

IN RARE FORM



One Person Can Make a Difference

Christina Whearley is a CRPS Warrior with long-standing CRPS who has chosen to work with RSDSA and the U.S. Pain Foundation to promote much greater awareness of CRPS while also making a substantial, positive difference in the lives of other CRPS Warriors. Since 2017, Christina has organized an annual awareness/fundraising walk in Manassas, Virginia, created the Saving Those Overwhelmed by Pain Facebook Group in early 2019, as well as a Warrior outreach program through her side business! She has been working with Origami Owl since September of 2018.

After Christina learned that several Warriors had died by suicide, she decided to try what her Origami Owl mentor did for her - reminding her that she was amazing and she mattered! Her mentor did this monthly by sending a card that always expressed how she felt about Christina (always beyond positive) and included some shiny piece of Origami Owl jewelry that conveyed a powerful and positive message. Christina knew that if her mentor could change how she felt about herself, she could potentially change how Warriors felt about themselves before they gave up. Little did she know how spot-on it would be.

Paying it forward, Christina sends each Warrior a piece of Origami Owl's empowering jewelry with an encouraging, handwritten message signed by a fellow CRPS Warrior. Her online VIP group sales almost fully fund the program. Christina also has an [online store](#)

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where anyone can purchase these same items and feel confident that the proceeds will go directly to her pain warrior program.

Remarkably, the founders of Origami Owl learned of what she had been doing. During a recent incentive trip to Florida, the founders stood on stage in front of hundreds of designers from all over the U.S. and shared about what Christina had been up to. They used it as an example for what they all can be out there doing. After the ceremony, a fellow designer chased her down to ask for her help as the designer's best friend's 10-year-old daughter had just been diagnosed with CRPS and they were justifiably terrified.

Weeks after returning from the incentive trip, Christina earned the company's highest honor. She won the Force for Good award during a virtual awards ceremony [broadcasted on YouTube](#) by Tyson Basha, the co-founder of Origami Owl.

For Christina, it was an honor to represent the company, but it was more exciting to know that thousands of Origami Owl's designers from all over the U.S. and Canada and their families and friends were watching this awards video! Subsequently, more than 11,500 have watched the video on YouTube. To Christina, that is 11,500 individuals who have now heard about CRPS!

If you are interested in Christina's program or want to contact her, send her an email at cwhearley.ea@gmail.com.

Have You Been Denied Care Because You're on Medicare?

A west coast law firm is interested in learning if people with CRPS have been denied care because they are Medicare participants. If you have been denied care because the physician will not accept Medicare payments, please email us at info@rsds.org.



2021 Rare Disease Week on Capitol Hill

Recap

RSDSA's Warrior community and Advocacy Committee joined EveryLife Foundation's Rare Disease Legislative Week in July. The legislative week consisted of virtual advocacy workshops, webinars and virtual meetings with Senators representing our states and House representatives standing for our districts.

Meetings with staff aides ran for 15-30 minutes. We joined other rare disease advocates asking for support for the STAT (Speeding Therapy Access Today) Act and were among seven other legislative priorities supporting the rare disease community. The STAT Act, which is the highest priority, will improve rare disease coordination, stakeholder engagement and policy development with the FDA by creating a Rare Disease Center of Excellence. It will inform rare disease policies and actions by creating a Rare Disease and Condition Drug Advisory Committee and fund regulatory science and related activities to support development of therapies to treat rare diseases. In addition, we asked our representatives to join the Rare Disease Caucus in both the Senate and the House.

Legislative week involves working with advocates from a spectrum of the more than 7,000 rare diseases. We met via Zoom and coordinated our asks. Other top priorities included the reauthorization of the Newborn Screening Saves Lives Act and requests to co-sponsor the Access to Genetic Counselor Services Act.

We had the opportunity to join with other advocates for rare diseases and have our voices heard and send each representative our "one-page ask," telling our individual stories outlining the issues important to the CRPS/RSD community.

The Advocacy Committee would love to hear from those of you who signed up and joined the Rare Disease Legislative Advocates with the EveryLife Foundation. Tell us about your experience and join us for next steps to get our issues heard.

Next year, we hope to meet face to face in Washington D.C. in our representative and senators' offices.

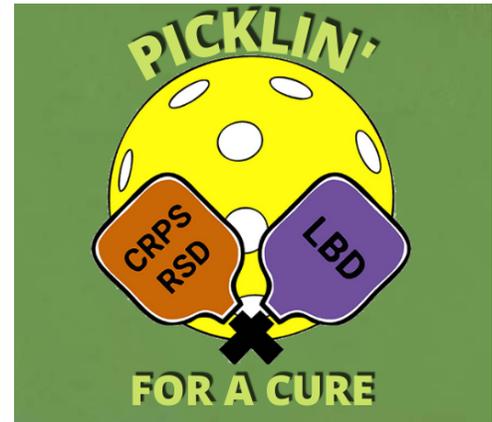


Register for Picklin' for a Cure in Tucson, Arizona

Please join us for 2021 Picklin' for a Cure: an awareness and fundraising pickleball tournament for RSDSA and Lewy Body Dementia Association.

Registration is now open and closes on September 30th. The tournament begins on October 15th and ends on October 17th.

