rsdsa

community update

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CALL FOR AUTHORS & IDEAS

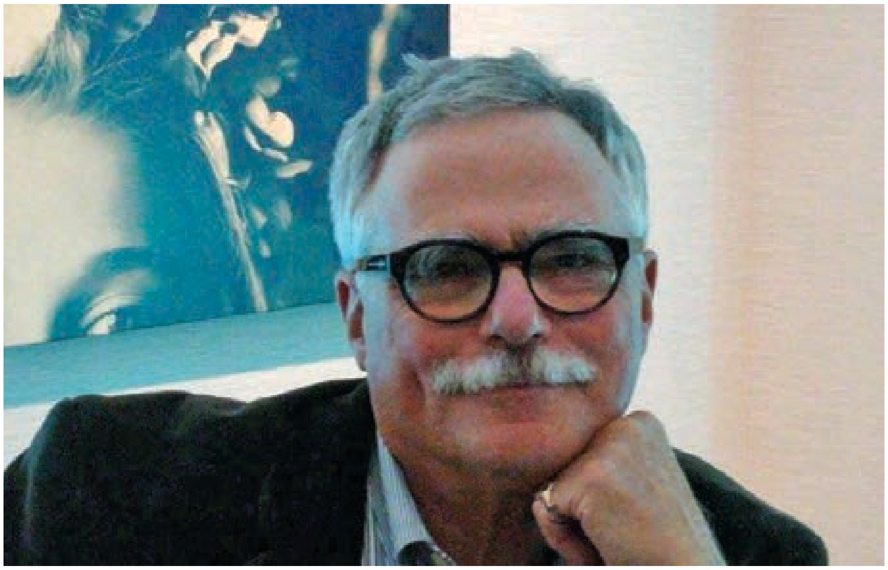
Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? Is there a special topic you would like to see included in the RSDSA Community Update? We would love to hear from you. Please email your thoughts to info@rsds.org.

SPECIAL THANKS

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Arkansas Pain Center, LTD, Baker Family Charitable Trust, Center for Pain Management, Edelman, Krasin & Jaye PLLC, Grünenthal, Law Office of Scott Callahan, MCARE Pharmacy, Sutliff and Stout Neurologic Relief Center, NoPainHanna, Oska, Pope/Taylor National CRPS/RSD Lawyers, Shirley Ryan Ability Lab, Vitalitus.

CDC Issues Clarification of Guidelines *for Prescribing Opioids for Chronic Pain*

BY **JAMES W. BROATCH, MSW** • RSDSA EXECUTIVE VICE PRESIDENT, DIRECTOR



Three years after the Center for Disease Control (CDC) released its Guidelines for Prescribing Opioids for Chronic Pain, (**intended for primary care providers** (**PCPs**), three of the Guideline authors recently wrote an article in the April 24 issue of *New England Journal of Medicine* **acknowledging untoward consequences related to the misapplication of the Guidelines.** For the past three years, RSDSA staff, the Board of Directors and I have struggled to help individuals with Complex Regional Pain Syndrome (CRPS) and other chronic pain syndromes deal with the misapplication of this Guideline. Individuals on long-standing high-dose opioid therapy reported being abandoned by their PCPs or pain specialists, were forced abruptly to taper to a much less efficacious dosage (90 Morphine milligram equivalents or below) or were forcefully tapered from stable medical regimes without regard to withdrawal symptoms. According to Thomas Kline, MD, PhD, at least 40 individuals have died by suicide due to physician abandonment, being forcefully tapered without patient consent and then being unable to find an alternative efficacious intervention or medication to treat their unrelenting pain (https://medium.com/@ThomasKlineMD/opioidcrisis-pain-related-suicides-associated-with-forced-tapers-c68c79ecf84d?_branch_match_id=654735689912191778).

Furthermore, insurance companies, state legislatures, pharmacy boards and chain stores have also created obstacles for access for opioid therapy for people with chronic pain.

If you are having difficulty with your physician regarding your ongoing opioid therapy, RSDSA can provide you with the NEJM article by calling 877-662-7737 or by emailing info@rsds.org

If you are on Twitter, consider following @bethdarnall; @ThomasKlineMD; @CIAAG-Lauren; @RSDSA; or follow Lynn Webster, MD: http://www.lynnwebstermd.com/

RSDSA ENDS ITS 20-YEAR STUDY

RSDSA has ended its 20-year study of the long-term health impact of CRPS on individuals diagnosed with it. We thank everyone who participated. We have begun the analysis of the almost ten years of data and hope to publish as soon as possible. We are very grateful for the Brodsky Foundation's underwriting of this groundbreaking study.

We're seeking sponsors for this newsletter for those who need it most. Earlier this month, we mailed a special appeal to our RSDSA community to ask for their help in sponsoring the newsletter for those who are housebound or don't have Internet access. For the past several years, RSDSA has published the newsletter in both electronic and print version at no charge. Other organizations have chosen to publish only an electronic version because of increased printing and postage costs, but we have not.

