NOVEMBER 2021 ISSUE 14

IN RARE FORM

IN THIS ISSUE

Thank you for attending our 2nd Annual Virtual Conference, Treating the Whole Person: Optimizing Wellness

The team at RSDSA would like to thank everyone who attended our free virtual Treating the Whole Person: Optimizing Wellness conference last month.

We had amazing participation across all four nights and have enjoyed receiving receiving so much positive feedback. Attendees enjoyed the informative content as well as connecting with other CRPS Warriors.

Please note that the videos from the event are currently being edited. As soon as they are edited, the videos and presentations will live on the RSDSA YouTube Channel here.

Special thanks to:
- Dr. Pradeep Chopra, MD, MHCM
- Kate Venison, LMFT
- Amberly Largo
- Christian Stella PharmD, ABAAHP, FAAMM
- Nancy Powers
- Tim J. Ireland, VMD
- Lisa Brzezicki
- Bryan Pope, Esq
- Shannon von Felden, MPP

CRPS Awareness Month Is Here!

In addition to our regularly scheduled programming and events, we have a few special occurrences for CRPS Awareness Month.

CRPS Memorial
RSDSA is honoring Warriors we have lost over the years by launching a CRPS Memorial on our website.

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 goals 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 GivingTuesday
GivingTuesday is devoted to global charitable giving. Join the global giving community by donating to RSDSA here.

Monday, November 1st was Color the World Orange™ Day!
Take a look at Color the World Orange™'s Facebook Page to see all of the local and state governments that released proclamations.

Carolyn's Cards Is Back!

by Carolyn McNoldy

My name is Carolyn of Carolyn's Cards. I have been battling Complex Regional Pain Syndrome (CRPS) for ten years now. One thing that has made my fight easier is being able to connect with other CRPS warriors. They are the only ones who can truly relate because they know exactly what it is like to have CRPS.

Carolyn's Cards is a program through RSDSA that sends cards and other small surprises through the mail to individuals with CRPS and their caregivers. Through these cards, my goal is to provide a feeling of not being alone and a feeling of support to every warrior who receives one of my cards. It is genuinely coming from one warrior to another. In addition, my goal is to thank caregivers for their love and support as it is often not an easy job. I also hope the cards give them a smile too!

It has been almost three years since the Carolyn's Cards program began. Since January 2019, over 300 cards have been mailed out to CRPS warriors and caregivers. Over 200 holiday cards have also been mailed out. These cards have reached 37 states and Canada. I can't wait until I can reach Warriors in all 50 states and even more countries!

Please send your request for a card to carolyns.cards2@gmail.com. I will need to know the recipient's name, if they are a Warrior or a caregiver, their mailing address, and if there is a special reason for the card. Cards can be sent for celebrations, after a medical procedure, when someone is having a hard time, or just because. Don't be afraid to request one for yourself! Please know that names, addresses, and other personal information will be kept confidential.

I look forward to hearing from you!

Join the Patient Protective Taskforce and 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 end.

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.

We are asking you to join the Patient Protective Taskforce. The first task for this new taskforce is asking your state legislators for an exemption to your state opiate guidelines and legislation for patients and physicians of specific chronic pain rare diseases such as CRPS. Addressing the opiate crisis is important, however, the restrictive legislation and guidelines are not protecting us. They are killing us. 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 out of five CRPS patients report that they seriously consider suicide, particularly during flares.

Will you join the CRPS Patient Protective Task Force? We have a template to help you make the case and you can help deliver an effective message. You can make a difference.

To join our CRPS Patient Protective Task Force, email Advocacy@rsds.org and include your name, phone number and mailing address so we can connect you to your legislator.

Graded Motor Imagery and Memantine Clinical Trial in Australia

We are pleased to announce a graded motor imagery and memantine clinical trial in Australia. To learn more, please visit memoir.neura.edu.au. Memantine is a nmda receptor antagonist as is ketamine. Hopefully, the trial will be successful and it will be another therapeutic option for people with CRPS as an earlier European publication of six cases showed its efficacy.

Begin your holiday shopping on Amazon Smile

Shopping for holiday gifts? Don't forget to start your shopping at smile.amazon.com so RSDSA can receive 0.5% of your eligible purchases!

