

IN RARE FORM



Treating the Whole Person: Optimizing Wellness Recap

RSDSA hosted its first Treating the Whole Person: Optimizing Wellness virtual conference last month and it was an amazing experience!

We thank each of our speakers for attending and for providing attendees with valuable information on CRPS. Our speakers included:

- Dr. Corey Hunter
- Dr. Sherri Haas
- Dr. Andreas Goebel
- Dr. R. Norman Harden
- Elisa Friedlander, LMFT
- Lindsey Kolb
- Jeffrey Rabin, Esq.
- Dr. Jonathan Fass
- Dr. Traci Patterson
- Dr. Katinka van der Merwe
- Dr. Hannelie van der Merwe

We also loved how many CRPS Warriors enjoyed the one-on-one networking session that allowed them to meet one another via an audio and/or visual conversation. Due to the positive feedback on that portion of the conference, we will be hosting a similar event to allow Warriors to network with one another later this month. Keep an eye on the [RSDSA Facebook Page](#) for more information!

All sessions were recorded and will be available on the RSDSA YouTube Channel once they are edited! Please [subscribe to our channel](#) so you will be the first to know when they are available

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November is CRPS Awareness Month



Monday, November 2nd was the seventh annual Color The World Orange™ for CRPS/RSD Awareness, but we want to see you in your orange all month since it is CRPS Awareness Month! Be sure to sport your favorite orange all month and tag Color The World Orange and RSDSA so we can also support and repost!



Also tag us in photos from proclamations and special congressional recognitions you may receive in your area such as this one from the Town of Smithtown, NY. Thanks again to Stacey Udell for her leadership!

Restoring Visibility - Eric Moyal - TEDxBrandeisU



[Watch](#) as Eric Moyal of Ride For Warriors delivers a TEDx Talk about his sister's journey with Thoracic Outlet Syndrome and Complex Regional Pain Syndrome.

CRPS Awareness Month Resource Page

Need assistance explaining what CRPS is to those who want to learn more? Share [this handy resource page](#) with your network this month!

Rare Disease Legislative Advocates

by Nancy Shurtleff

This year, I began my participation with the organization [Rare Disease Legislative Advocates \(RDLA\)](#). RDLA “is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collectively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers.”

Intrigued, I visited their website at rareadvocates.org. I first learned of Rare Disease Legislative Week in Washington, DC and read some great stories about the impact individuals with rare diseases can make. I believe everyone in the rare disease community has a voice and I was interested in becoming involved in the patient advocacy community.

My opportunity came on August 14, 2020. RDLA helped organize a phone call with my U.S. Representative for California's 45th congressional district, Katie Porter. Due to Covid-19 restrictions, we were not able to meet in person. Along with two others, we presented Representative Porter with our written and verbal request that she join the Congressional Rare Disease Caucus which is a bipartisan Congressional Caucus open to all members of the United States House and Senate. By definition, this Caucus is a forum for Members of Congress to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases. Representative Porter agreed and within a month had officially joined the Caucus!

Advocacy is easier than you may think. Advocacy is simply public support for a particular cause. Your cause! When you talk to your medical providers, pharmacist, co-worker(s), family and friends about CRPS, you are using your advocacy skills. As an advocate, you can also be an important part of the legislative and policy making process. You can make your voice heard by writing or calling your Senators and Representatives (view the sample letter on the next page!). RDLA's website is a wealth of information! Included are advocacy tools and tip sheets, along with information on how to foster a relationship with your Member of Congress, Schedule a Meeting with your Legislator and Lobbying for Rare Disease non-profit organizations.

Last year during Rare Disease Legislative Week on Capitol Hill, with the help of RDLA, 900 Rare Disease Advocates attended, 393 meetings with Members of Congress were held, involving 227 patient organizations. **In 2021, Rare Disease Legislative Week is July 19-22.** Please visit the RDLA website at rareadvocates.org for information on how you can be a part of this amazing week. Together, we can make a difference.

Sample CRPS Advocacy Letter

[Date]

The Honorable [First & Last Name]

Dear Representative/Senator/Congress[wo]man,

My name is _____ and I am a resident in your district residing at _____. I am writing you today as a member of the rare disease community. I suffer from a disease called Complex Regional Pain Syndrome (CRPS), formerly known as Reflex Sympathetic Dystrophy (RSD). CRPS is a rare neuropathic debilitating, painful condition. It is associated with sensory, motor, autonomic, skin and bone abnormalities. During these trying times it is important not to lose sight that the rare disease community, a population already underserved, has borne a disproportionate amount of sacrifice in the face of Covid-19 as compared to the greater population. We have lost access to our doctors, been cut off from treatments and watched as our medications were diverted. Now, we are asking for your help.

