

IN RARE FORM



Attend RSDSA's 2024 Young Adult Weekend Retreat in Denver from May 31 - June 3

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RSDSA is excited to announce that the [2024 Young Adult Weekend Retreat](#) will take place May 31- June 3rd in Denver, Colorado. Young adults with CRPS from the ages of 18-32 will spend the weekend retreat with people that understand what they are going through.

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

We are asking attendees to pay \$250 for the weekend. With help from sponsors and donations, RSDSA will cover the additional costs for rooms, meals, and speakers. Please note that all room fees are based on double occupancy.

A \$50 non-refundable deposit via check or credit card is required to reserve your spot or you may pay in full at the time of registration. Final payment of any outstanding balance is due by May 23, 2024, along with all information and emergency forms.

If you have any questions or concerns, please contact RSDSA's YAR Committee at DenverYAWR@gmail.com.

RSDSA Executive Vice President & Director To Retire

After 25 years of dedicated service and outstanding leadership to the CRPS/RSD community, our Executive Vice President & Director, James W. Broach, MSW, has decided to retire effective March 31, 2024. Jim's leadership and contributions have been invaluable, and we are immensely grateful for his unwavering commitment to the CRPS community.

Under Jim's guidance, RSDSA has achieved remarkable milestones and grown in ways that have positively impacted countless lives. During his 25 years of service, RSDSA became the go-to patient advocacy organization for people with CRPS. It invested more than \$2.2 million in basic and clinical research, conducted numerous conferences and educational presentations on the diagnosis, treatment, and management of CRPS, published evidence-based Treatment Guidelines, established an emergency financial assistance program, offered accredited CME courses on adult and pediatric CRPS to healthcare professionals, and created a compassionate patient-centered culture.

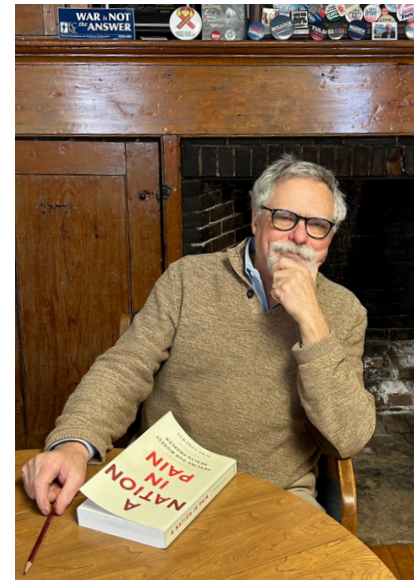
His vision, passion, and dedication have set a high standard for excellence, and he will be deeply missed in this role. His skills are not entirely lost to us, however, as he has promised to remain available to our incoming Executive Director, and ease her transition into the position.

While we bid farewell to Jim, we are excited to announce that current RSDSA Board Vice President, Sharon L. Weiner, will assume her new role as Executive Director. In addition to having CRPS for over 25 years, Sharon was also a founder and the president of Living with RSDS, Inc., a New Jersey not-for-profit that offers multiple support groups. Sharon is a co-founder of our Young Adult Weekend Retreat, a member of our Executive Committee, and the chair of our Support and Board Nomination Committees. She brings a wealth of personal and professional experience, including her numerous presentations at RSDSA conferences, that we believe will continue to honor our mission and give vision to RSDSA's future.

We are organizing a special farewell fundraiser to honor Jim's legacy. Please consider supporting the campaign by clicking [here](#). RSDSA will also organize a virtual meet and greet in March to introduce Sharon to our community. Details about this event will be shared in the coming weeks.

Again, we express our heartfelt gratitude to Jim and our warmest wishes to Sharon in her new position. We are confident that together they will effect a seamless transition which will enable Sharon to expand upon the strong foundation built by Jim and his 25 years of RSDSA stewardship.

Thank you for your ongoing support, and we look forward to the exciting journey ahead.



Host An Event With RSDSA In 2024

Here at RSDSA we pride ourselves in hosting in-person awareness and fundraising events across the country in addition to our stellar virtual events.

