APRIL 2025 ISSUE 38

IN RARE FORM

IN THIS ISSUE

- **RSDSA'S 6TH ANNUAL VIRTUAL CRPS AWARENESS WALK IS JUNE 7TH**
- **CONNECTICUT AND SOUTHERN CALIFORNIA WILL ALSO HAVE WALKS ON JUNE 7TH!**
- **FACEBOOK AND YOUTUBE LIVE WITH UC SAN DIEGO HEALTH**
- **REGISTER FOR THE 2025 YOUNG ADULT WEEKEND RETREAT**
- **CELEBRATING 10 YEARS OF SUPPORTING THE COALITION AGAINST PEDIATRIC PAIN**

RSDSA's Updated Patient Assistance Funds

RSDSA now has two patient assistance funds to help support CRPS Warriors.

Our newest is the TJ Whalen Patient Assistance Fund. In conjunction with the TJ Whalen Memorial Foundation, RSDSA has established a one-time **non-emergency assistance program fund** to help with accessibility support, assistance programs, medical needs, and other **long-term, non-emergency** assistance to the CRPS community.

The TJ Whalen Memorial Foundation was formed in honor of Thomas John Whalen who was born in April 1989 and passed away in July 2019. TJ was diagnosed with CRPS in 2011 a few months after fracturing his wrist in a mountain bike accident.

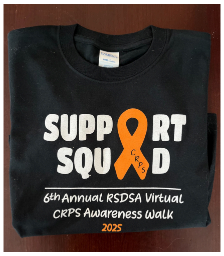
We have also revamped our Jenkins Patient Assistance Fund.

In conjunction with the Jenkins family, RSDSA has an **emergency patient assistance fund** to provide emergency financial aid to individuals with CRPS and their families. **The one-time Jenkins grant is for up to $1000.**

The fund is named in honor of Brad Jenkins, a young motorcycle racer who was injured during a race and developed CRPS. Tragically, Brad's life ended in an accidental overdose. The Jenkins family joined with RSDSA to create a fund in Brad's honor to help others with CRPS.

Learn more about applying for these funds on the RSDSA website by clicking here.

Support RSDSA's 6th Annual Virtual CRPS Awareness Walk on Saturday, June 7th!



Registration Information

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

RSDSA's 6th Annual Virtual CRPS Awareness Walk **t-shirt & medal are included for all United States and Canadian registrants** (pictured above).

To receive a t-shirt to wear on June 7th, **you must register by May 19th**.

Please remember that physically walking is not a requirement to participate.

Donors who do not register for the Walk will not receive a medal or t-shirt. **In order to receive a medal and t-shirt, please register for the Walk.**

It's hard to believe we started our virtual walk six years ago and every year it has become a bigger and better event. That's because of you, the RSDSA community of CRPS Warriors and the many family, friends, neighbors, and colleagues who support us.

On behalf of RSDSA and the individuals living with CRPS/RSD around the country, we invite you to register for our 6th Annual Virtual CRPS Awareness Walk.

On Walk day, we will host a Facebook and YouTube Livestream at 11:00 AM Eastern and connect with Alexis Johnson and Kelly Considine, our 6th Annual Virtual CRPS Walk Chair. We will check in with Kelly's team and then move across the country to meet and greet other RSDSA virtual walk teams. It will be a great morning!

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 7th.

Although we wish we could see all CRPS Warriors in person, the benefit of our virtual 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.

For questions and for more information on our virtual walk, contact Jeri Krassner at jkrassner@rsds.org or 917-597-7256.

Click Here To Register

Connecticut's Inaugural CRPS Awareness Roll 'n Stroll is Saturday, June 7th!

Join RSDSA and Kelly's Crusaders for Connecticut's CRPS Awareness Roll 'n Stroll in support of the CRPS community on June 7th.

Kelly's Crusaders virtual walk team has grown to 100 walkers over the years, so her team is hosting Connecticut's CRPS Awareness Roll 'n Stroll on virtual walk day!

Registration Information

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

Connecticut's CRPS Awareness Roll 'n Stroll **t-shirt & medal are included for all United States and Canadian registrants**.

To receive a t-shirt to wear on June 7th, **you must register by May 19th**. However, online registration closes on June 1st.

We are inviting people from the Northeast region to join us in person for the 2 mile walk! 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.