Instead, we 're reaching out to our readers for help. Please become a sponsor of your newsletter so those who need it most can continue to receive in the mail. Please make a gift in the enclosed envelope to help RSDSA serve as an instrument of hope and information to those struggling with CRPS. Thank you.

James W. Broatch

Color The World
Orange
for CRPS/RSD

THE SIXTH-ANNUAL
COLOR THE WORLD ORANGE™ *is*
NOVEMBER 4, 2019

Get your orange ready! The sixth-annual Color The World Orange™ for CRPS/RSD Awareness on November 4, 2019 will be here before you know it! Here are some ideas on how to get involved:

- The easiest way to participate is to wear orange on November 4 and post a picture to social media with the hashtag: **#CRPSORANGEDAY™**
- Plan a Color The World Orange™ party! We love receiving the amazing photos from Color The World Orange™ events from across the globe. Serve orange food and orange drinks, decorated with orange flowers, spread a lot of awareness and have a lot of fun!
- Change your Facebook page background to advertise November 4 as Color the World Orange™.
- Reach out to friends and family, encourage them to wear orange and learn more about CRPS/RSD.
- Ask local businesses to hang a sign advertising Color the World Orange™. You can find signs and pamphlets on our website: **www.colortheworldorange.com**

Pathways Pain Relief App

BY **SANDIP SEKHON** • FOUNDER OF THE PATHWAYS APP

HELLO@PATHWAYS.HEALTH

As a CRPS patient, many different parts of your life have been affected by pain. The list may include day-to-day pain management and relief, sleep trouble, balancing relationships, and so on.

From personal experience, we know how hard life can be when dealing with persistent pain. It does not have to be this way. Pain patients need and deserve more.

Because of that, we created the Pathways pain relief app: a self-help program that equips you with strategies and techniques to turn the volume down on persistent pain. These are designed to help calm your pain system and improve well-being.

Let's go through some specific ways in which the Pathways program may help you as a CRPS patient:

1. REDUCING FEAR OF PAIN

It is widely acknowledged that fear of pain leads to increased pain intensity, and CRPS patients are no exception.

As a first step, we help you to let go of this fear. Once we are able to do that, your pain system will be able to calm and reduce the intensity of pain.

2. ON-DEMAND PAIN RELIEF TECHNIQUES

When a painful episode comes on, you will often find yourself white-knuckling the pain. This can make a painful episode even worse.

We empower you with proactive techniques that help shorten, or even break the pain cycle. From mindfulness and meditation exercises, to follow-along breathing exercises, and guided visualizations, which brings me to the next point.

3. GRADED MOTOR IMAGERY AND VISUALIZATION PRACTICE

When dealing with CRPS, your perception on the affected parts of your body can become altered. The affected limb(s) may start feeling detached from your body, you may perceive it as larger, heavier or even a different temperature compared to objective assessment.

Guided imagery, such as visualizing movements, can help to correct this. Did you know that just imagining a painful part of your body moving helps to re-calibrate the brain's perception of that body part, often without the associated pain?

In other words, just thinking of a painful movement activates the same neural pathways associated with actual practice, but without the associated pain. You can think of it like sneaking under the pain radar. The more we do this, the more we desensitize your pain system.

As an example, we had a patient who was unable to move his left arm without feeling severe pain. So to start, he began imagining a painful movement - lifting a cup of coffee. After a week, he began watching his partner perform this movement, while continuing to imagine that he was moving his arm.

Two weeks later, he was able to perform the actual movement with 30% less pain, and he continues to improve.

4. GRADED PHYSICAL ACTIVITY

Moving safely is key to overcoming persistent pain and improving health. We want to do enough to feel the benefits of physical activity, but not too much as to risk a flare up and freak out your pain system. We guide you through this, and offer a growing number of physical activity sessions.

5. WELL-BEING

Chronic pain conditions including CRPS can sap the joy from life. But stay strong and have hope. There's no reason why you cannot still love life. We guide you on how to improve well-being in every part of life, whatever your level of pain.

From getting a good restorative sleep, to nutrition, working on your relationships, and more.

You can find the Pathways app on both the Apple AppStore and Google Play. It is free to download and one fifth of our pain relief program and meditations are free. You can then choose to subscribe with a money-back guarantee if you practice our techniques, and do not find pain relief.

A program like Pathways would have saved me years of debilitating RSI pain. That is why I created it, and I hope it helps you find relief.

To your health,
Sandip - *Founder*

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Take a look at how the Pathways Pain Relief App has helped fellow CRPS Warrior, Robert Hicks

The Pathways Pain Relief App has helped me in so many ways.

