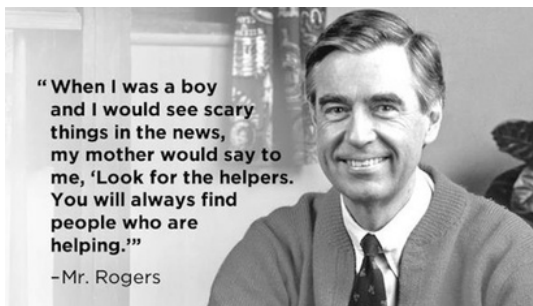


# IN RARE FORM



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## Our Best Advocate

by CRPS Warrior Megan Liebl

We CRPS Warriors want to feel better and live the life we should be living. We want to find a care team, a support system, and a tribe who encourage us and cheer us on.

However, these are not always easy to find, especially when it comes to CRPS. Providers and people in our lives may not believe us when we say, “It hurts.” We have been dismissed, doubted, critically questioned, and invalidated by others, and perhaps even by ourselves. This can make us feel very alone, disheartened, and beaten down by the systems and people we so badly want and need help from. Many of us have, at some point, allowed the pain and disability to take over our entire being. In CRPS, it is easy to lose who we truly are. But, the pain does not need to take us over forever.

If and when we get to that point, what can we do? Who can help us? How will we get our lives back? The answer is YOU. You are the solution to your own wellbeing. You do have that power. You are the expert in your own medical condition and your body. You need to be the detective and the fighter. And you must fight as if the future of your health depends on it, because it does. Nobody cares more about how you feel inside of your body than you do.

Hence, we must be our own best advocate. We must dig deeper than we have ever dug before for the strength and resilience we all have within us. This means being persistent in seeking quality care providers, asking probing questions when something doesn't feel quite right, getting a second opinion if necessary, and learning all we can about our condition so that we can help ourselves. We must do the work to manage the pain including activities such as Occupational Therapy, Physical Therapy, Pain Psychology, participating in a solid support group, meditating, inducing the parasympathetic nervous system and decreasing the sympathetic nervous system, pain journaling, setting firm

personal boundaries, as well as knowing what is good and right for us and our condition on a daily basis. It is hard work, but it is so very worth it. No one else can do it as well as you can. We all know more about our own condition than any specialist ever could, but we still need medical professionals to assist us through an effective treatment plan and organizations like RSDSA to support and educate us on CRPS.

As much as we must advocate for ourselves, there are also so many exceptional people, organizations, and medical care providers willing to champion our health alongside us. I often think of the Mr. Rogers quote that states, “Look for the Helpers. You will always find people who are helping.” Our job, Warriors, is to find those folks to aid us in getting back to the life we want to be living. The great news is that we are already on the right track in advocating for ourselves, as RSDSA is a fantastic resource for CRPS Warriors and our caregivers.

Many of us with CRPS have been sent from doctor to doctor, to specialist to specialist, to injections, to surgeries, to holistic medicine, and everything under the sun, but to no avail. However, from my own experience, I assure you that there are medical experts who study and recognize CRPS, who believe us entirely, whom we can trust, and who know we’re not “just imagining” this horrific pain. It took me years to find my current - and amazing - care team, but I kept advocating for myself, fighting for answers and understanding of what was going on inside my body, wouldn’t accept that pain will inevitably take over my entire life, and I continued to be the strongest proponent for myself that I could be. I found these experts. I work hard every day to manage my pain, and I’m now in the process of getting my life back. You can get your life back, too.

Please remain resilient, keep asking questions, never give up hope, and remember that you are your own best advocate because you are a CRPS Warrior.

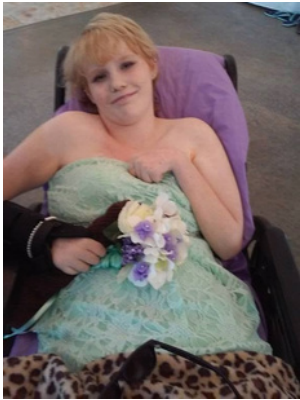
## Support RSDSA by Shopping at Big Y in Connecticut

RSDSA is benefiting from the Big Y's Community Bag Program through January 31, 2022.

