# IN RARE FORM



Make a list of words that describe who you are.			
Write about h	ow your illness h	as impacted you	r identity.

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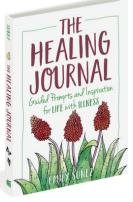
DISCOVER MAGAZINE: CHRONIC PAIN MAKES YOU THINK DIFFERENTLY Review of The Healing Journal: Guided Prompts and Inspiration for Life with Illness by Emily Sunez

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Our inner thoughts and the words we choose have a tremendous impact on our outlook on life. I found that as I read through some of the affirmations in <u>The Healing</u> <u>Journal</u>, I couldn't help but feel uplifted. I even caught myself smiling. At other times they made me a bit emotional because they echoed many of the truths that I had arrived at on my own path to healing over the past decade with CRPS.

The Healing Journal is filled with thoughtfully worded questions that you might hear at a chronic illness support group. It encourages you to challenge your inner thoughts and beliefs about your life, yourself and your future. Doing the inner work by answering the difficult questions and reaffirming positive thoughts sets you up for a very therapeutic experience.

Although you will find lovely floral illustrations throughout, it is not just another "flowery" journal. It is a wonderful resource that serves to support you through the tough days and acknowledge the positives on the better days. *The Healing Journal* is likely to benefit anyone with chronic illness, and I will recommend it to all of my support group members without hesitation. This beautiful journal just may help you find your way to a healthier outlook as it puts you on a clear path to healing.



## Facebook Live with Adeepa Singh, MD, FAAPMR and Robin Asken - Thursday, April 21, 2022



Dr. Adeepa Singh



Robin Asken

Join RSDSA for our next Facebook Live with Adeepa Singh, MD, FAAPMR and Robin Asken on Thursday, April 21st at 7:00p Eastern as they discuss an overview of @BrainAndSpineNY's IV Ketamine Infusion Program.

Dr. Singh is skilled with the intricacies of pain management and is double board-certified in Physical Medicine and Rehabilitation and Pain Medicine. She specializes in painful syndromes of the musculoskeletal system including the neck, back, and peripheral joints. As a pain management specialist and physiatrist Dr. Singh aims to restore function by alleviating pain that limits her patients from their daily activities. She has a particular interest in neuromodulation for the treatment of chronic neuropathic pain.

Robin Asken is the Director of the Ketamine Infusion Program for Infusion Therapeutix, an affiliate of Brain and Spine Surgeons of New York. Before joining BSSNY, Robin worked in pain management for more than 15 years, in both healthcare administration and practice development. In this capacity, she developed a ketamine infusion program positioning the medical

practice as a leader in the field. Robin's healthcare career spans over 40 years in multiple specialties. She works with passion and purpose as a patient advocate to ensure patients have access to the best treatments and care available.

Bring your ketamine questions to our Facebook Live session on Thursday, April 21st at 7p Eastern. The stream will be at the top of our newsfeed at <u>facebook.com/rsdsa</u> and the replay will be available after the stream on Facebook and on our <u>YouTube Channel</u>.



# Join us for Zoe's Virtual Zoomalong Camp for Youth In Chronic Pain



Through a sponsorship by Zoe's Heroes, RSDSA and The Coalition Against Pediatric Pain are inviting 20 children with chronic pain between the ages of 5 and 17 to join us virtually this summer for six sessions of hands-on fun and games, creating, building, and cooking!

Learn more and sign up <u>here</u> before Friday, April 15, 2022.

# Dallas Warriors: Attend and Support Walk Strong on Saturday, April 16th

18-year-old Miller Kerr is hosting a CRPS Awareness Walk, Walk Strong, on Saturday, April 16, 2022. The event will begin at 9:30 a.m. at Semones Family YMCA (4332 Northaven Road, Dallas, Texas 75229).

Learn more about Miller's journey and how to register/support by clicking <u>here</u>.

A special thank you goes out to J. Macklin's Grill for sponsoring Walk Strong! Be sure to visit them for a great meal when you're in Coppell, Texas.



# **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 are, send us an email at alexisdavis@rsds.org.

#### APRIL 2022

## RSDSA's 3rd Annual Virtual CRPS Awareness Walk is Saturday, June 11th, 2022



RSDSA is excited to announce that our 3rd Annual Virtual CRPS Awareness Walk is **Saturday, June 11, 2022**, and registration is open!

In 2021, we had 57 walk teams as well as participants and donors from 34 states and four countries. Our goal was to raise \$50,000, and we surpassed our goal and raised over \$60,000. Thank you to all who participated, registered, & donated.

We hope to make this year more successful with your help by aiming higher and raising our goal to \$75,000. We know that the CRPS community has the strength and dedication to band together and make amazing things happen!