I was diagnosed with CRPS three years ago and, as many of us have done, I saw doctor after doctor. In hindsight, some doctors contributed to the pain by instilling fear of movement while others offered tidbits of help, but nothing substantial.

With the app, it took into account every aspect of my life that had been affected by CRPS. The sleep therapy section helped massively. My body perception, especially on my left arm, was out of whack. The visualization process and graded imagery the program took me through seemed to have helped reduce pain by at least thirty percent.

The skin on that same arm was very sensitive. I heard about the desensitization process before but the way Pathways presented it was much more useful. I practiced skin desensitization and have seen a big improvement (although it is not completely better yet).

The program helped me understand how fear, fear-avoidance and pain-anxiety was a direct cause of my body's pain response. I was given techniques to combat these things, which again has helped.

I have never been into meditation or mindfulness. However, since that is an integral part of the program, I gave it a shot. It has become another tool that has really changed my perspective on my condition.

I cannot begin to give this enough credit. There's so many more ways this app has helped, such as understanding my hypervigilance, how pain works, getting me back into safe, graded movements.

For the first time in years, I'm hopeful about my future. I never normally write reviews and that sort of thing, but this changed my life, so the Pathways Pain Relief app deserves it. I can see this helping many people with persistent pain.

Best,
Robert

RSDSA Collaborating with Partners

BY **ELIZABETH A. SEICKEL (RN, BSN) • AKA "NURSE BETH"** • BSEICKEL145@GMAIL.COM

RSDSA has been a grassroots organization since 1984, and continues to create relationships with diverse groups, organizations, and medical communities to support the CRPS community.
This makes the partnership between RSDSA and American Society for Pain Management Nursing (ASPMN) so vital. RSDSA has expanded from a local partnership with ASPMN-*Long Island Chapter*, which began in 2016, to a national level, serving as an exhibitor at their ***ASPMN 28th National Conference, "The Changing Tides of Pain Management"*** in 2018.

The ASPMN mission is to advance and promote optimal nursing care for people affected by pain by promoting best nursing practices. This is accomplished through education, standards, advocacy and research, making ***nurses indispensable*** members of the healthcare team.
Jim Broatch, RSDSA Executive Director, VP and Nurse Beth had the pleasure of networking with a diverse group of nurses, advanced practice nurses, nursing administrators, CNOs, staff nurses, clinical nurse specialists, clinical educators, academic educators, NP and researchers who participated from across the country. For many, it was the first time hearing about the non-profit organization RSDSA and the CRPS community it serves.

On the flip side, Jim and I were pleasantly surprised to speak with practitioners who ARE actively treating CRPS patients across the country. Discussing the clinical treatment options in their communities will help RSDSA update our patient resource list. Throughout the conference, hundreds of nurses inundated the exhibit wanting to digest posters of *"What is CRPS?" "Signs and symptoms," "Pediatric accredited CRPS course," "What is Ketamine and LDN?"* (low dose naltrexone) and to obtain RSDSA's patient educational resources to utilize in their communities.
https://rsds.org/empower-yourself-with-the-latest-crpsrsd-information/

(one of the 17 exhibit booths)

It was a testament to the power nurses bring to their institutions and practices and the absolute importance of RSDSA in creating these relationships.
Did you know ASPMN has local chapters? Could this be the connection you and your medical practitioners network with to bring RSDSA and CRPS information to your community and support group?
http://www.aspmn.org/chapters/Pages/localchapters.aspx

Since nurses are the gateway to engaging communities and their workplaces with energy and knowledge about national issues and trends, RSDSA is moving forward in 2019 by expanding its role at *ASPMN 29th National Conference* in Portland, Oregon where this year's theme "Bridging the Gaps in Pain Management" enables RSDSA to continue its mission. RSDSA is grateful for this unique partnership.

Another unique partnership RSDSA has fostered is with the New York Chiropractic College (NYCC). With the support of Ms. Melissa Murphy, the Levittown health Center Administrator, RSDSA was able to exhibit at their November 17, 2018 event "A Women's Health Symposium on Natural Health Care." Meeting staff, students and community members, Nurse Beth was able

Nurse Beth & Ms. Melissa Murphy, NYCC administrator

to share resources about RSDSA as well as CRPS education. In fact, NYCC has supported the RSDSA Annual Long Island CRPS Awareness Walk & Expo since it's inception in 2016 through the donation of a raffle basket along with plans to continue CRPS education for staff and students, including student volunteer opportunities at future RSDSA walks. RSDSA appreciates this continued relationship.

RSDSA had another opportunity in 2018 to extend CRPS education with Zucker Medical Students at Hofstra University at the medical school as well as volunteer opportunities at "RSDSA 3rd Annual Long Island CRPS Awareness Walk." In addition to the students volunteering at the medical tent, they were provided unique opportunity to speak one on one with CRPS patients to hear their stories. This provided students first hand experience and insight into the complexities CRPS patients face, while having the opportunity to meet with diverse health professionals in the "education and exhibit" tent. All of which supplements the lack of pain education in medical school curriculums. On average, there are only five to seven hours of mandatory pain education in medical schools versus over 75 hours in veterinary school.