For every community shopping bag sold at the Big Y at [150 Boston Post Road in Milford, Connecticut](#), RSDSA, will receive \$1. Help us spread the word to those in the 06460 area!



# Apply for The Hannah Bernard Memorial Scholarship by April 30, 2022



The Hannah Bernard Memorial Scholarship is available to anyone fighting complex pain conditions and pursuing their education, including high school, college and online courses. A \$600 Scholarship will be awarded to the winner in memory of Hannah Bernard! Applications for The Hannah Bernard Memorial Scholarship 2022 will be accepted through April 30, 2022 [here](#).

Hannah Bernard was an indomitable warrior who remained strong, confident, and always kept her great sense of humor. She courageously fought CRPS, Ehlers Danlos Syndrome, POTS (Postural Orthostatic Tachycardia Syndrome), Gastroparesis and Dystonia for over 10 years until losing her battle in 2015 at the age of 19.

Hannah was incredibly bright and passionate about learning. She always gave her all, to everything that she did, despite having these painful and debilitating diseases. She wanted to educate and spread awareness about these rare illnesses in an effort to help improve quality of care for others.

Hannah loved attending school and when she could no longer do that, she still maintained straight A's on hospital homebound taking all honors classes. Quitting was never an option. Her dream was to attend Harvard Medical School. She wanted to treat children in pain with compassion and empathy.

She never gave up and appreciated every day. Her unwavering strength and determination can be summed up with her favorite quote.

“Life is not a matter of holding good cards, but playing a poor hand well.”

She was a supportive friend and always encouraged others to keep fighting. Our family is honored to be able to help another warrior realize their educational dreams and make a difference in the world.

Applications may be submitted through April 30, 2022. Our award will be announced in June 2022. If you are interested in applying for the Hannah Bernard Scholarship please fill out the application [here](#).

# RSDSA: The People and Programs Behind the Website

by Jim Broatch, MSW, Executive Vice President, Director

I would like to introduce the readers of *In Rare Form* to the many programs and activities of Reflex Sympathetic Dystrophy Syndrome Association (RSDSA). Often, people are referred to our website at [rsds.org](https://rsds.org) or find us via a link during an exhaustive internet search. They see that our site houses a tremendous amount of helpful information but may lose sight of the fact that RSDSA is a vibrant organization which has been serving the CRPS community since 1984. Two moms with children with CRPS started our organization.

Our mission is to provide support, education, and hope to everyone affected by Complex Regional Pain Syndrome (CRPS), formerly known as Reflex Sympathetic Dystrophy (RSD) while we drive research to develop better treatments and a cure.

In terms of the first part of our mission, RSDSA has established two funds to support those with CRPS:

- The Maria Lane Fund was set up to help individuals navigate the public/private insurance landscape and to promote greater professional awareness of CRPS. This fund also helps to sponsor the development of education programs for healthcare professionals to increase awareness of CRPS.
- Our second fund is the [Patient Assistance Fund](#) in honor of Brad Jenkins. It provides emergency financial grants to individuals in distress. Since 2015, the fund has provided over \$125,000 dollars in emergency financial aid to individuals and families with CRPS. Sadly, at times, our fund is the only available resource which keeps families from living on the street.

For three years, RSDSA has co-sponsored a free week-long camp for children in pain. One child remarked that the camp experience had literally saved her life. She had already attempted suicide. Due to the COVID-19 pandemic, the camp has been paused for the last two years. We look forward to the future when it is once again a running camp for our kids.

RSDSA also developed a young adults weekend to help those aged 18-29 transition into higher education, the workforce, and/or living on their own. Read about Melissa's experience [here](#).