Many people living with rare diseases are immunocompromised. This puts them at greater risk when they travel. Additionally, there are few experts specializing in rare disease conditions. This leaves patients and their families no choice but to take time and expense to see their provider, no matter how great a risk it is. In fact, a recent survey done by the National Organization for Rare Disorders (NORD) found that 39% of patients have traveled at least 60 miles to receive medical care, while 17% found the burden of travel so great that they had to move closer to treatment.

The CARES Act removed many barriers to telehealth services solving these problems. At the beginning of the pandemic, use of telehealth services went from 13,000 to 1.7 million visits per week among Medicare recipients. Under Medicare, at the height of the national lockdown, over 9 million telehealth visits were conducted. 88% of rare disease patients who were offered telehealth visits during Covid-19 accepted and 92% of them said it was a positive experience. 70% said that they would like the option of telehealth for future medical appointments.

Currently, Congress and state governments are trying to decide which changes to telehealth should be made permanent. I urge you to protect expansion of telehealth services, especially as it pertains to the rare disease community. Additionally, I ask that you re-examine the National Pain Strategy. As a patient who suffers from CRPS, one of the most painful conditions, I feel the National Pain Strategy is biased against the prescribing of scheduled pain medication for chronic pain. While it expressly provides for “responsible and reasonable use of opioids for individuals who can’t be helped by other modalities,” there are no protections for providers to prescribe at what they deem as therapeutic doses, nor is there a clear definition of what “responsible and reasonable” means. Overall, the National Pain Strategy narrative supports a false belief seen from policy makers that if non-pharmacological treatments are made more accessible, the need for pain medications will become obsolete.

Therefore, I ask that you protect the expansion of telehealth services and re-examine the National Pain Strategy.

Thank you for your time. I look forward to meeting you in your local office in the future.

Respectfully,

Angi Blake's Comfort Bears

by Kelly Hodgkins

Lying alone in the hospital waiting for surgery, Angi Blake felt helpless and hopeless. Her teddy bears of comfort are her response and her way of encouraging other Warriors suffering from CRPS by letting them know they are seen and that they aren't in it alone.

Angi's story of CRPS started 27 years ago when her hand was crushed between two iron microphone stand bases. It took six years for her to receive the correct diagnosis after being told it wasn't real and that it was all in her head. It was a long, painful and lonely journey. She now has CRPS throughout her shoulders and into her intestines.

No longer able to cope with the pain, she connected with a great pain doctor who worked through various therapies with her including 12 surgeries in a four year span as well as four failed spinal cord stimulators. Angi is now on a pain pump with supplementary painkillers as well as a ketamine nasal spray and monthly infusions.

Once she had recovered enough from her surgeries, she began her comfort teddy bear project. She carefully crafts each teddy bear including the necklace and bow tie. The teddy wears a Warrior team t-shirt with a number on his back (she's on bear 39 now!) to make each recipient feel a part of something beyond themselves and let them know someone cares. Along with the teddy bear, Angi writes a card of encouragement and sends a CRPS alert bracelet and flash drive of information pamphlets as well as a medical history document to complete and take with you to any doctor or emergency room so you don't have to cope with remembering important information in pain and have brain fog. In return for her kindness, she asks only that each teddy bear be named on arrival and the name sent back to her to be captured in her teddy bear library. Angi says, "Most people take their bear with them to the hospital. One friend travels for a living and her bear, Phil, goes with her all over."

Every three months, Angi reaches out to each teddy bear recipient with a card to keep in touch and remind them they are not alone.

Her teddies have been sent throughout the United States and Canada and have crossed oceans to North Wales in the United Kingdom, all at her cost. Her generosity to and empathy for those living with CRPS is immense and this project is incredibly important to her. She comments, "I never want others to feel how I did. CRPS can be a very lonely diagnosis. It is my mission to help others with it."

Join the #CRPSChat on the First Tuesday of Each Month on Twitter

On Tuesday, November 10th, there will be a #CRPSChat at 5:00PM Pacific for all individuals impacted by CRPS.

