

IN RARE FORM



Register for our 2nd Annual Virtual Conference, Treating the Whole Person: Optimizing Wellness, This Month

Join RSDSA for our *free* virtual Treating the Whole Person: Optimizing Wellness conference from Monday, October 25, 2021 through Thursday, October 28, 2021.

Register for day one and two of this event at bit.ly/rsdsa2021a. Register for day three and four of this event at bit.ly/rsdsa2021b.

This event will give you the opportunity to network and chat with other CRPS Warriors, visit our virtual expo hall, and hear awesome sessions on:

- Comorbid Conditions Associated with CRPS with Dr. Pradeep Chopra, MD, MHCM
- Compounded Prescriptions that Support CRPS
- CRPS and The Law
- How to Obtain a Service Dog
- Prevention of Suicide
- "Triumph over Tragedy" - Success through change, pain and uncertain times
- The Power of Patient Advocacy

Once you register, you will receive two tickets: One for our Monday & Tuesday sessions and one for our Wednesday & Thursday sessions. Caretakers and medical professionals are also welcome to attend.

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RSDSA ONLINE COMMUNITY AUCTION

CRPS Awareness Month Is Almost Here!

November is CRPS Awareness Month and this year it is flanked by two dates that are important to us.

Monday, November 1st is Color the World Orange™ Day

Keep an eye on [Color the World Orange™'s Facebook Page](#) to see all of the local and state governments that will release proclamations.

CRPS Memorial

CRPS Awareness Month is right around the corner and RSDSA would like to honor Warriors we have lost over the years.

If you are interested in having your loved one featured in this virtual memorial, please take a moment to fill out the form found [here](#).

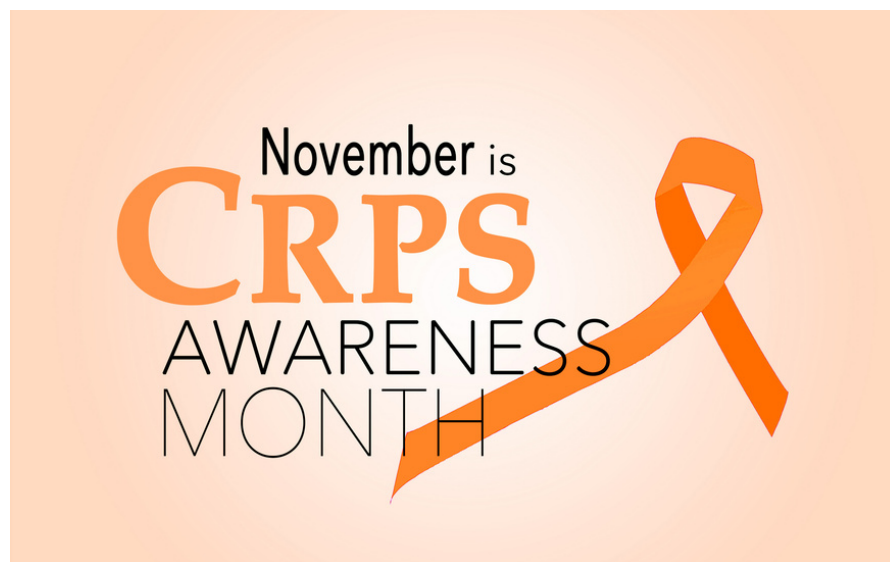
CRPS Awareness Campaign - Submit Your Three Minute Video

One of RSDSA's goal is to raise awareness for CRPS across the world. During CRPS Awareness Month, we are highlighting Warriors and their journey in their native language in an effort to make notes of commonalities around the globe.

Please fill out the questions found [here](#) and record a brief video so we can hopefully include you in our campaign for CRPS Awareness Month.

Tuesday, November 30th is Giving Tuesday

This day is devoted to global charitable giving. Keep an eye on our social media channels and email newsletters for details on donating to RSDSA.





RSDSA Online Community Auction

RSDSA invites you to our online community auction! It will close on the last night of the Optimizing Wellness: Treating the Whole Body conference, Thursday, October 28th.

There will be a variety of items and services that will appeal to all budgets. Some of the items will be specific to those with CRPS/RSD such as a virtual lunch with Jim (value priceless!) a basket of RSDSA merchandise items, self-care items and other wonderful goodies.

