

IN RARE FORM



Say Hello To The New RSDSA Website!

If you've been to rds.org lately, you've more than likely noticed our 40th anniversary facelift!

After months of hard work and dedication, we are delighted to announce the launch of our new website.

Our team has been working tirelessly to create an online hub that will provide an enhanced and user-friendly experience for everyone affected by CRPS.

We have carefully designed every aspect of the website to ensure that it aligns perfectly with your needs and preferences.

Here are some key features and improvements you can expect from our new website:

- The new design not only enhances the overall aesthetic, but also ensures intuitive navigation, making it easier than ever to find the information you're looking for.
- We have focused on optimizing the user experience to provide a seamless browsing experience across different devices. Whether you're accessing rds.org from your computer, tablet, or smartphone, you can expect consistent performance and functionality.
- Website accessibility is highly important, and we ensured the new site allows everyone to access and navigate online content effectively.

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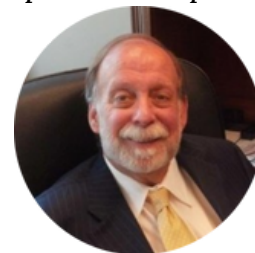
**CRPS HIGHLIGHTED IN
"WOMEN'S HEALTH"
MAGAZINE**

**READ "THE WOMAN WHO
CRIED PAIN" REPORT**

- We've combined our "News For You" page and our "Blog" to make it easier to find top stories focused on and by those with CRPS. Visit our News page and reach out to us if you're interested in sharing your story with our community.

We invite you to take the new RSDSA website for a spin! We value your feedback, so please don't hesitate to share your thoughts and suggestions at info@rsds.org. Your input will help us further improve the website and serve you better.

RSDSA is Sending Condolences to the Family of R. Steven Shisler, Esq.



Steve Shisler's loss will be felt keenly throughout the entire CRPS community. He was a fierce & compassionate defender of those who suffer from this debilitating syndrome. Unfortunately, he knew all-too-well the havoc CRPS can wreak on a body and a spirit, having dealt with its ravages himself as the result of a motorcycle accident many years ago.

While the CRPS community at large marks his passing, we at RSDSA are especially saddened. He served on our Board in several different capacities throughout his long tenure here.

He always provided ad hoc legal advice, and in recent years, functioned as the Board Secretary. Instead of a more traditional and formal roll call, Steve often began meetings with greeting each member by name as he recorded the Minutes.

More importantly, however, we could always rely on Steve to transform our divergent opinions into one cogent voice which enabled us to advocate successfully for our members. His was the voice of reason and the heart of understanding to which we all aspired. He will be sorely missed.

5th Annual Flame Out - A Walk to Extinguish RSD/CRPS | Sunday, September 10

Learn more about the 5th Annual Flame Out - A Walk to Extinguish RSD/CRPS on Sunday, September 10 in Oakhurst, NJ: bit.ly/44d2T5A. This walk will honor Judy Hopkins and her determination to forge a new path to success after being diagnosed with CRPS.

In 2002, Judy was an undergraduate junior studying Dance and Theater when she fell ill and became bedridden for 14 years. No longer able to sing and dance competitively, Judy's pursuit of her major dream ended. In 2018, she found the strength to return to school part-time in her 40s to pursue a new path and study Psychology. She later became a full-time student and graduated with a Bachelor of Science in Psychology!

Join us this fall as we celebrate achievements and walk to raise funds for CRPS research!

Facebook Live with Todd M Hess MD and Healthcare Advocate Cammie LaValle Wednesday, August 2 at 7p Eastern

Join RSDSA for our Facebook Live with Todd M Hess MD and Healthcare Advocate Cammie LaValle on Wednesday, August 2nd at 7:00p Eastern as they discuss the Minnesota Intractable Pain Bill, advocacy efforts, future legislation, and what patients, advocates and caregivers can do to get involved in their state.