Since we are based in Connecticut, we are lucky to have an engaged group of Warriors who love to lead events in the tri-state and New England area. Our East Coast Warriors also enjoy hosting events from here all the way down to Florida!

However, we would love to collaborate on additional events across the country and are seeking your assistance to make these coast to coast events a resounding success.

If you are interested in hosting an event (like a walk, expo, sports tournament, etc!), please send Jeri Krassner, our special events coordinator, an email at jkrassner@rsds.org so we continue to plan for 2024!



15 Things I Wish Others Knew During a Pain Flare-Up

posted by C. M. via [The Mighty](#)

Things can get crazy during a bad pain flare. The “pain brain,” as I like to call it, is in full effect and vastly limits my capabilities. My attention span and patience are nonexistent. Every day of a flare presents challenges, emotions, limitations and frustrations that many with chronic pain have to deal with regularly. I hope this list reminds you that you are not alone and I am fighting with you, and it proves to be somewhat cathartic as you read it, because it was cathartic for me to put my thoughts and feelings down on paper.

1. Sometimes, there is no cause.

There isn't always a moment where I know, “Oh, this is going to send me into a bad flare.” If I did know that ahead of time, I would steer clear of just about anything that could set my body off. Sometimes, I just wake up and I don't know if it is just a bad day or the start of weeks or months of debilitating pain. There are times when I am in the midst of something where I just know the next few days or weeks will be bad. There is nothing quite as bad as knowing that whatever I am doing will cost me for weeks to come.

2. I don't know when it will end.

I have flares that last two weeks and others that last upwards of three months. Sometimes I wake up and the pain has lessened and I am left with the “flare hangover” of severe fatigue and brain fog. Give me a few days and I can be back to my 100 percent. (Please note I said my 100 percent, which is not the same as a healthy person's.) Other times, I get admitted to the hospital. I receive infusions or steroid treatments in an effort to break the cycle. I try new treatments or medication combinations. Other times, my doctor just tells me to rest.

3. It can go away as quickly as it came.

Sometimes, I wake up and the increased pain is gone. I return to my baseline pain. Why? I don't know. My body fought it off? My body adjusted my pain tolerance and can now handle the increased pain? Who knows. But, I am so grateful when those days happen, however they happen.

4. I don't want to “waste” my medications in case tomorrow is worse than today.

Say I wake up at a eight out of 10 pain. I have abortive medications that can lessen that pain and make it more tolerable, but, I am only allowed to take them so many times each week or each day. What if tomorrow is a 10/10? I will be kicking myself for using the medications when I was at an eight.

5. I wonder, “why me?”

I feel like this doesn't need further explanation.

6. It takes so many more spoons to do things than when I am at my “normal.”

When I have no choice but to leave the house or do something, it is far more taxing than normal. I can only be up and active for two hours versus my normal eight. And if I am not back in my bed at my time of expiration, you can expect me to collapse right where I am. Literally. Like, when the clock strikes midnight and the carriage turns back into a pumpkin, the gown back into rags, and the horses back into mice. My body goes from capable to incapacitated in the blink of an eye.

7. I have zero patience. For anyone. For anything.

Being in constant pain wears on you. There is nothing I can do about it. Having no social life, being unable to leave the house, lacking human contact for weeks on end tends to make your tolerance run pretty thin. My house becomes my prison. My pain, the guard preventing me from leaving. Ask yourself, would you be in the mood for any demands? Drama? Lack of compassion or empathy? Pushy bosses or friends/family? Probably not.

8. I cry. Like, a lot. Often alone.

It's OK. I am not saying this to make you feel bad. I am saying it so you realize how difficult flares are on me, not just physically, but mentally. It could be my own pain, some sappy movie or missing out on activities. I am overly emotional and charged so the tears come far easier.

9. Sometimes, all I can do is breathe.

I can lose all my independence in a bad flare. There have been times my mother or fiancée have had to shower me. Help me to the bathroom. Take care of my dog. Help me put on my clothes. There is nothing that puts your pride in check like having to ask your significant other to carry you to the bathroom or wash your hair.