The Roll 'n Stroll is open to participants of all abilities. We look forward to seeing you in-person on June 7th.

If you are unable to make it to Connecticut you can still register for RSDSA's 6th Annual Virtual CRPS Awareness Walk, which is the same day.

For questions and for more information on the Connecticut walk please contact Kelly Considine at kelly.crpsawareness@gmail.com.

Please remember that physically walking is not a requirement to participate.

Donors who do not register for the Walk will not receive a medal or t-shirt.
In order to receive a medal and t-shirt, please register for the Walk.

Click Here To Register

CRPS/RSD SoCal Friendship Gathering & Stroll is Saturday, June 7th!

CRPS AWARENESS
FRIENDSHIP
GATHERING
STROLL

SATURDAY
June 7, 2025

WE'RE • ON • FIRE!!
RSDCA
CRPS / RSD
Friendship Gathering
&
Stroll

The Orange County Survivors and Caregivers Support Group invites all individuals living with CRPS/RSD and their families, friends, supporters, and caregivers to the Southern California (SoCal) Friendship Gathering and Stroll on Saturday, June 7, 2025 at Veterans Park in Cypress, CA.

Registration Information

- $35 for adults
- $22 for children ages 5-12

RSDSA's 6th Annual Virtual CRPS Awareness Walk **t-shirt & medal are included for all United States and Canadian registrants**.

To receive a t-shirt to wear on June 7th, **you must register by May 19th**.

For questions and for more information on the SoCal walk please contact Kristie McCurdy and Rose Temblador at CRPSweRonfire@gmail.com.

This event is an opportunity to gather and connect with others for a day of friendship and community. We will have a stroll and lunch followed by group activities and socializing.

The Stroll: There is a half-mile, flat, cement path around the park. Those who would like to take a stroll around the park are invited to do so. Chairs will be placed around the path in case one would like to sit and take a break. Canes, walking sticks, walkers, wheelchairs, and scooters are all welcome! Those who do not walk can be part of the cheer team at the finish line.

What to bring: A lawn chair or blanket to sit on and walking shoes. Feel free to bring a canopy for shade if you would like but please ensure it is no larger than 10×10.

We will provide lunch. Potluck items to share are welcome. We will have tables set up on the grass. The tables will be a few feet away from the cement path.

Facilities. The park does have restrooms.

Please remember that physically walking is not a requirement to participate.

Donors who do not register for the Walk will not receive a medal or t-shirt.
In order to receive a medal and t-shirt, please register for the Walk.

Click Here To Register

Register for the 2025 Young Adult Weekend Retreat

Click Here To Register

Click Here to Email RSDSA.Nashville2025@Gmail.com

RSDSA's Young Adult Weekend Retreat will take place June 27th - June 30th in Nashville!

Young adults with CRPS between the ages of 18 to 32 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. Our retreats are lots of fun and attendees often make lifelong friends!

Date: June 27 - June 30, 2025
Location: Holiday Inn Express Downtown Broadway
(920 Broadway Nashville, TN 37203) | (615) 244-0150
Cost: $250

Please note that all room fees are based on double occupancy. 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. Attendees will have the option to pay by check or credit card.

We have limited space so please register as soon as possible.

Final payment of outstanding balance is due 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.

We look forward to seeing you there!

Facebook and YouTube Live with UC San Diego Health

RSDSA is hosting a free livestream with UC San Diego Health on Wednesday, May 7th at 8p Eastern. Their researchers will join us to discuss a study examining the efficacy of a botanical CBD extract for pain relief in individuals diagnosed with CRPS. **They will also answer questions about finding studies focused on CRPS in your area.**

This session will be led by Dr. Fadel Zeidan. Dr. Zeidan is a Professor of Anesthesiology at UC San Diego's Center for Pain Medicine. He is also a Co-Founder and Neuroscience Director of the newly formed UCSD Center for Psychedelic Research, an Endowed Professor of Compassion Research at the T. Denny Sanford Institute for Empathy and Compassion, and a Co-Founder and Executive Committee member of the International Society for Contemplative Research.

His research is focused on determining the active mechanisms that mediate the relationship between self-regulatory practices and health. In particular, his research examines the neural mechanisms supporting the modulation of pain and health by mindfulness meditation and placebo. He is also dedicated to understanding how psychedelics like psilocybin, DMT and cannabis impact pain-related behavioral and neural processes.

