

rsdsa community update

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Fall 2019

4th Annual Long Island CRPS Awareness Walk & Expo

BY JERI KRASSNER • RSDSA SPECIAL EVENTS COORDINATOR

The 4th Annual CRPS Long Island Walk in Eisenhower Park on September 7th was a huge success! **Over 500 people showed up and over \$75,000 was raised for the RSDSA community.**

Luck was with us when the day began beautiful, warm and sunny. By 7 am, a host of volunteers had shown up to organize 28 tables for sponsors, 19 tables for teams, six tables dedicated to education, 12 tables for raffles, silent auction items, breakfast, and the all-important registration and check-in booth. The walk was three events in one!

This successful event was organized by three indomitable CRPS Warriors. Debbie O'Neal, Beth Seickel, and Stacey Udell each bring their own unique strengths to the organization of this Walk. The women

share the decision making, but each has their own strengths. Stacey is a public relations expert. She doesn't take no for an answer and with her perseverance, she wrangled two radio interviews, numerous mentions by local media, promotions on our sponsors' websites, and two excellent articles in mainstream newspapers. She even got WBAB radio station to attend and DJ the event!

Debbie covered the logistics. What does that mean? She organized the registration, t-shirt distribution, scheduling, supplies, and all our signage. As the saying goes, "the devil is in the details," and Debbie knows it well. She nailed down all the important and seemingly little details for the walk and kept on going.

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FOR RESEARCH STUDY** *See page 12*

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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

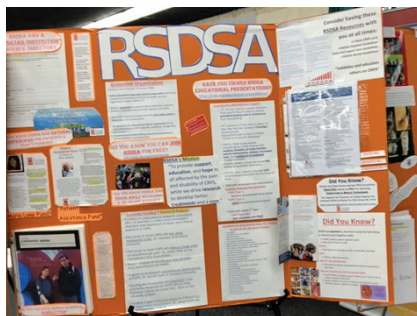
We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Baker Family Charitable Trust, Center for Pain Management, Edelman, Krasin & Jaye PLLC, Grünenthal, Law Office of Scott Callahan,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

Director's Report

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

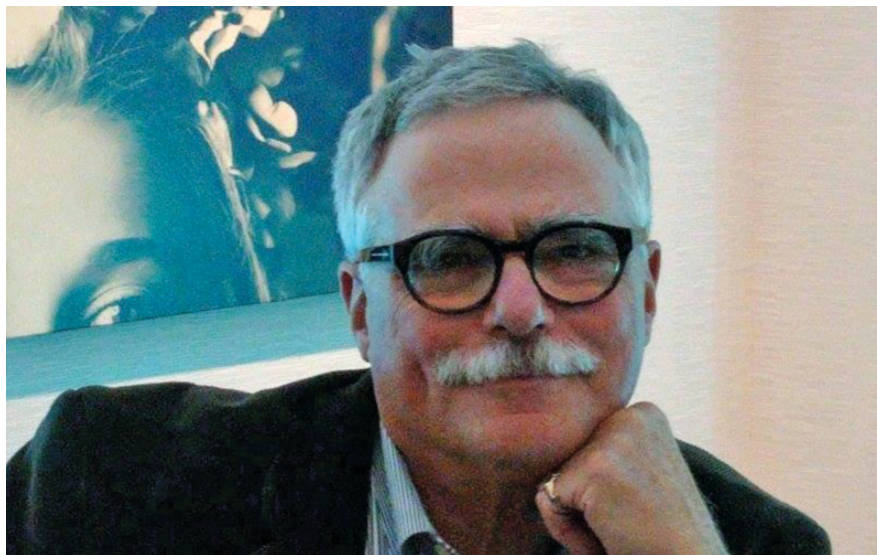
American Society of Pain Management Nursing (ASPMN)

Beth Seickel, RN and I presented and exhibited at the ASPMN meeting in Portland, OR in September. There was a great deal of interest in CRPS and especially regarding low-dose naltrexone (LDN), IV ketamine and our guidelines for the Emergency Department, Hospital, and the dental care. A lot of the pain management nurses were not aware that there was a patient advocacy organization for people with CRPS and will utilize our resources in the future. We are researching the feasibility of exhibiting at the American Academy of Nurse Practitioners or the American Academy of Physician Assistants next year.



