

rsdsa community update

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Fall 2018



PAIN DOESN'T DISCRIMINATE *by Christen Galup*

INSIDE
THIS
ISSUE

**FROM HOSPITALIZED CRPS PATIENT TO ADVOCATE:
BREAKING DOWN CHRONIC PAIN DISPARITIES** *(page 7)*

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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

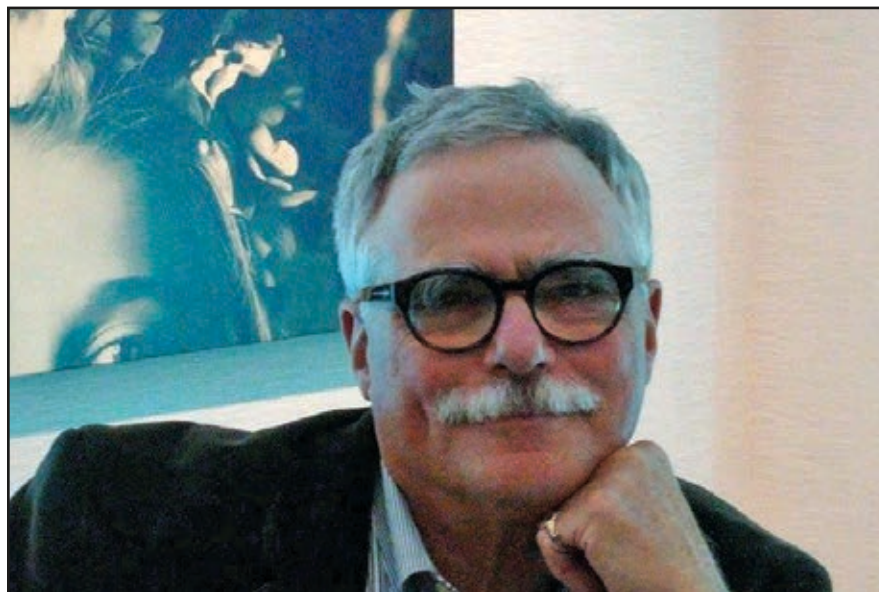
We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Aetna, Axsome Therapeutics, Baker Family Charitable Trust, Pope/Taylor National CRPS/RSD Lawyers, Neurologic Relief Center, NoPainHanna.com and Oska.

The Director's Letter - A Fall Update

BY JIM BROATCH, RSDSA'S EXECUTIVE VICE PRESIDENT, DIRECTOR

NOVEMBER IS CRPS MONTH

Help us Color The World Orange™ on November 5 by turning the night orange! A number of buildings and landmarks have the ability to turn orange, so let's request that they turn orange for CRPS/RSD Awareness. In 2017, more than 100 buildings and landmarks around the world turned orange. Please share your photos and proclamations with us and we'll post on RSDSA's social media platforms. Want to get involved? Visit Color The World Orange on Facebook: www.facebook.com/ColorTheWorldOrange



NEW ITEMS IN OUR STORE

RSDSA has added an attractive baseball hat to its online store. The RSDSA baseball hats are unstructured six-panel caps in washed chino twill with cloth strap and an antique brass sliding. Please help us promote greater awareness of CRPS by purchasing one in white or orange. They are affordably priced at twenty dollars each which includes s & h. Make sure you get one before CRPS Awareness month in

RSDSA COMMUNITY UPDATE

Our fall edition of the RSDSA Community Update contains a story and pictures from RSDSA's 4th Annual Center for Courageous Kids



Camp for children in pain. Fifty-six children attended with their families. If you want to help underwrite next year's camp, ask us to send you a plastic pig to collect your spare change. Your small change can make a huge difference in the lives of children in pain. Our Second Young Adults Weekend (YAW) was held recently in Nashville, TN. Our next YAW will be held November 2 through November 5 in Austin, Texas. Reserve your spot, as it will sell out!

Dr. Binkley has additional updates on emerging research in CRPS. Have you ever read her personal



story? Visit our research library and read it: www.rsd.org/wp-content/uploads/2015/02/Binkley-Improving-diagnosis.pdf

Thinking of applying for SSDI? Read Tai Prohaska of Allsup's article on how to best navigate the average 650 day wait for a disability hearing.

Finally, Beth Seickel, RN and Krisiti Hittepole share their stories of how to best advocate for yourself.

NOVEMBER IS CRPS AWARENESS MONTH

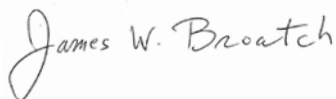
Last year, during November's CRPS Awareness month, we published the stories of the journey of people with



CRPS, family members, or health care professionals on our social media platforms daily. We would love to do that again. Please send us your story or a photo of an awareness event in which you participated or sponsored. Any questions, please call me at 877-662-7737.

WHAT TO GET MORE INVOLVED?

We blog every Wednesday on the #WednesdayBurn. If you like to write, please consider blogging for us. Disgusted with the lack of awareness about CRPS in the medical community? Work with us and distribute flyers about RSDSA's free accredited courses on pediatric and adult CRPS. Ask a local business to display our Penny Pig to raise funds for next year's camp for children in pain. Contact your local or regional newspaper and ask them to focus attention on CRPS and other chronic pain syndromes during the month of November. We can help you.



FREE ACCREDITED COURSES ON CRPS FOR HEALTH CARE PROFESSIONALS

Just recently, I read to my great dismay, that the time from onset of CRPS's symptoms to diagnosis is 30 months. That is unacceptable. Please join us and help educate health care professionals in your community about the diagnosis, treatment, and management of CRPS. Sadly, most medical and nursing schools still do not have a required course on the treatment of pain-the number one reason for a medical-office visit. We have developed post cards promoting the courses which you can distribute. Call us and we'll mail you the cards.