Dr. Zeidan's research program has recently expanded to appreciate how empathy and compassion can be cultivated through self-regulatory practices and psychedelic therapies. His work has also been featured in traditional media outreach (CNN; NPR; Time Magazine, CBS and others), TEDx and has personally presented his work to His Holiness, the Dalai Lama in Mongolia. Dr. Zeidan was also awarded the 2014 National Institutes of Health Mitchell Max Award for Research Excellence. His free time is consumed with quality hang time with his family, ideally swimming in the Pacific Ocean and eating his way through San Diego.

FAQs:

-How do I submit a question for Dr. Zeidan?-
Send us a message on Facebook or email it to us at info@rsds.org.

-How do I join the study?-
Learn more about "The Effects and Mechanisms of a High CBD Cannabis Extract (BRC-002) for the Treatment of Pain and Health in Complex Regional Pain Syndrome" clinical trial **here** (and on the next page!)

-How do I join the live?-
Visit **facebook.com/rsdsa** or **youtube.com/@RSDSA** on Wednesday, May 7th at 8p Eastern from your computer, tablet, or phone.

-What if I miss the livestream? Can I watch it later?-
The livestream will be recorded and will be available for replay as soon as it's over. You can rewatch it on mobile and desktop.

UC San Diego
MEDICAL CENTER

DO YOU HAVE COMPLEX REGIONAL PAIN SYNDROME (CRPS)?

Researchers at the University of California, San Diego (UCSD) are conducting a research study examining the efficacy of a botanical CBD extract for pain relief in individuals diagnosed with CRPS

- Participants will be seen at UCSD on four separate occasions over a two month period.
- Participants will be financially compensated.

BASIC ELIGIBILITY CRITERIA:

- Ages 21 to 75 years old
- CRPS Type I or Type II diagnosis
- Not taking opiods or barbituates

CONTACT YASMEEN ESSHAKI

619-786-0375 ☎

yesshaki@health.ucsd.edu ✉

SCAN ME

10 Years of Helping Kids With Chronic Pain

Since 2015, RSDSA has served as a co-sponsor for The Coalition Against Pediatric Pain's (TCAPP) Pediatric Pain Week. We recently caught up with our Sue Pinkham about the decade-long relationship.

Tell us about yourself and how you became involved with RSDSA + TCAPP. Hi, my name is Sue Pinkham, and I'm a member of RSDSA's Board of Directors, a founding member and president of The Coalition Against Pediatric Pain (TCAPP) and a board member of Tyler's Dream.

My daughter was diagnosed with CRPS when she was 15 years old after having a knee surgery, which was later learned to be unnecessary. After the surgery, when the pain wouldn't go away, she was referred to the Pediatric Pain Rehabilitation Center (PPRC) at Boston Children's Hospital (BCH), and they diagnosed her with RSD.

I met several Moms at BCH and we formed our own support group. The families would visit each other's houses, have pizza parties/cookouts for the kids, and it was a great way for both the children and parents to support each other. It was awesome hearing the children laugh and have fun together.

As Moms, we searched for support for our children living with chronic pain, and quickly discovered there was nothing available for children in pain. At the time, we discovered RSDSA, but they didn't have any information or events for children. We decided to support RSDSA through our fundraising efforts. RSDSA welcomed us with such compassion and love for our children. We named ourselves Mothers Against Chronic Pain! The MACPs. During the next several years, we fundraised for RSDSA, having yard sales, a Spring Fling, selling Macy's Coupons, etc. In fact, I remember one yard sale we made over $5,000 and RSDSA was wondering what we were selling! LOL!

After years of supporting RSDSA, I was asked if I'd like to join the Board of Directors. I was thrilled to be nominated and so thankful to the board for accepting me. I felt like it was a way to help not only my daughter, but all children suffering with CRPS. Soon after I joined, the board understood I was there to advocate for children with RSD/CRPS, because there was no support or understanding of what these children

live with daily. After working with RSDSA for several years, most of our children from the MACPs were beginning to show signs of other diseases such as Ehlers- Danlos Syndrome, Postural Orthostatic Tachycardia Syndrome, Gastroparesis, Mast Cell Activation Disorder, etc. As a group of Moms whose children were not only suffering from CRPS but many other diagnoses, we decided we needed to form our own 501(3) and The Coalition Against Pediatric Pain was formed. It was a long journey for five Moms but it's been the most rewarding experience of my life, other than being a MOM!

