

IN RARE FORM



Contribute to RSDSA's 40x40 Campaign as We Prepare for Our 40th Anniversary

RSDSA is hosting a 40x40 [campaign](#) to raise \$40,000 in 40 days as we prepare for our 40th Anniversary.

From now through Saturday, January 6th, 2024, we will raise funds to go towards two important research projects: **Clinically Relevant Mechanistic Subtypes of CRPS** and **AI Project for Physicians to Diagnose and Treat CRPS**

We invite you to support these two research projects that will impact the treatment of CRPS. Since 1984, RSDSA has stood as a guiding light for those with CRPS. We have an unwavering commitment to helping individuals and families with this rare, neuropathic disease. However, our ability to make a difference relies heavily on the generous support of community friends like you. We encourage you to donate an amount that holds significance for you. With your support we can get these projects off the ground, so their results can make positive changes in treatment of CRPS.

Thank you for helping us bring in our 40th year the right way!

[Donate Here](#)

IN THIS ISSUE

FACEBOOK AND YOUTUBE LIVE WITH GREGORY ANDERSON, MAYA KOWALSKI'S ATTORNEY, ON JANUARY 17, 2024

RSDSA'S PLAN TO BRING KETAMINE ON LABEL

SIGN UP FOR CRPS-RELATED STUDIES AND TRIALS

ATTEND THE CENTER FOR COURAGEOUS KIDS CAMP THIS SUMMER

REWATCH OUR 2023 TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS VIRTUAL CONFERENCE

Rewatch Our 2023 Treating the Whole Person: Optimizing Wellness Virtual Conference

Spend the holidays rewatching the Treating the Whole Person: Optimizing Wellness virtual conference on the [RSDSA Facebook Page](#) and [YouTube Channel](#)!

Our sessions include:

- An Update on Neuroplasticity and TrainPain with Dr. Elan Schneider
- A Conversation with Disability Activist, Author, and CRPS Warrior Tara Moss
- Lessons We Can Take Away from the Tragic Story of Maya Kowalski (Take Care of Maya) with Bryan Pope, Esq.
- KarunaHOME Program - CRPS Treatment Success with Matthew Sheers
- Qigong - A Natural Remedy for Pain and Stress Relief with Marie Theriault
- Understanding Suicides after Prescription Opioids are Stopped: The CSI:OPIOIDS Research Study with Stefan G Kertesz, MD and Allyson Varley, PhD



We want to hear from you! What topics do you want us to cover in our Facebook + YouTube Live series in 2024? Send us an email at info@rsds.org with your ideas!



Facebook and YouTube Live with Gregory Anderson, Maya Kowalski's Attorney, on January 17, 2024

Join RSDSA for our first Facebook and YouTube Live of 2024! We will speak with Gregory Anderson on Wednesday, January 17, 2024 at 7:00p Eastern as he discusses the Maya Kowalski case (Kowalski v JHACH).

This case would have never seen the light of day let alone made it to trial, but for the efforts of Gregory and Jennifer Anderson, and the Florida law firm of AndersonGlenn, LLP.

The story of how the case even came to be is one of limitless risk, perseverance, and superior lawyering against seemingly insurmountable odds.



Through the course of it, the Anderson's financed the five years it took to finally make it to trial by selling their home on the Intercoastal, downsizing things like their children's private schooling, and leveraging their retirement funds to keep the case going through brutal litigation.

Gregory's career leading up to the record quarter billion dollar Kowalski verdict was eclectic to say the least and includes numerous high profile cases.

Fellow Trial attorneys in Florida have referred to him as "legendary" and "...one of the greatest civil trial lawyers in America", based on the breath of his verdicts, which include multimillion dollar verdicts in the areas of legal malpractice, medical malpractice, lender liability, aviation, product liability, maritime product liability, in six different States, while at the same time serving as chief defense counsel for some of the country's largest automotive, marine, and RV manufacturers."

In an age of strident partisanship between plaintiff and defense practice, Anderson has managed to dominate the plaintiff and the defense side and do so without too much political animosity."

This trait of being able to move and interact with both sides, more than anything, has earned his reputation as one of the finest trial attorneys in America.

We can't wait to see you all on January 17th for this important livestream. Send any questions you have for us in a message or to info@rsds.org.

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.



