

IN RARE FORM



Painting Through the Pain

by Emily Suárez

My journey with CRPS began back in 2015 with a very minor injury – a fractured small toe. I made a trip to the ER to get X-rayed, and doctors informed me that the injury should heal in about 4-6 weeks. But six months later, the bone had still not healed and my pain levels were escalating. Not only was the toe still bothering me, but my entire foot was swelling up and turning shades of black, blue, and red.

Desperately searching for answers, I visited doctor after doctor. Each one examined me and concluded I was just slow to heal due to having an underlying autoimmune disease. Knowing my body and that something was seriously wrong, I kept pressing on for an accurate diagnosis. By this point, the inflammation and pain had spread to my other foot and even started climbing up my leg. I was completely debilitated and unable to be on my feet for more than a few minutes. Terrified, I sought help from yet another podiatrist – this time, completely breaking down in tears in his office. Witnessing the immense pain I was experiencing, it was like a lightbulb went off in the doctor's head, and he informed me, "I think I know what's going on. You have CRPS."

My diagnosis came as a relief, because I knew it meant that I could finally get treatment. But I was anxious and scared that the treatments might not be effective or that the pain might be here to stay. I needed a distraction from my symptoms and the

IN THIS ISSUE

**SENSORY INTEGRATION,
AND SENSORY
PROCESSING SURVEY**

**OUR 3RD ANNUAL
VIRTUAL CRPS
AWARENESS WALK IS
SATURDAY, JUNE 11TH,
2022**

**FACEBOOK LIVE WITH
CRPS WARRIORS JOSH
BORG, CASSIE
CHRISTENSEN, AND KELLY
CONSIDINE**

**EMERGENCY MEDICAL
SERVICES SURVEY**

**JOIN OUR PATIENT
PROTECTIVE TASKFORCE**



Suñez's oil painting
titled "Superbloom"

fears I had about the future. So I made the decision to enroll in a painting class to take my mind off my CRPS. I immediately began experiencing the therapeutic benefits of painting and loved the calming and relaxing effect it had on my body.

Painting became my escape from chronic pain and other symptoms I was experiencing. It helped me cope with the heavy emotional toll of battling CRPS. Creating beauty on canvas made me feel joyful and at ease. Painting helped me to feel better physically as well, as it gave me energy and helped to increase my stamina. I felt full of hope again and ready to try different medical treatments to combat my CRPS.

Along with medications, acupuncture, and biofeedback, I did a series of 6 sympathetic nerve blocks that successfully got my CRPS into remission. I can now use my feet normally again and am able to walk a few miles – something I'll never take for granted. And painting has now become a big part of my life! It continues to be my therapy and form of meditation, and it has brought so much joy into my life. It's been so exciting to share my work with others through local gallery shows and art fairs. And now that I'm in a much better place with managing my symptoms, I've had the energy to turn my attention to using my art to help other chronic illness warriors heal. A book that I wrote and illustrated with my watercolor paintings was recently published, called *The Healing Journal: Guided Prompts & Inspiration for Life with Illness*. (More info at EmilySunez.com/books.)

Painting has been my light through the darkness of fighting CRPS and other chronic conditions. Art is such a powerful tool for healing, and I'm grateful to have developed a creative practice that gives me so much relief. My greatest hope is that my story inspires other chronic illness warriors to try practicing a form of creativity to cope with their own illness!

You can view Emily's artwork online at emilysunez.com or on Instagram at [@emily_thePainter](https://www.instagram.com/emily_thePainter).



Facebook Live with CRPS Warriors Josh Borg, Cassie Christensen, and Kelly Considine

Join RSDSA for our next Facebook Live with CRPS Warriors Josh Borg, Cassie Christensen, and Kelly Considine on Thursday, May 19th at 7:00p Eastern as they discuss their CRPS journey, treatments, involvement with our annual virtual walk, and more!

We can't wait to see you all on the 19th at facebook.com/rsdsa.

Complex Regional Pain Syndrome, Sensory Integration, and Sensory Processing: Is There a Relationship? Survey and Study

Dr. Gretchen Bachman, OTD, OTR/L, MBA, CEAS, CHT is the Principal Investigator of a study titled "Complex Regional Pain Syndrome, Sensory Integration, and Sensory Processing: Is There a Relationship?"