How did RSDSA become a co-sponsor of TCAPP's Pediatric Pain Week back in 2015?
One of TCAPP's dreams was to sponsor a summer camp for children living in chronic pain, not to discuss their pain, but to have FUN and meet other children/families who deal with similar medical conditions. When I talked to Jim Broatch about helping sponsor the camp, he loved the idea. We brought it to the BOD and we've partnered every year since 2015 to bring a summer camp to our children who live with chronic pain.

Even during COVID, RSDSA and TCAPP came together to do an online camp for the children, which was very successful. This year, we are taking 20 families to Great Wolf Lodge in Connecticut as our regular camp, the Center for Courageous Kids, has decided to have mostly individual camps, not family camps. We are very excited for our children and families and have lots of activities and FUN planned for this event. Currently, this event is full, but we are accepting applications for a waitlist.

What does RSDSA's sponsorship entail?
RSDSA has co-sponsored TCAPP's Pediatric Pain Week since 2015 by supporting us financially, advertising the camp, and sharing their brochures with all the families.

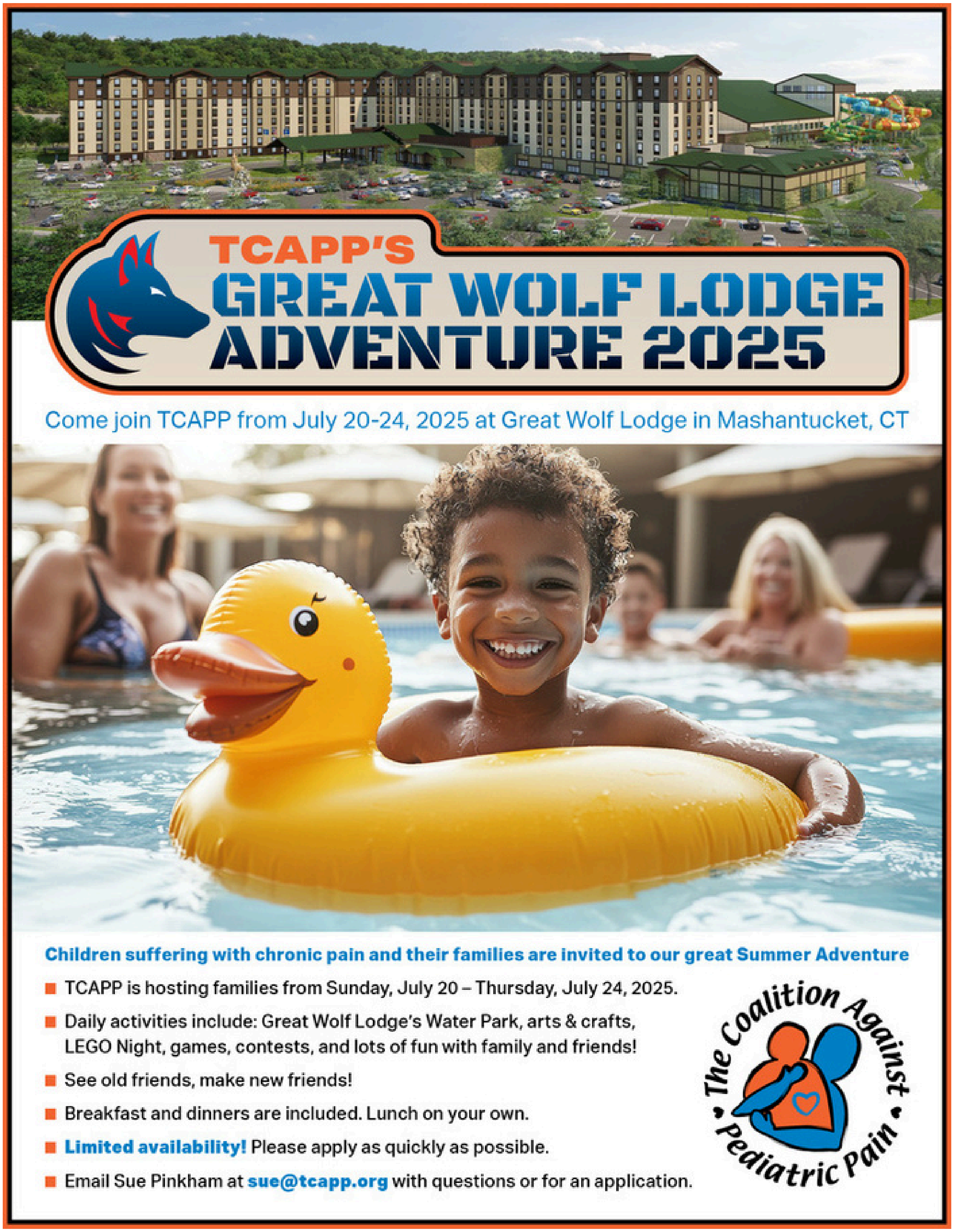
Together, we are making a difference in the lives of these children and families. It's awesome to have a "sister organization" that works together as equals to give these children such an amazing experience of summer camp, making friends and having FUN!