Our staff and board of directors are always available to help individuals navigate this scary, perplexing diagnosis and begin their recovery journey. People can call us via our toll-free line 1.877.662.7737 or send an email to [info@rsds.org](mailto:info@rsds.org). Whether you have had CRPS for decades or just months, we're here to help and listen. One young adult recently diagnosed, thanked us and wrote, "I have been completely overwhelmed and frustrated but you gave me some hope and inspiration to research and fight to get better."

Spreading awareness in the medical, legal and insurance fields, as well as to the community at large, is an integral part of our mission. Prior to the pandemic, RSDSA had hosted regional educational conferences for people with CRPS and their caregivers. Each conference was filmed and archived on RSDSA's [YouTube channel](#). We have also compiled hundreds of peer-reviewed journal articles in our [web library](#). During the pandemic, RSDSA has also hosted Facebook Lives to sponsor monthly presentations which are seen by thousands globally. So far, our YouTube videos have been viewed over one million times.

Additionally:

- Dr. Jay Joshi, an Illinois pain specialist who has treated hundreds with CRPS is featured in a [accredited course](#) for physicians, psychologists, and nurses
- We also have developed a [ketamine protocol](#) for emergency departments on how to manage CRPS flares
- A free pediatric CRPS [course](#) for pediatricians, nurses, and physical therapists is also available on our website
- In 2022, RSDSA will publish the fifth edition of the CRPS: Practical Diagnostic and Treatment Guidelines

The third leg of our mission is research. Since 1992, RSDSA has funded more than \$3 million dollars in pilot studies and pain fellowships. Five years ago, we established the International Research Consortium with the goal of fostering increased collaboration amongst CRPS researchers worldwide. Their mandate is to promote research directed at relieving the pain and disability of CRPS, facilitating its prevention, and ultimately, finding a cure. Read about RSDSA's current-funded research [here](#).

RSDSA exists to serve your needs, no matter how you are affected by CRPS. We are here to help and are guided by the thoughts of Henri J.M. Nouwen, "Often we are not able to cure, but we are always able to care." RSDSA is so much more than a website. It truly is a community of caring. We invite you to look beyond our website to see the people and programs which give it life.

## FAQs about RSDSA

1. The Board of Directors are volunteers. They are a diverse group of people consisting of three doctors, one PhD, an accountant, an attorney and at least three individuals with CRPS who donate their time and wisdom to the RSDSA community.
2. We are a national non-profit organization serving the US from coast to coast. We have support groups in forty-three states and Puerto Rico, a RSDSA YouTube channel and an active community on Facebook, Instagram and Twitter.
3. RSDSA collaborates with other organizations, namely National Organization of Rare Diseases (NORD), EveryLife Foundation for Rare Diseases, and the US Pain Association.
4. RSDSA funds come from grants, corporate sponsorships, and individual donations.
5. Our staff is small but mighty. Give thanks to Jim Broatch, Pam Kientzler, Jennifer Pincus and Endra Newell for keeping the doors open and the lights on and to Alexis Davis and Jeri Krassner, Social Media Director and Special Events Coordinator, respectively.



## 7th Annual Benefit for the CRPS/RSD community: Raising the Stakes



The 7th Annual Benefit for the CRPS/RSD community, Raising the Stakes, takes place on Saturday, February 5th from 10a-3p at Cajun Harley Davidson at 7241-10 S Frontage Road in Scott, Louisiana. There will be a gumbo cook-off, a Jeep Show-n-Shine, a live auction, and live music from Kip Sonnier, Karmic Souls, and Rory Suire.

We're excited to once again work with the Louisiana Jeepers on this awesome event. If you are interested in attending, entering the gumbo cook-off, being a vendor or sponsor, please click [here](#) for more details.

## Donate your old car to Charitable Adult Rides & Services (CARS) to benefit RSDSA

[CARS](#) is a 501(c)3 nonprofit social enterprise owned by a nonprofit supporting only nonprofits through vehicle donations.

When you donate a vehicle to CARS, RSDSA receives 70% of the proceeds. Learn more about donating your car to benefit RSDSA [here](#).