Reaccreditation of Adult CRPS Course for Physicians and Nurses

I traveled to Vernon Hills, outside of Chicago to film Jay Joshi, the CEO and Medical Director



of the National Pain Centers. The filming was excellent as Dr. Joshi was very passionate and knowledgeable about CRPS. The video named *The Only Pain Disease with Complex in Its Name: Learn about It and Treat It Well* is in edit and we hope to have it on line in early November. We already have an on-line free

accredited course on pediatric CRPS on our website: <https://rds.org/rdsa-pediatric-crps-accredited-online-course/> I also want to remind our members that RSDSA has a dedicated channel on YouTube where we archive all of our videos from our conferences: <https://www.youtube.com/user/RSDSAofAmerica/>

Dear Jenkins Patient Assistance Team,

I don't have the words to thank you enough for your amazing help at the perfect time. I didn't know I was going to be rushed in for emergency surgery & almost die & need my Ketamine troches more than ever and your gift of helping me get them by working with my care pharmacy is so appreciated! I have a long recovery ahead of me (sorry for delay in sending my thanks I've been in the hospital & then a long term care center) but it has been made easier by your help, I can't say thank you enough. It warms my heart & soul to have people who understand this disease & the torture & suffering it brings to our lives as it steals our lives from us, it isn't often you find people who understand or are willing to help & in your team I was blessed with both & am forever grateful. Thanks for being angels & helping me get my medication I would not have been able



Thanks!

for Choosing to help me ❤️

to get my Ketamine troches without your help. I have always been the giver & worked as a mental health therapist so thank you also for giving me the experience of knowing what it's like to reverse roles & be on the other side to get the gift. You guys are amazing! much love & gratitude,
Danelle Chase

Patient Assistance Program in Honor of Brad Jenkins

I've included a thank-you letter from a recipient who we recently helped. Since the programs' inception in 2012, RSDSA has awarded 209 grants totaling \$113,162.40 and the need is increasing. To help RSDSA continue to make a huge difference in the lives of people with CRPS, make a tax-deductible donation today by going to our [donate page](#) or call RSDSA at 877.662.7737.

Cross-Country Bike Ride in 2020

Eric Moyal is getting back on the road again next year to raise funds and awareness of CRPS on behalf of his sister Anais and RSDSA. This summer, despite thunderstorms and the sometimes oppressive heat, Eric biked 1,700 miles from Medford, Massachusetts to Bay Harbor Islands, FL (read his interview in this issue with our editor). Eric has asked our assistance in identifying possible corporate sponsors for his cross-country trek to cover his lodging and food costs.

James W. Broatch



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@rdsd.org

4th Annual Long Island CRPS Awareness Walk & Expo Proves You Are Not Alone (continued)

Beth, or Nurse Beth, as she is affectionately referred to, quietly covered her territory to pull the walk together. She ensured education about CRPS is presented at the walk, medical services are on site in case of emergency, and that we had our venue. She liaised with Nassau County Department of Parks and Recreation to ensure we had a beautiful place to hold our walk. Beth, aided by her husband, Glenn, and his golf cart crew, showed up at sunrise to supervise and set up for the day. And what about our participants? There were 26 registered walk teams, ranging from Amanda's Angels to Stay Strong Samantha. Some teams had one person, while others had as many as 26 members. They all came together on September 7 to support, laugh, and cry with one another. Most importantly, they came to share with each other. They all brought their stories, like Samantha Strong, a sixteen-year-old CRPS Warrior with a powerful spirit and a heart to match. Every Warrior has a story and overcame the pain to attend the walk like Jennifer Ogle's Flamestoppers, Team Uncle Roy and Kelly's Crusaders, to name just a few. Our attendees and donors also came from all over the map to attend. One team, The Pirates Cassandra and Phelan, traveled all the way from Vermont. Others came from Connecticut, New Jersey, and as far as Minnesota. Thank you to everyone who made this Walk happen. Thanks to everyone involved, especially our three intrepid

Warriors, Debbie, Stacey, and Beth, the Long Island CRPS Awareness Walk & Expo raised a lot of money for our mission. Our Warriors cast a wide net over the Long Island landscape, searching for suitable sponsors and donations - and we send a giant thank you to everyone who responded. It was a pleasure to see all our sponsors at the event, and to know that we have your support. None of this could have happened without your help.

Thank you to the firefighters who took the time to prepare and cook the barbecue lunch. They even went the extra mile to serve veggie burgers and offer gluten-free buns, right alongside the classic hamburgers and hot dogs. This is a group that cares for our community and we applaud their dedication.

This year's Long Island Walk & Expo was bigger and better than ever before. There were over 75 raffles and silent auction items, including signed Duke basketballs, gift baskets of baked goods, homecare, and bath items, and tickets to a Broadway musical! There was something for everyone to enjoy, and the ice cream truck giving out free treats at the end was the pièce de résistance.

Let's give a shout out to all the amazing people who helped make this event possible. It isn't easy to keep people entertained, educated, and engaged, but they gave everyone a reason to come out and support the cause. It is extraordinary what a small community can do.

Fun Meets Fundraising

BY **BRANDY ROMERO** • KBROMERO@BELLSOUTH.NET

One of the most effective ways to bring the CRPS community together and raise awareness in your hometown is to host an event. These may come in various shapes and sizes, and some may serve gumbo, but it all comes back to the RSDSA's mission of providing support, education, and hope to all affected by the pain and disability of CRPS/RSD, while also driving research to develop better treatments and a cure.

One example of a fun and unique fundraiser is the Mardi Gras Jeep Show and Gumbo Cook Off that was held last February in Scott, Louisiana. This was the fourth year the Louisiana Jeepers held this event and they managed to raise an incredible \$55,000 for the RSDSA. The Mardi Gras themed fundraiser featured local musicians, live and silent auction, lots of jeeps to see and gumbo to taste.