Dr. Hess is Board-certified in Anesthesiology and Pain Management. He is a medical director with over 31 years of experience overseeing medical practices from the ground up. Dr. Hess has a successful track record of developing strong administrative and healthcare teams and he is committed to continuous clinical quality improvement and business growth. Dr. Hess has done significant work with pain medical-legal cases involving Worker's Compensation and Injuries and extensive work with legislative process on behalf of pain patients and providers. He has many roles under this belt, but from 1994 to 2022 he was the Medical Director of the United Pain Center at United Hospital and Children's Hospitals and Clinics in St. Paul, Minnesota.



Cammie LaValle resides in Minnesota with her extremely supportive husband Dan. Cammie developed CRPS in 2013 after a carpal tunnel surgery on her right hand. Like most people with CRPS, the diagnosis was not quick, and to find physicians well versed in CRPS was extremely challenging. The CRPS gradually spread to other areas of her body, eventually becoming systemic and rendering her disabled in 2016. Prior to the surgery, Cammie operated her own consulting business providing paralegal services to numerous law firms in addition to contracting with a Minnesota Union as a Membership Specialist.

Recently, Cammie received a call from the Minnesota Council on Disability, informing her she was nominated for and won an Exceptional Advocate Award. The award is a recognition of individuals, or groups, based on their advocacy efforts that contribute to a better life for people with disabilities in Minnesota. You can learn more about the award here: <https://bit.ly/43EyZWE>

We can't wait to see you all on August 2nd. Send any questions you have for our guests to us in a message or to info@rsds.org.

Learn More About The National Pain Advocacy Center

The National Pain Advocacy Center is an organization advocating for individuals with chronic pain. Its mission is to advance the health and human rights of people in pain as an alliance of scientists and clinicians, civil rights advocates and people with lived experience.

They are focused on transforming the mindsets, systems and policies that pose barriers to the health of people living with pain.

They joined forces with others when they saw well-intended efforts to stem opioid prescribing resulting in patient harm.

Visit NationalPain.org to learn more.

Watch These Two Documentaries on CRPS

The 2020 Documentary, *Pain Warriors*, is a no-holds-barred film telling the story of five individuals with intractable pain as they struggle to obtain care in America. It also spotlights the battles of Dr. Mark Ipsen, a Helena, MT physician with the Montana Board of Medicine as it attempts to suspend his license to practice medicine.

Watch it for free on Freevee (via Amazon). Be forewarned, it is very difficult to watch at times.

Additionally, Netflix's much anticipated "Take Care of Maya" is now streaming. In the doc, Maya Kowalski shares how her CRPS diagnosis was classified as Munchausen syndrome by proxy, a mental disorder in which a caretaker of a child either makes up fake symptoms or causes real symptoms to make it appear that the child is injured or ill. The incorrect classification led to her mother's suicide.

Please note that some have said the documentary is hard to finish.

Maya's story has significantly increased awareness of CRPS over the past month as she also appeared on the June 19th cover of "PEOPLE Magazine"



CRPS Highlighted in "Women's Health" Magazine

Thank you to Korin Miller and the Women's Health team for writing the story, ["What Is Complex Regional Pain Syndrome? 'Take Care Of Maya' Health Condition, Treatment, Symptoms, More"](#) and putting the spotlight on CRPS as we continue to drive research to develop better treatments and a cure!

Free “Abbott: Neurostimulation for Foot Pain” Events

Abbott, who is a sponsor of RSDSA, will hold free national patient education event webinars through October 2023. The main topic of discussion will be neurostimulation for focal foot pain.

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

Please note that these events are managed by Abbott, and not RSDSA. Please reach out to them for questions and further details.

Contribute to the Jenkins Patient Assistant Fund

RSDSA recently helped CRPS Warrior Regina purchase a wheelchair lift via the Jenkins Patient Assistant Fund.

In conjunction with the Jenkins family, RSDSA has established an emergency patient assistance fund to provide emergency financial aid to individuals with Complex Regional Pain Syndrome (CRPS) and their families. The fund is named in honor of Brad Jenkins, a young motorcycle racer who was injured during a race and developed CRPS.

