

IN RARE FORM



CRPS is a Journey

by Felice Ivy

It moves uninvited into your body. It destroys your days and tortures your nights. No two days are alike. Some days are better than others, but the bad days are horrendous.

It's not easy to function as this thief seems to grow stronger. It plays games with your mind on the "good" days. It convinces you that you are healing, that the torment will soon end. Just when you are convinced of this, it hits you with the force of a cannon.

You cry knowing that this game will continue and there is little that can be done to help you. It's easy to fall into the dark hole that CRPS has dug for you, especially when one of those "sneak attacks" take root.

It amazes me just how destructive this disease is. Just how sneaky it is and how much it takes from us and all that it does to us.

Recently I had a hospitalization. It came as quite a shock. Both of my legs down by my ankles and lower shins broke out in heavy bubbling blisters. It looked as if something wet was placed over them. My legs started weeping so much that I was actually leaving puddles wherever I went.

After two hospitalizations I learned that this was the result of vasomotor and trophic sudomotor changes that CRPS had caused. These wounds were so big and were soaking wet. The skin was more sensitive than

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CYNTHIA TOUSSAINT AND
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GRACE IS THURSDAY, MAY
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2023 IN DALLAS**

**RSDSA'S 4TH VIRTUAL
CRPS AWARENESS WALK
IS SATURDAY, JUNE 3,
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**OUR YOUNG ADULT
WEEKEND RETREAT IN
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2ND-5TH - FOR WARRIORS
21-33**

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usual and it's still healing after about 4 weeks.

The lesions were very burn-like and were treated as such. Silverdyne cream, antibiotics, bed rest & pain killers. I also needed IV fluids as I was dehydrated from all the fluid being lost from my legs.

It's as if CRPS is that pesky relative that shows up unannounced with stories you don't want to hear. It just keeps coming at you in new ways.

I now have learned it is very important to stay hydrated. I take a Liquid I.V. lemon lime sleeve that I add to my water. I do the same with a strawberry collagen sleeve and Quercetin supplements, all of which work to keep the body hydrated and helps to prevent skin breakdown.

I also slather on lots of lotion numerous times a day in order to protect / heal the skin and prevent the always irritating neuroitch. It is also good for a CRPS body to avoid gluten and processed food. It is essential to keep your machine (your body) in top working condition.

As Nurse Beth Seickel always says, CRPS is a journey. CRPS isn't a sprint, it's a long marathon that throws things at you when you least expect it. The trick is learning to live with CRPS instead of allowing it to be the boss. It's easy to give up and you may toy with that idea, but deep down you know that you will carry on.

You are stronger than CRPS even though it is a wicked foe. Your new normal is a combination of positive energy and accepting that you are not the old. You are a whole new being and one who is entangled in an inner war created by CRPS. It takes work to keep your head above water. It takes guts to try and make the most out of each day. This is the journey of a CRPS warrior.

Luckily we aren't fighting alone.

There are doctors and other healthcare professionals armed with the tools that reduce the torment. CRPS turns us into teachers. The rarity of CRPS forces us to be an ambassador instructing others as to its torment and its destructive path. It can be a lonely road but there are caring people who seek to help you. Having a doctor well schooled in CRPS is a necessary component. It may take awhile to find such a doctor.

For me, I was lucky in finding a dedicated and brilliant doctor, Dr. Patrick Anello, who lends an ear and tries everything possible to lighten the load. I was also fortunate to meet Nurse Beth who has seen me through many a hard day. Her knowledge and compassion are a blessing and her friendship is a gift.

Facebook Live with Cynthia Toussaint and John Garrett of For Grace

Join RSDSA for our rescheduled Facebook Live with Cynthia Toussaint and John Garrett of For Grace at facebook.com/rsdsa on **Thursday, May 11th at 7:00p Eastern** as they discuss the journey of CRPS and cancer.

Cynthia Toussaint founded For Grace in 2002 to raise awareness about CRPS, and five years later expanded the organization's mission to include all women in pain. Cynthia has had CRPS for 40 years. She later developed Fibromyalgia and other over-lapping, auto-immune conditions. Her most recent diagnosis is Triple Negative Breast Cancer, which she is currently battling.



Toussaint was the first CRPS sufferer to be featured in the New York Times, Los Angeles Times and on the Public Broadcasting System and National Public Radio. She is a consultant for The Discovery Channel, ABC News, FOX News, the National Pain Report and PainPathways, the official magazine of the World Institute of Pain. Also, she is a guide and guest contributor for Maria Shriver's Architects of Change website.

