

IN RARE FORM



Living with Chronic Pain: My Path to Freedom

by CRPS Warrior Rebecca (Last name omitted for privacy)

I was injured in a work-related accident in 2011, and sustained significant damage to my leg and ankle. I fractured my fibula, dislocated my knee, tore my peroneal tendon, and damaged my peroneal nerve. Ultimately, in 2014, I was diagnosed with Reflex Sympathetic Dystrophy, now referred to as Complex Regional Pain Syndrome. By 2016 I was begging God to take me.

Throughout the first five years, I did everything in my power to improve, but I couldn't break free from the unrelenting pain. I kept going to physical therapy despite an increase of pain. I tried all of the recommended medications, none of which I could tolerate long term. I did all the standard procedures recommended by my pain management doctors, including injections and nerve blocks. I attempted a series of Ketamine infusions but was forced to discontinue them due to severe side effects. I was devastated because Ketamine gave me miraculous pain relief for the very first time since I was injured. It was a terrible blow, and I began to lose hope that I would ever find relief. I had two surgeries on my ankle, and three surgeries on my knee. Some were successful, some not.

Continued on page 4

IN THIS ISSUE

ZOE'S ZOOMALONG VIRTUAL CAMP CONTINUES THIS AUGUST!

FLAME OUT - A WALK TO EXTINGUISH RSD/CRPS IS THIS SEPTEMBER!

PICKLIN' FOR A CURE IS OCTOBER IN TUCSON, AZ

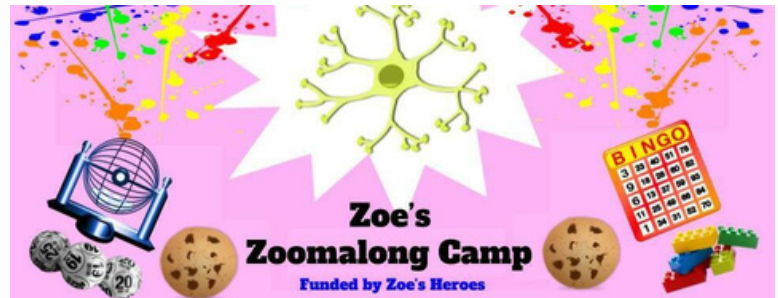
AIRLINE PASSENGERS WITH DISABILITIES BILL OF RIGHTS

COMPLEX REGIONAL PAIN SYNDROME: PRACTICAL DIAGNOSTIC AND TREATMENT GUIDELINES, 5TH EDITION

Zoe's Zoomalong Virtual Camp Continues this August!

Thank you to everyone who has supported Zoe's Zoomalong Virtual Camp this summer!

Camp will continue from August 9-11 and August 16-18th! Learn more and register by July 31st [here](#).



Purchase a Reusable Bag at Big Y to Benefit RSDSA

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!



Flame Out - A Walk to Extinguish RSD/CRPS is this September!



Save the date for the 4th Annual Flame Out - A Walk to Extinguish RSD/CRPS on Sunday, September 18, 2022 at Joe Palaia Park in Oakhurst, New Jersey.

[Learn](#) more about registering, donating, and participating!

Treating the Whole Person: Optimizing Wellness Virtual Conference is September 12-15, 2022

Our live conference sessions will stream each evening from September 12-15. Stay tuned for more details on our speakers and how to register!



Picklin' for a Cure is October in Tucson, AZ



The 2nd Annual “Picklin’ for a Cure” event supporting RSDSA, Lewy Body Dementia Association, and The ALS Association will take place October 14-16, 2022 at Udall Park in Tucson, Arizona. Learn more [here](#).

Interested in writing for the RSDSA blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog!

If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or in order to help those who may be in the same part of their journey as you, send us an email at alexisdavis@rds.org.