I hope you will join us [online](#) to bid on our auction items/services.

Nintendo Switch OLED model



Malibu C Hair & Skin Package



Rose Farmers 3 Month dozen roses



Italian Cookery Basket with Zoom Cooking Lesson



Help End the CRPS Suicide Crisis

An estimated 233 CRPS patients took their own lives in 2020 and we need your help to reach out to your federal and state legislators to make it stop. The primary motivation for suicide among CRPS patients is inadequate pain management. The primary reason for inadequate pain management is restrictive legislation, which tragically ensnares our most vulnerable patients and their families.

Asking your legislators to sponsor a simple amendment that will exempt and protect properly diagnosed rare disease patients and their physicians from federal and state legislation restricting access to pain medications will save lives. Addressing the opiate crisis is important, however, this legislation is not protecting those with CRPS, it is killing them. We will also ask for mandated financial relief for opiate sparing therapies like low dose naltrexone and ketamine therapies, which do not even have a reimbursement code.

A 2021 National Institute of Health [peer reviewed article](#) on the ideation of suicide among CRPS patients concluded 74.4 percent of CRPS patients are at a high risk of suicide. Three of five CRPS patients report that they seriously consider suicide, particularly during flares.

If you are interested in joining the CRPS Patient Protective Task Force, email Advocacy@rsds.org, Please include your contact information, name, email address, phone number and your mailing address, so we can connect you to your legislator.

We will help you to make the case and how to deliver an effective message. You can make a difference.

Attend the Pain Patient Protest in Washington DC

The American Pain & Disability Foundation is hosting a peaceful Pain Patient Protest in Washington DC on **Wednesday, October 20th from noon to 2p Eastern.**

If you are in the DMV area, or if you are able and willing to travel, considering attending to join others whose mission is to tell the real story of the other side of the "opioid crisis."

CALLING ALL PAIN PATIENTS & THEIR ALLIES!

PAIN PATIENT PROTEST

Washington, DC, Union Square

OCTOBER 20th, 2021, 12p-2p

The Other Side of the Opioid Crisis

Turn this October into Cartober!

RSDSA benefits when you donate your car, truck, motorcycle or boat to CARS (Charitable Adult Rides & Services)! The process is easy, the pick-up is free, and your vehicle donation is tax-deductible. To learn more, call 877-999-8322 or visit careasy.org/nonprofit/rsdsa.



CARS accepts running and non-running vehicles at no cost to you as they pickup and tow at a convenient time & place.

Navigating Insurance Coverage and Payment in the Rare Disease Community

[The Burden of Rare Disease Study](#) is a wonderful study published in February 2021 that dives deep in to the financial burden of rare disease. Michelle Willes, a Genetic Counseling Intern at University of Nebraska Medical Center, is hoping that her research will work in support of the Burden of Rare Disease Study to shine a greater light on the experience of navigating insurance coverage and payment in the rare disease community when receive a rare disease diagnosis.

Willes invites you to complete [this](#) anonymous survey which will ask about your rare disease diagnosis, your experience with health insurance coverage, and your awareness of financial resources for rare disease diagnoses.

The survey will take approximately 15-20 minutes to complete. It will be available until November 5, 2021.



What's Your Perception of Doctors' Care?

Help a current undergraduate student with a study on doctors' care.

Maggie Neiman is currently an undergraduate Applied Psychology major at Penn State Berks. In one of her classes, she was given the opportunity to create her own study, have it approved by the IRB (Institutional Review Board), and follow through with conducting her own study. The study is entitled, "What's Your Perception of Doctors' Care?"

The purpose of the study is to try to improve the quality of doctors' care for patients by allowing individuals to provide generalized feedback on their perceptions.

The survey is completely anonymous, she does not ask for any specifics that will violate HIPPA, or ask for names of doctors.

Take 10 minutes to fill out the study [here](#) November 4th.

Host an Event with RSDSA

You can make a difference in the lives of CRPS Warriors and those who love them by helping to raise awareness, funds, and by building a community when you host a special event. Help spread the word about CRPS by inviting your friends, family, coworkers and everyone you know to get involved in our mission, events and activities.

You can organize in-person, virtual, or hybrid events. Special events can be opportunities for fun, engagement, and education. Every dollar raised supports RSDSA's mission and makes our work possible. Your donations are gratefully received, impactfully used, and profoundly appreciated.

