OCTOBER 2020

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RSDSA'S FIRST VIRTUAL CRPS AWARENESS WALK

THANK YOU FOR SUPPORTING RSDSA'S LONGEST DAY OF GOLF

#CRPSCHAT ON THE FIRST TUESDAY OF EACH MONTH ON TWITTER Join us for Treating the Whole Person: Optimizing Wellness Virtual Conference October 19-22

RSDSA invites you to register for <u>part one</u> and <u>part two</u> of our free Treating the Whole Person: Optimizing Wellness virtual conference from Monday, October 19th, through Thursday, October 22nd, 2020.

Our live conference sessions begin at 7:00p Eastern each night, but you'll want to join us 30 minutes earlier at 6:30p Eastern for virtual networking chats and our exhibit hall!

We'll also have the networking sessions and the exhibit hall open for 30 minutes after sessions end.

Our sessions topics include:

- CRPS & Viruses
- The Immune System & CRPS
- Intimate Relationships
- Meditation & Other Alternative Therapies
- Social Security & DisabilitySubtypes of CRPS
- Meditation & Other Alternative Therapies
- Physical Therapy & CRPS

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

Seventh Annual Color the World Orange[™] for CRPS/RSD Awareness is November 2nd

Get your orange ready! The Seventh Annual Color The World Orange™, aimed at spreading awareness of complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD), is coming up on November 2nd.



Supporters will wear orange to spread awareness of CRPS/RSD, as well as raise funds to support research of this debilitating condition. In addition, buildings and landmarks will be lit orange to mark the event. This year there will be a special focus on recognizing our caregivers – doctors, nurses, physical therapists, support groups, family and friends.

The easiest way to get involved is to wear orange and post a picture to social media with the hashtag: **#CRPSORANGEDAY**. In addition, we are encouraging supporters to share a message to thank their caregivers in photos and post with the hashtag: **#CRPSORANGEDAYTHANKYOU**.

The sixth-annual Color the World Orange[™] in 2019 was the largest yet with 176 buildings, bridges and landmarks in nine countries including Niagara Falls, SSE Arena, Wembley in London, the CN Tower in Toronto, Eden Park in Auckland, New Zealand, the Wrigley Building in Chicago, the Story Bridge in Brisbane, Australia and Mansion House in Dublin lit orange for Color The World Orange[™].

You can find more information about Color The World OrangeTM along with signs to thank your support teams at <u>colortheworldorange.com</u>.

RSDSA's First Virtual CRPS Awareness Walk

RSDSA's First Virtual CRPS Awareness Walk on Saturday, August 22, 2020 was a resounding success. We raised over \$40,000, a full \$10,000 over our goal. We had 33 teams from 40 states and three countries, with a total of 233 participants and close to 500 donors.

This is fabulous for our RSDSA Warrior community, especially in these difficult times. There is a message here that goes beyond successful fundraising and support for RSDSA programs, a message that says that WE ARE A COMMUNITY that comes together and supports one another.



Nicole Foley of Foley's Flame Fighters with her mom and dad at the beach!

The virtual walk was the brainchild of Debbie O'Neal, one of the three cochairs of RSDSA's largest in-person event, the annual Long Island CRPS Awareness Walk and Expo. The Long Island Walk had to be postponed this year due to COVID-19, but it will be back in 2021 bigger and better for its celebratory fifth year. Debbie first suggested a virtual walk this spring in the first few weeks of the coronavirus lockdown. She also came up with the name and designed the medals. The RSDSA communications team got the word out and you Warriors took it from there. The RSDSA Support Group facilitators were invaluable in spreading awareness of the virtual walk to their networks. A few support groups even created their own teams. This walk was successful because team captains and individuals reached out to their families, friends, neighbors, and colleagues raising awareness and funds.

Though the walk is over, we are still accepting donations and matching gifts. Many companies offer donations to the charity that matches the gifts of their employees. Matching gifts is an easy way to double the gifts and double the impact of one donation. We could not have done it without you, our Warrior community. You are the heart of RSDSA. Your engagement means everything from your comments on our Facebook Live videos, to donations, and to our Facebook fundraisers. Your support makes a huge difference in the lives of our CRPS community. From our hearts, thank you.