As event organizer Brandy Romero said "the day was perfect gumbo weather, sun was shining, people dancing and will to open their wallets to show their support! It was amazing to meet new people with this disease and share our story."



Is there a tradition, food or season that is unique to your home town? Get creative and think about how it could be turned into a fundraiser or special event.

If you are interested in learning more about hosting an event, please contact Jeri Krasser, the RSDSA's Special Events Coordinator at jkrasser@rds.org or Jim Broatch, RSDSA Director, at jwbroatch@rds.org

Plan on attending next year on February 1, 2020.



Opportunity

BY **LAURA HINKLE** • JUST41KH@OUTLOOK.COM

On August 24, 1994, I fell climbing up to Grinnell Glacier in Glacier National Park and had a minor break to my ankle. My life changed forever as I was diagnosed with RSD. I went through the common treatments of the time. The only thing that I found helpful was methadone and methadone became my answer to my RSD pain. But by 2013, the methadone was destroying my heart. In 2014 after 20 years on methadone, I was told that if I stayed on methadone I wouldn't live much longer, or I could detox off methadone and live experiencing more pain. What a choice! I opted to detox off methadone and had to do it cold turkey because I was allergic to the detox meds. It was terrible! After 2 months, I thought the pain would once again kill me. I returned to my chronic pain doctor and he wanted to put me back on methadone in order to give me some type of life until my heart gave out. I filled the script and went home. However, after taking the first set of pills, I realized what I was doing. I had just detoxed off it and now I was actually taking it again! Once again, I stopped taking methadone and returned to my pain doctor. That was when he told me that if I didn't stay on narcotics that I would not be bringing money in for the clinic. I got up and walked out of my appointment. I never returned. But now what?

I began my search on what to do. I came across PEAPure® and tried it. I had some good results. I also went into counseling and learned to mourn the death of my dreams through RSD. I learned how to make peace with my RSD instead of always being in a battle with it. I learned that I had been missing a very important pain coping mechanism, called my brain. My pain was still there, just as intense, but I slowly started developing a new life.

Part of my new life was swimming. I've always enjoyed swimming, though I've never thought I did it very well. My primary doctor encouraged me to go to this place called OPC and use their therapy pool. At first, I could barely last even 5 minutes. But I kept going back. I started to meet people and develop friendships. By the end of the first year, I could tolerate a half hour or so. The following year, I increased my time even more. One day, I took a leap of faith and went into their lap swimming pool. I swam one length. Everyone applauded for me. I was shocked at the support. They knew what a milestone this was for me.

Flash forward to August of 2018... My RSD is now everywhere in my body. I'm still using my walker. I'm often rescued from the pool by the lifeguard, because my legs, and my body in general, just stop working because the pain is too intense. Yet, I'm so thankful that

I'm in a safe place and around understanding people. They help me out when I need it. I also met two people who were part of the Senior Olympics and they started encouraging me to go to the next Olympics. I started training yet took it as easy as possible for my RSD. And, I continued to be rescued monthly.

This year, 2019 has been a game changer for me. It started with me landing in the hospital because in January, I fell from the pain and didn't regain consciousness for about 8 hours. But in April, I felt strong enough to no longer use my walker. The pain was still there, but I was physically stronger. In May, I walked the first mile I'd ever walked since August 24, 1994. (I couldn't even walk to my mailbox in 2017! I just started slow. Halfway to my mailbox, and kept increasing the distance.) I was still being challenged to do swimming in the Olympics. My problem is that my pain skyrockets with vibrations. In the water, the vibrations were bruising my entire body. I was scared that my body would give out and I'd have to be rescued at them. I was going to dive into the pool, and even though it was off the side, that "smack" into the water was sometimes paralyzing me. I also had never competed in any athletic event my entire 59 years of life. I was terrified. I had a long list of reasons not to do them.

My new friends kept encouraging me. Lisa told me that life has opportunities in it. It was up to me if I seized them and lived in that moment for all it had to offer. Or, if I declined the opportunity. RSD had and does take away opportunities in my life. Maybe it was time to do something different. To know that I could rely on people if my pain went out of control. To seize the opportunity that was before me. So, I signed up for the Olympics in July. Deciding that if I didn't go, the cost would be a donation to them. By the end of July, once again, my RSD was so flared that I could barely walk or do much of anything.

Forward to August 12, 2019... at 8:00 in the morning, I was warming up for two swimming competitions at the Michigan Senior Olympics. It was all just blowing my mind. I dove in about 9:15 AM for the 50-meter breaststroke. I dove in again about 11:15 for the 200-meter breaststroke. I was high on adrenaline and competing in my very first athletic competition. Yes, I hurt like crazy. My RSD wasn't happy with me. And yet, I was still doing it. I was swimming in the Senior Olympics. Much to my surprise I received a silver medal in the 50 and a gold medal in the 200! I had won 2 Michigan Senior Olympic medals! I was blown away.