The purpose of the [survey / study](#) is to explore the relationship between CRPS and sensory processing. The results will help guide future research investigating innovative therapy treatments for CRPS.

You must be at least 18 years of age and have had a diagnosis of CRPS in an upper extremity.

For any questions, please contact Dr. Gretchen Bachman at gretchen.bachman@nau.edu.

This research has been approved by the Northern Arizona University Institutional Review Board.



RSDSA's 3rd Annual Virtual CRPS Awareness Walk is Saturday, June 11th, 2022

RSDSA is excited to announce that our 3rd Annual Virtual CRPS Awareness Walk is **Saturday, June 11, 2022**, and registration is open!

In 2021, we had 57 walk teams as well as participants and donors from 34 states and four countries. Our goal was to raise \$50,000, and we surpassed our goal and raised over \$60,000. Thank you to all who participated, registered, & donated.

We hope to make this year more successful with your help by aiming higher and raising our goal to \$75,000. We know that the CRPS community has the strength and dedication to band together and make amazing things happen!

Living with a chronic disease, and constant pain, is daunting to say the least, but to see everyone come together to raise awareness for this rare condition is very inspiring. Seeing the support from so many reminds CRPS warriors to keep fighting and reminds them that they are not alone!

Registration Information

- \$25 for adults, \$10 for children ages 5-12
- Register either as an individual or by creating a team
- RSDSA's 3rd Annual Virtual CRPS Awareness Walk t-shirt & medal are included for all United States and Canadian registrants

\$100 Level RSDSA Coffee Tumbler	\$200 Level RSDSA Duffle Bag
	
\$500 Level Big Lounger Chair	\$1000 Level Chenille Blanket
	

Prizes are not cumulative and subject to change

Emergency Medical Services Survey

RSDSA has created a [survey](#) about your experiences when interacting with emergency medical services workers after calling 911. We are planning to create an educational course for emergency medical services workers such as first responders, emergency medical technicians (EMTs), and paramedics.



Your input is important so we can develop an instructive and helpful course. The survey will take approximately five minutes to complete and is completely anonymous.

Podcast on Embracing the Complexity of Pain



Kate Bowler of the *Everything Happens* podcast recently invited Dr. Haider Warraich on her show to discuss chronic pain and how we understand and treat it. In this conversation, Kate and Haider discuss the difference between pain and suffering, why pain might be subjective, yet should be taken just as seriously, why we should erase the arbitrary demarcations between mind and body when it comes to understanding and treating chronic pain, and more. Listen [here](#).

Interested in Writing for the RSDSA Blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog!

If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or in order to help those who may be in the same part of their journey as you are, send us an email at alexisdavis@rsds.org.



Purchase Tickets to the Connecticut Sun vs. Seattle Storm Game - Friday, June 17, 2022

RSDSA is excited to be teaming up with the Connecticut Suns of the WNBA for a community building fundraiser at their game against the Seattle Storm on Friday, June 17, 2022 at Mohegan Sun Arena in Uncasville, Connecticut.

RSDSA will have a table on the concourse and will be involved in other activities during the game including a raffle.

[Tickets](#) are now available. If you are in need of ADA seating, email Casey Wegrzyn at cwegrzyn@connecticutsun.com.



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

Our live conference sessions will stream each evening from September 12-15. Stay tuned for more details on our speakers and how to register!

Facebook Live with Facebook Live with Vivianne Tawfik, MD, PhD - May 26th



Join RSDSA for our Facebook Live with Vivianne Tawfik, MD, PhD on Thursday, May 26th at 7:00p Eastern as she discusses updates on CRPS from basic science to clinical practice.

Dr. Tawfik is a board-certified Anesthesiologist and Pain Medicine physician who specializes in the treatment of complex chronic pain disorders including chronic post-operative pain, complex regional pain syndrome and peripheral nerve injury. If you have questions for Dr. Tawfik, email them to us at alexisdavis@rsds.org.

We're on Fire! Walk, Roll, Stroll – CRPS Awareness Walk in Cypress, CA on June 11th



The Reflex Sympathetic Dystrophy California Support Community (RSDCA) and the Orange County CRPS Survivors and Caregivers Support Group are hosting the We're on Fire! Walk, Roll, Stroll – CRPS Awareness Walk on Saturday, June 11, 2022.