Continued from page 1

I took steps toward emotional and mental health as well. I tried to continue practicing meditation every morning as this was my routine for over 20 years prior to my accident. I knew that I had to stay disciplined because if I didn't, that would mean I had completely lost myself on the very deepest level. I tried my best, but pain was a major distraction. I also spent one year seeing a Pain Psychologist every week. This was my saving grace. I was fortunate to talk with someone who understood the hopelessness a person feels when they lose their livelihood, their career and their body as they knew it, to chronic pain. By 2015 the CRPS had spread up my left leg and into my left arm. For the first time in my life I could truly define agony and despair. Although my Pain Psychologist gave me a safe place to express my feelings and to examine the enormous losses I was suffering, my depression and anxiety still held me down. I wasn't able to climb out from under it. With no relief in sight, I truly wished my life would end. My desperation scared me. I didn't trust myself anymore. I thought if the opportunity presented itself, I would choose death. Finally, one day I told my doctor that although therapy had been invaluable, it was not enough. I needed more.

He understood and told me about the Inpatient Pain Treatment Program at Johns Hopkins Hospital in Baltimore. He described the program to me and sent me home with a packet of information about it. There were aspects of the program that sounded perfect for me, and there were some that would give anyone pause, but I was truly desperate and willing to do anything.

I was terrified the day I admitted myself into the hospital in 2016. The unit was located on a locked floor where I was not permitted to bring any items that could potentially hurt me. The staff was kind, professional and most of all, empathetic. Never once did any doctor or nurse question my level of pain. That made me feel comforted and understood. They operated under the assumption that what we feel is to be taken as truth. No judgements, no feeling criticized or being doubted.

While the medical team worked diligently to find the right combination of medications for me, I was kept very busy with an interdisciplinary program which was designed to treat all aspects of life with pain. It included a host of therapeutic modalities used to educate and develop coping skills for chronic pain patients. Twice daily I attended nurse-led classes where I was constantly learning and developing skills relevant to life with chronic pain. Throughout the weeks I participated in physical therapy, occupational therapy, individual therapy, group therapy, bio-feedback, and learned about cognitive behavioral therapy. I used journal writing and art projects in my personal time as a creative outlet. I ate a healthy balanced diet and used that time to connect with other patients. I put everything I had into the program and found that I had become so busy engaging in healthy activities that pain was no longer the very first thing on my mind at every moment. Thoughts of pain were still there, of course, but more in the background. I would be amazed every time I would catch myself "not" focusing on pain. I had learned the art of distraction.

I stayed the course, and after two months Inpatient and one month in Day Hospital, I was well enough to be discharged. The combination of medications plus mental, physical and emotional support worked for me. Of course the pain was still there, and still is, but I had learned to separate the physical pain from the emotional pain. I left feeling renewed. Integrating back into normal life, however, was unnerving. Going from such a rigid routine to having total freedom scared me. I didn't know if I'd continue to be successful without the support I had grown accustomed to. But I was. This had been a life-changing experience. I had truly come to accept myself and my situation, and that changed my entire outlook on my future. I made the decision to carry on with grace and with faith that things were going to be okay no matter what, instead of living in fear and resentment. I understood that I am much more than my diagnosis, that I am an entire being with a life and a purpose.

These are some of the lessons gleaned from my time in the program at Johns Hopkins Hospital:

1. The more I do, the more I "can" do.
2. We are not alone. There are professionals who do understand and who are determined to help us.
3. I can relate to all chronic pain patients, not just those with CRPS.
4. Practicing mindfulness reduces stress, which reduces pain.
5. Remember to challenge negative thoughts with fact-based evidence and replace those thoughts with positive ones.
6. Eliminating alcohol, cigarettes, caffeine and sugar brings some relief.
7. The way I feel physically is not a reflection of who I am as a person.
8. My label, title, profession does not define who I am, and does not determine my worth. My heart and soul do. And they remain unchanged with CRPS.
9. When I accept my situation instead of fighting it, a more hopeful outlook emerges.
10. Most importantly *CRPS is not going to kill me, but depression could. So, treat what is treatable.

One of the aspects of the program that I missed the most was group therapy. I was unable to find a local support group, so six months after being discharged, I founded an in-person, patient-led support group which I facilitate in New York. Eventually I moved to Connecticut and started another support group. My goal is to start more groups in years to come. Connecting CRPS patients with one another has become the single most important thing I've ever done. I've had the pleasure of watching group members help one another, and improve the quality of their lives. Most are managing well and living full lives despite their diagnoses.