RSDSA followed up with a presentation to the neurology club students and its professor titled "Your Patient has CRPS: Now What?" provided by Jim Broatch, Nurse Beth and Nurse Amanda, both of whom have CRPS. Interesting to note, one of the students shared that there was a question about CRPS on a state board's exam. RSDSA outreach is making a difference!

Finally, RSDSA appreciates all the media outreach in 2018 thanks in part to Stacey Udell, PR counsel volunteer for "RSDSA Annual Long Island CRPS Awareness Walk & Expo."

To hear a sample of this, please visit https://rsds.org/rsdsa-newsroom/

*WBAB (102.3FM); "Plugged into Long Island" with radio host: Ted Lindner aired August, 26 2018

*WLI News Radio,(102.3FM) Non-Profit Voice, WLI radio host: Allison Brecher August 4, 2018 LIVE

*WHRU Hofstra Student Producer Emily Sauchelli and Kimberly Donahue, WRHU News Director

*Newsday reporter Janelle Griffith https://www.newsday.com/long-island/nassau/complex-regional-plan-syndrome-1.21037011

*East Meadow Herald reporter Brian Stieglitz

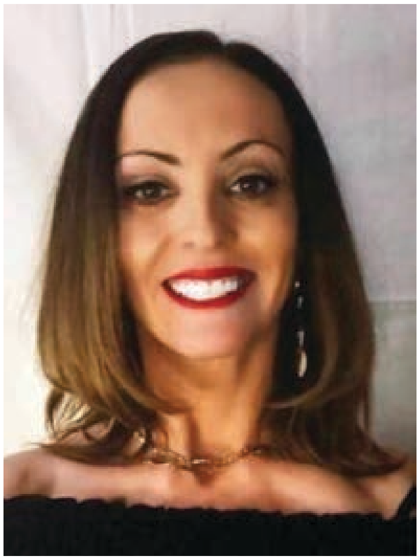
Jim Broatch, Nurse Beth, radio host: Ted Lindner

Long Island walk committee: Nurse Beth, Stacey Udell, Debbie Hunter, WLI radio host: Allison Brecher

Long Island Walk Committee members, Jim Broatch, and Newsday Reporter Janalle Griffith

Advocating for the Chronic Pain Community

BY **JENNY PICCIOTTO**



Lauren Deluca is the founding member of the nonprofit Chronic Illness Advocacy and Awareness Group (CIAAG) which advocates and lobbies for the chronically ill. The organization is dedicated to patient education and empowerment. According to their website:

The Chronic Illness Advocacy & Awareness Group (CIAAG) envisions a world where those with disabilities and chronic illnesses are guaranteed palliative care and access to prescription life sustaining medications without stigma, fear or push-back, particularly from the medical community. We shape social narratives to promote inclusion of disabled rights and individualized patient-centered care. We lobby against political agendas and misinformation campaigns that interfere with patient's access to vital medications and palliative care.

In this time of healthcare policy change, a complex array of factors is contributing to a loss of adequate medical care for pain patients. The overreach of CDC Opioid prescribing guidelines has left many people with intractable pain suffering without adequate treatment, leading to an increase in suicides.

Healthcare policy is also subject to economic factors such as the influence of special interest groups, drug manufacturers, corporate profit, and the financial incentives for insurers to reduce the cost of pain care, estimated at $650 billion/year. The business of healthcare has dehumanized real people, reducing them to statics.

Lauren's own experience at the hands of the healthcare system compelled her to create the organization. After her condition was mishandled, misdiagnosed, and left untreated, she faced a life threatening medical emergency. Yet she was perceived as a person seeking drugs, not a person in a medical emergency. "If I wasn't living it, I wouldn't believe it," she says.

She explained what happened to her at a session of the UN General Assembly Special Session (GASS) on Drugs in Vienna, Austria, in September of 2018. GASS is tasked with developing a plan to address the global drug problem and CIAAG, as a nongovernmental organization, was invited to speak on behalf of the chronic pain community. Lauren presented the policy solutions CIAAG has developed to address the needs of the chronic pain community while balancing the issues of world drug abuse. Her compelling address is shared below.

