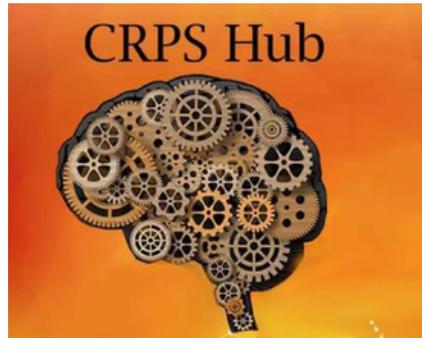


# IN RARE FORM



## CRPS: Treatment Options and Resources

by Dr. Traci Patterson, President of Holistic Centered Treatment

**Sponsor of the June 2022 Issue of In Rare Form**

### IN THIS ISSUE

**3RD ANNUAL VIRTUAL CRPS AWARENESS WALK AND WE'RE ON FIRE! WALK, ROLL, STROLL CRPS AWARENESS WALK RECAPS**

**ENTER EVERYLIFE FOUNDATION FOR RARE DISEASES'S RARE ARTIST CONTEST**

**RACHEL ZOFFNESS ON "MANAGING PAIN IN YOUR BODY AND BRAIN"**

**THE SHOW OF FORCE: LADIES OF THE LOW COUNTRY WHO RIDE – OCTOBER 1, 2022**

Complex regional pain syndrome (CRPS), formerly known as reflex sympathetic dystrophy (RSD), is a condition that causes pain, swelling, changes in skin color, texture and temperature and other symptoms. It usually affects your extremities – an arm, leg, hand, or foot – but can affect any part of your body.

Most cases of CRPS start after a soft tissue injury (such as a sprain), fracture or surgery. The pain can be intense and is much more than what would be expected during recovery from an injury, fracture, surgery, or incident.

Experts believe that CRPS occurs as a result of dysfunction in the central or peripheral nervous systems. Your central nervous system consists of your brain and spinal cord. Your peripheral nervous system relays information from your brain and spinal cord to your organs, arms, legs, fingers, and toes. The abnormal functioning results in an overreaction to pain signals that the nervous system can't automatically shut off.

### **What is an effective treatment for CRPS?**

It's time to take a new look at CRPS. The majority of allopathic treatments are focused on symptoms alone – they are bandaids. The days of just treating



by Dr. Traci Patterson, President  
of Holistic Centered Treatment

the symptoms are over. CRPS is a complex diagnosis that can lead to uncertainty and suffering for people around the world.

The challenges range from uncertain diagnostics and testing - to ineffective treatments. CRPS is a multi-faceted, systemic diagnosis requiring a multilevel integrative approach.

Holistic Centered Treatment takes a new look at CRPS and has designed a program to take into account multiple aspects of the diagnosis and co-existing conditions, and addresses these on multiple levels.

Despite the fact that CRPS is a serious diagnosis, we believe patients can regain their lives. Our protocol focuses on the importance of a balanced and foundational approach to treating CRPS and co-existing conditions. Not all standard treatments are bad and not all alternative treatments are good. In fact, we believe it is important to incorporate the best of each into an integrative program that is individualized to meet each patient's specific needs and goals.

The Holistic Centered Treatment protocol is designed to assist you in getting out of 'fight or flight' (sympathetic overload), breaking the pain loop, managing stress and anxiety, and building skills to overcome life's challenges. We do this working with the biology and physiology of the body, the biology of pain, neuroplasticity, and cutting-edge science.

Our multi-modality protocol includes - laser and photobiomodulation, pulsed electromagnetic field therapy (PEMF), neuroplasticity training, biofeedback, neurofeedback, microcurrent, clinical hypnosis, breathwork, Neurosage, EMDR, vagus nerve stimulation, brain training, etc. Think of the protocol as a blueprint that can be individualized to meet each patient's specific needs.

We encourage you to contact our office to schedule a free consultation (844) 994-0999 or via our website at [HolisticCenteredTreatment.com](https://www.HolisticCenteredTreatment.com).

## Resources

CRPS Hub, is a free app on [Apple](#) and [Google](#). It is a social hub and network dedicated to those living with CRPS. It provides resources, information, support and insights to patients, families, and caretakers. CRPS Hub aims to empower our members while fostering a safe, supportive and inclusive environment where individuals feel comfortable discussing their experiences.

# Thank you for supporting our 3rd Annual Virtual CRPS Awareness Walk!

We did it again! The 3rd Annual Virtual CRPS Awareness Walk has been a success once again surpassing our goal of \$35,000 and climbing as more donations roll in!