By the time I got home, I could barely move. By evening, I couldn't move. The last week has been filled with extra intense pain. And I'm smiling. I'm smiling inside and out. See, RSD took a

“I was swimming in the Senior Olympics. Much to my surprise I received a silver medal in the 50 and a gold medal in the 200! I had won 2 Michigan Senior Olympic medals! I was blown away.”

lot of things from me (as it does anyone). For the first time, since August 24, 1994, I'm getting a life back. Yes, it is a different life than I ever thought, but it still is a life... a life that I can call good. The pain is intense, and I'm learning how to have an intense life any way. It blows my mind that I swam like I did. It blows my mind that I actually walked a mile even though it took me 24-1/2 years to do.

This week, I'll have had RSD for 25 years. Every day I hurt and wonder how I'll get through the day. And yet, now I've learned how to challenge myself in small opportunities that accumulate into big adventures. I have been able to develop a new life with RSD that I keep tweaking daily. I keep looking for those opportunities now that I can work towards obtaining. I've learned my brain has just as much to do with my RSD as my body.

My newly found friends who are swimmers ask me what my goals are for next summer. My response was that I hope to try kayaking. (I have no idea how I will

ever get my legs into the kayak.) I also want to try paddle boarding. (I have no idea how I'll ever be able to stand, and even fall into the water with my RSD taking over my body.) My friends clarified their question by asking me what I'd be doing for swimming. My response was simple. To get physically stronger, swim faster by swimming more effectively. I was told that next summer are qualifiers to go to the National Senior Olympics (All the winners of each state come together to compete) They want me to attend the Nationals. I explained that my RSD doesn't permit me to travel more than several hours in a car, and there's no way I can go on an airplane. There are way too many vibrations. I live in Michigan and the Nationals are in Florida. They looked at me, smiled and said that I never thought I'd be able to swim in the Michigan Senior Olympics either!



ABOUT THE AUTHOR

Laura Hinkle is a 25-year warrior who is also a frequent RSDSA donor.

CRPS Changes Lives

BY JENNY PICCIOTTO

On the morning of May 15th in 1973, Steve Shisler was enjoying the second week of summer after his sophomore year of college. He said goodbye to his Grandmother and hopped on his motorcycle to head to his summer job. When a car pulled into the intersection he was crossing, he swerved to the right and tried to lay the bike down to get out of the way, but the car just kept coming. He woke up in the hospital five days later. That morning would change his life forever.

His left arm was paralyzed because of damage to the nerves attaching the arm to the spine. Two nerves were partially torn from his spine, another two were completely torn from his spine. After his shoulder muscles atrophied his shoulder kept popping out of the socket. He was diagnosed with a severe brachial plexus injury and Reflex Sympathetic Dystrophy, which has since then been renamed Complex Regional Pain Syndrome (CRPS). For several years he underwent numerous surgeries to recover movement in his arm, and treatments for CRPS. Severe pain prevented him from completing his studies on time, and ultimately shaped the direction of his career.

For two years he wore his arm in a sling, and his shoulder repeatedly subluxed, partially dislocating. After the partially severed nerves regenerated, he regained limited

use of his arm. He could close his hand, open his thumb and first finger, and regained the ability to slightly pull the arm toward his body.

During this time, he was also being treated for CRPS. Pain medications were not sufficient and made concentration difficult. He underwent 32 cervical nerve blocks. He remembers the day the doctor forgot to put a cloth over his eyes to prevent him from seeing the needle approaching his throat. "Wait, wait, Doc," he said, "you forgot the blindfold!" But the doctor jokingly told him he didn't need it any longer because he already knew what was coming. After that a "blindfold" was no longer used during the injections.

He was referred to a surgeon who recommended a surgical sympathectomy of the nerve ganglion to stop the pain signals. He remembers his dad's face draining of blood as the procedure was described. Ultimately, he declined the surgery because he would no longer have control over the facial muscles on one side, leaving his face permanently drooping. At 20 years old, he didn't want to look like he had suffered a stroke for the rest of his life.

He also tried acupuncture, which he had to travel to Washington DC to obtain, because it was not yet legal in Pennsylvania. While

standard acupuncture did not help, he received some relief from electroacupuncture, which uses an electrical frequency pulsed through the needles. But it wasn't until he underwent surgery that he began to get relief from CRPS.

Two years after the accident, he underwent additional surgeries to regain use of his arm. His neurologist referred him to an orthopedic surgeon who surgically fused his shoulder, relocated muscles in his forearm to create a bicep, and tied the extensor tendons of his fingers together to allow him to open his hand. The joint fusion surgery involved breaking the bone and placing three screws in the shoulder to fuse the upper arm to the shoulder blade. Once fused, it no longer pulled on the nerve plexus or pulled out of the socket. With the nerve irritation reduced, his CRPS symptoms died down, but have never disappeared completely.

Today he has some pain free days, some days with tolerable pain, and some wicked pain days when he diverts his frustration into his work.