PEDIATRIC PAIN WEEK: HOW YOUR DONATIONS ARE MAKING A DIFFERENCE IN CHILDREN'S LIVES

RSDSA has served as a sponsor for The Coalition Against Pediatric Pain's (TCAPP) Pediatric Pain Week for the last three years. This year is our fourth year helping to sponsor this amazing week at The Center for Courageous Kids (CCK) in Scottsville, KY. Over 56 children and their families attended camp this year from July 28 - August 1, 2018. During Pediatric Pain Week, children experienced horseback riding, fishing, swimming, arts & crafts, Messy Games (one of the favorites), archery, stage day, bowling, etc. It is a family camp, so every family member is encouraged to join in the FUN! Not only does this benefit the child(ren) living in pain, but it also opens doors for parents. CCK is a place where nobody is judged for using a wheelchair during one activity and being able to stand for another activity. Everyone at camp respects each other as a person, not as an illness. The most amazing part of Pediatric Pain Week watching the children laugh, smile, conquer activities they have never done before and develop friendships with people who "get it." Living in chronic pain is difficult for anyone, but seeing children in chronic pain is heartbreaking. They are amazing warriors for all the challenges they endure every day, both medically and socially. Often, they lose friends and family members who just don't understand their pain conditions. They become lonely and, sometimes, depression hits them. Pediatric Pain Week is a perfect distraction for these families from their daily struggles. It also gives them HOPE and something to look forward to in the future. They make new friends who understand and keep in touch during the year. We've had families meet up for a weekend, at a doctor's office, for lunch, etc. All the children become part of the CCK family and are never alone again. If you would like to donate to Pediatric Pain Week or have questions, please email Jim Broatch at jwbroatch@rds.org.

THE LONGEST DAY OF GOLF AND THE THIRD ANNUAL LONG ISLAND AWARENESS CRPS AWARENESS WALK

Believe it or not, Josh Rosen golfed 130 holes on September 24 and raised more than \$30,000 to support RSDSA, doubling the amount raised in 2017. Hank Ludington, RSDSA's co-president and I accompanied Josh during his 12-hour-golf marathon. We witnessed Josh's near miss of two holes-in-one by mere inches and his chip for an eagle as the sun was setting. There is still time to contribute to this fundraiser, <https://www.firstgiving.com/event/rsds/2018-Longest-Day-of-Golf>

The Third Annual Long Island Awareness CRPS Awareness Walk was held on September 15 in Eisenhower Park in East Meadow, Long Island. More than 500 individuals with CRPS and their supporters attended and enjoyed a bagel breakfast, the opportunity to take a chance on winning one of an unbelievable array of raffle prizes, & a scrumptious barbecue. Attendees had the opportunity to meet others with CRPS, listen to short educational talks given by our sponsors, vendors, knowledgeable health care professionals, and children & adults with CRPS.

The event raised almost \$62,000! Special thanks to Nurse Beth Seickel, Debbie O'Neal, Stacey Udell, and Tiffany Mazza. We are scheduling next year's walk for either September 7th or 14th, 2019. Don't miss this event. Save those dates now.

Visit our Facebook page, https://www.facebook.com/groups/1895701040695508/permalink/2143924529206490/?comment_id=2144023442529932¬if_id=1540397761079917¬if_t=group_comment_follow

Swimming Against the Current: An Interview with Konnie Parke

BY JENNY PICCIOTTO

November is National Complex Regional Pain Syndrome Awareness Month, and November 17, 2018 holds special significance for Konnie Parke. On the 7th anniversary of the surgery that led to her CRPS, she intends to celebrate in an unusual way - she will televise a swim-a-thon in her garage to raise awareness about this rare disease.

Her goal is to swim for seven hours over a 24 hour period - in 15 to 30 minute increments - while live streaming the event. "Doing a fundraiser feels intimidating," she says, "but it's a passionate project of the heart. I can't walk, I can't run, I can't Zumba, but I can swim. It's my way of giving back." In fact, swimming has become an integral part of her pain management strategy, which includes medications, acupressure, biofeedback, and participating in a choir. Interspersed between swim sessions, her family will talk about how CRPS has affected them, and Konnie will share alternative therapies that have helped her adapt. She hopes to include a taped interview with her pain doctor, and will post a video about her experience on a fundraising website.

Having CRPS affected everyone in Konnie's family, and they hope that sharing their story will help others by validating their experience and offering tips on finding ways to cope with the life altering dynamics of living with CRPS.

Konnie developed CRPS after knee surgery. She was back to work as a Registered Nurse (RN) within 24 hours, but three days later she couldn't finish her shift. Her leg was blue and mottled. The pain was so intense that she could barely drive home and had to pull over. As

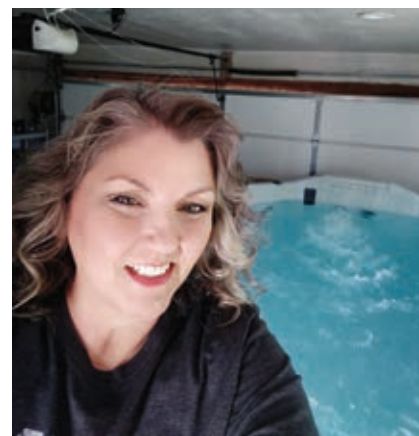
an RN, she knew the icy pain and blue color signaled lack of blood flow. "It looked dead," she says.

When she visited her surgeon, he told her she had RSD but offered no advice. "You're a nurse," he said. "Look it up." Then he walked out of the room. Her primary care physician's only advice was to "Get used to a new normal." "I was furious with this advice," says Konnie. "I liked my life just as it was." Over time she came to understand how important this advice was, she was going to have to be the driver of her own treatment plan.

She began to research treatment options, sorting through information gleaned from the internet and RSDSA newsletters. She started working with desensitization, but even the light touch of a feather caused extreme pain. She was referred to a pain management clinic where she tried many different medications, painful spinal injections, a spinal cord stimulator, and physical therapy. When these failed, her doctor told her that opiate therapy was her last resort.

Within a year of her diagnosis, she had to give up her job and her career. For the next 18 months she was restricted to bed, relied on a cane for walking, and developed full-body spasms that resembled seizures. She needed progressively higher doses of medications and felt like a walking zombie. Like many people taking opioids to manage chronic pain, she endured monthly doctor visits, urine tests, judgmental pharmacists, and insensitive comments by family and friends.

Prior to CRPS, Konnie worked as a public health emergency planner, and managed the Medical Reserve



Corps, a volunteer organization made up of medical volunteers. She also participated in community and church emergency preparedness activities. Research and planning for public health emergencies prepared her for research of another kind - surviving.

"I had a full life," she says, "but CRPS changed everything. My husband and I had our retirement all planned out. I carried the life and health insurance policies through my employer. We were out of debt, and I deposited my checks into retirement accounts in the hope of filling missions for our church after retirement. Developing CRPS was like a boat full of water suddenly tipped upside down. We had to change our whole life plan."

