

IN RARE FORM



Facebook and YouTube Live with Philip Getson, D.O. on Wednesday, March 5, 2025 at 7PM Eastern

RSDSA is hosting a livestream with Philip Getson, D.O. on Wednesday, March 5th at 7p Eastern. He will join us on [Facebook](#) and [YouTube](#) to speak about the latest developments with CRPS and answer 20 questions provided by the CRPS community. **Submit your question via email at info@rsds.org.**

Philip Getson, D.O. is a family physician in practice since 1976 in New Jersey. He is an internationally recognized expert in the diagnosis and treatment of Complex Regional Pain Syndrome and has lectured extensively on the subject at national conferences such as Pain Week and the American Association of Pain Management as well as internationally.

He is a former member of the Scientific Advisory Committee of RSDSA and one of our designated speakers. To date, he has evaluated over 2000 patients with CRPS, and his YouTube presentations have been viewed by more than 250,000 individuals.

He was an Assistant Professor of Medicine in Neurology at Drexel University College of Medicine in Philadelphia until its closing and a member of the medical staff at Virtua, Thomas Jefferson University, and Cooper Hospitals. His work at Drexel, in collaboration with Dr. Robert Schwartzman, included formulating the initial protocols for in- and outpatient Ketamine infusion therapy and he was one of the first physicians in the country to utilize this treatment for CRPS.

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He is a Board Certified Thermologist and has reviewed more than 50,000 Thermographic Studies of the breast, thyroid, dental and neuromuscular systems since 1982. He has been certified by four Thermographic Boards, has lectured nationally and internationally regarding Thermographic testing, and has authored several papers on the subject. He served as Vice President of the American Academy of Thermology during which time he was Chairman of the committee responsible for formulating the first ever protocols for breast and neuromuscular thermography that have since been accepted by the National and International Thermographic Communities.

FAQs:

-How do I submit a question for Dr. Getson?-

Send us a message on Facebook or email us at info@rsds.org.

-How do I join the livestream?-

Visit facebook.com/rsdsa or youtube.com/@RSDSA on Wednesday, March 5th at 7pm Eastern from your computer, tablet, or phone.

-What if I miss the livestream? Can I watch it later?-

The livestream will be recorded and will be available for replay as soon as it's over. You can rewatch it on mobile and desktop.

We want to hear from you! Who should we have on future livestreams?

We're always looking to have credible CRPS professionals on our livestreams so they can further educate our community. If you have a suggestion for a guest, send us an email at info@rsds.org.



Register for the 2025 Young Adult Weekend Retreat



[Click Here
To Register](#)

[Click Here to Email
RSDSA.Nashville2025@gmail.com](mailto:RSDSA.Nashville2025@gmail.com)

RSDSA is excited to announce that the next Young Adult Weekend Retreat will take place June 27th - June 30th in Nashville! Young adults with CRPS between the ages of 18 to 32 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. Our retreats are lots of fun and attendees often make lifelong friends!

Date: June 27 - June 30, 2025

Location: Holiday Inn Express Downtown Broadway
(920 Broadway Nashville, TN 37203) | (615) 244-0150

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 June 13, 2025 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 rsdsa.nashville2025@gmail.com.

We look forward to seeing you there!



DO YOU HAVE COMPLEX REGIONAL PAIN SYNDROME (CRPS)?



Researchers at the University of California, San Diego (UCSD) are conducting a research study examining the efficacy of a botanical CBD extract for pain relief in individuals diagnosed with CRPS



- Participants will be seen at UCSD on four separate occasions over a two month period.
- Participants will be financially compensated.

CONTACT YASMEEN ESSHAKI

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BASIC ELIGIBILITY CRITERIA:

Ages 21 to 75 years old

CRPS Type I or Type II diagnosis

Not taking opioids or barbituates

SCAN ME



[If you qualify, click here to fill out the prescreening form for this study.](#)
[RSDSA is not a sponsor of this study.](#)

Self Advocacy and Family Communication

Written by Lisa Van Allen, Chair of the RSDSA Advocacy Committee

There is a generally accepted idea that your family is there to support you when you're down, encourage you when weakened, have your back when threatened. Unfortunately, the reality is that our families are made up of people - simple human beings, each with their own sets of strengths, weaknesses, opinions, attitudes, ideas and biases. Some of us are blessed with family members who are able to empathize with us when we are hurting. Those people are golden. But even they can suffer burn out and compassion fatigue when faced with your unrelenting pain.