Need ideas of what to do?

- Be creative. Do it your way; run a beard growing contest, bake cookies, host a pool party with tickets, whatever works for you and your community.
- Fundraise on Facebook: Create a Facebook Fundraiser to celebrate a birthday, milestone or holiday and invite friends and family to donate to your fundraising page.
- Do you have access to a community or outdoor space? Throw a senior prom, game night or pancake breakfast.
- The yard sale is one of our favorites. It raises money and gets rid of stuff at the same time!

We are here to help you plan your own special event. When you're ready, please contact Jeri Krassner, RSDSA's Special Events Coordinator, at jkrassner@rsds.org or 917-597-7256.

Painting the World One Brush at a Time

By uniting virtually, we can raise awareness for RSD/CRPS and show the world that “while in pain, we are strong!”

Come join instructor Kathy Albritton Gustafson, as we “make the world beautiful one piece of art at a time.” Gustafson has been teaching painting classes for over five years via [A Broad and a Brush](#).



The Painting the World One Brush at a Time (from your home!) event will take place virtually on Sunday, November 7th at 2:00p Eastern.

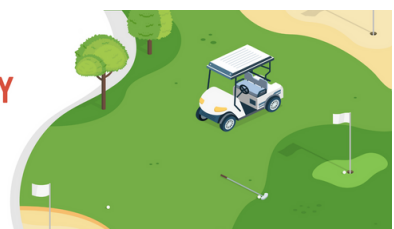
The cost is \$ 40.00 which includes the instructor fee & supplies. Please RSVP by October 25th [here](#).

For further information or any questions, please contact Shannon Leidig at arialyric@aol.com.

Longest Day of Golf Fundraiser - Thank You!

Our Longest Day of Golf (LDOG) fundraiser was a considerable success! With the donations of our generous supporters, we raised over \$25,000.

RSDSA'S
LONGEST DAY
OF GOLF
FUNDRAISER
SEPTEMBER 27, 2021



RSDSA's Longest Day of Golf is a one-day event to raise funds and bring awareness to CRPS. Tony Consiglio was our new partner this year golfing for us at Innis Arden Golf Club. Consiglio, who does not have CRPS, had a successful LDOG by playing 150 holes this year!

Because of your help and generosity, we can continue our work in the RSDSA community. Your caring support truly makes a difference!

Thank you,

RSDSA Board of Directors

Your Rights under the Air Carrier Access Act

The Air Carrier Access (ACAA) was passed in 1986 to prohibit any discrimination against people with disabilities by air carriers. The specific rights of air passengers with disabilities is outlined in [14 CFR Part 38](#).

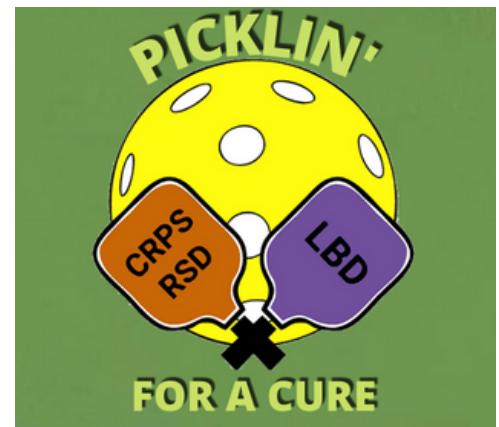
The Guidelines outline policies regarding assistance at the airport and onboard the airplane, transportation of personal wheelchairs and mobility equipment, accessibility features of the aircraft, notifying airlines of needed services, care attendants, and service and emotional support animals.

John Morris has created a very informative website to guide individuals with disabilities utilizing wheelchairs during their air travel called wheelchairtravel.org. Take a look at this resource and keep it handy when traveling.

Picklin' for a Cure is this Weekend in Tucson, Arizona

The 2021 Picklin' for a Cure: an awareness and fundraising pickleball tournament for RSDSA and Lewy Body Dementia Association takes place this weekend from October 15th to October 17th.

While registration is closed, it is not too late to learn more about donating to the [event!](#)



We want your feedback!

Please send any suggestions or upcoming events of interest to our community to info@rds.org and please consider donating at rds.org/donate.