, I turned around thinking it was in the locked position only to discover that the ladder did not couple. I would find this ladder come crashing down on the same arm that was damaged by the pencil stabbing. We quickly made an appointment with our neurologist. With testing completed, we discovered that there was a tumor imbedded in the upper portion of my right arm; and the neurologist; at this juncture; diagnosed me with RSD, as well as the start of a laundry list of other medical concerns. At this point, we are now over 26 years misdiagnosed and will start a myriad of medication for various concerns, not even sure any of this will help the cause. Plus, we shall commence physical therapy for some type of strengthening and rebuilding in my arm and hand, and treatment with the prognosis of healing completely. Unfortunately, none of this materializes.

I locate the RSDSA office that is only a few short miles from our home in New Jersey and quickly become involved with the organization. I start reading more and more about this offering to help in any way I can.

I also venture west to a doctor claiming he is working with RSD patients and is having extreme success in revitalizing these patients into "remission." This does not work either and as it turns out, this doctor ends up in prison for fraud.

In the meantime, we are attempting acupuncture and other mediums until an article appears in the newspaper after further documentation arose about RSD that reveals if you treat RSD within the first six months, you can put this dystrophy into remission. Otherwise, you will end up in a wheelchair or worse the rest of your life.

Well, forget that. I did not want to hear such news. Therefore, I started my support group in Burlington County, which developed into three support groups before I moved to Tennessee in 2006. We met regularly and even shared online discussion as well as telephone chats. So when we moved, I made sure we would keep the word active in Tennessee as well as offering groups here.

The groups were open not only to the afflicted, but to their families and friends as this is where the support originates. With the Jersey groups, we would have fundraisers like our Afternoon of Elegance Tea Parties raising money for RSDSA research and financial support for the afflicted. We would have local artists share their crafts via fashion shows, artwork and jewelry. Our guests could purchase from them at our teas and auctions. All proceeds, items sold, and monies benefited RSDSA 100%.

As the pain continued to worsen for me, I discovered Meilus Muscular Treatments to be helpful and then I found Cold Laser Therapy and Fenzian Treatments that really were beneficial to me. They made a significant change in my life. I wrote several articles about this – one appearing in the RSDSA newsletter several years ago. These treatments have aided so many RSD patients as well as countless others. Where my cold and dark-colored limbs caused me so much pain, I would have these treatments and the limbs would return to warm and a normal pink color. The pain levels would decrease and I would be a functional person for a good amount of time. I could even decrease some of my medication and perform tasks unable to handle prior to treatments.

As the years have progressed, the RSD has spread throughout my body and into my internal organs. I am now in third-stage kidney failure and watching a diet to eliminate the use of dialysis. I have heart, lung, and blood clot issues surviving a pulmonary embolism and as stated earlier a laundry list of other medical concerns.

My supportive, loving, and caring family stands by me completely through this ordeal. My husband is my steady rock and has been faithfully by my side throughout our entire relationship. 2020 marked 50 years of marriage and I thank God for him every day. To put up with this monster and me this long, he IS a Saint for sure! It is a blessing for me to be surrounded by such wonderful children and family members who are always there to aid me through these most difficult times.

I hold firm to my faith, for without God in my life I doubt very much if I would be here today. For without Him, I am sure I would have taken a different path. He continues to bless me in

so many different ways, saving my life many times sending the right people to me for that to be a reality. Even though I still am in pain and still have this affliction, He has been there to comfort my way, giving me hope that through Him all things are possible.

I have caught a few friends and acquaintances before succumbing to this; but it is getting rougher for people to cope with the horrific pain that ravages our bodies from this culprit. People do not realize the anguish we bare day in and day out as we "look too good to be ill and we must be faking it!" My answer has always been, "Please come home with me. Spend the night in our home. See firsthand for yourself the life we lead. I guarantee you that you will not last six hours witnessing this pain should you decide to wear these shoes."