Here's how to get set up on Amazon Smile if you have not yet selected a charity:

- Visit smile.amazon.com
- Sign in to Amazon
- Under “Start by picking your charity” type in RSDSA or Reflex Sympathetic Dystrophy Syndrome Association and click search
- We are the only option that will come up so once you see our name click “Select”
- On the next page when it asks “Yes, I understand that I must always start at smile.amazon.com to support Reflex Sympathetic Dystrophy Syndrome Association or (RSDSA),” click the checkbox and then click "Start Shopping"

Here's how to get set up if you have already selected a charity that is not RSDSA

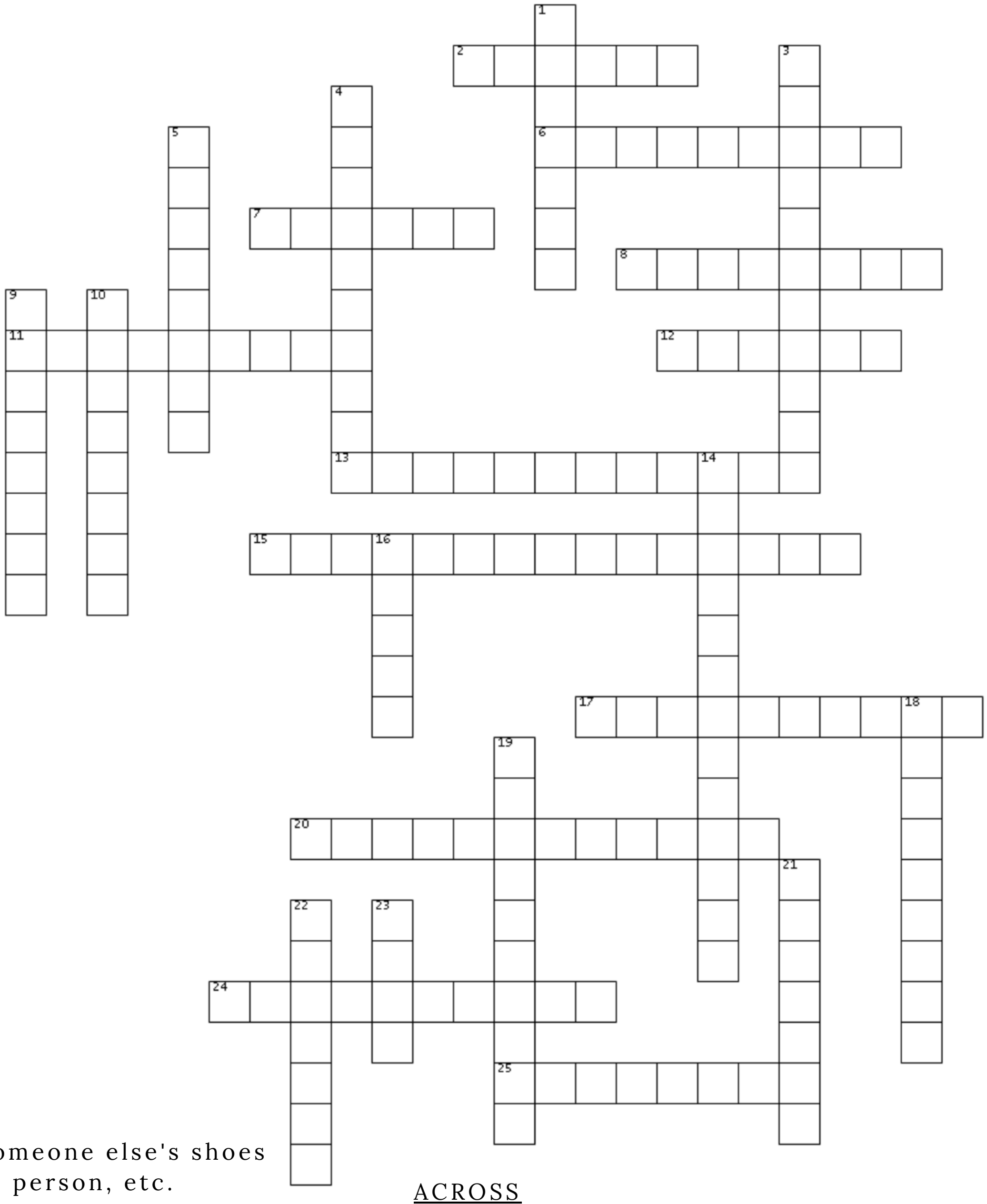
- Visit smile.amazon.com
- Sign in to Amazon
- If you have already selected a charity, on the left-hand side of the main menu you will see “AmazonSmile” with a drop-down arrow. Click it.
- Click the "Change charity" button
- From there, search for RSDSA or Reflex Sympathetic Dystrophy Syndrome Association.
- We are the only option that will come up so once you see our name click “Select.”
- You will then see in green "You have changed your charity to Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)."

Send us a message if you have additional questions!

amazonsmile

You shop. Amazon gives.