I am blessed with a husband whose love language is service. He has never complained about my health issues in over ten years of living with CRPS. Not once. He is generous with our money, supporting my decisions to try expensive treatments that have often delivered nothing in the way of relief. He is willing to be my 'go-fer' any time I need something, whether it's a cup of tea or something from the store. He has voiced frustration over the lack of a treatment plan or a doctor who oversees my care. It's hard for him to fathom that I have to juggle seven different specialists and their often conflicting recommendations as I deal with the co-morbid conditions that developed as CRPS progressed. It wasn't until COVID created a powder keg of tension in our home that my husband finally blew up and expressed his anger. It was a horrible time, but looking back, a good thing as we have talked about topics we had buried for too long. It made me realize that I needed to bring up difficult topics and not just live with the stories building in my mind.

Brene' Brown has shared how she and her husband deal with these uncomfortable conversations. She will start with, "The story I'm telling myself is that I'm getting older and don't look as good as I used to and..." she goes on describing the fears that have been speaking in her head. Then her husband says, "Well the story I've been telling myself is that I've dropped the ball and am not being the person you need or want and..." he continues describing the fears created in his mind. Just openly sharing the fears that have cropped up clears the air and sets us up for frank conversations about what is really happening. It gives us opportunities to talk about expectations that were unfulfilled - and might have been unrealistic.

I used this technique with my mom recently, who is not the easiest person to disagree with. She has strong opinions, and being the daughter she raised, so do I. We had gotten into each other's hair one afternoon when I felt like she was constantly trying to keep me in my chair rather than working toward doing what I can do. This conversation had been brewing for awhile. I snapped at her and hurt her feelings, and then she got angry because she was only trying to help. And then it hit me - we weren't really talking to each other about the real issues. I finally said something about "the story I have been telling myself is that you are so afraid I'll make myself hurt even more that you don't want me to do anything - but I can't live like that. I can't avoid pain, just manage it. I spend way too much time thinking about how to avoid pain." My mom sat down next to my chair and thought for a minute. Then she said that she had never thought about how focused my mind had to be on avoiding pain, and that by trying to protect me she wasn't respecting my ability to navigate through life with pain. That's when I realized I wasn't mad about being protected, but that I felt disrespected. The conversation was a turning point for both my mom and I. She now realizes she needs to give me the chance to ask for help and not smother me with well intentioned acts of kindness.

I now realize I need to be clearer on what helps, to be more gracious about asking for and receiving help, and be honest about the deeper problem I have with fear of making my pain worse. The tension has lifted - for now... until we hit the next human roadbump.

Families are challenging enough without throwing intractable pain into the mix. But learning how to advocate for yourself with clear communication can help ease tensions and make life just a little bit easier.

Here's a homework assignment: Use the phrase "the story I'm telling myself is"... and invite your family member to respond with the story in their mind. You will be surprised at how this simple technique smooths the way to better communication and improved relationships.

Rare Disease Day is February 28, 2025!

Rare Disease Day is right around the corner! Whether you're heading to Washington, D.C. to raise CRPS awareness in-person, or you're hoping to do so virtually, let's come together!

February 24th-26th: [Rare Disease Week](#) on Capitol Hill is being led by the Rare Disease Legislative Advocates. If you're heading to **Washington, D.C.**, [read our tips](#) for cultivating a relationship with your Senators and Representatives before arriving and learn more about the [PROTECT Rare Act here](#).



FDA-NIH **RARE DISEASE DAY**
Feb. 27-28, 2025 | #RDDatFDANIH

Additionally, Lisa Van Allen, Chair of the RSDSA Advocacy Committee, will be in DC that week so be sure to reach out to her via advocacy@rdsds.org if you're interested in connecting.