She continues to be a leading advocate for health care reform in California. She was instrumental in changing public opinion which sparked sweeping HMO reform legislation that was signed by Governor Gray Davis in 1999. Her focus has now shifted to creating a single-payer, universal health care plan in California that would provide a model for the rest of the country. Her work is now strongly reflecting her passion for the pain-cancer connection and Post-Traumatic Growth.

John Garrett serves as Director at For Grace and was instrumental in launching the organization in April 2002 along with his partner, Cynthia Toussaint. Garrett has been partner and caregiver to Toussaint for 41 years. He has done extensive research about the gender disparity toward women in pain, compiling a comprehensive library on that issue along with specific chronic pain conditions.

Garrett's work focuses on speech presentation, grant writing, research, media outreach and the development of branding strategies. He has also advised California's Department of Managed Health Care and other state agencies regarding pain management practices in the HMO industry. Commenting on her long-term partnership with Garrett, Toussaint said, "My story as a woman in pain is also a love story because John's support has been total and unwavering. Without his loving presence in my life, I wouldn't be here."

Garrett made numerous writing contributions, reflecting on his role as a caregiver, trauma survivor, witness and partner, in Toussaint's memoir, *Battle for Grace: A Memoir of Pain, Redemption and Impossible Love*. Also, Garrett continues to make public speaking and media appearances that share the virtues and challenges of the caregiving experience.

Join the Kilgore College Rangerettes and their 2023 Captain, Miller Kerr, for Walk Strong on Saturday, May 13th in Dallas

At 10 years old, my journey with Reflex Sympathetic Dystrophy (RSD)/Complex Regional Pain Syndrome (CRPS) started after a playground basketball injury.

After many pain-filled months of trying to find a doctor who knew what was wrong with me, hours of therapy, many different hospitals, and a failed procedure, we finally found the Cleveland Clinic.

There, they identified the issue, helping me learn how to walk again and how to cope with the pain through their pain management program. Months later, I returned home from the hospital and joined a dance class to help rehab my way back to normal activity. Dancing has since become my passion and release.

I have suffered from pain on a daily basis from this debilitating disease for the past nine years. Some days the pain is so strong it consumes me, and I can barely stand or get out of bed.

However, CRPS has shown me just how STRONG I can be, prevailing over the pain as a an active college student and dancing as a World Famous Kilgore College Rangerette!

This is my second year organizing Walk Strong to support RSDSA and the CRPS community. I want to bring awareness to this awful disease so others with RSD/CRPS know there is hope and that they are not alone. Be a Warrior with me today in support of the RSD/CRPS community and consider sponsoring/donating and joining us as we [WALK STRONG](#) in support of research and treatment options.

Thank you to my friends and family for your support in creating Walk Strong!

For more information contact Miller Kerr at millerckerr@gmail.com. Friends and family can make a donation by texting #WalkStrong to 50155.

[Register and Donate Here](#)

- DATE: Saturday, May 13, 2023 (Rain or Shine)
- TIME: Pre-registration begins at 1:15pm. Walk starts at 2:00pm.
- LOCATION: Northaven Trail & Inwood Parking Lot, (Across the street from Grace Bible Church) Dallas, TX 75229
- REGISTRATION:
 - \$25 - Adults (T-shirt included, while supplies last)
 - \$10 - Children (12 and under)
 - Online registration closes May 12



RSDSA's 4th Virtual CRPS Awareness Walk is Saturday, June 3, 2023!

Now is the time to [register](#) for the RSDSA 4th Annual Virtual CRPS Awareness Walk!

If you are the first fundraiser in your state to register, you will receive a \$20 Amazon gift card and the race to the states is wide open. There is still time to win from these states:

Arizona	Indiana	Minnesota	New Jersey	Rhode Island	Utah
Arkansas	Iowa	Mississippi	New Mexico	South Carolina	Washington
Delaware	Kentucky	Montana	New York	South Dakota	West Virginia
Georgia	Maine	Nebraska	North Dakota	Tennessee	Wisconsin
Hawaii	Massachusetts	Nevada	Oklahoma	Texas	Wyoming

If you don't want to register for the Walk, but still support RSDSA and the Walk, you can be a [donor here](#)! You can also donate by texting #4CRPS to 50155

Want a walk t-shirt? You can buy one on the Walk website [here](#) for \$25. Sizes range from youth small to Adult 3X.

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Community
Our Facebook Lives and conferences unite CRPS Warriors and clinicians to hear about the latest treatment options for patients.

Advocacy
We advocate for our CRPS patients to help them get the care they need.

Research
We raise funds for research to find better treatments and a cure for CRPS while working with research groups and healthcare professionals worldwide to foster collaboration, communication and awareness.

Education
We advocate for our CRPS patients to help them get the care they need. We have also built a strong community that participates in conferences, and fundraising events.