# Virtual Rare Disease Week on Capitol Hill 2022 is February 22nd – March 2nd, 2022



Virtual Rare Disease Week on Capitol Hill 2022 is February 22nd to March 2nd and is organized by The Rare Disease Legislative Advocates (RDLA) of the EveryLife Foundation for Rare Diseases.

This annual event brings rare disease advocates from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators.

The EveryLife Foundation for Rare Diseases will schedule meetings with your Senators and House Representatives with other advocates from other rare diseases. No prior experience is necessary. Registration for this event and all RDLA events are free for all rare disease advocates.

If you register and participate, please let us know at [advocacy@rsds.org](mailto:advocacy@rsds.org). We would love to hear about your experience. Together we can make our CRPS voices heard and seen.

Register [here](#) for Virtual Rare Disease Week on Capitol Hill 2022.

## Treating the Whole Person: Optimizing Wellness Videos Are Available



### TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS

VIRTUAL CONFERENCE

OCTOBER 25-28



Don't forget to visit the [RSDSA YouTube Channel](#) to view our videos and presentations from our Treating the Whole Person: Optimizing Wellness virtual conference and be sure to subscribe while you're there!

## Host an Event with RSDSA

It's a brand-new year, and the perfect time for an event or activity to raise awareness and funds for your community. Any activity can be an opportunity to raise support for advocacy, research, and education. Every dollar makes a difference. You can make a difference!

The opportunities to create, organize, and host are limitless! You can do it your way, whether that's a movie night or a Facebook fundraiser, or join an already established event. You can even turn a birthday, wedding, or other personal celebration into a fundraiser by inviting others to donate on your behalf.

There is no limit to what you can do, even with the pandemic and bans on large gatherings. There are many unique hybrid and virtual events that can raise awareness and money. There are fundraisers you can do as an individual and ones that include your family, your caring circle, your congregation, or your neighbors. We will be there to help you plan and execute any event you like!

Here are just a few fundraising event ideas:

- Zoom Bingo
- Costume contest (or a pet costume contest!)
- Craft night
- Trivia night
- Game night
- Poker run – I admit, I find this one intriguing. Instead of any poker night you can do a poker run. This involves players using various forms of transportation to visit 5-7 locations. At each location, the player draws a card, with the goal to have the best poker hand at the end of the run. It is more luck than skill, but it is a fun time.

## Give to RSDSA When You Search on Bing

Give with Bing and Microsoft Rewards members have donated \$9 million and counting. Join [here](#) today to make your searches matter. All you have to do is sign up, select RSDSA (Reflex Sympathetic Dystrophy Syndrome Association) and then Search on Bing! When you're signed in, you'll earn points that turn into donations for our organization and mission.



# Microsoft Bing



## Facebook Live with Dr. Neal Pollack, D.O., F.A.A.N.



Dr. Neal Pollack, D.O., F.A.A.N. is a Board Certified Neurologist and Director of Neurology & Pain Treatment Ltd. in Milwaukee, Wisconsin. He is a Fellow at the American Academy of Neurology, a Fellow at the American Academy of Disability Evaluating Physicians, and is a State of Wisconsin Neurological and Orthopedic Disability Examiner.

He will join us for a Facebook Live on Thursday, January 27th at 7p Eastern.

Dr. Pollack will be referencing principles and practices from his new book [Pain Relief is Only One Call Away: An interactive book enabling contact with a pain specialist](#). He will also be illustrating pain treatment techniques with an RSD patient. Following his presentation there will be ample time to ask questions.

Join us at [facebook.com/rsdsa](https://facebook.com/rsdsa) on Thursday, January 27th at 7p Eastern to chat with Dr. Pollack.

Don't forget: If you miss one of our Facebook Live sessions, you can always watch the replay on the RSDSA YouTube Channel as we do record each one.

## We want your feedback!

Please send any suggestions or upcoming events of interest to our community to [info@rds.org](mailto:info@rds.org) and please consider donating at [rds.org/donate](https://rds.org/donate).



**rsdsa**  
SUPPORTING THE  
CRPS COMMUNITY