RSDSA's Plan to Bring Ketamine on Label

There is real science and overwhelming evidence to support that ketamine is THE drug to treat CRPS and its two primary comorbidities – PTSD and treatment resistant depression. Presently, ketamine is not covered by any insurance because it is “off-label,” because it has not performed a Clinical Study Proving that it is safe to use over time.

Ketamine use in treating CRPS for over two decades with tens of thousands of patients provides a strong track record of safety and effectiveness. So, why hasn't the FDA approved it for CRPS/RSD?

Read the full post from Jim Doulgeris on the RSDSA blog [here](#).

KETAMINE

Strength _____ mg/mL

Exp. Dt./Tm. _____

Restoring Hope and Saving Lives With Angel Flight NE

Angel Flight NE is a 501(c)3 nonprofit organization that coordinates free air and ground transportation for medically stable patients seeking medical care for healthcare conditions including rare and ultra-rare diseases that requires them to travel hundreds if not thousands of miles for the specialized care they need.

Their vital mission is made possible thru the generosity of their volunteer pilots and commercial aviation partners who fly medically stable children & adults for FREE. They have been humbly providing their services for 27 years and have assisted more than 108,000 patients who have flown over 15 million miles to 750+ medical facilities throughout the United States. Angel Flight NE also provides services to patients who need to travel internationally to receive specialized care.

Over the last several months, there has been an increase of flight requests for patients - children and adults - diagnosed with rare and ultra rare diseases. Angel Flight NE's mission/flight coordinators, who are available 24x7, use their web-based system to schedule flights made possible by their 400+ volunteer pilots or commercial airline partners. The flights are completely FREE of charge to the patient & family for as long & as often as they need to fly.

Having seen the recent spike in requests from people diagnosed with rare diseases, Angel Flight NE has begun an initiative to reach out to rare disease organizations and groups, like RSDSA, to let them know about their services.

Please feel free to reach out to Angel Flight NE at rsica@angelflightne.org or via phone at (978) 794-6868 if you have any questions. They also have a recent video that features just a few of the patients they have assisted [here](#).



The "CSI:OPIOIDS" (Clinical Context of Suicide Following Opioid Transitions) Study

The University of Alabama at Birmingham is working to better understand suicides that are taking place after prescription opioids are reduced or stopped in patients with long-term pain by applying a research approach to case examination known as "psychological autopsy."

The "CSI:OPIOIDS" (Clinical Context of Suicide Following Opioid Transitions) study is funded by the US Department of Veterans Affairs, and it involves a formal collaboration between University of Alabama at Birmingham and Birmingham Alabama VA Healthcare and 2 other VA's.

More importantly, they are explicitly authorized to seek survivors who have lost someone to suicide, regardless of whether the decedent was a Veteran.

Learn more about the study [here](#).

In the event a person who has lost someone actually wishes to test the waters and be screened for inclusion, the "entry point" (approved by IRB, etc) can be found here: go.uab.edu/csiopiods

Every aspect of the study is protected by two Certificates of Confidentiality issued by National Institutes of Health.

Tell A Story About Chiropractic for Complex Regional Pain Syndrome: A Story Completion Study

Derick Luu, DC, a practicing chiropractor and masters student at the School of Rehabilitation Science at [McMaster University](#) in Hamilton, Canada, under the supervision of Dr. Tara Packham, is interested in learning about how people living with CRPS perceive chiropractic care as part of his thesis.

Learn more and take the survey here: bit.ly/3QgVayO



Millburn High School Junior Receives National Teen RareVoice Award by the EveryLife Foundation

Congratulations to Samantha R. for winning the 2023 National Teen RareVoice Award by the EveryLife Foundation for Rare Diseases at Rare Disease Legislative Advocates (RDLA) ceremony. Samantha's mother has #CRPS and she advocates for her mom and everyone waiting for a cure by volunteering with RSDSA. She was also the #2 individual fundraiser for our 4th Annual Virtual CRPS Awareness Walk! Read the full article [here](#).

Attend the Center for Courageous Kids Camp This Summer

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

Dear RSDSA,

Hi! My name is Abby Roe. I'm a thirteen-year-old CRPS warrior who lives in Huntington, West Virginia. I have been fighting CRPS for two years, since early 2021. While my CRPS journey is still new, I've realized that whenever you have a rare disease or are different, support in that can be hard to find. Thank you for supporting so many kids and adults who need it the most.

