

IN RARE FORM

This edition of *In Rare Form* is sponsored by Fight the Flame.

FIGHT THE FLAME

**2023
CRPS
CONFERENCE**

**"Learning to Thrive
with CRPS"**



Knowledge Is Power

by Beth Stillitano of *Fight the Flame*

They say knowledge is power. That statement cannot be truer than when you are talking about Complex Regional Pain Syndrome (CRPS).

As patients, we need to learn as much as we can about CRPS. I have had CRPS for more than 25 years. I only wish there had been wide-spread knowledge about this disease when I was first diagnosed.

My orthopedic doctor, who performed two out of my four right knee surgeries, knew that there was something else wrong besides the mechanical functioning of my knee. He believed I had some sort of pain disorder and recommended that I go to a pain management doctor. This pain management physician completed a thorough physical examination and followed up by asking a series of direct questions about my condition. Within moments, he told me that I had Reflex Sympathetic Dystrophy (RSD) which is now referred to by many as CRPS. He followed up by saying that I needed to get scheduled immediately for a series of four to six injections. He said that this was the treatment for RSD but there were no guarantees the injections would work. I left without making any further appointments.

Not only had I never heard of this disease, I was not prepared to receive a bunch of shots not knowing if they were going to help. I decided to get another opinion and sought out another specialist. Again, within moments of her examination, she indicated that I had RSD.

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She was certain of it. She had several patients with RSD and we all had the classic symptoms (exaggerated pain, magnified swelling, extreme temperature and color distinctions between my left and right knee). After the appointment, I went home and of course I Googled "RSD." There was not much information available, but the doctor was right as RSD explained all of my symptoms. I began treatment soon after.

I am glad my orthopedist acknowledged that something was wrong right away, however he had never heard of RSD. My primary care physician had no knowledge of the disease either. My husband and sister were almost relieved to put a name to what was happening to me and supported me fully. However, that was not the case for the rest of my family. No one believed I was truly in so much pain and since they had never heard of RSD, it was easy for them to not acknowledge that I was suffering.

It was then that I decided to become my own advocate and learn as much as I could about the disease. Not just for myself, but to educate my family, friends, and doctors. I scoured the internet and read every book I could find on the subject. I became an informed patient. I kept a succinct record of my medicines and diagnostic treatments. I would not allow a procedure to be done unless I understood the reason for it, the underlying risks and the expected outcomes. Before I received any injection, I asked and then recorded the medication I was receiving. I did not just want to know that I was getting a trigger point injection, I wanted to know the exact medication.

At every doctor's appointment I had or accompanied a family member to I would ask the treating nurses, doctors, EMTs, and lab attendants if they knew about CRPS. Occasionally some had heard of it, but generally they were not really familiar with the disease. Basically, most of the medical professionals I spoke with had never even heard of Complex Regional Pain Syndrome. The idea that doctors do not know anything about this disease unnerves me. CRPS has been around since at least the Civil War. This is not a new disease.

Fast forward to present day. There are still too many people not getting diagnosed correctly or in a timely manner. So many are being told they are crazy and that there is nothing wrong. This is where [Fight the Flame](#) comes in. Fight the Flame is a nonprofit whose mission is to raise awareness and educate medical professionals and the public about Complex Regional Pain Syndrome; while providing resources to support the CRPS community.

As part of Fight the Flame's commitment to raise awareness and educate others, we are coordinating a pain conference entitled, ["Learning to Thrive with CRPS" on April 22, 2023 in Charlotte, NC](#). The conference is open to all!

Living with a rare disease like CRPS is challenging on so many levels. Having a doctor that does not understand the disease should not be one of them. Learn as much as you can, research, and ask questions. Become your own advocate and help spread awareness about CRPS. You are not alone on this journey. Fight the Flame and RSDSA have many resources to help you along your path to a lower pain lifestyle.

RSDSA is seeking your stories of achieving remission

As mentioned in RSDSA's organizational mission statement, our goal is to educate, support and provide hope. Hope is the belief that good things lay ahead.

Too often, social media is filled with horrific stories of CRPS and endless suffering. Although that sadly is a reality for far too many, we want to collect stories from individuals with CRPS who have achieved remission (absence of symptoms) and their ongoing efforts to avoid a relapse.

Topics can include: How long you've had CRPS and where? What were your predominant symptoms? What treatments, practices and/or medications did you use? How long did it take to achieve remission? Do you still have flareups? or Advice/hopeful words for other Warriors

Please submit your stories to RSDSA by emailing info@rds.org.