I speak for everyone at RSDSA when I say thank you to each one of you for supporting CRPS whether through a sponsorship, donation, participation in the walk, or spreading awareness about the event! We appreciate all our teams who worked so hard to help us meet our goal once again! From a single individual to large teams, from Connecticut to California, we had a great showing of support for our annual walk.

During the virtual walk, we were joined by CRPS Warriors across the country including the first in-person walk in California since 2010. Take a moment to watch the full walk livestream on [Facebook](#) or [YouTube](#).

Livestream participants included:

Kelly Crusaders Team | Josh Borgen | Cassie Christensen & Linda Spear Ellinwood | Kristie McCurdy & Rose Temblador | Lynda Louisa Avallone | Debbie Josiah

## Thank you to our walk teams:

Alagona's Army	JustKeepSwimming!
Audrey's Flame Fighters	Kate's Walking Flames
Boni's Believers.	Keep on Rolling
Callow Crew	Kelly's Crusaders
Campbell - Olsen	Leo's CRPS Awareness
Christina's	TheMaysFamily4
Crazy Witches	Newtown Vet Pet Lover's
Cleopatra	O'Keefes Hope to Cope
Colorado Flame Walkers	Pirates Cassandra and Phelan
Debbie's Warriors	Resilient Thunder
Deb's Web	Sachs Squad
Garbanzo's Beans	Seickel Warriors
Ginther's Go-Go Girls	Sheryl's Shoulders to Lean On
Heather's Haverford Trail Walk	Team Josh Borg
Journeying with Jeeves	Uncle Mazen's Support Squad

Thank you to our top 10 fundraising individuals:

- Kelly Considine
- Rachel Hymel
- Jim Considine
- Barbara Agostino
- Kristine Campbell
- Rachel Considine
- Susan Considine
- Sherry Games
- Jon Wells
- John Heffner

Also, a big thank you to our walk sponsors who helped make this happen:

- The Cochran Firm
- Everylife Foundation for Rare Diseases
- Maletta Pfeiffer and Associates
- NY Ketamine

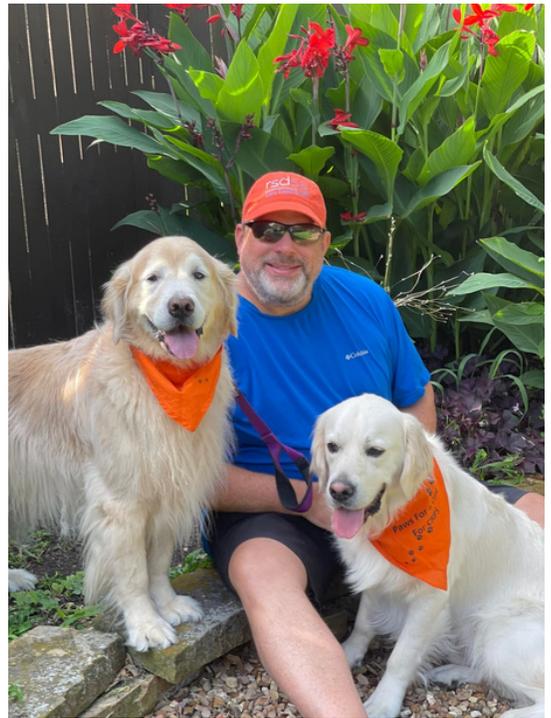
Thank you to everyone for another great year! Enjoy the photos on the next page to see what an amazing, supportive community we have created and what an amazing time we had at the 3rd Annual Virtual CRPS Awareness Walk. **We are still accepting donations until December 31st.**

Sincerely,

Kelly Considine  
Chair of the 3rd Annual Virtual CRPS Awareness Walk



rsdsa  
SUPPORTING THE  
CRPS COMMUNITY



# Thank you for supporting the We're on Fire! Walk, Roll, Stroll CRPS Awareness Walk!

Thank you to everyone who attended RSDCA (RSD California)'s We're on Fire! Walk in-person and virtually! It was a day filled with so much joy. The joy of seeing smiles on the faces of individuals with CRPS that haven't smiled in quite some time was priceless and heartwarming!

The new friendships and understanding that developed amongst family and friends is why we worked so hard to put this walk together for our California community! It was wonderful to see some of our long-standing CRPS community members interact with our newer CRPS community members—people they just met, have only met virtually through Facebook, or have only interacted during video calls.