RSDSA Crossword Puzzle



DOWN

1. to walk a mile in someone else's shoes
3. telephone, iPad, in person, etc.
4. Neurontin
5. Atticus Finch
9. Dr. Robert Schwartzman
10. The ____________ Criteria
14. first doctor, not after seven doctors
16. REM, deep, restorative
18. Friends, I Love Lucy, This Is Us
19. astrocytes, oligodendrocytes, microglial
21. provides up-to-date information on current CRPS research and treatments, helpful coping tips, and other useful information
22. Golden State (singular)
23. Kundalini, Vinyasa, Hatha

ACROSS

2. Sister Sledge
6. pain from touch of clothing, a breeze, a shower, etc.
7. carrots, Cheetos, pumpkins, etc.
8. stretching, sleeping, maintaining a healthy diet, etc.
11. grade school, high school, experience
12. a scientific pain scale
13. ketamine, low dose naltrexone
15. therabands, bucket of rice, balance board, etc.
17. Chumbawamba
20. reading, coloring, TV, etc.
24. nannies, home health aids, partners, etc.
25. ha ha, tee hee, giggle

Federal Student Loans Being Waived

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School Loans? They may be waived!

Many of the clients we represent have tried going to school for better opportunities. To pay tuition many have taken out school loans, some of those provided by the federal government. **Recently the Biden Administration announced that federal student loans will be waived for some people who are receiving Social Security disability benefits.**

People who are not expected to have medical improvement will have their federal student loans automatically waived via a computer match in September 2021.

To determine if someone is in the Medical Improvement Not Expected (MINE) category check their Notice of Award which was sent shortly after they were approved for benefits. If it indicates that medical review will not be for five to seven years, then they should fall into the waiver group. This is a huge development from the Department of Education that will impact more than 323,000 disability recipients and waive more than $5.8 billion in loans.

Clients in this group should get a letter indicating that your debt has been waived.

Disability recipients who are not in the MINE category can still apply to have federal student loans waived. There are law firms and agencies that help people file those applications – just give us a call for a referral. This typically requires paperwork to be completed and reporting of income for the 3 years following waiver. Some of that reporting has been suspended due to the pandemic but will likely be resuming soon.

Also, some private lenders are following the federal guidelines regarding waivers so clients with student loan debts originating from private banks should also ask about debt elimination or reduction.

Take part in the following study if you have CRPS and live in the UK

The survey intends to answer research questions that still exist regarding Complex Regional Pain Syndrome (CRPS). These include questions such as ‘Who is more likely to suffer from CRPS?’, ‘Which are the most effective treatments for CRPS?’ and ‘How much does CRPS affect the lives of patients?’

Learn more and take the survey here.

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rsdsa
SUPPORTING THE
CRPS COMMUNITY

Charitable Giving for 2021

The one-time $300 "deduction": For the 2021 tax year, individuals who take the standard tax deduction (that is, they’re not eligible to itemize their charitable contributions) may, in addition, take an “above the line” deduction for cash gifts made to qualified charities, up to $300.

Unlimited charitable deduction for 2021: For those who itemize their deductions, in 2021 these taxpayers may deduct the entire amount of the cash gifts made to qualifying charities - meaning that these individuals can choose to entirely “zero out” their tax obligation for the year.

Have you been told that CRPS is not real?

Eleven internationally renowned CRPS researchers have published a recent article in the Journal of Pain Research debunking this absurd assertion.

Their conclusion is, “the level of evidence for the claim that CRPS does not exist is very weak. Published accounts concluding that CRPS does not exist, in the absence of primary evidence to underpin them, can harm patients by encouraging dismissal of patients’ signs and symptoms.”

To access the article, click here.

CRPS Assist: A Great Resource for Physiotherapists in Europe

CRPS Assist is a free online tool designed by British physiotherapists in collaboration with a respected medical expert for all European physiotherapists who may know a little about Complex Regional Pain Syndrome, but need practical guidance and perhaps don’t have easy access to it.

Providing fast access to expert advice, CRPS Assist can help clinicians identify patients with CRPS and decide what to do next. Highlighting common pitfalls and practical tips, it also includes a downloadable Budapest diagnostic criteria form. Learn more here.

Thank you to everyone who attended this month's Painting the World One Brush at a Time with A Broad and a Brush for CRPS Awareness Month! We loved having participants from coast to coast.

Keep an eye out for future events.

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 and 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.

Give to RSDSA When You Search on Bing

Give with Bing and Microsoft Rewards members have donated $9 million and counting. Join here today to make your searches matter. All you have to do is sign up, select RSDSA (Reflex Sympathetic Dystrophy Syndrome Association) and then Search on Bing! When you're signed in, you'll earn points that turn into donations for our organization and mission.

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.