Over her lifetime, Konnie had overcome several injuries and health challenges, but developing CRPS in her left leg was a game-changer. It was hard for her family, co-workers and neighbors to understand why she wasn't getting better. She remembers being "silly grandma," the one who would romp on the floor on hands and knees, giggling with her grandchildren. But now they were cautioned by their concerned parents to stay away. Even a slight bump sent her pain through the roof. She was relegated to sitting with her leg elevated and

wrapped in heat blankets. To help the grandchildren understand, she euphemistically referring to her legs as the “happy leg” and the “sad leg.” This was one of many adaptations needed to find a new normal while living with chronic pain.

Frustrated by the side effects of opioid therapy, Konnie continued to research alternative treatments. She discovered a video of Dr. Pradeep Chopra at an RSDSA patient conference discussing the pathophysiology of the inflammatory response. As an RN, she was interested to learn that glial cells in the Central Nervous System release cytokines, which travel to the site of an injury to create inflammation, a normal process to heal damaged tissue. In CRPS, however, the inflammatory response doesn’t shut down and glial cells remain activated. Dr. Chopra explained that in the short term, opioids reduce pain by blocking glial cell receptors, slowing the release of inflammatory cytokines. In the long term, however, opioid therapy can misfire, as glial cells develop the capacity to grow more receptors that release even more cytokines, setting up a self-perpetuating cycle of inflammation. According to Dr. Chopra, low dose naltrexone (LDN), which cannot be used in combination with opioid therapy, deactivates glial cells.¹ It was a therapy Konnie was determined to try.

At the same time she was exploring biofeedback, a method of learning to control body processes, and Tapping, a practice that merges Eastern acupressure with Western affirmation. During flares, she would practice these techniques, which encouraged her to lovingly accept herself, to acknowledge her feelings, and to visualize her body cancelling the pain. “But I felt like I couldn’t have a conversation with my brain while I was taking opiates.”

For many months Konnie brought research about LDN therapy to her doctor, but he refused to consider

this alternative therapy. Finally in March 2016, facing another dosage increase, she took a drastic measure. Against doctor’s advice, she decided to wean off opiates to show her doctor how serious she was about trying LDN.

“I tried to get a weaning schedule from my doctor, but calls weren’t returned,” says Konnie. “Using my medical knowledge, I took the next six weeks to wean from two types of opioids.” Then, with research in hand, she went back to her doctor, told him she was off opioids and asked him to reconsider LDN as an option. “He made me wait another four weeks to prove I was opiate free, but he finally gave me a prescription for LDN based on Dr. Chopra’s dosing schedule.”

Stopping opioid therapy wasn’t easy. “The physical withdrawal was really bad,” she says, “even though I had a physical dependence on opiates, I had no psychological addiction.” Working with biofeedback and Tapping, she learned to tamp down the anxiety that comes with unpredictable severe pain; letting go of thoughts like “I can’t live like this” and “what if it never goes away?” With practice, she has had success reducing pain. Her flares last days now, not months or years. She still has “damn it days,” when she takes to bed with a heating pad, but she feels like she has more options to deal with it, and that gives her hope.

Today Konnie relies on a combination of medications, pool therapy, audio books, Tapping, and biofeedback. She no longer needs a cane, and dedicates the first two hours of the day to her swim-spa. “Depending on how rough a night it’s been, sometimes I’m toast after that.” She also enjoys participating in a choir, which distracts her from the pain by engaging her mind.

Although her insurance covered an expensive surgery to implant a spinal cord stimulator, she had to save for two years until she could afford the

indoor swim-spa, which has become her daily therapy. She swims against a current of water, modifying her strokes to compensate for the CRPS in her left leg, and the damage to her right hip from extra load bearing. The buoyancy of the water allows her to move in ways she couldn’t outside the water. “I use an aqua-jogger belt to keep afloat, and foam barbells. I have developed ways to do step aerobics, dance, hula and Tai chi.”

When she began, she could only be in the water for two minutes at a time, but has built up to being in the pool for several hours. Some days she blasts Led Zeppelin while exercising, and other days she just lets the bubbles pour over her body. “The 92 degree water helps my blood flow, because the capillaries in my leg shut down in water below 90 degrees. It also helps manage my spasms,” she said. “It’s my happy place, where I feel I have the most control over my body.”

By sharing her story, Konnie hopes to inspire other people coping with CRPS. She also wants to encourage doctors, physical therapists, and insurers to consider (and pay for) alternate therapies. “It’s about the bigger picture,” she says, “above and beyond my own little story. If someone can glean something useful from my story, that’s mission accomplished.”

She will donate contributions from her First Giving page to RSDSA, which has been a source of information and hope during her journey.

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.

1. www.ldnresearchtrust.org/content/low-dose-naltrexone-and-chronic-pain-pradeep-chopra-md

From Hospitalized CRPS Patient to Advocate: Breaking Down Chronic Pain Disparities

BY **BETH SEICKEL**

Have you ever wondered what you would do if you had an injury as a CRPS patient? Minor or major, we all face the same thing: misunderstanding and lack of supportive medical care due to our chronic pain history.

I'm here to share my recent journey as an in-patient following a fall through my deck. Yes, you read that correctly. As unbelievable as it sounds, one minute I was standing up watering my plants and in a split second, I found my leg (YES the CRPS Type II one) falling through the deck. I landed on my pubic bone and wondered "what just happened?" As my senses were overloaded with "are you kidding me?" and "of course my CRPS leg would be the one to fall through the deck," I knew I had to roll out of this ditch before the rest of me fell in. Somehow, I crawled onto the couch in the living room, hoping this would just resolve fairly quickly.

Despite abrasions, bruises and being totally banged up, I knew this would set off a CRPS flare that I would just have to deal with until it passed. But I never could have imagined this type of CRPS flare turning into a full blown "CRPS crisis." This is where the nightmare began.

After three days of resting, elevating leg, taking anti-inflammatories, antispasmodics, pain medication, ketamine troches, and NOT being able to ice the CRPS leg, I found myself with an escalated flare beyond any ability to quantify the depths of pain that covered every inch of my body. Never in the 12 years since my diagnosis, have I EVER had this amount of burning, stabbing, and relentless physical torture of pain throughout my entire body. Knowing there was nothing else I could do at home, I made the agonizing decision to go to the Emergency Department (ED) where at least my pain management doctor, who is on staff there, could intervene with my care.