The chat is intended to help the CRPS community meet and connect with each other. It is to share information, learn about treatments and coping strategies, make friends, and of course, to check in and support one another.

Each chat will have a different topic and the chat leader, [@KateandCRPS](#) is open to topic submissions. If you have a topic idea, please direct message the [@CRPSChat](#) account or email kateandcrps@gmail.com.



Facebook Live on Thursday, November 12th

Join our next [Facebook Live with Richard Rauck, MD](#) on Thursday, November 12th at 7p Eastern.

Dr. Richard Rauck graduated from Wake Forest University Bowman Gray School of Medicine in 1982. He received his bachelor's degree from Davidson College in Davidson, N.C., and graduated magna cum laude. He completed his residency in anesthesiology in 1985 at the University Of Cincinnati College Of Medicine in Cincinnati, Ohio. In 1986 he completed a fellowship in pain medicine at University of Cincinnati College of Medicine.



Dr. Rauck is board certified in pain medicine and anesthesiology. He has been actively engaged in clinical research in pain medicine, speaks frequently at many national and international professional meetings, and has an active clinical practice in pain management. Currently, Dr. Rauck is practicing pain management at Carolinas Pain Institute and is the medical director for The Center for Clinical Research.

Yoga Resources

During our Treating the Whole Person: Optimizing Wellness virtual conference we had a guided Yoga session with Lindsey Kolb. Lindsey provided the following resources for those who are interested in continuing with yoga.

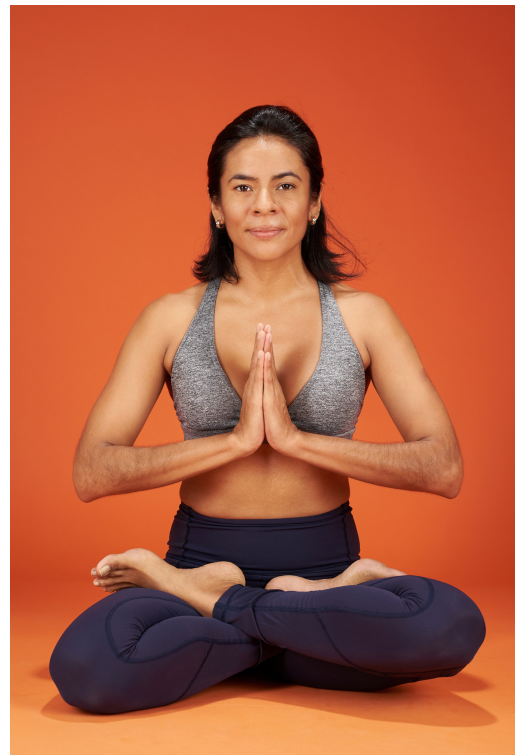
If you are a CRPS Warrior looking to work with a yogi, be sure to look for someone who is a yoga therapist, someone who works with clients who have chronic pain, or someone who has a PT background as well as a yoga background.

Books specifically for yoga and chronic pain:

- [Yoga for Pain Relief](#)
 - This book is more practice focused
- [Yoga and Science in Pain Care](#)
 - This book is more theory focused
- [The Yoga of Breath: A step by step guide to Pranayama](#)
 - Perfect if you are looking for breathing practices
- [Sun Chair Yoga, Yoga for Everyone](#)
 - For those looking for information on chair yoga

Video resources:

- [Accessible Yoga Class](#) [18-minute video]
- [Mini Adaptive Chair Yoga Class for People in Wheelchairs](#) [8-minute video]
- [The YogaJP YouTube Channel](#)
 - This channel features great chair yoga videos



Word Up

Neuro-autoantibodies [nur·ow aa·tow·an·tee·baa·deez]

Neuro-autoantibodies are immune proteins that inappropriately target a person's own nerve cells and cause pain and other symptoms.

The binding of a neuro-autoantibody to a nerve cell can cause dysfunction, damage or cell death.

Such antibodies are responsible for a broad range of neurological diseases.

Neuro-autoantibodies can contribute directly to a disease, serve as biomarkers of that disease or do both.



Disability Grants for Home Improvements & Repairs

Check out and (bookmark!) this list of federal and state disability grants for home improvements and repairs from Best Mobility Aids [here](#).