Steve was able to complete his coursework and graduated from college with a degree in English Literature. He taught English in a preparatory school for four years, but as he approached 30 years old, his experience attempting to

“What began as a carefree day during summer recess in the life of a 20-year-old college student became a life’s work. Steve has fueled his passion for helping people with CRPS with the fire of his own experience, turning tragedy and persistence into dedication and purpose.”

get compensation for his injuries inspired him to go to law school. He wanted to change the law which at that time in Pennsylvania held that if a plaintiff was even one percent at fault for an accident, they were not entitled to collect anything.

Although that particular law changed before he entered law school, Steve has been at the forefront of other changes in the way the law is practiced. After working for over a decade at other firms, in 1996 he opened his own practice which focuses on representing people with CRPS. He has become a national expert in legal matters related to CRPS, appearing on television and

radio programs and as a guest speaker at legal and medical events. He is on the faculty for the American Association for Justice (Association of Trial Lawyers of America), and is the co-founder of the Association’s Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy Litigation Group. He was instrumental in drafting and causing enactment of Social Security Policy Ruling for disability claims involving Reflex Sympathetic dystrophy/Complex Regional pain syndrome. He works with attorneys across the country to help people with CRPS.

Through clients and friends with CRPS, he became aware of the RSDSA and became a supporting member in 1996. He has written articles about Worker’s Compensation and retaining legal advice for the communityⁱ, and been a speaker at RSDSA conferences. In 2013 he was elected to the Board of Directors and currently serves as Secretary.

“As Secretary,” he says, “I am responsible for producing minutes of the meetings. But all of us on the Board are engaged in trying to help people with CRPS, through outreach, presenting at conferences, and funding medical research.”

What began as a carefree day during summer recess in the life of a 20-year-old college student became a life’s work. Steve has fueled his passion for helping

people with CRPS with the fire of his own experience, turning tragedy and persistence into dedication and purpose.

You can learn more about Steve at his website: www.shislerlaw.com

ⁱ <https://rsds.org/workers-compensation-101-an-overview-of-wc-for-employees/>, <https://rsds.org/how-to-lose-your-case-in-12-easy-steps/>



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.

Role of Physical Therapy in an Interdisciplinary Team for Chronic Pain Management

BY **WENDY WURTZEL PT, DPT** • SHIRLEY RYAN ABILITY LAB

Physical therapy is a first-line intervention for individuals with pain. However, when it comes to chronic pain, particularly Complex Regional Pain Syndrome (CRPS), working with an interdisciplinary team of healthcare providers can be a more effective treatment approach. Often, the responses to physical therapy as a stand-alone intervention can vary. Physical therapy alone may have no effect on pain and functioning, or result in triggering flare-ups, leading to increased debility.

At times, individuals may believe during physical therapy sessions that “pushing through” the pain will be beneficial – the “no pain, no gain” mindset. However, these beliefs run counter to the goal of increasing function while managing pain or sensitivity symptoms associated with CRPS. In the setting of an interdisciplinary healthcare team, the physical therapist’s approach involves providing a graded exposure to exercise partnered with integration of active pain management techniques from other disciplines.

At the Shirley Ryan AbilityLab Pain Management Center, interdisciplinary team members include a pain physician, physical therapist, occupational therapist, pain psychologist, biofeedback therapist, and vocational rehabilitation counselor. These team members each have a

role in optimizing different aspects of the individual’s function – biological factors (medications, sleep, strength, conditioning), psychological factors (depression, anxiety, fear), and social factors (roles, responsibilities, recreation). Collaboration between team members allows for integration of techniques from other disciplines into physical therapy treatment in order to more effectively manage CRPS symptoms during physical therapy treatment.

Over time, CRPS symptoms limit an individual’s function, resulting in deconditioning, muscle tightness, and weakness of foundational muscle groups. Active physical therapy techniques, such as therapeutic exercise, cardiovascular conditioning, and education have been shown to be more effective than passive techniques, such as modalities (heat, ice, electrical stimulation) and manual therapy (soft tissue mobilization, joint manipulation). Passive techniques may provide short-term reduction in symptoms but lack evidence demonstrating long-term benefits, and can also lead to dependence on healthcare providers to receive the passive treatment.

Physical therapists have a variety of active interventions to draw on when treating a diagnosis such as CRPS. Therapeutic exercise can include stretching to address

muscle tightness and guarding, gradually increasing adaptability of structures to being stretched during exercise and functional movements. Strengthening of deep neck, shoulder blade, core, and hip stabilizer muscles will reinforce utilization of endurance muscles and, by result, decrease compensation from other muscle groups. Performing aquatic-based exercise is another evidence-based tool at the physical therapist’s disposal. Water decreases load of body weight on joints by up to 65 percent. Performing walking activities, functional strengthening, and balance exercises in water allows for optimization of movement patterns for eventual carry-over into land-based exercise. In an interdisciplinary model, the physical therapist will partner with the occupational therapist to develop a graded desensitization program for individuals with sensitivity to water.