As I reached the ED, I couldn't stand, walk or move. Somehow, with my husband's help, I was wheeled into triage area literally screaming in absolute agony with what appeared to be a possible pelvic fracture. The nurse practitioner in triage ordered blood work, abdominal X-Rays and NO pain medication support. As I found myself sliding out of the wheelchair from the sheer agony of "non-quantifiable" pain, I was sent directly to the "fast track" area only to lay on a stretcher, ignored for hours, screaming in pain.

One would think my care would have been **escalated** to the ED head nurse, nursing supervisor and or assistant



director of nursing, if the staff was unable to act swiftly. If not only from the sheer level of pain crisis I was in, but geez, I am a former ED nurse! I most certainly escalated cases to my head nurse, nursing supervisor, assistant director of nursing or chief nursing officer to expedite care if I was totally bogged down with patients. After all, the ED is unpredictable. One minute it can be quiet and the next minute it can be total chaos.

As the first hour passed, I was transferred to X-Ray, without any pain medication, screaming, and unable to express "please do NOT touch my feet or legs when transferring me from stretcher to X-Ray table." The tears rolled down my cheeks as I just struggled to keep from passing out, but knew what was coming. As both my legs were grabbed to slide me over, all I could hear were the comments of the techs, "Why was this patient sent over like this?" Clearly, I was in obvious distress. So as I tried to just stay in the moment, I kept thinking "I use to be an ED nurse, why then am I not having the care I use to give?" Every hospital, in order to have (TLC) The Joint Commission accreditation, is required to implement pain policies to assess, manage and respect the "patient's rights" to pain management. Yet I laid there for another hour without any intervention.

All the while, my husband tried to intervene. Sharing my medical history alongside documentation, which I carry at all times, to educate and validate my CRPS. This includes:

- Medical history, allergies, medications, diagnoses and my team of doctors, including my pain management doctor on staff at the hospital
 - RSDSA's "I have CRPS card"
 - RSDSA's ED/Urgent Care Guidelines "Handle with Care"
 - RSDSA's Hospital Guidelines "Handle with Care"
- www.rsds.org/empower-yourself-with-the-latest-crpsrsd-information

Obviously, CRPS didn't ring a bell with the staff because I laid for another hour un-medicated as I was packed up to go to CAT scan to assess for internal bleeding/injury.

As the CT tech approached me, I was told the scan could not be done, since the ED had not drawn the proper blood work needed to assess my kidney function before IV contrast could be given. Are you kidding?

Back to the ED I went for another traumatic blood draw which should have been done initially. Worse yet, I needed a 3rd needle stick to start the IV. Again, as an ED nurse all I could think about was, “why not get all the blood work during the IV insertion and avoid numerous needle sticks?”

Finally, after my family escalated my care to the Assistant Director of Nursing (ADN), things started to move. The ED physician ordered pain medication including IV dilaudid and IV ketamine bolus, all of which didn’t help as the “CRPS crisis” was beyond speech.

The plan was to admit me for high dose IV dilaudid and IV ketamine infusions, since I was NOT allowed to use my specialty compounded ketamine troches as an in-patient (not on hospital formulary and the unit-based pharmacist was unable to validate compound, despite the fact my on-staff doctor has prescribed). However, the dose of IV dilaudid and ketamine was only permitted in the ICU.

As I tried to wrap my head around this ridiculous, non-productive situation, this too had to be escalated as a direct admission to ICU in order to receive the care I needed.

Honestly, I cannot put into words how much pain falling through the deck caused. Never in my 12-year history with CRPS did I ever feel my entire body seething in such burning, agonizing torture. Even the EKG leads were painful. Thankfully I knew hospitals have “**hypo-allergenic**” materials including hypoallergenic EKG leads. But removing the old ones sent me over the edge again in sheer torture. It was as if my skin was being peeled away. Truthfully if I was an injured animal, I would have been euthanized.

Despite the ICU nurses’ attempts to control my pain, it wasn’t until the ketamine infusion was increased that I required less IV doses of dilaudid. Here are few things I did to help myself:

- Kept my room cold (visitors wore coats) and temperature controlled
- Wore dark sunglasses to minimize additional triggers and sensitivities (fluorescent lights are big triggers for me)
- Laid on my own soft, velvety blanket (hospital linens are too noxious to my skin)
- Asked for *hypoallergenic* gowns & linens (hospital detergents were too harsh on burning skin)
- Utilized soft, pre-soaped with warm water, disposable washcloths
- Utilized my portable fan (which at beginning of CRPS, I could NOT tolerate, but now is helpful)
- Utilized my cellphone to take pictures of the ever changing skin colors of my feet to validate and educate the benefits of ketamine infusions

In spite of agonizing torture, I made it my mission to educate as many as possible. Although ICU staff had experience with ketamine infusions, they really did NOT have a grasp on what CRPS was

and why ketamine could help. They do now!

My stay was unfortunately complicated with the development of esophageal/throat thrush, pneumonia, respiratory distress and exacerbation of asthma, all within two days of being hospitalized. You just can’t make this stuff up. My immune system took a nose dive from the biggest “CRPS crisis” of my life.

Between daily needle sticks for bloodwork on my left arm and the multiple IV’s on my right arm for IV antibiotics, IV steroids, IV ketamine infusions, and IV dilaudid infusions, my arms were so bruised & tender, I lost peripheral vein access for any further blood drawing.

Finally I told them to stop. NO more sticks. My veins were frail and fried. Time for new plan! A *midline PICC* (this type of PICC line does NOT need chest x-ray confirmation) was inserted in my upper left arm which was a blessing. Daily blood work was drawn from this line, as well as the many IV fluids, IV steroids, and IV antibiotics required. **NO MORE TRAUMA** from another needle stick. Thankfully, I had the midline PICC until being discharged.

Now, I know what you must be thinking: “if Nurse Beth is going through this, then what can I do?”

