

IN RARE FORM



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

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THE IMPORTANCE OF DEVELOPING A SPECIAL CARE PLAN FOR ED/HOSPITAL CARE

THIS MIGHT HURT - 2 WEEK SCREENING WINDOW + LIVE RSD/CRPS FOCUSED Q&A

RSDSA invites you to register for our free Treating the Whole Person: Optimizing Wellness virtual conference from Monday, September 12th, through Thursday, September 15th, 2021 on our new platform, Airmeet [here](#).

This year, our live conference sessions will not overlap so you will have the opportunity to join two sessions each day. This new platform also has closed captioning and the networking and lounge feature we all know and love so guests can network with one another 30 minutes before sessions and 30 minutes after our sessions end.

A few of our sessions titles include:

- Can I Legally Blame Someone For My CRPS? Advocacy
- What do health professionals and people with CRPS need to know about CRPS?
- An Untethered Truth: Optimizing One's Wellness
- Song of Our Scars: The Untold Story of Pain
- And more to come!

Caretakers and medical professionals are also welcome to attend!



JOIN US VIRTUALLY AT THE 2022 RSDSA NATIONAL CONFERENCE

NAVIGATING YOUR PATH TO PAIN RELIEF WITH DORSAL ROOT GANGLION STIMULATION

8:00 p.m. EDT | September 12, 2022

Kiran V. Patel, M.D.

To learn more about dorsal root ganglion stimulation, visit
bit.ly/2022RSDSAWebinar

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RSDSA's Longest Day of Golf is Monday, September 19, 2022

For the past 38 years, RSDSA has faithfully served the CRPS community. We provide up-to-date information, compassionate support, and funding for research while continuing to look for a cure. One of our major annual fundraising events, the [Longest Day of Golf](#), will take place on **September 19, 2022**. Our golfer, Tony Consiglio, will complete as many holes as possible from 7AM to 7PM. **Donors will have the opportunity to contribute per hole completed, give a one-time gift, or a recurring monthly gift.**

Please consider giving a gift for our 5th Annual Longest Day of Golf to support individuals and families who live with CRPS every day. Every day, we try to help those with CRPS find the best treatment and learn to live fulfilling, functioning lives despite their unrelenting pain through initiatives and programs like:

Virtual Educational Opportunities Because of Covid, we have not held in-person conferences. Instead, RSDSA provides current information and support by offering webinars via Facebook Live. To date, we have hosted more than 50 presentations on the

science, treatments, and pain management of CRPS. Our YouTube Channel has over 1 million views as our webinars are viewed across the globe. The RSDSA website is visited more than 10,000 times each month by both newly diagnosed and longstanding CRPS Warriors for information and guidance.

**RSDSA'S
LONGEST DAY
OF GOLF
FUNDRAISER**
SEPTEMBER 19, 2022



Zoe's Zoomalong Camp RSDSA has previously sponsored Pediatric Pain Week, which includes sponsoring the Camp for Courageous Kids (CCK) where youth with CRPS and a family member could spend a week at camp having fun, and meeting other youth with CRPS and conquering unique challenges. In 2022, RSDSA launched a virtual alternative to CCK, Zoe's Virtual Zoomalong Camp due to the pandemic. Virtual campers actively participated in interactive sessions and together, watched each other laugh, smile, and develop friendships with those who "get it." Living in chronic pain is difficult for anyone but seeing children in chronic pain is heartbreaking. Pediatric Pain Week and Zoe's Zoomalong Camp give families hope and the opportunity to make connections.

In September 2022, RSDSA is sponsoring a translational research meeting in Toronto. **The critical research question is "Which treatments work for which sub-types of CRPS?"** We propose that the efficacy of CRPS interventions could be improved by using a precision medicine approach, in which treatments are targeted based on a patient's CRPS subtype and the presumed mechanisms contributing to CRPS in that patient. That could be the key to funding the studies required to produce meaningful, relevant, and statistically robust results.

Join RSDSA for our [5th Annual Longest Day of Golf](#) on September 19th, 2022, to support individuals and families who live with CRPS every day. Living with CRPS is incredibly difficult. Every day, we help CRPS Warriors find the best treatment and learn to live fulfilling, functioning lives despite their unrelenting pain.



Flame Out - A Walk to Extinguish RSD/CRPS is September 18, 2022!

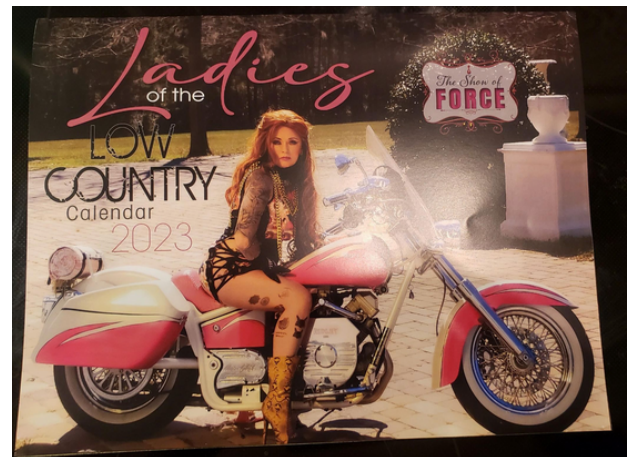
Save the date for the 4th Annual Flame Out - A Walk to Extinguish RSD/CRPS on **Sunday, September 18, 2022** at Joe Palaia Park in Oakhurst, New Jersey. [Learn](#) more about registering, donating, and participating!