Initiating a cardiovascular conditioning program is another intervention that is essential for addressing overall endurance. The American College of Sports Medicine recommends 150 minutes of moderate-intensity conditioning per week. The endorphin release that is associated with cardiovascular exercise in a target heart rate zone can be utilized as an active pain management strategy. Additionally,

cardiovascular conditioning can increase overall endurance for functional mobility. Thorough education allows individuals to have the skills to progress their home exercise program and cardiovascular conditioning efforts for continued long-term gains. By the conclusion of their intensive therapy program, individuals will have the knowledge to be aware of how to be more functional while keeping CRPS symptoms under better control.

Within a physical therapy treatment session, the interdisciplinary model allows for integration of active pain management techniques from other disciplines. For example, the physical therapist will often encourage patients to perform a biofeedback breathing technique during a pacing break to reinforce optimal breathing patterns and as pain management tool. Likewise, psychology techniques can be leveraged to reframe maladaptive thoughts, such as fear of movement or anxiety related to exercise. As a patient makes progress with occupational therapy interventions, such as desensitization techniques and graded motor imagery, the physical therapist can then begin to incorporate exercise with the affected body region into physical therapy treatment.

Current evidence supports the role of active physical therapy techniques for individuals with CRPS. By addressing the underlying flexibility, strength, and endurance impairments, combined with interdisciplinary pain management techniques, such as pacing, mindfulness, and

biofeedback, individuals make progress in physical therapy to improve their function and quality of life. An interdisciplinary pain management program like the Shirley Ryan AbilityLab Pain Management Center empowers individuals with the insight needed to apply pain management techniques for the lifespan.



ABOUT THE AUTHOR

Wendy Wurtzel PT, DPT is a senior physical therapist at the Shirley Ryan AbilityLab Pain Management Center, specializing in both pain management and vestibular rehabilitation for adolescents and adults. Wendy graduated with a Doctorate in Physical Therapy from the University of Florida in 2012. She serves as a District Representative in the Illinois Physical Therapy Association and as a member of the Scientific Planning Committee for the Midwest Pain Society. Wendy has also been involved in research throughout her career, publishing in peer-reviewed journals and presenting at national conferences.

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).

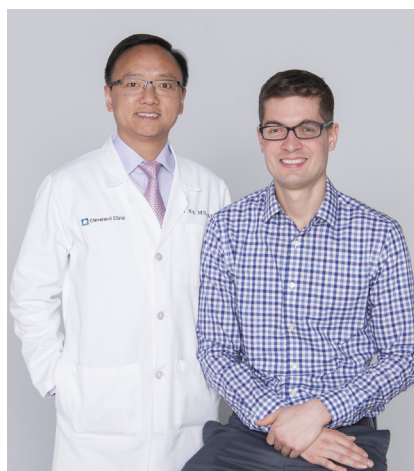
RSDSA Approves New Grant Application for Research Study

BY JASON HALE, MD • HALEJ3@CCF.ORG

The RSDSA Board of Directors recently approved Jason Hale's, MD's grant application. According to Dr. Hale, a resident physician in anesthesiology at the Cleveland Clinic, the goal of the study is to determine whether nitrous oxide, also known as "laughing gas," would be effective in treating pain caused by CRPS. Essentially, Dr. Hale wants to see if brief periods of nitrous oxide exposure can treat CRPS pain. Dr. Hale is working with Dr. Jijun Xu, MD PhD, and Dr. Alparslan Turan, MD, who are staff physicians in the Anesthesiology Institute at the Cleveland Clinic.

The rationale for the research trial is based on the molecular mechanism, or how a drug works at the molecular level, of ketamine, a powerful intravenous pain medication. Brief periods of ketamine therapy are sometimes effective in treating CRPS pain, even after the effects of ketamine have worn off. Unfortunately, ketamine is fraught with side effects such as hallucinations, the therapy is costly and requires intravenous access, and toxicity can limit the amount of medication that is able to be used.

Ketamine's primary molecular mechanism is NMDA antagonism, meaning it blocks NMDA receptors in the brain, and this underpins its efficacy as a pain medication. NMDA receptors are believed to play an important role in the development and



Jijun Xu, MD, PhD (1) and Jason Hale, MD

persistence of chronic pain, especially neuropathic pain in CRPS. Blocking NMDA receptor activity in the brain is also believed to be important in treating chronic neuropathic pain. Unfortunately, there are very few medications that act as NMDA antagonists (like ketamine), and the true utility of NMDA receptors as a therapeutic target remain unclear.

Nitrous oxide, however, is also an NMDA antagonist. This explains why nitrous oxide, while also being sedating, directly treats pain. Nitrous oxide is cheap, safe, and easy to administer with a simple breathing mask. Based on some scientific studies in animals, the research team believes the pain relieving effect may continue even after a patient recovers from breathing nitrous oxide. Temporarily exposing neurons in the brain to an NMDA antagonist is believed to help "reset" the maladaptive cellular

mechanisms that contribute to neuropathic pain.