The one to 10 pain scale is antiquated – and thank goodness, they just passed that prescriptions for medications be scripted for chronic pain patients in the additional dosage amounts we require. I cut back on mine so I could care for my mother as her caregiver. It was tough to do, but I wanted a clear mind to speak to her doctors and I just wanted to be the best I could be for her for as long as I could. I did not want to be involved with pain clinics that did absolutely nothing for me accept write a script for a couple pills. Treated like a piece of raw meat caused enough feeling to eliminate further visits to pain clinics and seek alternate ways to reduce my pain as I only needed just one small new script each month for a "few" pills. Given the third degree, placed through needless entry "lab work", and receiving no assistance with psychological or knowledge of current aid for RSD evoked enough interest to seek other sources of medical assistance for me.

I tried alternatives such as akuamma, kratom, and CBD oil. I have seen Brazilian healers, seen doctors across the country, taken every test in the book, and been involved with research studies. I hope and pray that one day soon I meet the person or persons that will face me and say, "We have the cure for Reflex Sympathetic Dystrophy and we can correct the nerve that is damaged from this affliction!" I am throwing the biggest party ever and all of you are invited!

Sleepless nights full of pain – tossing and turning so much arrest that even disturbs your soulmate's rest. Skin changes – peeling, discoloration, blotches and sores, swelling, pins & needles that turn into jostling stabs entering your body already consumed with enough fire that a fire extinguisher cannot filter your skin quickly enough to extinguish the enormous fire brewing internally. The lack of social acceptance from the public, your friends, and even your family members, not realizing the severity of the extreme pain you are encountering through this ordeal, let alone realize the height of the pain levels this offers your system, leaving you to suffer on your own. The feel of sheets and blankets on our beds that are excessively hard and heavy for us to situate on our bodies and the need for them to be elevated by some type of contraption so they do not touch our skin as it sends our system

into a destructive electronic storm. The feel of touch, hot or cold, as we shower, swim, or eat, sends us into a galaxy of raging electrified hornets. Even a simple hug or soft kiss can set our nervous system to a painful catastrophe. We devise ways to re-communicate with our soulmate in order to keep that sweet intimacy alive as long as we have a strong support system with them, as we need all their love to carry us forward.

Preface encouraging faithful indulgence into our daily homework, keeping abreast of the latest information on RSD/CRPS; and, then in turn, offering all this information to our family, friends, doctors, and public remains a true necessity on our behalf. We need to locate more medical people to come forward to our aid as the more awareness, the closer we are to that long-awaited miracle cure for us. Support groups are quite beneficial as we have the opportunity to not only meet others afflicted but also share and learn more about our disease. We can share relaxation/focus imagery techniques with one another and be a comfort to one another.

As long as there is a sun that rises every morning, there is a ray of hope for all of us. Hold strong to this, hold fast to whatever faith you possess, and pray. This does work. Keep that beautiful, radiant smile upon your faces, and we shall be the VICTORS! This monster will take a hike. I am confident of this. The cure is close. I am confident of this, and we shall survive the black fire hole we are presently in and truly be the winners of this amazing fight TOGETHER with faith, hope, and prayers! God bless you all!

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@rsds.org!

The latest posts on the RSDSA blog feature insights on ketamine-assisted therapy, stories of hope and survival from CRPS Warriors, and advocacy updates.

Catch up today at rsds.org/blog

RSDSA Support Group Corner

The Carolinas are preparing for a busy Q3!

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

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The Fight The Flame Support Group is hosting the 2026 Fight the Flame 5k and 1k Family Roll & Stroll in Charlotte this September!

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/fightheflame

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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.

- Friday, June 26 - Monday, June 29 - Young Adult Weekend Retreat in Scottsdale, AZ
- Tuesday, June 30 - Karen "Lexi" Alexandra Richards Uslu Scholarship Deadline
- Sunday, August 23 - Myrtle Beach Pelicans vs. Fayetteville Woodpeckers Game Fundraiser in Myrtle Beach, SC
- 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

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