I feel extremely fortunate to have learned so much from my time at Johns Hopkins. The program helped to reduce my pain to a more manageable level, improve my functionality,

and leave me with a hopeful outlook. I owe everything to my pain psychologist, Dr. Allen Lebovits, who put me on the path to healing by recommending me for the program. The Inpatient Pain Treatment Program at Johns Hopkins Hospital was nothing short of transformative. The outstanding team of doctors, nurses and staff saved my life. This experience changed me forever and I am forever grateful.

Airline Passengers with Disabilities Bill of Rights

The U.S. Department of Transportation worked with members of the Air Carrier Access Act Advisory Committee, which includes voices from the disability community and industry stakeholders, to create the [Airline Passengers with Disabilities Bill of Rights](#). The Bill of Rights describes the fundamental rights of air travelers with disabilities under the Air Carrier Access Act and its implementing regulation.



This easy-to-use summary will empower travelers to understand their rights and help the travel industry uphold those rights!

Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines, 5th Edition

RSDSA has funded the publication of the fifth edition of *Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines* in the May issue of *Pain Medicine*. The Guidelines are intended for a medical audience.

We intend to publish a lay version for the CRPS community in the future. To view the Guidelines, click [here](#).

Add The Disorder Channel to your Roku or FireTV

Rare Outreach Coalition has launched The Disorder Channel, a new platform that will have programming about rare diseases via short films and features, documentaries, narratives, and even fantasy films and talk show episodes focused on rare humans.



Learn more about the content on The Disorder Channel and how to add it to your streaming lineup [here](#).

The Show of Force: Ladies of the Low Country Who Ride – October 1, 2022



The Show of Force is a unique fashion show experience, combined with a gala of catered dining, art exhibits, auctions, and more, benefitting RSDSA. CRPS Warrior Jessica Dutkiewicz wanted to use her platform and background as an artist, storyteller and philanthropist

combined with her love of motorcycle riding to bring light to CRPS. She's created an exclusive, memorable experience unlike any other through poignant visual arts for the Southeast region to enjoy.

Jessica has been working on "The Show of Force" for over four months raising awareness for CRPS and doing additional events to support her big show. She has been running up and down Florida and Georgia to share information about CRPS by organizing multiple events to sell tickets and calendars, appear on podcasts, give local radio interviews with WIXV I-95, and run small fundraisers.

Show of Force sponsors:

Beach Insurance Group – Hannah Valentine | Coaches Corner | Designs by Ruby | Lewis Color | Southern Biker Gear | Savannah River Logistics | VG Collision Center | Woodstock Productions

With support from:

ABATE District 11 | WIXV, I-95 Radio | Bikers of the Coastal Empire

Show of Force volunteers and models:

Ashley Dean | Kristina Dutkiewicz | Marlee Edgar | Tabatha "Peaches" English | Toni Hauser | Legend Hendrix | Faye Holloway | Logan Jones | Jackie Phillips | Daijha Porter | Skyler | Anne Marie Tillman | Hannah Valentine

Surviving CRPS Through Peer Advocacy



CRPS Warrior Melissa Wardlaw joined Melissa Adams on the "I Am Not My Pain" podcast on an episode titled, "Surviving CRPS Through Peer Advocacy."

Melissa was diagnosed with CRPS type 2 as a result of a non-paralyzing injury. She learned early the value of being her own advocate, but she also realized the tremendous gap in support, which is why this fierce warrior spends her time providing free peer counseling and advocating for CRPS and chronic illness awareness.

Listen to Melissa share incredible insight into CRPS as well as offer valuable advice for living with chronic illness on [Spotify](#) and [Apple](#). If you are interested in online peer counseling with Melissa or if you live in the Metro Atlanta area and want to attend her in-person empowerment group for CRPS/RSD, chronic illness and pain, contact Melissa at crpsatl@gmail.com.

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](#) | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager | Lynn & Michael Coatney
[The Cochran Firm, National CRPS/RSD Lawyers](#) | Takeda