Learn more about how to request assistance, and donate to the fund [here](#).



Support RSDSA Via a Facebook Fundraiser

Looking to support RSDSA? Consider creating a Facebook birthday fundraiser!

A Facebook birthday fundraiser is an innovative way to celebrate your special day while supporting a cause that matters to you. Instead of receiving traditional gifts, you can rally your friends, family, and the broader Facebook community to make a donation to a charity or nonprofit organization of your choice.

When your birthday is approaching, Facebook will prompt you to start a fundraiser on your behalf.

→ Create the fundraiser: Visit your Facebook profile page on or around your birthday. You'll notice a prompt asking if you want to create a fundraiser. Click on it!

→ Choose a cause: Select a charitable organization or nonprofit that aligns with your passions and values (or course we recommend RSDSA!).

→ Set a goal: Determine a fundraising target that you'd like to achieve for your chosen cause. It can be any amount you desire, whether big or small.

→ Add a personal touch: Write a heartfelt message explaining why this cause is important to you. Share your story, express your gratitude, and let your friends know how their support can make a difference. You can even do like [Simone S.](#) did with his recent fundraiser and design a custom header!



→ Spread the word: Once your fundraiser is all set up, invite your Facebook friends to participate.

→ Engage and express gratitude: Throughout the duration of your fundraiser, make sure to engage with your donors. Respond to their comments, thank them for their contributions, and keep them updated on the progress of the fundraiser.

→ Celebrate and make an impact: As donations pour in, you'll see your fundraising thermometer rise, bringing you closer to your goal. When your birthday comes to an end, Facebook will transfer the accumulated donations to the chosen nonprofit, ensuring that your impact is realized.

Let us know if you have any questions about birthday fundraisers! Thank you to everyone who has created one for us so far.

Register for the 5th Annual RSDSA Long Island CRPS Awareness Walk & Expo

The 5th Annual RSDSA Long Island CRPS Awareness Walk & Expo, our largest annual event, takes place on Saturday, September 9th!

Visit our Walk & Expo page to learn more about registering, sponsoring, and donating to this amazing event at Eisenhower Park in East Meadow, NY: bit.ly/3NQz1qd. Be sure to register by August 4th to receive a free t-shirt!

Learn more about the Chronic Pain Healthcare Communication Survey

The Chronic Pain Healthcare Communication Survey is being funded by Converse University's Office of Research and Engagement and by the Nisbet Honors Program at Converse; the project has received Institutional Review Board approval.

The goal is to develop recommendations for better healthcare communication about chronic pain for families and youth, and possibly to start developing resources.

Please help distribute the [survey](#), which is designed for young adults ages 18-25.

Read "The Woman Who Cried Pain" Report

22 years ago, the landmark report "The Girl Who Cried Pain" spotlighted the gender bias toward women in the treatment of their pain. A recent follow-up to that report, ["The Woman Who Cried Pain: Do Sex-Based Disparities Still Exist in the Experience and Treatment of Pain?"](#) took a retrospective look at how much better, if at all, women in pain are faring.

The report concluded, that while some progress has been made, there remains a significant shortage in research about how and why men and women experience pain differently and that there is a nagging implicit bias among healthcare professionals that impedes equitable pain care.

For Grace founder Cynthia Toussaint, who is a previous RSDSA Facebook Live guest, was a key advisor on the report. Check it out and let us know your thoughts by emailing us at info@rdsd.org.



5th Annual RSDSA Long Island CRPS Awareness WALK & EXPO

Walk, Run, Roll 1K / 2.5K
 Adults: \$30, Veteran's with ID: \$15
 Seniors 62+: \$20, Children (5-12): \$10
 Day of walk registration: \$35

• Register online by August 4, 2023 to receive **FREE** T-Shirt
 • Online registration ends September 1, 2023

OUR MISSION
 To provide support, education, and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

Saturday, Sept. 9, 2023
8am - 2pm
Eisenhower Park
East Meadow, NY
 Pear and Peach Picnic Area

Register online at secure.qgiv.com/event/rdsal2023/
 For more information, or interest in volunteering call RSDSA at 1-877-662-7737 or email rdsalongisland@gmail.com

Twitter: @rdsalongisland Instagram: @rdsalIWALK
* Complex Regional Pain Syndrome, Reflex Sympathetic Dystrophy

REGISTER NOW!