> *"Thank you for the floor, Chair, honored delegates, ladies and gentlemen. I would also like to thank the Vienna NGO Committee on Drugs and the International Association for Hospice and Palliative Care for their encouragement and support for my statement on behalf of patients who need internationally controlled essential medicines for the relief of pain.*
>
> *My name is Lauren Deluca and I am the Founding President of Chronic Illness Advocacy & Awareness Group, a national non-profit working in the United States to raise awareness of the crisis of untreated pain in our country.*
>
> *Our organization was formed as a result of my personal healthcare struggles in 2017 when I suffered from a pancreatic attack and was denied access to appropriate care.*
>
> *I have, quite literally, been fighting for my life since May of 2017 and I am only standing here today due to the extreme measures I took to get myself and fellow patients the help we need to manage our pain and severe symptoms. For nearly a year I was bounced doctor to doctor and turned*

away. One doctor told me he had taken all their patients off opioids rather than risk losing his license for anyone.

Legitimate pain patients such as myself have been slandered by care teams when we attempt to advocate for pain control as our right. Several pain management clinics have told us they no longer take new patients as the US Drug Enforcement Agency has advised them they would be shut down and their licenses withdrawn if they prescribed to any new patients.

I recently had a feeding tube put in as I can now, no longer eat solid foods due to the damage I incurred; all stemming from a denial of care based on wholly on physicians' fear of law-enforcement and the legislative changes taking place to address the overdose crisis. Let me be clear. These measures are not addressing the current opioid overdose crisis. The tragedy of people using illicit opioids and dying from overdoses, should not impact pain or palliative care patients such as myself. Our lives matter as much as theirs, yet we are being punished by bureaucrats, regulators, and law enforcement agencies with no medical training.

Sadly, what I went through, and many others are going through in the US is becoming the "new normal" for patients suffering with chronic illness, disease and incurable conditions. Law enforcement targeting of physicians and patients increased, and there is no relief in sight, either for families suffering from the opioid epidemic, or for patients and physicians. This is why I paid my own way to come from the US to speak to you today.

If the current direction continues, all individuals will be cut off from rational access to essential opioids except for patients suffering from end-stage cancer. And even some cancer patients are coming under scrutiny, as regulators question whether their cancer is "painful enough" to warrant an opioid prescription, rather than Tylenol.

Chronic Illness Advocacy & Awareness Group is working with elected officials and the patient community to help restore balance between protecting the public health from drug abuse and the safe, essential access to opioid analgesics for the chronically ill, older persons, and persons with disabilities.

CIAAG is proposing a practical solution: we have recommended a Palliative Care Model to properly enable those with known painful conditions and illnesses to receive the appropriate care they need using a coordinated care team approach. Individuals would receive treatment for the various symptoms of their illness or condition, including appropriate pain relief, to promote quality of life for the patient and their family.

In addition, we have devised a tracking method via the ICB-10 codes to categorize the data by the illnesses type rather than number of opioid doses. This tracking mechanism will permit law enforcement to ensure proper controls are in place to alleviate diversion of controlled substances, while maintaining the ability to develop data on "best practices" for opioid prescribing.

While we recognize the importance of having controls on scheduled medications, we must not lose sight of the fact that opioids are life-sustaining, essential medications. The United States' approach to combatting the overdose crisis is fatally aggravating it, as reflected in the record breaking number of deaths in 2017 and 2018, despite prescribing being at a 25 year low.

Failure to protect patients' rights to access essential medications and healthcare will result in the loss of innocent lives through suicide, and inflate an already deadly statistic to a human rights crisis. And, we as a nation and a community, deserve better.

The INCB and CND have been helping the world become aware of the crisis of access to controlled medicines in more than 75% of the world. The US opioid crisis must not be allowed to derail the progress made during the UNGASS, at the Human Rights Council, and at the World Health Organisation.

I thank you."

In the course of advocating for herself, Lauren realized two important things. First, that the State and Federal legislators she reached out to for help had no interest in meeting with her as an individual. By reframing her message and becoming a corporation, her voice gained legitimacy and she could get meetings with policy makers. Second, she realized how wide spread the problem of inadequate health care is.

Through the Facebook group she launched in fall of 2017, she met many people who shared similar stories. "Learning this was happening to people all over the country was a wake-up call. It wasn't just my problem, it was society's problem. I felt compelled to fight for all these people who had no special interest group to speak for them."

CIAAG was formed to be a resource for patient advocacy education and a platform for lobbying on behalf of patient interests. Through their partnerships with other pain organizations, they can collaborate, monitor, and speak out, giving a voice to the chronic pain community. RSDSA was the first member of the coalition, which includes the National Pancreas Foundation, Chronic Disease Coalition, and the Endometriosis Research Center, among others.

"The biggest problem," Lauren explains, "is the lack of communication between independent disease groups. When we collaborate, we realize we have shared needs across different communities. Together we have a lot more strength to be heard in Washington, D.C."

Taking on topics like affordable drug prices, big pharmacy interests, and the effects of the CDC Opioid Guidelines, members of CIAAG meet with governors, legislators, and international organizations. Their efforts include sending a Joint-Letter to House health care representatives in support of Medicare negotiated prices, ending monopoly abuses, and requiring transparency from drug manufactures and pharmacy benefit managers. They meet with leaders and present information at seminars educating both the public and policymakers about how "the current approach to the Opioid Epidemic is in fact now creating a crisis of untreated pain leading to increases in patient abandonment, abuse and a drastic rise in suicides in America."