1. Always, when possible, bring someone with you who can **advocate** for you when you’re not able
2. Bring a journal to keep notes
3. Empower yourself by carrying:
RSDSA’s “I have CRPS card”
RSDSA’s Hospital Guidelines “Handle with Care”
RSDSA’s ED/Urgent Care Guidelines “Handle with Care”
4. Medical documentation of your health history, doctors, and diagnoses
5. If you’re having challenges obtaining care, **escalate** to the ADN or CNO (Chief Nursing Officer). In fact, patient relations can be helpful as well.
6. Take pictures of your “CRPS flares or crisis”

I use all of these tips as tools to educate and validate my CRPS.

After all was said and done and I recovered, I decided to take a stand. Every hospital wants to be designated as a **Magnet Status Hospital**, with recognition for excellence. To obtain this, hospitals utilize responses from hospital surveys. Yes, those longwinded surveys really do impact patient care. Can you guess what Nurse Beth did?

I did my due diligence, answering all the questions, while adding a few additional comments. I made note of the professionalism and care of the ICU nurses in stark contrast to the ED staff who clearly didn’t understand CRPS, along with asking for clarification as to why the nurse practitioner of triage was unable to have pain management privileges?

After completing my survey, I also wrote a formal letter addressed to the hospital ADN, CNO, Executive Vice President/Chief Administrative Officer, Director of Patient

Experience and copied my pain doctor and to Jim Broatch, the RSDSA director. The impact was immeasurable.

My formal letter in conclusion stated: "I hope the hospital will broaden the ED **response time** to pain, **improve staff education and compassion** for all patients with chronic pain such as CRPS, which is a "real medical condition," as well as expand ability for patients to continue use of their prescribed medications when hospitalized, especially when prescribed by their physician on staff."

I did receive a personal call from the ED head nurse to apologize for my care, while acknowledging the lack of education ED staff has about CRPS. She also explained that at the time of my admission to ED, the nurse practitioners did not order pain medications, rather this is done by the ED physicians after their bedside assessment is completed. They recognize that perhaps the role and responsibilities of their NP triage nurses need to be re-evaluated and will bring this issue forward at the next Emergency Department meeting. Staff would be re-educated on the need for continued clear, accurate and timely communication, as they should have escalated my severe pain to the physician immediately.

She did share that RSDSA materials were printed out, as I suggested, including ED/Urgent Care Guidelines for CRPS patients, and said she would most definitely share with her staff. In addition, I was told my letters and survey had a direct impact on Emergency Department policy changes.

Starting January 2018, Nurse Practitioners, will be able to order pain medication for acute pain in addition to diagnostics. Had I received prompt pain management, the intensity of flare/crisis could have been avoided. However, improved education and response time for all patients, but especially for those that present with chronic pain syndromes, which require additional education and policy evaluations of change, has been brought to the forefront. This is a HUGE change!

The only way to create changes is to advocate and educate for ourselves in a calm, non-aggressive manner, especially with the current atmosphere of opioid fear and phobia. This includes completing every **hospital survey** you receive. This is your **patient responsibility**.

So, how can each of us make lasting change?

- Find out if your hospital has a yearly pain symposium for health professionals, especially for the emergency department staff. If so, discuss possible collaboration with hospital pain management service, alongside the emergency department and RSDSA.
- If your hospital does not have pain symposiums, ask your pain management doctor if he or she would be interested in developing a forum to educate others about chronic pain such as CRPS.
- Determine whether your physician is part of a technical advisory panel (TAP) at the hospital
- Inquire about whether your hospital and or pain management doctor develop annual health

fairs in which CRPS can be included?

- Find a local ASPMN chapter (American Society for Pain Management Nursing) www.aspmn.org/chapters/Pages/localchapters.aspx to bring CRPS directly to ALL facets of nursing (Jim Broatch and I presented to ASPMN-Long Island Chapter and exhibited at 2018 National ASPMN September conference.
- Advocate for our future health professionals in medical and nursing schools to include chronic pain education in their curriculum, as many are implementing opioid education
- Share RSDSA's current publications, peer-reviewed literature, research, etc. as a lasting resource for practitioners to use with their patients
- Carry copies of RSDSA's guidelines to share with every health professional you meet
- Most importantly, presentation is everything. Believe me, I totally understand what intractable pain can do to one's personality, but to make any advances we need to remember our P's and Q's

Advocating for oneself is a fulltime job. But despair breeds stagnation. Education builds empathetic understanding to create changes. No change is too small.

Finding partnerships is the key to a *strategic plan of action*. Discover your hospital organizations "goals and objectives" and "expectations and measurable goals." Organizations who want to maintain their accredited Hospital status by TJC need to follow the new and revised pain assessment and management standards effective January 2018. This includes: Assess and Manage the Patient's Pain and Minimize the Risks Associated with Treatment. www.jointcommission.org/assets/1/18/R3_Report_Issue_11_Pain_Assessment_8_25_17_FINAL.pdf

Investigate your hospitals strategic goals such as:

- Safety of patients (opioid phobia can be replaced with improved plan of action)
- Quality of care (improvement with prompt assessment and implementation of a plan)
- Satisfaction of patients (important towards hospital receiving a "Magnet Status")
- Decrease turnover rates of staff (or recruit more VESTED Practitioners)
- Relevant and responsiveness to patient needs (If staff is overloaded, excavate for help)

If hospital facilities have tangible strategic goals, then staff can be better educated to identify & understand CRPS, to implement a plan of action to handle flares and or CRPS crisis more effectively.

Nurse Beth, alongside RSDSA continues to develop partnerships with other health professionals, medical facilities, organizations, medical/nursing schools, not-for-profit organizations, CRPS patients and the public to create change. Whether a practitioner treats CRPS or has never heard of CRPS, we can make a difference one step at a time. If Nurse Beth is a force to be reckoned with, then imagine what a group of us can do?

Keep Your Specialty Doctors Close, Your Primary Care Doctors Closer

BY KRISTI HITTEPOLE

Four years ago, I was a healthy 37 year old single mother climbing the professional ladder. My goal of meeting the needs of my two very talented daughters through their high school years and college was my fuel. Long days and even longer nights were met with a body and mind able to tackle each day. On November 22, 2013 everything changed. I was diagnosed with DCIS (breast cancer) and on that day in November, I had a bilateral mastectomy. The complications were copious and there were times I felt the infections or constant trips to the operating room would take my life. My body rejected implants over and over again. Again, I turned to my little girls for fuel to fight. In 2014, I had my breasts reconstructed with no complications by two of the best surgeons in the world. This time, I had a ten-hour DIEP Flap reconstruction whereby my own tissue was transplanted from my abdomen to my chest which created the illusion of breasts. Once recovered, I returned to a thriving career and started to make up for lost ground.