> Top fundraising team MB's Fierce Fighters

Team with the most members Foley's Flame Fighters

- Abbott **Burning For A Cure** Calloway Crew **CRPS** Conquerers **CRPS** Philly Area CRPS Slayers Walk Roll & Stroll Along **CRPS** Strong Debbie's 4 Leaf Clovers **Debbies Warriors DIY Warriors Everyday CRPS** Foley's Flame Fighters Inspired Just Keep Swimming Kell's Sheltie Warriors Kelly's Crusaders
- **Krassner-Murray Dragons MB's Fierce Fighters** Miles for Melissa Not Fast, Just FURIOUS! Pints for Pain Proctor RSDCA - We're on Fire! Seickel's Warriors SHAYnation Sheryl's Shoulders to Lean On Tales of the CRPS Team Hot and Cold Team Jeff Doyle Team Kona The Mighty Warriors The Pirates Cassandra & Phelan You Are Not Alone Team





Thank you for supporting RSDSA's Longest Day of Golf

Our Longest Day of Golf (LDOG) fundraiser was a big success and raised over \$25,000.

Through your help and generosity we are able to continue our work in the CRPS community. Your support truly makes a difference!

RSDSA's Longest Day of Golf is a one-day event to raise funds and bring awareness to complex regional pain syndrome (CRPS) with our partner, prolific golfer and CRPS advocate, Josh Rosen. Rosen, who does not have CRPS, showed his support and had a successful LDOG by playing 117 holes this year!

"Like many people, I didn't know much about CRPS before connecting with Hank Ludington, co-president of the RSDSA board of directors," says Rosen. "I love that I can use my golf ability to help people with CRPS. My goal is to help RSDSA fundraise enough to help more people get just a little bit of happiness or relief."

Thank you,

RSDSA Board of Directors



Join the #CRPSChat on the First Tuesday of Each Month on Twitter

On Tuesday, October 6th, there will be a #CRPSchat at 5:00PM Pacific for all individuals impacted by CRPS.

The chat is intended to help the CRPS community meet and connect with each other. It is to share information, learn about treatments and coping strategies, make friends, and of course, to check in and support one another.



Each chat will have a different topic and the chat leader, @KateandCRPS is open to topic submissions.

If you have a topic idea, please direct message the @CRPSChat account or email kateandcrps@gmail.com.



Don't Punish Pain Rallies

On Wednesday, October 7th, there will be rallies in major cities across the United States to "protest and to have our voices heard regarding the neglect the chronically ill community/pain patients have experienced due to the new CDC guidelines, the DEA, and the FDA's involvement."

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For more information, <u>click here</u>.



IASP Research Forum

The International Association for the Study of Pain provides a unique free benefit for individuals interested in the latest published peer-reviewed journal articles in pain research. To sign up for their newsletter and to read the latest papers of the week, visit painresearchforum.org.

Word Up

Neuroplasticity [noor-oh-pla-stis-i-tee] The capacity of the nervous system to develop new neuronal connections.

Click <u>here</u> to view a short video and accompanying article on how neuroplasticity can cause persistent pain and how it can harnessed to reduce the resulting centralized pain. The brain continually reorganizes itself by forming **new neural connections throughout life.**

This phenomenon is known as neuroplasticity.





The Warm Line

<u>The Warm Line</u> is a telephone support line where the caller is able to talk to trained peers that can listen to concerns and offer support. The Warm Line Peer Responder has a unique perspective on issues since they may have experienced many of the same feelings in the past.

An Examination of State and Federal Opioid Analgesic and Continuing ED/JR

According to Katie Duensing, JD, "In just three years, 527 opioid-related policies (statutes, rules/regulations, and guidelines) were adopted at the state and federal levels. While most of these policies focused on prescription drug monitoring programs, 170 specifically imposed limits on opioid prescribing and an additional 35 specifically referred to, or incorporated, the CDC opioid prescribing guideline. Further, 46 states and DC mandated pain or opioid prescribing continuing education for prescribers renewing their licenses, affecting as many as 1.7 million prescribers.:

To access this free full article found in the newest issue of the Journal of Pain Research, <u>click here</u>.

Request Color The World Orange[™] Gratitude Cards

CRPS Warrior Kathy Krenn loves the idea of gratitude for this year's Color The World Orange[™] Day and would like to offer up her talents to fellow Warriors so they can send cards to those they are greatful for.

Once you donate to Color The World Orange[™], email Kathy Krenn at kkrenn209@comcast.net to request your handmade cards. Kathy's cards come from a smoke free, COVID-19 free home and would be sent within 24 hours of donation.



Please send us feedback!

This is the inaugural issue of a monthly digital update of helpful information for the CRPS community. We hope you found it useful. Please send any suggestions or upcoming events of interest to our community to info@rsds.org and please consider a donation to <u>rsds.org/donate</u>.