CIAAG invites you to join their efforts by becoming a member of the community through their website. Membership provides you access to their library of materials, advocacy training, tools for reaching out to your legislators, and email updates. You can also volunteer to take local action by becoming a member of the state leadership program. State leaders work together to monitor the progress of local healthcare legislation, make calls, write letters, and attend local meetings or hearings so patient's concerns can be weighed alongside the other factors driving the legislation of new laws.

"We want to develop a panel in each state to follow legislation," Lauren says. "We need to know what hearings are taking place, what bills are being written now. We need to be there or our rights will be taken away."

According to their website:

> *We all deserve compassionate, patient centered care that improves quality of life. CIAAG provides personal empowerment & education in our local communities. Learn about how you can get involved locally to help effect real time policy change to ensure access to medicine. This affects all of us: We are all one accident away from this becoming your life.*

Reflecting on her journey, Lauren says that since getting her feeding tube, she has gained weight and gotten stronger, both physically and mentally. "I was bed bound and hated being alive," she says. "I am still mostly homebound, with nerve damage and gastric episodes, but I'm learning how to deal with my limitations. I am relearning how to live my life, accepting what is, and adjusting my activities around my body. Having a focus – advocacy – keeps me sane. I was just an individual, but I learned how to engage legislative power. I want to teach others that their voices can be heard too, without even leaving the house."

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[i] http://www.unodc.org/documents/commissions/CND/2019/Contributions/Thematic_Debate/26_Sept/Lauren_De_Luca_NGO.pdf

[ii] https://www.ciaag.net/uploads/1/1/6/5/116509489/membership_tier_flyer.png

[iii] https://www.ciaag.net/uploads/1/1/6/5/116509489/why_become_a_member_of_ciaags_advocate_army__1_.pdf

ABOUT THE AUTHOR

Jenny Picciotto is a writer and CRPS patient who enjoys reading and playing the piano. She was a yoga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.

RSDSA Young Adult Support Group Facebook Page

BY **CAROLYN MCNOLDY** • CMCNOLDY@GMAIL.COM

If you are currently a young adult or remember what it is like to be a young adult, you understand that it can be a uniquely confusing time. You are not a child anymore but do not quite feel like an adult yet. There are so many life decisions to make about friends, dating and marriage, having children, college, careers, finances, where to live, etc. Throwing RSD/CRPS into the mix of young adulthood makes these life decisions even harder and more complicated.

During the last RSDSA Young Adult Weekend in November, attendees discussed how there is a lack of a young adult centered support groups online. No other support group page seemed to be what we were seeking out. We discussed starting a new online young adult support groups to fill the void and continue the peer support we experienced during the weekend. In April, the discussed page became a reality.

The goal of this page is to create a positive environment for young adults with RSD/CRPS to support each other and share information. If you are a young adult between the ages of 18-31 and are interested in joining the closed Facebook group, please visit the link (https://www.facebook.com/groups/332916620662853/?fref=mentions&__tn__=K-R) and answer the questions as prompted. We promise you will be among some awesome fellow warriors and you will not be disappointed!

ON THURSDAY, FEBRUARY 28, 2019 THE EMPIRE STATE BUILDING WAS LIT GREEN, PINK, LIGHT BLUE AND PURPLE IN HONOR OF ROCKET PHARM & RARE DISEASE DAY

WANTED

Individuals to:

- ✔ Set up a collection canister in your local grocery/convenience store.
- ✔ Plan an event with the help of RSDSA by emailing us at info@rsds.org.
- ✔ Fill up a Penny Pig with your spare change to help RSDSA sponsor children in pain at summer camp
- ✔ Help educate health care professionals by promoting the availability of our accredited courses on adult and pediatric CRPS
- ✔ Blog for our weekly Tuesday's Burn. Do you have a story or experience to share?
- ✔ Write an article for the RSDSA Community Update
- ✔ Promote awareness of CRPS by sharing your story with TV or newspapers (we can help you)
- ✔ Share your story of hope. Inspire others who are struggling as you have.
- ✔ Join our peer-to-peer program (see our back cover.

Ride For Warriors: *An Interview with Eric Moyal*

BY **LAUREN BENTLEY** • LAURENBENTLEY93@GMAIL.COM

As the editor of the RSDSA Newsletter, there are many aspects of the job that I love: reading about the latest research studies, promoting community awareness events, learning about alternative methods for coping with pain; but perhaps my favorite part is making connections with other members of the RSDSA community and listening to their stories.