In loving memory of their daughter Stephanie, Peter and Diana Smith would like to support RSDSA by matching all monies received for the 4th Annual Flame Out from **August 15 to September 14, 2022** up to a total amount of \$10,000. This is to thank RSDSA for all the support that they offer patients and their families as they struggle with this disease and for their efforts to find better treatments and a cure.

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

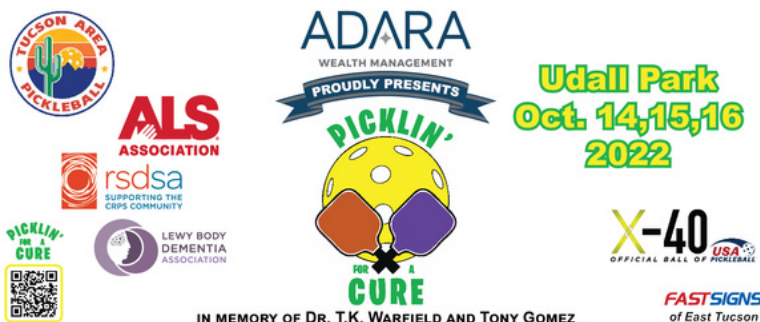
THE SHOW OF FORCE: Ladies of the Low Country Who Ride has created a unique 2023 calendar featuring biker fashions designed by CRPS Warrior Jessica Dutkiewicz.

Jessica wanted to use her platform to bring light to CRPS, so she used her background as an artist, storyteller, and philanthropist, along with with her love of motorcycle riding, to create an exclusive art calendar that you can purchase for \$28.00 (shipping and handling included).



The models are all volunteers, so all proceeds from the sale of the calendar benefit RSDSA and its mission. Calendars are available for purchase [here](#). If you buy two calendars, you will receive a free "Show of Force: Ladies of the Low Country Who Ride" poster.

Picklin' for a Cure is October in Tucson, AZ



The 2nd Annual "Picklin' for a Cure" event supporting RSDSA, Lewy Body Dementia Association, and The ALS Association will take place **October 14-16, 2022** at Udall Park in Tucson, Arizona. Learn more [here](#).

Purchase a Reusable Bag at Big Y to Benefit RSDSA

RSDSA is benefiting from the Big Y's Community Bag Program through August 31, 2022.

For every community shopping bag sold at the Big Y this August at [150 Boston Post Road in Milford, Connecticut](#), RSDSA, will receive \$1. Help us spread the word to those in the 06460 area!



The Importance of Developing a Special Care Plan for ED/Hospital Care

CRPS Warrior Jeff Doyle has several health conditions which necessitated frequent trips to Emergency Department (ED). In the beginning, the ED and hospital were not helpful as they were not familiar with CRPS or his comorbidities. He was treated as a “drug-seeker.”

After several visits to the hospital and advocating strongly for himself, Jeff successfully had what's called a special care plan put in his electronic health record. This notifies the staff when he goes to the ED what are his health conditions, his medications, and his special needs. It took two years to establish this plan.

But now, when Jeff recently went to the ER with his care plan in place, it was flawless. He arrived, was admitted, and they started administering pain medicine. His recommendation is that others with CRPS schedule a meeting with the hospital social worker to set up a special care program.

A special care plan will allow you to go into the hospital and be known. Now the Danbury, Connecticut ED has stopped dismissing him as a drug-seeker.

This Might Hurt - 2 Week Screening Window + Live RSD/CRPS Focused Q&A



This Might Hurt is a movie focused on three chronic pain patients who have spent years trying to cure their illness without success and then enter an intensive program to retrain their brains.

The film will be available to watch [here](#) from **September 25th to October 9th**. Once you enter the code **RSDSA** you will receive the special discounted rate of \$7.99 instead of \$9.40. Please note that the code is case sensitive.

Join the Q&A on October 5th at 7pm Eastern with panel including Dr. Howard Schubiner, Tamara Gurin a CRPS patient and the director, Marion Cunningham. Pre-register [here](#).

New Suicide Hotline Number Established

The [988 Suicide & Crisis Lifeline](#) — formerly known as the National Suicide Prevention Lifeline — collaborates with more than 200 local crisis centers across the nation to provide the free, confidential service 24 hours a day, seven days a week.

The hotline is operated by the nonprofit Vibrant Emotional Health on behalf of the Department of Health and Human Services' Substance Abuse and Mental Health Services Administration.

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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