Living with a chronic disease, and constant pain, is daunting to say the least, but to see everyone come together to raise awareness for this rare condition is very inspiring. Seeing the support from so many reminds CRPS warriors to keep fighting and reminds them that they are not alone!

#### **Registration Information**

- \$25 for adults, \$10 for children ages 5-12
- Register either as an individual or by creating a team
- RSDSA's 3rd Annual Virtual CRPS Awareness Walk t-shirt & medal are included for all United States and Canadian registrants

Together we have the power to do so many wonderful things with the goal of having CRPS Warriors lead better lives. The time to find a cure is NOW, and we can't do that without your help.

#### Fundraising Tips to Have a Successful Walk

- Set a fundraising goal, don't be afraid to stretch and put an aspirational goal. You know what you're working towards, and your goal will motivate others to help you!
- Lead by example. Donate to your own page! People are more likely to give if you support your own cause! It can be any amount, but it is your donation that often sets the bar. If you'd like to see your donors give \$25, start with your own \$25 donation.

- On your team page be sure to express why you formed this team and what it means to you.
- Create a personal page, share your own story and experience with CRPS including photos such as pictures from previous walks you may have been involved in.
- Post information on your social media, so people know how to join your team for the Walk or how to donate. People in your social media circles will surprise you in wonderful ways!
- Remind your teammates to fundraise among their friends and family.
- Ask your employer if they have a matching gift program. Many companies will match what you fundraise which doubles the donations.
- Identify your donors. Start with the people closest to you. Send emails from your customized Walk page to ask for support. You can also thank your donors and email your team members from your walk dashboard.
- Send an email or text to your family/family friends, college friends, high school friends, Facebook friends, neighbors, and colleagues!
- Share on Facebook about your walk, whether people want to join your team or give a gift. Go to "My Fundraising Tools" Select "Fundraising Dashboard" Then select "Share My Personal Fundraising Page
- Fundraise on Facebook and Twitter with a personalized message
- Please don't be afraid to ask businesses, companies, and organizations, such as a physical therapy practice, if they are interested in sponsoring the walk.

We look forward to "seeing" you on June 11th. Although we wish we could see all of you fighters in person, the benefit of our virtual walk is that you can have team members from across the country or even around the globe! This allows people freedom to walk on their own schedule and still feel involved in such a wonderful experience!

We have dealt with the burning pain; we have walked through the fire, and it is time to light it up and blaze a trail to our goal of \$75,000!

For more information or questions, please contact Jeri Krassner, Special Events Coordinator, at jkrassner@rsds.org or Kelly Considine, 3rd Annual Virtual CRPS Awareness Walk Chair at kelly.crpsawareness@gmail.com.



# Purchase Tickets to the Connecticut Sun vs. Seattle Storm Game - Friday, June 17, 2022

RSDSA is excited to be teaming up with the Connecticut Suns of the WNBA for a community building fundraiser at their game against the Seattle Storm on Friday, June 17, 2022 at Mohegan Sun Arena in Uncasville, Connecticut.

RSDSA will have a table on the concourse and will be involved in other activities during the game including a raffle.



<u>Tickets</u> are now available and the arena will have ADA compliant seating available.

## Save the Date! Our annual 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 guests and how to register!

## It Hurts Until You Die Full-Length Documentary

<u>"It Hurts Until You Die"</u> tells the saga of millions of Americans with chronic pain who are unable to obtain compassionate, humane care. They live in the shadows, stigmatized, fearful, and ashamed. This no-holdsbarred exposé of the U.S. healthcare system's failures demonstrates the complicity of the DEA, regulatory bodies, criminal justice system, insurance companies, and a political system that denies people with pain their



basic right to pain relief, empathy, and understanding. Yet the production leaves the audience with some hope that there is a way forward if society and the people in power are willing to listen.

## Discover Magazine: Chronic Pain Makes You Think Differently

A CRPS Warrior recently shared this article with our team and mentioned that he found it "to be very interesting in some ways and sadly naïve in others." What do you think?

Chronic pain can shape lives in profound ways, from hastening an early retirement to causing a reliance on prescription painkillers. Yet studies into long-term pain reveal an even more



insidious consequence — people in pain often make poorer decisions, including risky financial ventures and unhealthy food choices. <u>Read the full article here.</u>

## Save the Date: The Show of Force on Saturday, October 1, 2022 from 6-10p in Thunderbolt, Georgia

"THE SHOW OF FORCE" is a unique fashion show experience, combined with gala art exhibits, auctions, catered dining 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.

Learn more <u>here</u>.



### **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.

## We want your feedback!

Please send any suggestions or upcoming events of interest to our community to <u>info@rsds.org</u> and please consider donating at <u>rsds.org/donate</u>.