What drives you to put on this camp each year?
Children living with chronic pain often miss parties, sleepovers, dances, vacations, etc., due to their medical conditions. Sometimes they are left out of friends' gatherings, too, because they are the "sick" kid. TCAPP's dream was to provide these children with a place where they felt safe, could make friends who "get it", and to have FUN! Every child I've met at camp is inspirational, kind, and caring. It is an honor to be able to provide this camp for them and their wonderful families every year. It brings the community together and lets us know we are not alone in this journey.

Do you have a story that touches you the most over the last decade?
During one of our camps, one of the campers shared with the entire group that camp "saved her life". She stood up in front of everyone and explained that she had attempted to take her own life two times, before attending Pediatric Pain Week. But, after attending our camp, she now had friends who understood what she was going through, and she could call or text them if she needed a friend. This was extremely emotional for everyone, but it made me realize how important it was to bring these children together and give them the experience of meeting others and learning to enjoy themselves even though they were still in pain. Distraction is an amazing tool for chronic pain patients.

How can CRPS Warriors get involved with Pediatric Pain Week?
During Pediatric Pain Week, parents are responsible for being with their children 24/7, therefore, we don't have a lot of room for volunteers while camp is in session. Lodging is limited for volunteers as we want to serve as many children as possible. If you have a child living with chronic pain and have questions about our camp, please email sue@tcapp.org or call Sue at 781-771-2095.

Thank you very much for the opportunity to share RSDSA's and TCAPP's special relationship over the last 14 years. We are thrilled to have an amazing relationship with RSDSA and are very grateful for their support.



TCAPP'S

GREAT WOLF LODGE

ADVENTURE 2025

Come join TCAPP from July 20-24, 2025 at Great Wolf Lodge in Mashantucket, CT

Children suffering with chronic pain and their families are invited to our great Summer Adventure

- TCAPP is hosting families from Sunday, July 20 – Thursday, July 24, 2025.
- Daily activities include: Great Wolf Lodge's Water Park, arts & crafts, LEGO Night, games, contests, and lots of fun with family and friends!
- See old friends, make new friends!
- Breakfast and dinners are included. Lunch on your own.
- **Limited availability!** Please apply as quickly as possible.
- Email Sue Pinkham at **sue@tcapp.org** with questions or for an application.

The Coalition Against Pediatric Pain

RSDSA recently donated $10,000 to help The Coalition Against Pediatric Pain bring children and families to TCAPP's Pediatric Pain Week at the Great Wolf Lodge Adventure in Connecticut!

We have supported TCAPP since 2015. Our partnership is changing lives for children living in chronic pain. Learn more about Sending Children with Pain to Summer Camp on the RSDSA website.

Choosing Hope: How to Keep Moving Forward on Hard Days

May is Mental Health Awareness Month. Our Special Events Coordinator, Jeri Krassner, contacted a few CRPS Warriors to ask for their strategies on how they safeguard their mental wellbeing. They have chosen to stay anonymous.

When you have CRPS, nothing related to the body seems easy. Living with chronic pain wears a person down emotionally and physically. It can even feel unbearable. It is easy to become frustrated and for that frustration to develop into despair, hopelessness, and depression. Therefore, taking care of your mental health should become a priority.

Mental health is the cornerstone of our overall well-being, impacting every facet of our existence. When we can attend to our mental health, we can impact ourselves emotionally, psychologically and socially. I am sure none of this advice will be new, but even if we have heard these tactics before, the message does not get old. With repetition and encouragement, we can embark on a journey of self-care and resilience, exploring actionable steps and insights to nurture our mental health through a fog of pain that seems determined to test your limits.