Learn more about registering for the event [here](#).



Register for the 3rd Annual Flame Out Walk to Extinguish RSD/CRPS in Oakhurst, New Jersey

Join the Hopkins Family in supporting RSDSA at the 3rd Annual Flame Out Walk to Extinguish RSD/CRPS in Oakhurst, New Jersey on September 12th. This event is sponsored by the Vietnam Veterans of America, Oakhurst, Chapter 12.

The Hopkins' daughter, Judy, has RSD, and they are hosting this 3rd annual event to support her, RSD/CRPS Warriors, and RSDSA. Please join them as attendees step off to remember those who, daily, battle the syndrome.



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.

Mark Your Calendar for CRPS Awareness Month Events

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™, and Tuesday, November 30th is Giving Tuesday, the day devoted to global charitable giving.

RSDSA is currently planning for our month. We will work with Color the World Orange™ to raise awareness with local and state government proclamations declaring November CRPS Awareness Month and the lighting orange of public buildings.

You can find out “how to ask” for a proclamation on the Color the World Orange™ Facebook Page [here](#).

Please stay tuned for announcements of upcoming events for CRPS Awareness Month!

CDC Opioid Workgroup Recommendations

On Friday, July 16, 2021, the CDC's Board of Scientific Counselors (BSC) and National Center for Injury Prevention and Control (NCIPC) held a public meeting to discuss the overview and progress of the update to the CDC Guideline for prescribing opioids and the BSC's progress on the draft guideline. The meeting was open to the public for comment and members of the Advocacy Committee attended the virtual meeting and submitted public comments.

Overall observations from the BSC Workgroup:

- Unbalanced – Focus on risks of opioids, less attention on potential benefits of opioids or risks of untreated/under-treated pain. Missing key studies.
- Concern for misapplication guideline, leading to potential harm to patients
- Tension between public health benefits vs individual patient benefits; not sufficiently patient-centered
- Too little attention to racial/ethnic disparities and inequities in how pain is perceived, valued, and managed
- Cautious about including specific opioid dose thresholds in the recommendations
- Sense of exceptionalism – Certain conditions with “real” pain or warrant specific types of treatment

For a full viewing of the report presented at the meeting, [click here](#). Release of a final updated guideline is anticipated to occur in late 2022.

Donate to RSDSA

Have you thought about your legacy? Are you looking for a long-term way to make a meaningful difference in the CRPS community?

Please consider making a planned gift to RSDSA today. Planned giving options include:

- Gifts of stocks and bonds
- Including RSDSA as a beneficiary in your life insurance policy
- Including RSDSA as a beneficiary in your will.
- Contributing via an IRA

Tax benefits apply to each of these options. Please contact your attorney, a financial attorney, or a financial advisor for more info.

Tell Us About Your Experience From Palliative Care For Your CRPS

We would like to hear from members of our community who have been successful in obtaining palliative care for their CRPS.

Palliative care is defined as specialized medical care for people living with a serious illness. This type of care is focused on providing relief from symptoms and stress. The goal is to improve quality of life for both the patient and the family. Too often, palliative care is misconstrued as only pertaining to those needing end-of-life care.

Please share with us how you obtained palliative care and details such as:

- Who referred you
- If it was an inpatient or outpatient experience
- If insurance paid for it
- Which palliative care team members worked with you
- What didn't work
- Any suggestions for others applying for palliative care, and/or
- How did it improve your quality of life

We greatly appreciate your assistance as it is our intention to learn more about the experience of individuals with CRPS who have accessed the palliative care system.

Please share your experience with us via email at info@rsds.org.



Save the Date: Treating the Whole Person: Optimizing Wellness Virtual Conference is October 25-28, 2021

Our live conference sessions will stream live each evening from October 25-28. Stay tuned for more details on our guests, how to register, and our community auction.

Help Us Develop Guidelines for Health Care Aides

Many individuals with long-standing CRPS require the assistance of home-health aides (HHA) to help with life's daily activities. Yet too often, the resulting experience turns out poorly for both individuals. It is our belief that one reason for these failures is that the majority of HHAs are not familiar with CRPS and its diverse manifestations and the varying needs and difficulties experienced by CRPS Warriors.

We want to enlist your lived experience to develop Guidelines to educate Home Health Care Administrators and their employees about the special needs of those with CRPS prior to a HHA assignment to your home.

RSDSA has developed similar Guidelines for [Dentists](#), [Hospitals](#), and [Emergency Departments](#) which has improved the experiences of people with CRPS.

We need tangible, doable suggestions based on your experience for both Warriors and HHAs. Examples include ask always before touching, being aware that some individuals with CRPS are sensitive to bright light, noise, particular aromas, etc.

Please send your suggestions to info@rsds.org.

Looking for a booklet on CRPS in Spanish?

If you or someone you know needs information on CRPS in Spanish, the National Institute of Neurological Disorders and Stroke (NINDS) has published a small booklet, *Síndrome de dolor regional complejo*, which outlines the diagnosis and management of CRPS.

To order your booklet(s), please call 1-800-352-9424 or email braininfo@ninds.nih.gov.

Please send us feedback!

Please send any suggestions or upcoming events of interest to our community to info@rsds.org and please consider a donation to rsds.org/donate.