The walk will be at Veterans Park in Cypress, CA and everyone is invited to attend. The route was designed with the CRPS community in mind. The loop is just under half a mile and there will be chairs along the path for those who may need to take a break. Canes, walking sticks, walkers, wheelchairs, and scooters all are welcome!

Check-in begins at 9:30 a.m. and the official kickoff is 10:45 a.m. All funds raised will be donated to RSDSA. You can [register](#) as an individual or form a team and invite your friends, family and supporters to join us for a fun day and support a great cause! Everyone is invited to stay after the walk for an afternoon of friendship and community. Bring your lunch and comfort items (chairs, cushions, blankets, etc.) and spend time with fellow CRPS warriors, caregivers, and supporters. For questions or further information, email Rose or Kristie at CRPSweRonfire@gmail.com. We look forward to seeing you there!

Learn More About the Patient Protective Taskforce

Be your best advocate by joining the Patient Protective Taskforce. RSDSA's Advocacy Committee has created a Patient Protective Taskforce (PPT) to advocate on the local, state and federal level for policies that support CRPS Warriors treatment while raising awareness of chronic pain issues. For example, the primary reason for inadequate pain management is restrictive legislation, which tragically ensnares our most vulnerable patients and their families. This is one of the issues the PPT would focus on. We will also work to raise the profile of CRPS and bring light to our healthcare issues.

The PPT will meet every third Friday of the month led by our coordinator Sheryl Freed. All our meetings are virtual. Our next meeting is Friday, May 20th at 1:00pm Eastern. To join mail patientprotectivetaskforce@gmail.com for the Zoom link. Be sure to include your name, email address, phone number, and your mailing address.

Walk Strong CRPS Awareness - Walk Texas Style!

The Walk Strong CRPS Awareness Walk last month exceeded all expectations! Created by Miller Kerr with the generous support from the Kilgore College Rangerettes, Jesuit Rangerettes and the '812 Rangerettes, Walk Strong raised over \$13,000 for RSDSA and the CRPS community.

Luck was with them when the day dawned beautiful and sunny at the Semanes Family YMCA in Dallas, Texas for the 3K walk. The sidewalks on the route were decorated with walkers in colorful orange tees with the bold Walk Strong design. Also, along the route were staked lawn signs with CRPS facts for awareness and education. Miller's Rangerette teammates performed to get the participants off to a rousing start.

Thank you to Walk Strong's sponsors, J. Macklin Grill, as well as Bryan Pope and The Cochran Law Firm. Thank you to all the registered walkers and donors. Walk Strong reached its goal because of your generous support. Thank you to Miller and her parents, Holly & Todd for the fine planning that culminated in a successful walk. In Miller's words, "I had an absolute blast, and I cannot wait to do it again next year!"

Let's give a shout out to all the amazing people who help make this event possible. It is extraordinary what a small community can do. Watch the full recap [here](#).



Anti-Inflammatory Foods Word Search

ANTI-INFLAMMATORY FOODS



Brussel Sprouts

Tart Cherries

Anchovies

Green Tea

Collards

Almonds

Olive Oil

Sardines

Dark Chocolate

Blackberries

Broccoli

Truffles

Turmeric

Herring

Oranges

Spinach

Strawberries

Blueberries

Avocados

Mackerel

Legumes

Peppers

Grapes

Kale

Host an Event with RSDSA

Summer is the perfect time for an event or activity to raise awareness and funds for your community. Any activity can be an opportunity to raise support for advocacy, research, and education. Every dollar makes a difference. You can make a difference!

The opportunities to create, organize, and host are limitless! You can do it your way, whether that's a movie night or a Facebook fundraiser, or join an already established event. You can even turn a birthday, wedding, or other personal celebration into a fundraiser by inviting others to donate on your behalf.

There is no limit to what you can do, even with the pandemic and bans on large gatherings. There are many unique hybrid and virtual events that can raise awareness and money. There are fundraisers you can do as an individual and ones that include your family, your caring circle, your congregation, or your neighbors. We will be there to help you plan and execute any event you like!

Here are just a few fundraising event ideas:

- Zoom Bingo
- Costume contest (or a pet costume contest!)
- Craft night
- Trivia night
- Game night
- Poker run – I admit, I find this one intriguing. Instead of any poker night you can do a poker run. This involves players using various forms of transportation to visit 5-7 locations. At each location, the player draws a card, with the goal to have the best poker hand at the end of the run. It is more luck than skill, but it is a fun time.

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.