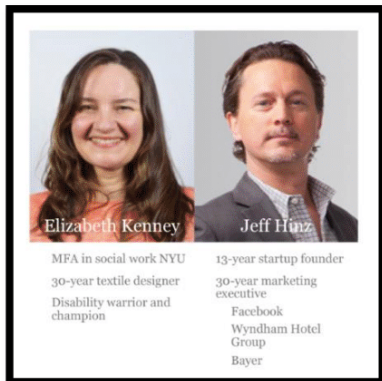
Dwellability

Home Sharing for People with Disabilities, By People with Disabilities

Who We Are

Dwellability started as an idea between two friends with disabilities over a cup of coffee. Why did it have to be so hard to find a safe, appropriate place to live or visit? We dreamed about creating a way to connect people across the full spectrum of disability because as a community, we know we are a powerful force, but society simply isn't meeting our housing needs.

So, we started working on Dwellability as a solution for connecting people who need a home with those who have space to share. Pretty simple, right? We hope you will join our community and let us know what we can do to make the site do its absolute best for you!



Our Founders

Dwellability is a passion project for Elizabeth Kenney and Jeff Hinz (partners in business and marriage), as Kenney has an invisible disability that affects her ability to travel and stay in hotels. Kenney is the creative soul behind Dwellability, given her textile design career and a recent graduate degree in social work from NYU. Hinz is the operations expert with 30 years of experience in advertising and startups.

What We Do

Dwellability is an online community that connects people with disabilities who are looking for accommodations, whether it be finding a roommate or a vacation rental. Dwellability caters to all disabilities: Mobility, Deaf, Blind, Cognitive, and Environmental, all in the hopes of helping meet housing and accommodation needs. People with disabilities who have a place to share or are looking for a place can become Dwellability members and find what they need. In addition, people who have spare rooms to rent can benefit by renting either short-term or long-term to people with disabilities.

Dwellability Serves People With Disabilities

- Online two-sided community marketplace
- Meeting their home-sharing needs
 - Roommates
 - Vacation rentals
- Providing emotional relief
- Creating savings and income



Please visit www.dwellability.com to search listings, post accommodations, and read our newsletter!

Breakthrough research shows hope for reversing damage in neurological disease

Scientists say they found an immune cell that can reverse damage and restore function.

The nervous system is challenging. Once nerve cells die, particularly in the brain and spinal cord, they don't regenerate in adults.

It's been Dr Benjamin Segal's life's work.

Read the full article [here](#).

New in the RSDSA Store: Laminated CRPS Medical Reference Cards

Purchase one of our reference cards for \$2 so you can keep information about CRPS handy in your wallet at all times!

Click [here](#) to purchase.

For dx. of Complex Regional Pain Syndrome (CRPS)

- Continuing pain, **disproportionate** to any inciting event
- Must report 1 **symptom** in 3 or more categories
- Must display 1 **sign** in 2 or more categories
- There is **no other diagnosis** that better explains the signs and symptoms

Sensory	<ul style="list-style-type: none"> Allodynia (to light touch, things that shouldn't be painful, are painful) and/or Hyperalgesia (heightened sensitivity to pain)
Vasomotor	<ul style="list-style-type: none"> Temperature (more than 1 °C) Color (red, purple, pale, cyanotic, mottled) Skin condition (swelling, shiny, brittle, itchy, sores, blisters, rashes, lesions)
Sudomotor	<ul style="list-style-type: none"> Changes and/or asymmetry Edema Sweating
Motor/Trophic	<ul style="list-style-type: none"> Decreased changes in Movement (<i>ROM</i>) Motor Function (<i>dystonia, weakness, tremor, atrophy</i>) Trophic (<i>hair, nails, skin</i>)

RSDSA reserves all rights. Adapted from Harden/Brusch criteria.

Could your patient have **Complex Regional Pain Syndrome (CRPS)** formally known as Reflex Sympathetic Dystrophy (RSD)?

- Suspect in patients with unexplained, **disproportionate allodynia & hyperalgesia**
- Nervous system "winds up" in a **persistent state** of central sensitization
- A **normal sensation** produces an **abnormal response**
- Goal: modify pain & restore function

CRPS type 1 (without documented nerve injury)
CRPS type 2 (**with** a documented nerve injury)

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rdsd
SUPPORTING THE CRPS COMMUNITY

Please send us feedback!

Please send any suggestions or upcoming events of interest to our community to info@rdsd.org and please consider a donation to rdsd.org/donate.