This small research trial will help us determine if nitrous oxide can provide effective pain relief, reduce oral opioid medication use, and improve functional status in patients with CRPS. If beneficial, nitrous oxide could become an alternative treatment option for patients with CRPS and other chronic pain conditions. Dr. Hale and his colleagues are excited to start this clinical research trial at their institution!



HAVE YOU THOUGHT ABOUT YOUR LEGACY?

Are you looking for a long-term way to make a meaningful difference in the lives of people with CRPS?

Please consider making a planned gift to RSDSA today. Planned giving options include:

- Gifts of Stocks and bonds.
- Including RSDSA as a beneficiary in your life insurance policy.
- Including RSDSA as a beneficiary in your will.

Tax benefits apply to each of these options.

Please contact your attorney or a financial advisor. For more info, contact RSDSA at info@rdsd.org or go to <https://rdsd.org/donate/>

Spotlight On Support: A Newsletter Addition

BY **SHARON L. WEINER** • FSG.RSDSA@GMAIL.COM

Spotlight On Support is a new addition to the RSDSA newsletter that focuses on showcasing the accomplishments and activities of the over 60 CRPS support groups, including in person, online and virtual groups. Support groups, whether our in-person, online, or virtual groups, can be crucial to our community and the wellbeing of those with CRPS, along with their family, friends and caregivers.

If you are interested in submitting information about your support group's activities, please send an email to FSG.rsdas@gmail.com.

If you wish to start a new support group, please contact RSDSA.

This Edition's Spotlight: The Northeast Philadelphia RSDSA Support Group, a newly formed group, recently welcomed Stephen Shisler Esq. to speak at one of their meetings. He discussed the critical need for medical teams to use the precise language of the "Budapest's Criteria" in medical records for CRPS patients to increase their chances for success when winning legal challenges presented by both Workman's Compensation and

Social Security Disability cases. "Many of the patients attending our support group meeting and especially our newly diagnosed members have never heard of the "Budapest Criteria" much less knew the importance of using this very specific diagnostic language," says support group founder and facilitator, Kimberly Russo.

For more information about this support group and the Budapest Criteria, please email: rsdphilly@yahoo.com

The Longest Day of Golf

BY **JERI KRASSNER** • JKRASSNER@RSDS.ORG

On Monday, September 30, 2019 Josh Rosen teed up to play golf for RSDSA's third Longest Day of Golf fundraising event. The Longest Day of Golf (LDOG) is a unique fundraiser that costs RSDSA no expense. Josh plays golf from 7:00am to 7:00pm on the day of, during which the golf club is closed to members. Individuals contribute by pledging either an amount per hole played or by making a one-time gift to aid RSDSA's mission of education, support and research. A round of applause goes to our Co-President Hank Ludington for organizing and promoting this special tournament.

For the second year, Josh lent his prodigious talent to the event, playing from 7 a.m. till 7 p.m. He loves playing golf, especially when it benefits RSDSA. He played a grand total of 128 holes. It was a beautiful day on the links, during which Josh was accompanied by Hank and Jim.

Josh had a slow start toward his goal to birdie every hole. He missed the green on a short approach shot on the first hole, then hit two balls in the water on the second hole. Despite his inauspicious start, Josh quickly got back on pace with a par and two birdies on the next three holes. Josh kept going and going.

It's his ability to stay undaunted and persevere that makes him the perfect representative for our community. And thanks to Jim he can now tell the difference between an Osprey and a Hawk.

The RSDSA Board set an ambitious goal of \$50,000 and we are 1/3 of the way to goal. However, it is not over and there is still time to contribute to this fundraiser. LDOG campaign is open and we accept donations to the end of the year. You can still be our best hope and help fulfill our mission by making a donation to <https://www.firstgiving.com/event/rsds/2019-Longest-Day-of-Golf>.

Ride for Warriors Recap - An Interview with Eric Moyal

BY LAUREN BENTLEY • LAURENBENTLEY93@GMAIL.COM



Driving from Medford, Massachusetts to Miami, Florida takes approximately 23 hours and 47 minutes. Hop on a flight at Medford's nearest airport and you'll land in Miami in just a few hours. So, how long does it take on a bike? Two and a half weeks. That's the amount of time it takes to bike the seventeen thousand miles between Medford and Miami.

How do we know this? Eric Moyal biked those 1,700 miles in the Ride for Warriors campaign, a fundraiser created by Eric and his family to raise money for research and awareness of CRPS. It was also inspired by Eric's sister, Anais Moyal. She was 15 years old when she was diagnosed with CRPS. Anais was enjoying a bike ride when she was suddenly hit by a car. After over a year of going back and forth with doctors trying to determine why she was in pain, Anais was diagnosed with CRPS. Since then, Anais, Eric and their family have been dedicated to raising awareness of "the most painful disease known to man."

During the summer edition of the RSDSA Update, we sat down with

Eric as he prepared to hit the road. In the weeks leading up to the ride, Eric felt in good shape physically. He trained and had previously completed a 120 mile bike ride in just about ten hours. Mentally though, Eric questioned whether he would be able to bike those 120 miles for ten hours every day for two weeks. Would he get bored? Would he get discouraged? Not to mention, it was hard to condition for a ride that would take him through the hot and humid southern heat when he was living in the northeast.