Through those years, I made a terrible mistake. I lost contact with my primary care physician. I had so many doctors and medical professionals involved with my treatment, it never occurred to me that I went two years without one visit with a general practitioner. I had an oncologist, plastic surgeons, in-patient physicians, infectious disease attending and numerous nurse practitioners. They were not a "team" of doctors. They were individual entities making recommendations and choices based only on what they knew. When the dust settled and I was adjusting to my life post-mastectomy, I came

down with a cold. Not just the sniffles, I needed antibiotics. I called my general practitioner's office and was told that he was no longer practicing with them as he chose to go into academia. I hung up the phone after declining an appointment with his partner and went to an urgent care to be diagnosed with a sinus infection and was written a prescription for an antibiotic. Of course, my life was still full of regular appointments with the aforementioned "team of individual" cancer doctors, so I again lost sight of finding a "me" doctor.

About six months later, I began to have pain in my chest area. At this point, my chest wall had been operated on eighteen times. It goes without saying that my chest took a mighty dose of trauma. I never thought about what I should be doing to rehabilitate myself and neither did anyone on the cancer team. Nobody said "perhaps you should have some PT and OT to build strength." Nor did they recommend that I see a mental health specialist to sort out the trauma to my emotional space. When I went back to them to talk about the pain that was getting worse in my chest, they simply did not have the ability to assess and treat it because the truth is that it's 100 percent out of their expertise. I equate it to seeing a podiatrist for chest pains. My plastic surgeon once said "sure, I can write a script for gabapentin, but I am totally not qualified to manage it because it is not something I regularly manage. Perhaps you should go to pain management." I rejected that idea, as I could just push through the pain without having to go through the wringer that is associated with being a patient in a pain management clinic. Instead I sought out a QB1. A captain of my team. A doctor that would be the center of my medical world.



It took a handful of failed attempts. I met one doctor who was in family practice. She saw that I had 18 surgeries and recommended Advil and Ambien for sleep. I left that appointment scratching my head. I made sure that each doctor I spoke with was acutely aware of my intentions. I was interviewing them to perform a job for me - to understand me looking through a microscopic medical and holistic lens. I needed an advocate representing me for all of my medical and mental health needs. I craved someone who would respect the problems that my mind, body and spirit would encounter from the day I hired him or her until the day the relationship no longer made sense.

Then I met him. I did not have to give him the aforementioned disclaimer because he was hired when he walked in the exam room. This physician came highly recommended by a trusted source, so I was already confident going into the appointment. I started talking and he just listened. As with most general practitioners, I knew he was on an insurance mandated time limit, but he never once looked at the time or started the prognosis conversation prior to hearing every single thing there was to know. He knew about surgical neuropathy and that it was terrifyingly real. The attention he paid to detail was beyond impressive. I got this feeling that if I was not well, he wasn't either. Therefore, he became what I needed all along. An internal medicine primary care physician with

vast experience and a strong desire to improve my quality of life. My QB1.

I have never been more grateful for this center of my medical world than I was in March of 2017. I went to my plastic surgeon to discuss a complication that arose with my reconstruction. The “why” isn’t important, but I had to have a surgery to correct this problem. It was supposed to be “easy.” The surgeon said “I will go in and remove the adhesions and fix the muscle and just put a tiny implant in between so that adhesions don’t return.” I had grave fears of the word “implant” because my troubles of 2013 were due to the foreign nature of an implant. He assured me “Kristi, your body is different now. We have to do this and there is a less than one percent chance you will ever develop infection.” I proceeded with a great deal of fear, but had confidence in the extraordinary ability of this surgeon.

Six days later, I was septic.

QB1..... he was the guy I turned to this time. Rather than counting on a team full of doctors who were never a team to begin with, I called QB1. Two years prior to this health crisis, I sought and found a partnership with this physician so one person could see my health, wellness and sickness without tunnel vision. He could see the entire field, which was so important because three letters came out of the mouth of the surgeon that changed my life forever. “R.S.D.”

QB1 was there. His knowledge of who I am as a person rather than just a patient was critical for the journey we were about to embark on. He knew I would never accept that diagnosis without first being sure we traveled the road to every single possible ailment. At this point my chest had been operated on twenty times and debilitating pain was starting to envelop my chest, my leg, foot and later, my hand. We were on a mission to find answers because that is what I needed to move forward.

The specialists changed from oncologists, plastic surgeons and infectious disease to rheumatologists, hematology, neurologists and even the dreaded pain consult. I traveled to doctors all over Ohio and even went to the Mayo Clinic in Minnesota. It took seven months, numerous consults and tests for me to get close to acceptance. The final proof I needed came via results of a high positive three-phase bone scan that stated “consistent with RSD.”

I had RSD.

Through the diagnostic phase, I am certain QB1 always knew it was RSD. He had to know. All signs pointed that way, but he knew I would never accept the diagnosis, nor would he make such a permanent diagnosis prior to exhausting all other possibilities. We mutually decided that he should be the one to manage my pain meds. We have sat together every two weeks for nearly a year. I always have the last appointment before lunch because our conversations are in depth and very detailed. He often reminded me that he was painting a picture - that all the specialists contributed ideas, but he was the one gathering their contributions to paint the picture. He would take their recommendations under consideration and combine their conclusions drawn from a 30-minute consult with the 30 hours of knowledge he had collected over the last 12 months.

Without even realizing it, I believe we have set a new standard of care that should be the model for all people with chronic disease. I do not believe that just any general practitioner has the capability to do what he has done. They have to be confident with the handling of pain medication without fearing the political climate we are currently in. They have to embody the strength to tell you when you are wrong or that you need to change course when that isn’t what you want to hear. They have to possess a level of knowledge that exhibits experience

beyond the clinical setting. Above all, there has to be mutual trust. Mutual respect. A mutual desire to obtain the best possible quality of life, no matter the circumstances.

I encourage all people to seek the standard of care that I receive. I read so many heartbreaking stories of people living life with RSD in the ER and I know they can do better. This diagnosis was worse than having a mastectomy. The pain is agonizing at times, however, I have never been to the emergency room due to lack of pain control. I believe strongly that the approach of my physician is the reason for that. He has taught me how to use my mind when the flare is out of control. He has taught me to respect my new limits and he does so without making me feel like I am less than who I was before.