- Morning coffee and bagels
- Education Center
- Presentations
- Crafts for kids
- Lunchtime BBQ
- Raffles
- Rain or shine

CRPS/RSD is rated the most painful chronic pain condition in the world today. Currently there is no cure. **Help us change that!**

rdsda
 SUPPORTING THE CRPS COMMUNITY

Listen to the RSDSA Team on The Non-Profit Voice Radio Show

Interview with Debbie O'Neal and Jim Broatch for the 5th Annual RSDSA Long Island CRPS Awareness Walk & Expo

THE NON-PROFIT VOICE
103.9 FM LI NEWS RADIO



Thank you to The Non-Profit Voice on 103.9 FM LI News Radio for hosting our Jim Broach and Debbie O'Neal as our team prepares for the 5th Annual RSDSA Long Island CRPS Awareness Walk & Expo on Saturday, September 9, 2023 in Eisenhower Park in East Meadow, NY.

Listen to the full interview here:
youtu.be/5mQUAzU-Skk

Thank You For Supporting Our RSDSA 4th Annual Virtual CRPS Awareness Walk!

\$50,000 Raised! 293 Registered! 40 Teams! 500 Donors!

A huge thank you to everyone who donated to our annual CRPS Awareness Walk. With your help and the support of an untold number of amazing and generous donors, we raised over \$50,000!

At RSDSA, we receive countless letters from those we serve who are continually amazed at the wide-reaching, life-changing - often lifesaving - effect of our programs. Your donations provide critical support, and you also give those within our RSDSA family something priceless - hope. We take seriously our commitment to be good stewards of your gifts. We value your confidence.

We can't thank you enough for giving and sharing messages on social media. It is truly an honor to have your support. To all of you who donated in memory or in honor of a loved one, we hear you and we are grateful for your support. We understand that everyone's gift comes from the heart.

If you have not had a chance to donate, but would like to make a gift to RSDSA, you still can. The 4th Annual Virtual CRPS Awareness Walk [page](#) will be open for donations until the end of 2023.

Continuing our work is only possible because you are on our team!

Thank you to our Walk Sponsors:

Bronze Donors: Power Cooling, Stratford Engineering, MD RSD/CRPS Support Group

Orange Donors: Ashland Maintenance, Inspired Living with Amberly Lago LLC, Jimmy's Store, Total Fire Protection

Thank You To RSDSA's 4th Annual Virtual CRPS Awareness Walk Teams!

Allie's Allies | Amandas Angels | Asheville Alligators: Tough & Resilient | Beth and the Newport Warriors | Burning Love For Danielle | Calloway Crew | Campbell Crew | Chuck's Psalm 34:8 Walk | Colorado Flame Walkers | Disabled Advantage | Erica's Lucky Fin | Everyday CRPS | Feathers & Flames | Foley's Flame Fighters | Garbonzo's Beans | Grit Don't Quit | Heather's Homies | Help Mary Fight RSD/CRPS | Hill & Friends | Jenny G's Launch Pad | Journeying with Jeeves | Just Keep Swimming! | Kate's Crew | Katie's CRPS Team | Keep on Rolling | Kelly's Crusaders | Laury'n's CRPS Crushin' Crew | Leo's CRPS Awareness MD RSD/CRPS Support Group | Newtown Vet Rovers | O'Keefes Hope 2 Cope | Philly CRPS Warriors | Rosie's CRPS Champions! | Seickel Warriors | SHIFRA | Team Ginger | Team Hot and Cold | Team Persevere | The J-Squad | The Pirates Cassandra and Phelan



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!

[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