

rsdsa community update

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WWW.RSDS.ORG/NEWSLETTER

Spring 2018



Four young women at rock: Kappa-Phi sponsored sign-a-thon at Ohio Northern University

Jim Broatch welcoming participants at December seminar in Greenwich

Two photos: 2018 Crazy Sock Walk for Invisible Disease Campaign in Florida (group under canopy and crazy socks)

INSIDE
THIS
ISSUE

EMERGENCY OUTREACH WITH BILLY ALEXANDER, MD *(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, Aetna, Axsome Therapeutics, Grunenthal, Ketamine Treatment Centers Partnership, McLarty/Pope, Neurologic Relief Center, NoPainHanna.com, Oska and Relax Release Relief. For more information about becoming an RSDSA Partner, please contact Jim Broatch at info@rsds.org.

The Director's Letter - A Spring Update

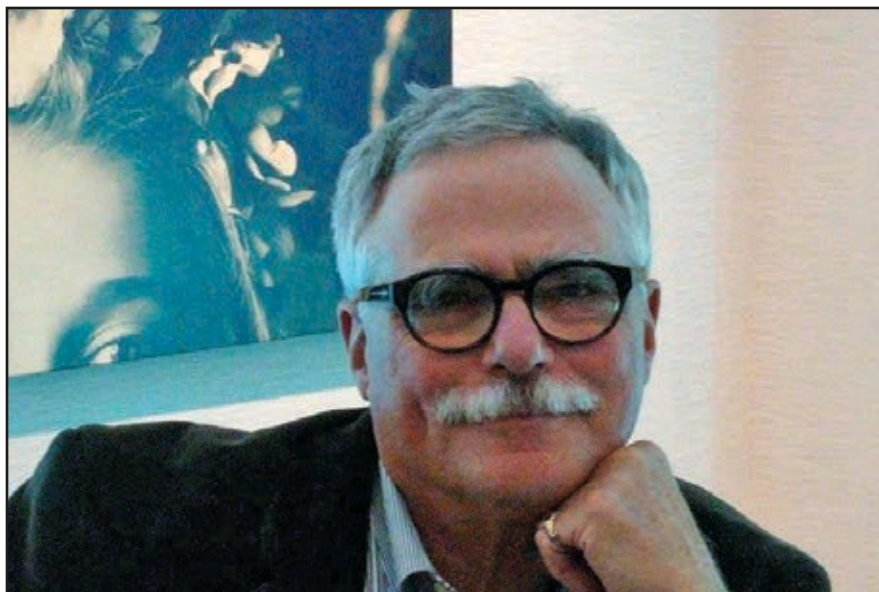
BY JIM BROATCH, RSDSA'S EXECUTIVE VICE PRESIDENT, DIRECTOR

TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS CONFERENCE IN SAN JOSE ON MARCH 24

RSDSA is returning to the West Coast. We are partnering with the Bay Area Pain and Wellness Center to sponsor an exciting full-day conference: Our faculty are experts at the forefront of the latest research and state-of-the-art treatments. They will discuss a variety of topics including: brain neuroplasticity and brain-based treatment modalities, navigating the health system, medical cannabis, complementary therapies, interdisciplinary treatments, incorporating psychological care into treatment, and movement-based therapies. We will also share information and support for caregivers, who are an important part of care. Here is a link to view our agenda and to register: <https://rds.org/event/treating-whole-person-optimizing-wellness-san-jose-ca/> We're also planning half-day seminars later in the year in Charlotte, NC. To view previous conferences lectures, please visit https://www.youtube.com/results?search_query=rdsaoamerica

2018 CALENDAR OF EVENTS

RSDSA has compiled a year-long calendar of events on our



website: <https://rds.org/events/>. If you are interested in organizing a fundraising or awareness event in your community, please email info@rds.org or call me at 877-662-7737.

OUR PATIENT ASSISTANCE FUND IN HONOR OF BRAD JENKINS

In 2012, The RSDSA Board of Directors, in conjunction with Andrea Jenkins, established a Patient Assistance Fund in honor of her son, Brad, who passed away from an accidental overdose. Over the last six years, RSDSA has awarded grants totaling over \$81,000 dollars. This fund has been able to prevent individuals from becoming homeless, pay for overdue utility bills to forestall shutoffs, enable individuals to

travel for consultations with out-of-state CRPS specialists, provide wheelchairs and durable medical equipment, pay for compounded prescriptions not covered by insurance, and much more. Each grant application is reviewed by a five-person committee consisting of a nurse with CRPS patient, a physician, Andrea Jenkins, and two RSDSA Board members with CRPS. One hundred percent of the proceeds donated to the Jenkins fund are passed along to our recipients. To help RSDSA make a difference, please donate at <https://rds.org/donate/> or by calling 877-662-7737. To obtain an application for assistance, please visit <https://rds.org/jenkins-patient-assistance-fund/> or call us at 877-662-7737.

BLOGGERS NEEDED!