My daughter asked me why I was telling this story for so many people to read. In answering, I reminded her of the time I took her with me to an appointment. She joined me because she had concern about opioid medications. I asked her to recall how my doctor spoke with her and that he explained, on her level, how these medications work and how not all people use more than they are supposed to. She remembered.

I wanted to tell my story in hopes that people with chronic illness can feel empowered to demand nothing less than QB1. This disease is forever. This disease knows no limits and has no mercy. I have teetered on the line of total loss of control and every single time I am toeing the ledge, I know where to throw the ball and everyone with RSD should have a center to their universe. The model of care that we established reminds me a little of Jerry McGuire and his mission statement.

Fewer patients. More individual attention. A partnership in care that can reach even further than the infinite limits of RSD.

I owe my life to QB1. Because he chose to stop and listen.

Hope on the Horizon

BY KAREN E. BINKLEY, MD, FRCPC
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If you have CRPS, you may already realize that existing treatments do not work as well as we would like. The best hope for improved treatments will come from a better understanding of what is going wrong in CRPS, so that we are better able to fix it. In this column, new developments in our understanding about CRPS, and implications for treatment are reviewed.

PROGRESS WITH IL-10 GENE THERAPY DEVELOPMENT

Xalud Therapeutics recently announced that their lead compound for interleukin-10 (IL-10) gene therapy, called XT-150, has entered Phase 2 clinical trials for osteoarthritis pain. Why is this important news for CRPS patients? IL-10 has been shown to reduce pain in animal models of neuropathic pain, like the pain of CRPS. The pain of CRPS is due, at least in part, to inflammation in the spinal cord and parts of the brain. IL-10 is a master anti-inflammatory substance that the body produces to control unwanted inflammation, and it is low in CRPS patients. And while investigation for the use of the IL-10 gene product is only in the investigational new drug stage for neuropathic pain, once it is approved for osteoarthritis and available for clinical use, it may be possible for physicians to prescribe it “off label” for CRPS.

MYCOPHENOLATE

Mycophenolate is a medication that suppresses the immune response, which may contribute to the increased inflammation seen in CRPS. Recently, researchers in the UK and Philadelphia found that four out of nine patients treated with mycophenolate had reduced CRPS symptoms, but side effects caused 45 percent of the patients to stop taking the drug. This is a very small study, but encouraging enough for the researchers to recommend a more definitive trial with larger number of patients.

EPIDERMAL GROWTH FACTOR RECEPTOR INHIBITION

Researchers in Norway treated 20 patients with chronic neuropathic pain with inhibitors of epidermal growth factor receptor, which is thought to play a role in the activation of neurons and glial cells, resulting in inflammation and chronic pain. They found that 18 of those patients had significantly improved pain scores. This same group reported that four out of five patients treated responded. Further trials will be necessary to confirm these results.

HYPERBARIC OXYGEN THERAPY

Hyperbaric oxygen is not a new treatment for CRPS. In fact, there is information regarding it on the RSDSA website. But it seems that it is often overlooked as a treatment for CRPS by both clinicians and patients, so it seemed worthwhile to review some of the evidence for its use. Unfortunately, this evidence is limited to case reports, or small case series. There are a lot of anecdotal claims on the internet and YouTube of successful reduction in CRPS symptoms with hyperbaric oxygen. Most insurance providers do not find this evidence sufficient to convince them to cover hyperbaric oxygen therapy for CRPS patients. But it is well tolerated, with few side effects. Larger trials demonstrating its effectiveness may convince insurers to cover this treatment in the future. In the meantime, it is something that CRPS patients can discuss with their treating physicians.



References:

1. <https://www.xaludthera.com>
2. Scand J Pain. 2018 Jan 26;18(1):29-37. Mycophenolate for persistent complex regional pain syndrome, a parallel, open, randomized, proof of concept trial. Goebel A, Jacob A, Frank B, Sacco P, Alexander G, Philips C, Bassett P, Moots R
3. Br J Anaesth. 2015 Nov;115(5):761-7. Epidermal growth factor receptor-inhibition (EGFR-I) in the treatment of neuropathic pain. Kersten C, Cameron MG, Laird B, Mjåland S
4. Scand J Pain. 2017 Dec 29;4(1):3-7. doi: 10.1016/j.sjpain.2012.11.011. Epithelial growth factor receptor (EGFR)-inhibition for relief of neuropathic pain-A case series. Kersten C, Cameron MG, Mjåland S.
5. Pain Res Manag. 2016;2016:3458371. Successful Treatment of Lower Limb Complex Regional Pain Syndrome following Three Weeks of Hyperbaric Oxygen Therapy. Katznelson R, Segal SC, Clarke H.
6. Pain Pract. 2016 Jun;16(5):620-8. Hyperbaric Oxygen Therapy: A New Treatment for Chronic Pain? Sutherland AM1, Clarke HA, Katz J, Katznelson R
7. J Int Med Res. 2004 May-Jun;32(3):258-62. Effectiveness of hyperbaric oxygen therapy in the treatment of complex regional pain syndrome. Kiralp MZ, Yildiz S, Vural D, Keskin I, Ay H, Dursun H.
8. Undersea Hyperb Med. 1995 Dec;22(4):407-8. Hyperbaric oxygen and the reflex sympathetic dystrophy syndrome: a case report. Peach G.

Don't Get Stuck in the Disability Backlog

BY TAL PROHASKA

Most people do not know a lot about the Social Security Disability Insurance (SSDI) program until they have to stop working because of an illness or injury. Then, one of the first questions asked is "am I eligible?" You may qualify for monthly income (based on what you have paid into the system) and other benefits if you:

- Are unable to work for at least 12 months or more, or your condition is terminal
- Have paid FICA taxes for at least five of the last 10 years
- Are over 21 and under full retirement age (65-67)

The "SSDI 101" (www.allsup.com/ssdi-101) crash course continues with the following facts:

- It's not easy to obtain benefits. Two-thirds of people who apply are denied and must go through an appeals process that can take years.
- People are waiting an average 605 days for a disability hearing. Almost half of U.S. hearing offices report waits of 600-plus days, including 14 offices whose times exceed 700 days. To see the average wait in your state go to www.truehelp.com/wp-content/uploads/2018/03/state-by-state-hearing-backlog_Mar2018.pdf.
- After the hearing, people wait an estimated 78 to 120 days to find out the judge's decision.