10. Sometimes, I don't leave the couch or my bed for days.

Sounds kind of pitiful, but it is completely true. I get up to use the bathroom and that is the extent of my physical activity. I will carry an armful of water bottles to my nightstand or side table so I don't have to repeatedly get up for water.

11. I won't eat.

I have no energy to do anything except exist. The thought of getting up to go to the kitchen and cook something is excruciating. Calling to order takeout would require looking at a menu, making coherent sentences to order and then answering the door. Nope.

12. I try to weigh the cost of what I did in the days leading up to this.

I try to figure out how much things will cost me in advance and plan accordingly. Then, there are the flares that are unexpected, and in my opinion, unwarranted. If I knew that one day of fun would cost me four days on the couch, I may choose differently next time.

13. I wonder what I could have changed.

I curl up in my blanket and wonder had I gone to bed earlier, not eaten as much junk food, taken a nap during that long day or just simply said “no” if I would be in this condition.

14. I try to rationalize my pain.

It never quite works. I try to validate myself, even though I shouldn't need validating. I list the things I did the day before, like a checklist, to determine if I deserve the rest I am taking. If I feel like I didn't do a lot and am in bed because of it, I feel guilty. If I did a lot and am in bed, I don't feel quite as bad, unless I had to cancel plans or call in to work, but that is another beast entirely.

15. It's not you, it's me.

It really is. If you speak to me or see me on a bad flare day, I am antisocial at best. And it isn't anything you said or did. It is 100 percent me. I am tired, hurting, frustrated, possibly guilty and/or angry depending on what landed me in this situation. It isn't your fault and I am sorry if I seem grumpy. I promise you did nothing. My body did.

Attend the Center for Courageous Kids Camp This Summer

The application for The Coalition Against Pediatric Pain's' Pediatric Pain Camp is open!

The July 16-20, 2024 camp is for children 5-17 years of age and their families who live in chronic pain. Camp will be at The Center for Courageous Kids in Scottsville, KY. Learn more! ↓

HELPFUL TIPS FROM ADMISSIONS AT CCK

- Applications will not be processed until the camper and all family members are at 100% complete.
 - CCK will be closed December 22nd-January 1st. All applications submitted during that time will be reviewed and processed once camp reopens.
- Once everyone is at 100% an invitation will be sent via email from Joanie Ford.
 - Please monitor your spam/junk folders for communications.
 - These invitations do expire after 72 hours. If you do not respond that invitation then goes to the next in line.
- The registration for a camp session ends one week before the camp start date.
 - No applications will be processed or accepted for that specific session, after that point.
- Changes to the account can be made, but that opportunity ends one week out from the camp session. Example: changing family members, adding a member, etc.
 - Family retreats can have 2 adults per household.

Please contact Joanie Ford at jford@courageouskids.org or at 270-618-2900 ext. 277 if you have any questions or need help with your application.

Learn more about sending a child to camp [here](#) on the RSDSA website. Read more about a camper's experience at the Camp for Courageous Kids on the next page!

Abbott Is Hosting Neurostimulation for Foot Pain Webinars Through June 2024

Abbott is holding a free national patient education event webinar series through March 26, 2024 at 7p Eastern.

The webinars will focus on how Abbott's neurostimulation therapy offers an FDA-approved, medication-free, long-term treatment option for chronic pain.

Feel free to join the [free session](#) that is most convenient for you. Each session will provide the same information.

Abbott is a proud sponsor of RSDSA.

Planned Giving to RSDSA

Gift plans can create opportunities for you, as well as for RSDSA. It is important that the gift is right for you and your family, and there are many options from which to choose.

Recognizing that this may be a sensitive topic for your family, it deserves care and consideration. We encourage you to contact us at info@rsds.org for information about providing for RSDSA in your estate and financial plan.

Please notify us if you have already arranged for a bequest or other planned gift as we would like to honor your support!

Learn More About the CRPS Warriors Memorial

RSDSA is highlighting CRPS Warriors we have lost over the years via our [CRPS Warriors Memorial](#).

If you have a loved one you would like added to this memorial, please send us an email at info@rsds.org.





We want your feedback!

Please send any suggestions or upcoming events of interest to our community to info@rds.org and please consider donating at rds.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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