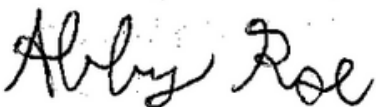
Where can you find a fantastic, supportive camp experience for a variety of different kids? At the Camp for Courageous Kids! Thank you, RSDSA, for sponsoring our week at CCK! It has made an enormous impact for many, especially me. I was able to go to the last CCK camp for the summer a few weeks ago, and I'm so glad I did!

The community there is supportive, understanding, and fun! There was so much to do at camp, and I did everything I could. Camp meant a lot to me, and it was amazing to meet, talk, and bond with others that have pain conditions! I made lots of new friends who understood what I had gone through.

The Camp for Courageous Kids was a whole new experience, one that I enjoyed in its entirety and one that I hope to have again next year. Camp is a safe space and has everything that kids like me need while they're there! CCK is a fantastic place, and it's become everything to me. Thank you for giving me and others like me a safe place to have fun without worrying about our pain for a week. I had a lot of fun at camp and can't wait to return next summer!

Thank you again for supporting kids like me and sponsoring our week at CCK this summer! I hope you do next year, too, so that others can have the great, supportive experience I did.

Sincerely,

A handwritten signature in cursive script that reads "Abby Roe". The ink is dark and the signature is fluid, with the first name "Abby" and last name "Roe" clearly distinguishable.

Abby Roe

10th Annual Fight the Flame 5k and 1k Family Roll & Stroll Recap

Ten years ago, a twelve-year-old boy wanted to find a way to raise money and awareness for Complex Regional Pain Syndrome (CRPS) – a disease his mother has had for over 20 years. With support from his family, that young boy founded Fight the Flame.

Fight The Flame® is a 501(c)(3) non-profit organization whose mission is to raise awareness and educate the public about CRPS while also providing support to the CRPS community. Every year, Fight the Flame hosts a 5k and 1k Family Roll & Stroll to help us achieve our mission. Participants have the option to run, walk, fundraise, cheer, and/or volunteer. On September 24th, we hosted the 10th annual race at Mcalpine Creek Park in Charlotte, North Carolina, and it was the biggest one yet!

The race kicked off at 9:00 a.m. on a beautiful Sunday morning. We had the park decorated in bright orange, an abundance of prizes to be won, and a village of sponsor tables set up. With over 200 runners from all across the country, we were able to raise over \$33,000 for the cause. That money will go to providing the CRPS community with more resources as well as help fund CRPS research.

What started as a young boy with a dream of helping his mother has become a community for CRPS warriors and their loved ones to rally around one another. Thanks to the overwhelming support from our community, Fight the Flame is not just a race. We also offer support groups, scholarships, internships, and so much more. With your support, we hope to accomplish even more.

We would like to extend a huge thank you to our sponsors (Ayers, Whitlow, & Dressler; ARBY'S - Brumit Restaurant Group; Silver Investments Limited; Action Plus Ideas; Southeast Pain & Spine Care, and so many more) as well as everyone who came out to support on race day. We appreciate each and every one of you.

For more information regarding Fight the Flame, please visit our website at fighttheflame.org or contact Beth, our Executive Director, at Beth@fighttheflame.org.

Written by Summer Campbell

Summer is a marketing intern with Fight the Flame and a senior at the University of North Carolina at Charlotte. She is studying Health Systems Management and Marketing. With a passion for healthcare and the nonprofit sector, she absolutely loves working with Fight the Flame. For more information on what it is like to be a Fight the Flame intern, contact Summer at scampb89@uncc.edu.





FLAME OUT – EXTINGUISH THE PAIN
September 10, 2023

THANK YOU TO OUR SPONSORS

Vietnam Veterans of America, Chapter 12

Diana & Peter Smith in memory of Stephanie Theresa Smith

Assistive Choices, Inc., Ocean

Green Leaf Pet Resort, Ocean

Daniel Higgins

O'Dowd Transportation, Montville

Patricia & Anthony Corbella

Jag-One Physical Therapy

VFW Post 2226, Oakhurst

VFW Post 2179, Middletown

In-Kind Sponsors

Smith Hospitality Group

Wawa Store #8269, Oakhurst

Sweet n Joe, Wanamassa

Cravings, Allenhurst

Dani Risi, Allenhurst

THANK YOU FOR YOUR SUPPORT

Interested in participating in a CRPS Research Clinical Trial?

To determine whether there might be a CRPS clinical trial recruiting near you, visit clinicaltrials.gov. Some clinical trials have been stopped due to their inability to recruit individuals with CRPS.



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](#) | Brodsky Family Foundation
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