I recently had the privilege to interview Eric Moyal, an energetic, enthusiastic young adult who recently earned his masters' degree and works in fundraising for Brandeis University. He is also the brother of a CRPS Warrior.

Throughout our conversation, there seemed to be one theme that prevailed above everything else: Eric really loves his sister – so much so that he is biking 1,700 miles to raise awareness and research funding for CRPS. No, 1,700 miles is not a typo. Eric will bike from Medford, Massachusetts, where he currently resides, to his hometown of Bay Harbor Islands, Florida. Along the way, he plans to stop in various cities and meet with those who have CRPS, along with their families. This biking fundraiser is fondly named the "Ride for Warriors."

Eric first became aware of "the most painful disease known to man" when his younger sister, Anais, was diagnosed with CRPS approximately five years ago. Anais was riding her bike one November day when she was suddenly hit by a car. She was fifteen years old at the time of her accident. Although the initial trauma of Anais's accident began to heal, she still felt incredible pain – and that something was still incredibly wrong. It took doctors two years to finally diagnosis Anais with CRPS and, by that time, the disease had already taken a tremendous toll on her body.

When asked what inspired him to create the Ride For Warriors, Eric said "I really love my sister, we're like best friends. We talked a lot over the past few years about what she is going through and how hard it is. Part of the struggle isn't just about getting a diagnosis, it's convincing yourself that your pain is real when everyone else is telling you nothing is wrong." He added, "it's crazy to go through something like this and have nobody believe you. I want to make sure people are aware that CRPS exists."

As somebody who has watched her mother battle CRPS for over a decade, I understand feeling pure helplessness and frustration when there is nothing you can do to take away their pain. During our conversation, we bonded over shared stories of misdiagnosis, doctors' disbelief of our loved ones' pain, and the protectiveness felt every time we heard somebody say "but you don't look sick." It can be hard to figure out how you can help your loved one when the disease is still relatively unknown to the medical community. Nevertheless, Eric has a simple, yet tremendously impactful way to support our Warriors – be a source of understanding. We will never be able to comprehend the level of their pain but we can offer our understanding when they endure frustrating conversations with doctors, experience the judgement of others or just need to go to bed. Anais, now 20 years old, is quite busy being a college student. Although she spends a lot of her free time raising awareness and supporting other college-aged students with CRPS through an organization called Ferocious Fighters, Anais still often experiences a lack of understanding from her peers. Understanding, Eric believes, is something every CRPS Warrior deserves.

The Ride for Warriors is set to kick off on Saturday, June 29th and conclude on July 14th. There are several ways to offer support. Follow and share the campaign on Facebook and Instagram. As mentioned, Eric will be stopping in various cities along the way and would love to speak with fellow members of the CRPS community. Reach out and arrange a time to meet Eric along his ride. If you have the means, consider offering your home as a place for him to stay (Bike route included below, for reference). There are also financial ways to support this cause – all of which go to furthering research. Pledge 10 cents for every mile that is peddled, have your local spin studio host a fundraising event or ask business or governmental organizations to serve as sponsors. Any donation, no matter the size, can be made by visiting the Ride for Warriors Giving Page, which can be found here: https://www.firstgiving.com/event/rsds/RIDE-FOR-WARRIORS

Aside from supporting this bike ride specifically, Eric also encourages everyone to share the information they have about CRPS with others, whether that is swapping treatment stories with another Warrior or educating a family member about the disease.

The RSDSA is excited to wish Eric, and everyone else working with the Ride for Warriors, the best of luck. But, before Eric hits the road, he has one message for each and every CRPS Warrior: "There IS support and there ARE people out there fighting for you. Keep on being Warriors!"

Social Media Links:
https://www.instagram.com/ericmoyal /
https://www.facebook.com/Ride4Warriors/

Ride for Warriors Giving Page
https://www.firstgiving.com/event/rsds/RIDE-FOR-WARRIORS

Medford, MA to Hartford,	126 Miles
Hartford, CT to New York, NY	127 Miles
New York, NY to Wilmington, MD....	129 Miles
Wilmington, MD to Washington,DC	118 Miles
Washington, DC to Goochland, VA	131 Miles
Goochland, VA to Oxford, NC	120 Miles
Oxford, NC to Carthage NC	99 Miles
Carthage, NC to Turbeville SC	135 Miles
Turbeville, SC to Ridgeville, SC	68 Miles
Ridgeville, SC to Garden City, GA	102 Miles
Garden City, GA to Kingsland, GA	122 Miles
Kingsland, GA to Jacksonville Beach, FL	53 Miles
Jacksonville Beach, FL to Daytona Beach, FL	83 Miles
Daytona Beach, FL to Vero Beach, FL	128 Miles
Vero Beach, FL to West Palm Beach, FL	71 Miles
West Palm Beach, FL to Bay Harbor Islands, FL	65 Miles

RSDSA YOUNG ADULT WEEKEND

Friday, August 9 – Monday, August 12, 2019

RSDSA is excited to announce that the second Young Adult Weekend of 2019 is coming to the west coast and will be held in San Diego, CA.