We are so thankful for the amazing turnout! Our goal was to have 50 participants and we surpassed that with 66: 61 in-person and 5 virtual! We could not be happier, and, to our surprise, we even had an in-person participant from Utah!

We are very grateful to everyone who donated to the walk. Our goal was \$5,000 and we blew past that raising nearly \$8,000 for RSDSA! RSDSA has done so much for the CRPS community, and we are happy to support their amazing work.

We were blessed to have from Southern California Aquatic Physical Therapy in Huntington Beach, Payton Trollman, DPT, to kick-off our walk with a gentle warm-up for all the walkers.

A special thank you to Rose and Kristie's husbands and parents for running errands all week, helping with set-up, being gofers, running registration, first-aid, water station, and tear-down! We could not have done it without your support. A huge thank you to all of Kristie's neighbors who loaned us supplies, helped set-up the night before, and generally came to our rescue every time there was another errand or another task. Thank you, Dina, and Rosie, for setting up and running registration!

**Thank you to our sponsors as we could not have done it without you:**

Gold: Medtronic | Bronze: Credit Union of Southern California  
Keck School of Medicine of USC —USC Pain Center | Por Vida Natural Nutrition and CBD |  
Signature Mobile Detailing

**We are also grateful for our in-kind donations:**

CVS Pharmacy | IV Hydration | Terrain Pharmaceuticals

We can't wait to repeat this in 2023!

Thank you,  
Kristie McCurdy & Rose Temblador



## EveryLife Foundation for Rare Diseases's Rare Artist Contest is accepting submissions until July 13th

# RARE ARTIST

The Rare Artist Program was established in 2010 to exhibit the unique gifts of individuals impacted by rare disease to tell their story through art. Now in year 12, the Rare Artist Annual Contest is focused on providing a national platform for artists to advocate for the rare disease community through visual artwork and powerful artist statements.

For more information about the contest and the guidelines for entry, click [here](#).

## BLB Solicitors: CRPS on the rise but 62% of the UK have never heard of it

In a survey of a diverse sample of 1,000 people across the UK, over 62% had not heard of CRPS, with almost 29% not sure whether they had heard of it. Less than 9% of respondents replied that they had heard of the condition. [Read more](#).

## Interested in writing for the RSDSA blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog!

If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or in order to help those who may be in the same part of their journey as you are, send us an email at [alexisdavis@rsds.org](mailto:alexisdavis@rsds.org).



## Recap of the Connecticut Sun vs. Seattle Storm game fundraiser

RSDSA teamed up with the Connecticut Sun of the WNBA for a community building fundraiser at their game against the Seattle Storm on Friday, June 17, 2022 at Mohegan Sun Arena in Uncasville, Connecticut.

Thank you to everyone who made it out!



## Treating the Whole Person: Optimizing Wellness Virtual Conference is September 12-15, 2022

Our live conference sessions will stream each evening from September 12-15. Stay tuned for more details on our speakers and how to register!

### Dr. Rachel Zoffness on "Managing Pain In Your Body and Brain"

Dr. Rachel Zoffness is a pain psychologist, international speaker, medical consultant, educator, and author of *The Pain Management Workbook: Powerful CBT and Mindfulness Skills to Take Control of Pain and Reclaim Your Life*.

She recently appeared on *The Jordan Harbinger Show* to discuss how pain works and why we have it, the ways in which trauma, anxiety, and depression amplify pain, why some of us are more sensitive to pain than others, and how we can alleviate the root causes of pain

Watch or listen [here](#).

# The Show of Force: Ladies of the Low Country Who Ride – October 1, 2022

The Show of Force is a unique fashion show experience, combined with a gala of catered dining, art exhibits, auctions, and more, benefitting RSDSA. CRPS Warrior Jessica Dutkiewicz wanted to use her platform and background as an artist, storyteller and philanthropist combined with her love of motorcycle riding to bring light to CRPS. She's created an exclusive, memorable experience unlike any other through poignant visual arts for the Southeast region to enjoy.

Jessica has been working on “The Show of Force” for over four months raising awareness for CRPS and doing additional events to support her big show. She has been running up and down Florida and Georgia to share information about CRPS by organizing multiple events to sell tickets and calendars, appear, on podcasts, give local radio interviews with WIXV I-95, and run small fundraisers.