When the ride began in Medford, Eric says he struggled to get a rhythm down. In order to complete the ride in the two week timeframe and to stay on schedule with meeting RSDSA community members along the way, Eric had to determine the speed he would need to take in order to complete 120 miles every day. Luckily, Eric had the help of his mom, Anat Moyal, throughout the entire ride. Anat drove beside Eric with a car full of water, snacks, and extra bike supplies. Talk about teamwork!

Eric and Anat traveled down the East Coast, passing through eleven states along the way. He described this journey as an amazing and once-in-a-lifetime opportunity. They saw beautiful parts of the country for the first time. "I also had no idea how many people were following the ride!" Eric exclaimed. People shared Eric's updates from the road on

"If there is one thing Eric has learned during the Ride for Warriors, it is that CRPS Warriors are doing amazing things. "Do not undermine your accomplishments!" he says.

social media. He spotted Ride for Warriors stickers in local towns. Donations continued to flow in. But perhaps the most meaningful part of the journey was the people they met along the way.

"I loved talking and hearing people's stories with CRPS," says Eric. "It was amazing to hear how people are still doing incredible things in their lives despite this debilitating condition." While biking through New Jersey, Eric was invited by board members Hank & Mary Beth Ludington to have lunch at their home. Mary Beth was 21 when she first experienced symptoms of CRPS, but was not diagnosed for many years. With support from her family, she was able to get



married, have 3 girls, 4 grandkids and go to grad school. However, Mary Beth did have a fear that she was holding her family back from different experiences because of her physical limitations. This is a fear that many people living with chronic illness have faced with loved ones. When Mary Beth apologized for feeling as though she was holding her family back on a vacation, her family's response was "are you kidding me?!" Mary Beth's children felt this statement could not be farther from the truth. In fact, they expressed gratitude and love for the experiences and memories she provided her children.



Although the beginning of the ride was difficult, Eric says the very last weekend was the hardest part of the journey. Up until this point, Eric could see clear progress as he moved from town to town and state to state. However, Florida was one long stretch of hot and humid heat and the highway. The wind was strong from the coast. Eric struggled to keep pedaling.

It was the second to last day of the ride when the front tire of Eric's bike hit a crack in the pavement. He flew over the handlebars, injuring both his leg and his bike. "Do you want to call it?" Anat asked. There was about a half a day worth of biking left. If he threw in the towel now, at least he could say he biked most of the way. But to Eric, calling it quits wasn't an

option. "The people I met along the way gave me the strength to continue the ride," says Eric. "Biking was nothing compared to the fight people with CRPS battle every day."

The last day of the race finally arrived. Eric and Anat met some fellow bikers after lunch who were going to finish the race alongside Eric. After peddling thousands of miles of unknown land, Eric was back in his hometown. It was comforting to ride through familiar territory and not need directions – or so he thought! As the excitement of reaching the finish line was upon him, Eric missed the last turn! A quick U-turn was made and the bikers were back on track. By then, the leg Eric had injured the previous day was numb.

Finally, the finish line was in sight! Dozens of people, including Eric's friends and family lined the street to cheer him along. Seventeen thousand miles had brought him to this point. When asked how it felt to cross the finish line, Eric replied "It felt surreal. I put my hands up, got to the finish line and hugged my sister."

Approximately two months later, Eric still finds it hard to believe



such an accomplishment was made, even after watching the highlight reel created by his sister. The Ride for Warriors exceeded its \$5,000 fundraising goal, raising a total of \$6,069. One hundred percent of these proceeds went to the RSDSA to further research efforts.

If there is one thing Eric has learned during the Ride for Warriors, it is that CRPS Warriors are doing amazing things. "Do not undermine your accomplishments!" he says.

Eric and the RSDSA would like to thank everyone who supported this cause, whether that was by donating, sharing posts on Facebook or providing a meal for Eric along the ride. Without this support, the ride would not have been possible. They would also like to extend a special thanks to:

- Jessica Kennedy Dutkiewicz who drove for an hour with her husband just to meet Eric in Georgia. She shared her story and treated him to dinner.
- Linda Horan who housed Eric and his mother, made them dinner and shared her story.
- Mary Beth and Hank Ludington who met Eric and Anat for lunch, shared her story and helped sponsor the ride

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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 UPCOMING EVENTS WWW.RSDSA.ORG



OCTOBER

10/19	3rd Annual Tame the Pain Golf Event, Galena, OH - Sharon & Matt Weiner
10/26	Treating the Whole Person: Optimizing Wellness - Denver, RSDSA
10/26	Flamin' 5K Fun Run - West Liberty, KY

NOVEMBER

11/3	Fight the Flame 5K - Cleveland, OH
11/4	Color the World Orange - Worldwide
11/16	RSDSA Funny Fundraiser - Philadelphia, PA

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