Our first advice is to adjust your **perspective**. Although your pre-CRPS norm is over, we hear that by adjusting your perspective you can still have joy.

“There are many ways that we can still spark joy for ourselves and ease stress. Maybe not always in the way we thought or hoped, but in new or exciting ways. The bottom line is don’t allow illness or disease to win over what joy life can bring!”

Anything physical you did before your diagnosis can spark joy and can be “experienced” in different ways, whether through a podcast, a TV show or movies. It’s a matter of flipping the perspective. For example, if you were an avid camper before, you can still find joy in watching Nat Geo and HBO shows that focus on travel and surviving in the wild! It’s all about perspective.

The second suggestion that we received from every Warrior was focused on **movement**. “Movement of any kind helps to manage stress levels and therefore will help with your overall mental health management. Regardless of your limited movement or activity, even making small intentional movements with your body will relieve and reduce stress. If you’re like me with extreme sensitivity and limited ability to move your arms and legs, you can still find movements that are workable.”

In that case, do something that moves your body without triggering it. Don’t trigger yourself but move intentionally and in a slow and methodical way that will allow you to get some movement without flaring you up or triggering a tremor response or event. Examples include moving your head from side to side or up and down throughout the day.

Also focus on breathing. Breathing exercises with movement are extremely helpful in reducing the amount of stress in our bodies. Your needs may change from day to day, but whatever it is you can do, celebrate it, and find a way to do it because it will help the flow of circulation, which will help lessen the flow of inflammation.

Think of movement not as your enemy, but your biggest challenge and eventually your closest companion. Modify it to fit your needs, but make sure you move. Whatever and however you can tolerate it, move!

Our final tip is **education**. “Educate yourself about your disease. It’s not just up to the doctors and specialists and sometimes sadly not everyone will know what you’re going through. Understanding the basic principles and mechanisms will help you navigate the waters. When you take the wheel and understand and learn about your own disease, it lessens the stress and anxiety of that disease because it’s no longer unknown. It becomes a part of your journey.”

Education will help you with any future challenges. By empowering yourself with the knowledge of your disease, it helps you to feel less afraid and less anxious. That will help your overall mental health management. Your understanding of CRPS arms you with the knowledge of how to combat it and formulate questions to ask your experts.

It’s super important to ask questions. Any doctor or specialist you see that is annoyed or bothered by questions is NOT someone you want on your team. It’s important you feel like you have people on your team whose only goal is to help you to remission. But that also includes you! Educating yourself to the best of your ability will help you accomplish that.

It’s important that the doctors you choose also view it as a team effort because this disease requires a full-body holistic multidisciplinary approach for recovery and remission. CRPS is not “one method heals all.” It’s similar in mechanism and presentation, but unique to each individual.

Focusing on our mental well-being is not just a May initiative, but something we can practice all the time. Thank you to our participating Warriors for their advice and spirit. We believe - with our whole hearts - that we are better together.

PRIORITIZE MENTAL HEALTH

Counseling, in combination with one's medical treatment plan, inspires a higher, positive outcome in the long-term, thus improving one's quality of life and offering hope for positive change.

Gabrielle Baylor, APPC, CRC

Having developed a severe chronic pain condition at a young age, Gabrielle adjusted her lifestyle to foster independence and success. Treating a patients condition and addressing mental health needs that interact with symptoms is a complex process, which may greatly improve with counseling. As an associate psychotherapist, certified rehabilitation counselor, and certified in Pain Reprocessing Therapy, Gabi offers a unique perspective and insight of what you are going through.

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Thank You For Making Walk Strong 2025 a Success!

Walk Strong 2025 was an overwhelming success with 240 registrants and $35,000+ raised!

Thank you to everyone who attended the fourth annual event in-person in Dallas and on-location across the country to support RSDSA and Burning Hope!

OUR EMAIL ADDRESS IS INFO@RSDS.ORG

Not info@rsdsa.org

rsdsa
SUPPORTING THE CRPS COMMUNITY

As a reminder, our email address is **info@rsds.org**.

If you email info@rsdsa.org, we will not receive your request.

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!

Abbott | The Baker Family Charitable Fund | Brodsky Family Foundation
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