On Sunday, June 12th, Jessica ran a bike wash and cleaned 75 bikes to raise over \$2,000 for RSDSA and its programs! On July 16, 2022, with the support of American Bikers Active Toward Education (ABATE) District 11, Jessica will host a Bike Ride / Black Jack Run from Savannah Harley Davidson to the Brass Rail, Bar & Grill in Guyton, GA. Registration opens at 11:00am to noon and the Run begins at 12:30pm. You can purchase dinner tickets to The Show of Force Gala and Fashion Show and the calendars of the Ladies of the Low Country at the Black Jack Run event. For more information about Jessica’s events, please go to [theshowofforce.com](http://theshowofforce.com).

## Show of Force sponsors are:

Beach Insurance Group – Hannah Valentine | Coaches Corner | Designs by Ruby | Lewis Color | Southern Biker Gear | Savannah River Logistics | VG Collision Center | Woodstock Productions

## With support from:

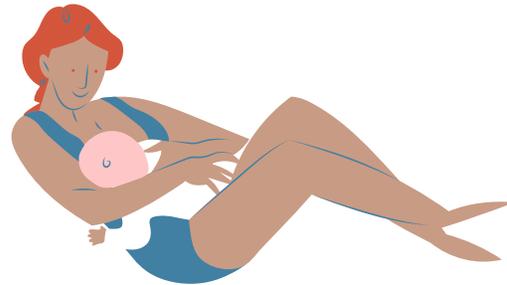
ABATE District 11 | WIXV, I-95 Radio | Bikers of the Coastal Empire

## Save the Date for Color The World Orange™



The ninth-annual Color The World Orange™ for CRPS/RSD Awareness is November 7, 2022! Mark your calendars now and stay tuned for updates via [colortheworldorange.com](http://colortheworldorange.com).

## Moms and Future Moms CRPS/RSD



If you are a mother or mom-to-be who has CRPS/RSD, then consider joining the Moms and Future Moms CRPS/RSD Facebook Group to find support and resources that you need during pregnancy and motherhood. Partners are also welcome! Learn more [here](#).

*Please note that this group is not managed by RSDSA. Please direct any questions to the group admins!*

## Learn more about the Patient Protective Taskforce

Be your best advocate by joining the Patient Protective Taskforce. RSDSA's Advocacy Committee has created a Patient Protective Taskforce (PPT) to advocate on the local, state and federal level for policies that support CRPS Warriors treatment while raising awareness of chronic pain issues. For example, the primary reason for inadequate pain management is restrictive legislation, which tragically ensnares our most vulnerable patients and their families. This is one of the issues the PPT would focus on. We will also work to raise the profile of CRPS and bring light to our healthcare issues.

To join, email [patientprotectivetaskforce@gmail.com](mailto:patientprotectivetaskforce@gmail.com) with your name, email address, phone number, and ZIP code.

## "An Untethered Truth: A Medical Journey"

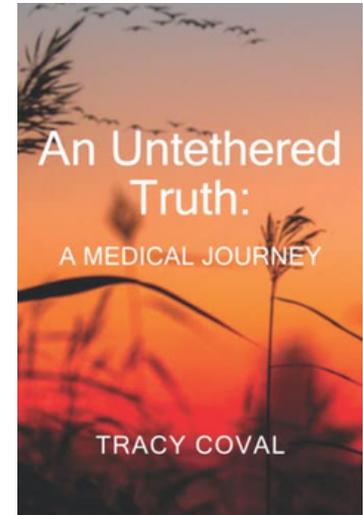
Tracy Coval is excited to share that her first book, *An Untethered Truth: A Medical Journey*, has been published and released!

The book focuses on how one must be their own best advocate. Especially navigating the healthcare system. This book provides a guide for finding one's voice in a complicated medical world and finding support and resources for those living with disabilities. This project has been in the works for the last three years, and Tracy cannot wait to share it with all of you!

You can purchase *An Untethered Truth* on [Amazon](https://www.amazon.com). It's offered both in paperback and e-book.

On [tracycoval.com](https://tracycoval.com), you will find various resources that can be beneficial to anyone. Along with this, you will find Tracy's artwork, blog, and how you can purchase the book.

Tracy's hope is this book can help others steer through the healthcare system and learn to be their own best advocate. Your voice matters.



## We want your feedback!

Please send any suggestions or upcoming events of interest to our community to [info@rsds.org](mailto:info@rsds.org) and please consider donating at [rsds.org/donate](https://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](#) | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager | Lynn & Michael Coatney  
[The Cochran Firm, National CRPS/RSD Lawyers](#)