The disability backlog was also an issue in 2009, when Allsup surveyed individuals going through the SSDI appeals process. Of those surveyed, 90 percent said they faced negative repercussions while waiting for their SSDI award. These included:

- Stress on family – 63 percent
- Worsening illness – 53 percent
- Draining of retirement/savings – 35 percent
- Lost health insurance – 24 percent
- Missed mortgage payments – 14 percent
- Foreclosure – 6 percent
- Bankruptcy – 5 percent

BANISH THE BACKLOG

One way you can improve your likelihood of avoiding the SSDI backlog is to get help at the very beginning of the process, starting with an eligibility assessment before you ever go to the SSA. Most people who apply through the SSA's website for SSDI are denied. They don't have enough work credits, do not submit adequate medical records, do not fill out SSA's forms properly, or do not respond to the SSA's requests for additional information. The process can be overwhelming and confusing.

Many websites offer tips on how to apply for disability. Allsup.com has a free online screening tool, empower by Allsup®, that incorporates return-to-work information. Getting help with the initial application can mean the difference between getting benefits in a matter of months instead of years.

If you already have SSDI benefits, and would like to see if you can return to work without fear of losing your cash and Medicare benefits, go to www.truehelp.com/return-to-work for free help using the Ticket to Work program.

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 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).

The Fight the Flame 5k

By Beth Stillitano



The 6th annual Fight the Flame 5k and 1k Roll & Stroll was a HUGE success! With our highest numbers of registrants and a beautiful fall day everything was amazing.

Geoff Schwartz, 8 year-NFL veteran kicked things off as our Master of Ceremonies. The race was dedicated to a Fight the Flame committee member and friend who we lost this year, Steve L.

This race has now raised over \$140,000 for RSDSA. The money also supports a local Fight the Flame/CRPS College scholarship and support group.

All of this could not be possible without the help of our generous sponsors:

- Platinum Level: Ayers, Whitlow, & Dressler; Bojangles
- Gold Level: Connolly Orthodontists; Omega Sports; Southeast Pain & Spine Care; Hendrick Honda, Silver Investments
- Silver Level: McKee Dental, Pizza Peel, Metrolina Pain Relief
- Bronze Level: Camp Gladiator; European Wax Center; Dennis Coffey-Realtor; Honest-1 Auto Care; Performance Growth Advisors; Stacks Kitchen of Matthews; Stanley Specialty Pharmacy
- Mile Markers: Shelf Genie; Leroy Fox; 2 Envision Fitness



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 info@rsds.org.**

Cauliflower Fried Rice

INGREDIENTS

- 1 large head cauliflower, cut into florets (you can also find the bags of "Cauliflower Rice" in the produce section of the supermarket or frozen section of some specialty stores. Personally, I get mine in the freezer section of Trader Joes).
- 2 tbsp. extra-virgin olive oil, divided
- 1 medium onion, diced
- 1 clove garlic, minced
- Fresh ginger, minced
- 6 oz. frozen peas and carrots
- Cooked, shredded chicken
- 1 tbsp. chili paste (optional)
- 2 large eggs
- 5 tsp. soy sauce, divided (use coconut aminos if you are on an auto-immune diet)
- 1 tsp. sesame oil (optional)
- 2 bunches green onions, chopped
- The above are all recommended vegetables, but you can use anything that you enjoy!

DIRECTIONS

If not using the precut version, working in batches, place cauliflower into the bowl of a food processor fitted with the blade attachment. Process into small crumbles that resemble rice, and then set aside.

In a large skillet over medium heat, heat one tablespoon oil. Add onions and cook for two minutes. Then, add garlic, ginger, peas, and carrots and cook for five more minutes, stirring often. When vegetables have softened, add chicken and chili paste and cook for two minutes. Add your riced cauliflower and cook for two minutes, stirring often.

Push rice mixture to one side of the pan and crack eggs into the open area of the skillet. Add one teaspoon soy sauce to eggs and scramble. Once cooked through, stir eggs into rice mixture. Add remaining four teaspoons of soy sauce and stir.

Continue cooking for five minutes until everything is heated through and soft. Remove from heat and drizzle with sesame oil. Sprinkle with green onions and serve.



Product Recommendation



Living with CRPS is difficult. Aside from taking care of ourselves, some of us also have the responsibility of feeding a family.

Cooking is a tough task that requires a great deal of work and time - most of which is spent on our feet. Putting together good, hearty meals often requires a great deal of steps. We have to be on our feet consecutively for at least an hour watching the stove, prepping, stirring, pulling food in and out of the oven and many other related tasks. Using a crock pot is great because you put all the ingredients in and a meal is ready within hours. But wouldn't it be great to have a product that made your meal cook faster? A product that can do many things with set cooking times for a great deal of items.

The good news is this product exists. The Instant Pot is a staple in my kitchen. It is similar to the crock pot, which is a slow cooker. However, this item is actually a pressure cooker! It has so many cooking options, most of which would normally take five hours using the slow-cooking technique, that can be done in under an hour. I am in no way getting paid to write this review, I am just someone who would like to help the rest of the CRPS community. This product isn't too expensive and is often on sale. I highly recommend it for anyone who wants to make delicious food quickly and easily!

SO, WHAT SPECIFICALLY CAN BE DONE IN YOUR INSTANT POT?

- Pressure cook.
- Slow cook
- Cook rice- Yes it does replace your slow cooker!
- Steam
- Sauté
- Keep food warm after cooking
- Make yogurt
- Some models can sterilize and make cakes, and even have specific settings for cooking eggs
- Stew, make soups, and chili

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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.

EVENTS CALENDAR

2018 CALENDAR OF EVENTS THROUGH NOVEMBER

NOVEMBER IS CRPS AWARENESS MONTH

November 5 - Color the World Orange, Worldwide

November 16 - Boscov's Friends Helping Friends- Suzanne O'Toole

November 17 - RSDSA Swimming Fundraiser, Salt Lake City, UT

Visit RSDSA's Events Calendar:

<https://www.facebook.com/pg/RSDSA/events/>

PEER-TO-PEER THOSE IN NEED OF SUPPORT:

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

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

Don't see an event near you?

Contact Jim Broatch info@rds.org
to discuss planning an event in your area!