After the success of the previous events and the expressed need we will continue to schedule these events across the country!

This event is for young people 21-31 with CRPS. You are invited to attend a weekend of workshops, free time to sightsee, group excursions and spending time with people who truly understand what you are going through to the fullest extent.

Date: Friday, August 9 – Monday, August 12, 2019

Time: Starts Friday at 3:00 PM and ends Monday 12:00 PM

Hotels details to follow.

Fee: $250.00 with a $50.00 non-refundable deposit which will hold your spot. Final payment is due by July 26, 2019.

To register or for more information please contact RSDSA YAW Committee at rsdsayawknd@gmail.com

rsdsa
SUPPORTING THE CRPS COMMUNITY

Easy Ways to Give

- Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.

- Use AmazonSmile.com and make RSDSA your charity of choice while shopping online.

- If you're selling things on eBay, you can give a portion of the profits straight to RSDSA.

- Set up a collection canister in your local grocery store.

- Plan an event with the help of RSDSA by emailing us at jjkrassner@rsds.org

Carolyn's Cards

Carolyn's Cards is a program that sends cards and other small surprises through the mail to individuals with Complex Regional Pain Syndrome (CRPS) and to their caregivers.

The purpose is to help those feeling isolated or down because of CRPS by sending them a card to help them feel less alone, provide encouragement and support, help them feel part of a community, and most importantly to give them a smile. I received the inspiration from my Mother who would send me cards when I was down, in a lot of pain, or recovering from surgery. These cards would help to brighten my day. I thought it would be great if I could reciprocate that feeling for others. I started sending cards to the attendees of the first Young Adult Weekend as a way to stay connected to them and show support. I was surprised to hear how much they genuinely enjoy the cards. I have continued to add names to my list after each Young Adult Weekend.

The cards can be sent for birthdays, holidays, other celebrations, after medical procedures, or when we receive notification that someone is having a difficult time. Carolyn's Cards will receive names and addresses via recommendations provided by RSDSA or directly emailed to carolyns.cards2@gmail.com.

Please consider purchasing a magnetic awareness ribbon for your car for only $5. Please send your check to: RSDSA. PO Box 502, Milford, CT 06460 or call us at 877-662-7737.

Poetry Corner

The Breeze

by Sheryl Freed

Like panning for gold from the sky
I stand beneath the breeze
tossed trees
Hands spread wide
and eyes a shimmer
Reaching for the leaves

One last monarch flutters on by
I rest amid the amber drop
Breathing deeply,
my cheeks a glow
Drinking in the warmth

Snuggle close the chill is near
I hold inside my soul the blaze
Arms spread wide
and hearts a fire
Lean in for a kiss

Joy is found but in the moment
I will push aside the sorrow
The burning is pain,
the fear is real
Careful not to touch

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99 CHERRY STREET
P.O. BOX 502
MILFORD, CT 06460

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SUPPORTING THE CRPS COMMUNITY

TEL: 877.662.7737
FAX: 203.882.8362
WWW.RSDS.ORG

THE RSDSA provides 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.

RSDSA 2019 EVENTS CALENDAR TO DATE

JUNE	
6/29 - 07/16	Ride for Warriors - Eric Moral
JULY	
7/27	Charity Ride for Pain Survivors (CRPS). Derry, PA - Jason L. Caldwell, Sr.
AUGUST	
08/8 - 08/12	Young Adults Weekend, San Diego, CA - RSDSA Sue Pinkham and Sharon Weiner
SEPTEMBER	
9/7	4th Annual Long Island Awareness Walk Eisenhower Park, Long Island, East Meadow, NY
9/22	1st Annual Walk in Ocean Township New Jersey - Judy and Bob Hopkins
9/29	6th Annual Fight the Flame 5k, Charlotte, NC - Beth and Steven Stillitano
9/29	4th Annual Knock Out Pain 5k - Easton, PA - Sarah O'Steen
OCTOBER	
TBD	3rd Annual Tame the Pain Golf Event, Galena, OH - Sharon & Matt Weiner
10/26	Treating the Whole Person: Optimizing Wellness, Denver, RSDSA
NOVEMBER	
11/3	Fight the Flames, Mentor, OH
11/4	Color the World Orange, Worldwide
TBD	RSDSA Swimming Fundraiser, Salt Lake City, UT - Konnie Parke

PEER TO PEER

If you wish to take advantage of this program, please do the following.

- **Please contact LindaLang@rsds.org**
- **Please provide your email, phone number and a little bit about yourself.**

Don't see an event near you?

Contact Jeri Krassner jjkrassner@rsds.org to discuss planning an event in your area!

Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rsds.org