Support
CRPS can be isolating, but we don't want those affected to feel alone. Through our online community, mentoring, support groups, and other activities, we are able to offer comfort and information to patients and families dealing with CRPS.



AND MOST OF ALL WE PROVIDE HOPE!



For questions and more information on the walk, contact Jeri Krassner at jkrassner@rds.org or 917-597-7256 and/or Kelly Considine at kelly.crpsawareness@gmail.com.

RSDSA's Young Adult Weekend Retreat is June 2nd-5th

RSDSA is excited to announce that the next Young Adult Weekend Retreat will take place June 2nd-5th in Philadelphia! Young adults with CRPS between the ages of 21 and 33 will spend the weekend with people who fully understand what they are going through.



Our Young Adult Weekend Retreats have been a great success as they offer young adults with CRPS the opportunity to network, attend workshops, learn to advocate for themselves, and build a support system all while leaving time to sightsee and have unique experiences.

Date: June 2-5, 2023

Location: Holiday Inn Express Midway | 1305 Walnut Street | Philadelphia, PA 19107

Cost: \$250

Please note that all room fees are based on double occupancy. A \$50.00 non-refundable deposit is required to reserve your spot. You can also choose to pay in full at the time of registration. Attendees will have the option to pay by check or credit card.

We have limited space so please register as soon as possible.

Final payment of outstanding balance is due **May 20, 2023** with all information and emergency forms. With help from sponsors and donations, RSDSA will cover the additional costs for rooms, meals, and speakers.

If you have any questions or concerns, please contact RSDSA's Young Adult Retreat Committee at yaphili.rsdas@gmail.com.

We look forward to seeing you there!

Additionally, RSDSA's Young Adult Retreat Committee is looking to rebrand our Young Adult Group! Please submit your ideas for a new name and an image/logo as a .jpg or .pdf. The RSDSA Young Adult Weekend Retreat organizers will choose five submissions to vote on at the retreat and attendees will choose their favorite.

The submission with the most votes will be the new name and face of the Young Adult group and the winner will also receive a \$100 Amazon gift card! Please email your creations to Jkrassner@rsds.org.

You do not have to attend the Young Adult Weekend to send us a submission, but we would love to have you!

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Friends and family are necessary components of your journey. I am lucky to have three great friends Eileen, Roberta & Diana. It is never lost on me how great it is to have friends who are never too busy to listen and help out in anyway possible.

Most importantly you have to remember that you are an integral part of your healthcare team. Keeping a positive mindset and never giving up hope is so very important. You have to become your own best friend and as Nurse Beth says "be conscious of your body and take care of it."

Prepare for emergencies. I keep a "go bag" packed with things I may need for a hospital stay. The CRPS Warrior has the duty of discussing the disease as it falls to us to educate a world that in most cases can't fathom what we go through. CRPS is an enemy that we go to war with daily. Yes it is an enormous enemy, but everyday we breathe, every moment of joy we have strikes a blow against this foe.

The best weapon the CRPS warrior has is themselves. Learn to listen to your body. Do research.

Contact RSDSA.

Don't pay attention to those who think CRPS doesn't exist and that we are all just drug seekers. Even though in many cases CRPS is invisible it certainly isn't invisible to those of us who suffer. Have faith in yourself. Don't be afraid to reach out.

Together, perhaps in the near future, we will reign victorious over CRPS. Until then, smile and fight on.

Please consider supporting RSDSA with a monthly gift

RSDSA receives no governmental support. We are totally reliant on [donations](#) from the CRPS community and from our fundraising events. I'm asking you to consider making a monthly donation. We receive monthly gifts as low as \$5 to a high of \$100. Dividing your gift over 12 months is very doable for most. Thank you for your kind consideration.



Important Resources for Caregivers

Take a moment to bookmark these important resources for caregivers:

[Get paid as a caregiver for a family member](#)
[National Family Caregiver Support Program](#)
[How Do I Get Paid to be a Family Caregiver?](#)



Resources from Bethany Ranes, MA, PhD's Facebook Live

RSDSA's April 4th [Facebook Live with Bethany Ranes, MA, PhD](#) focused on The Neuroscience of Brain-Based Pain Therapies.

During the talk, Dr. Ranes shared numerous resources for our community. They include:

[Find a Tension Myositis Syndrome \(TMS\) Doctor or Therapist](#)
[Mental Health Clinician Directory - Pain Reprocessing Therapy Institute](#)
[Resources - Multidisciplinary Association for Psychedelic Studies \(MAPS\)](#)



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.

Thank you to our Title Sponsors

Our title sponsors make RSDSA events and awareness activities possible. Please join us in thanking and supporting them!

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