Facebook Live with Bethany Ranes, MA, PhD

Join RSDSA for our Facebook Live with Bethany Ranes, MA, PhD at facebook.com/rds on **Tuesday, April 4th at 7:00p Eastern** as she discusses The Neuroscience of Brain-Based Pain Therapies.

Dr. Bethany Ranes specializes in mental health from the perspective of cognitive neuroscience (a bridge between neuroscience and psychology). Her work focuses on translational science, taking new ideas discovered in laboratories and helping turn them into effective therapies that benefit patients directly. Her current passions involve working on brain-based therapies for chronic health conditions, especially chronic pain. She also regularly collaborates with other health professionals to help develop neuroscience-informed interventions for behavior change and non-pharmacological treatment options for conditions like depression, anxiety, diabetes, cardiovascular health, and auto-immune disorders. She has previously worked as a lead research scientist for UnitedHealth Group, Hazelden Betty Ford Foundation, and the U.S. Army.

Currently, she works as a consulting scientist for organizations and companies who wish to blend emerging science about the brain with accessible healthcare solutions in order to help bring a balanced mind-body approach to modern healthcare.



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

Much more than just a fundraising event, our Walk brings together individuals, families, friends, and the CRPS community. The walk supports research, educational programs, networking, patient emergency assistance and hope. You are not alone!

Our event is open to participants of all abilities. Whether you walk, roll, or run along with us, we want to see you on June 3rd!

Registration Information

- \$25 for adults, \$10 for children ages 5-12
- Register either as an individual or create a team
- Be the first in your state to register and we will send you an Amazon gift card for \$20.

RSDSA's 4th Annual Virtual CRPS Awareness Walk t-shirt & medal are included for all United States and Canadian registrants.

Please remember that physically walking is not a requirement to participate.

Whether you are joining us for the first time or have been with us every year, you can participate by:

- Donating your ideal amount here!
- Registering for the event
- Helping us spread the word about our virtual walk by sharing our walk website page or your personal fundraising page on social media
- Walking or running in your neighborhood, or at home, on Saturday, June 3rd.
- Proudly wearing our walk t-shirt, or orange, to represent CRPS awareness and sending us a photo or video!

For questions or more information, please contact Jeri Krassner, RSDSA's Special Events Coordinator, at jkgrassner@rds.org, or Kelly Considine, our 4th Annual Virtual CRPS Awareness Walk Chair, at kelly.crpsawareness@gmail.com.



Saturday, June 3, 2023

rdsda
SUPPORTING THE
CRPS COMMUNITY

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 31 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@rds.org.

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

COPING WITH RSD/CRPS



Adaptation
 Acupuncture
 Sleep
 Positivity
 Reading
 Exercise
 Patience
 Mindfulness
 Comedy
 Hobbies
 Music
 Visualization
 Lavender Lotion
 Ketamine
 Bisphosphonates

Warrior
 Orange
 Physical Therapy
 Advocacy
 Smiling
 Distractions
 Breathing
 Writing
 Yoga
 Social Support
 Diet
 Fundraising
 Kindness
 Volunteering
 Laughter

Tell Us What You Want to See on Facebook Live

What Facebook Live sessions are you interested in watching this year? Let us know by messaging us on [Facebook](#) or by emailing us at alexisdavis@rsds.org.

Thanks For Supporting Us on Facebook!

Our Facebook Page had a little hiccup this month and we want to thank everyone who let us know and helped us dispute our flags. We appreciate this community!

Create Content for RSDSA's TikTok Account

RSDSA has officially joined TikTok @RSDSAofficial in order to further educate others about CRPS in addition to our events and activities!

We want to ensure more people learn about CRPS, especially Gen Z (people born between 1997-2012) and Millennials (people born between 1981-1996) as they have a large footprint on the app in addition to being future + current medical leaders.

If you or your children, grandchildren, nieces/nephews, godchildren, etc. are interested in creating content for TikTok, please reach out to us at alexisdavis@rsds.org. And don't forget to tag us in any CRPS-related content you create!

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!

[Abbott](#) | [The Baker Family Charitable Fund](#) | Diana and Peter Smith in memory of Stephanie Theresa Smith | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager Lynn & Michael Coatney | [The Cochran Firm, National CRPS/RSD Lawyers](#) | TJ Whalen Foundation