February 27th-28th: If you're staying home this February, the FDA and NIH are hosting virtual programming for Rare Disease Day. Registration is [free on the NIH website](#).

BRC-002 receives Orphan Drug Designation from FDA for CRPS

Biopharmaceutical Research Company (BRC), a specialty pharmaceutical company developing proprietary cannabinoid therapeutics, announced that the U.S. Food and Drug Administration (FDA) has granted Orphan Drug Designation for the treatment of CRPS to BRC-002, which is being investigated in an investigator-initiated clinical Phase 1 trial.

The FDA grants Orphan Drug Designation to a drug intended to treat, prevent, or diagnose a rare disease or condition that affects fewer than 200,000 people in the US at the time of designation. The designation provides incentives, such as tax credits for qualified clinical trials, user fee exemptions, and the potential of seven years of market exclusivity after approval.

[Learn more here.](#)

Register for Walk Strong 2025 on Saturday, April 19th in Dallas, Texas



Join Burning Hope in walking a 3k in support of the CRPS community. Lace-up for a walk dedicated to raising awareness, funding research, and improving treatment options for those affected by CRPS. All proceeds will benefit RSDSA & Burning Hope, helping to advance care and bring hope to those in need.

Register as an individual or grab your friends, family, team, co-workers or organizations and create a team to participate and raise money for Walk Strong! If you can't make it to Dallas, participate from your hometown and register as On-Location. But don't walk alone! Start your own On-Location team and have your friends, family, team, co-workers or organization walk with you.

- **Date and Time:** Saturday, April 19, 2025 | 10:00 AM
- **Pre-registration:** 9:15 AM
- **Location:** Northhaven Trail & Inwood Parking Lot, Dallas, TX 75229 (Across the street from Grace Bible Church)
- **Registration Fees:** Adults \$25 | Children \$10 (12 and under)
- **Online Pre-Registration closes April 17th.** Attendees can also register in-person at the event.

Create a Team

Bring together a group of your friends, family or members of your organization to participate and raise money for Walk Strong! Select a team captain, create a fun team name and then tell your friends, family, colleagues, and associates to register or donate under your team name. The more people who register and donate to your team, the bigger impact you will have on the CRPS community and the closer you will be to raising the most funds for Walk Strong. The team that raises the most money and has the most participants will win a prize!

Burning Hope

Burning Hope is a nonprofit focused on giving hope to those affected by Complex Regional Pain Syndrome, raise awareness of CRPS among all people, and support research and treatment opportunities through events and fundraising.

About Burning Hope's founder, Miller Kerr

At 10 years old, Miller's journey with CRPS started after a playground basketball injury. CRPS is an abnormal nerve condition caused by an overreaction to pain signals that the nervous system can't block, and unfortunately, there is no cure. After many pain-filled months of trying to find a doctor who knew what was wrong, hours of therapy, many different hospitals, and a failed procedure, Miller finally found the Cleveland Clinic. Through their pain management program, they helped Miller learn how to walk again and cope with the pain. Miller has suffered from the pain on a daily basis for the past 10 years. However, CRPS has shown her just how STRONG she can be, prevailing over the pain as an active college student!

Tell Your CRPS Story By Self-Publishing Your Book!

Why wait for a publisher to agree to tell your story when you can do it yourself?

Krystal Jones is a CRPS Warrior who recently self-published her CRPS story on Amazon as she wanted to share her journey with others. Her book, [Overcoming Obstacles - This Is My Testimony](#), was written to inspire and uplift CRPS Warriors. In the book, Krystal encourages people to keep searching until they find the help they need.

Over the years she has been told so many different things by numerous doctors as she works to manage her CRPS and a few other medical conditions to the best of her ability. Since writing is a passion of hers (and it also helps her relax!) she took pen to paper to help spread awareness.

Have you ever been interested in self-publishing?

Thanks for helping us start 2025 with a bang! As we prepare for the 41st year of our organization, we are excited to usher in new systems, personnel, and procedures to better serve this community now and in the future.

We sincerely thank you for your patience as we make these adjustments. As always, we're all ears when it comes to suggestions so keep letting us know what you want to see from our team!

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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