RSDSA recently compiled a listing of its top ten most-read blogs on its website.

1. CRPS & GI Frustrations From a Nurse's Perspective by Beth Seickel
2. The Club No One Wants- The CRPS Club by Jamynne Bowles
3. The Top 10 Shoe Brands for CRPS from a CRPS Perspective by Ashley Epping
4. Magic Wand- Experiences Living with CRPS by Alessia Zen
5. New Year, New RSDSA Goals- Helping the CRPS Community by Samantha Barrett (Anderson)
6. From One Family to Another- A Pediatric CRPS Journey by Bobby and Lauren Gellert
7. Fear of Distance- RSD/CRPS and the Journey Away from Home by Rachel Ehrenberg
8. Just Wanted You to Know: CRPS PRISMA Trail by Jim and Sammie
9. Palliative Care for the Person with Complex Pain Generating Syndromes by Dr. Terri A. Lewis
10. The Importance of People- Friends with CRPS by Samantha Barrett (Anderson)

MEDICAL EQUIPMENT EXCHANGE PROGRAM

RSDSA is creating a program that will facilitate the donation of durable medical equipment such as wheel chairs, shower aids, hospital beds, walkers, etc. We will list the equipment available and where each piece

is located. Although we cannot pay for shipping, we will connect the donor and the individual interested in obtaining the equipment.

We continue to post every Tuesday for "The Tuesday Burn." If you would like to

write something from your perspective, please contact Samantha by calling 877-662-7737 or by emailing sanderson@rsds.org



Fluoroquinolones and CRPS

BY BILLY ALEXANDER, MD

Disclaimer - The opinions expressed in this article are the personal opinions of Billy Alexander, MD, and do not reflect the official position of the RSDSA. This advice is not meant to replace the advice of a patients' personal provider, but rather serves as an educational tool.

Recently several inquiries have been submitted to the RSDSA concerning adverse effects of fluoroquinolones in patients with CRPS. To adequately address the issue and question of the adverse effects of fluoroquinolones in patients with CRPS, we will first briefly look at the history of this class of antibiotics.

The class of antibiotics known as quinolones are all derived from a parent compound named nalidixic acid, which was marketed for the treatment of urinary tract infections in 1962. This class of antibiotics was discovered as a byproduct of the synthesis of chloroquine, an antimalarial antibiotic still used today. Since 1962, several newer versions of quinolones have been developed, with the most recent ones including a fluoride atom in the structure: hence the tweaking of the class name to fluoroquinolones. In America, the two most commonly used fluoroquinolones are ciprofloxacin (Cipro) and levofloxacin (Levaquin).

“The vast majority of medicines and pharmaceuticals are foreign to our bodies and immune system. Therefore, it shouldn’t surprise us that (thankfully) only an exceptionally small percentage of patients will have adverse reactions to these medicines.”

The vast majority of medicines and pharmaceuticals are foreign to our bodies and immune system. Therefore, it shouldn’t surprise us that (thankfully) only an exceptionally small percentage of patients will have adverse reactions to these medicines. Fluoroquinolones are no exception: they are foreign materials and chemicals to the body and its immune system that can also cause adverse reactions in a small percentage of patients.

Now, let’s turn to the relationship between fluoroquinolones and CRPS. As we investigate how this issue relates to our community, we will focus specifically on neurotoxicity issues and forego other types of reactions involving other bodily systems



or organs. Before we examine the fluoroquinolone class of antibiotics, it is important to note that neurotoxicities of different types occur with many different classes of antibiotics. In an excellent, although quite technical, article, Grill and Maganti thoroughly catalogue the adverse neurological effects of many different antibiotic classes: ¹the penicillin class can rarely cause seizures, encephalopathy, and confusion; aminoglycosides can rarely cause neuropathy and encephalopathy; cephalosporins can rarely cause confusion, seizures, or encephalopathy; and sulfa drugs can rarely cause encephalopathy and psychosis. The list could go on into several other classes of antibiotics that can rarely cause neurotoxicity, but the point is already made clear in this brief list: virtually all classes of antibiotics have a very low possibility of causing neurological reactions and disorders. Fluoroquinolones are not the exception.

However, when compared to these other classes, it appears that the fluoroquinolones are more likely to cause neurological derangements and reactions. In July of 2016, this increased risk prompted the US Food and Drug Administration to issue a black box warning stating that the risks of serious side effects including nerve and central nervous system side effects were high enough that the benefits of using these medicines for acute bacterial sinusitis, acute exacerbation of chronic bronchitis, and uncomplicated urinary tract infections were outweighed by the risks and thus these medicines should only be used if there are “no alternative treatment options.”

In looking at many of the actual reports in the Adverse Event Reporting System (FAERS) on the FDA website concerning fluoroquinolones, the most common adverse reaction cited was tendon and joint issues. There were also many references to neuropathy-type symptoms of burning, stinging-fire sensations, and the like. Unfortunately, because CRPS is so rare, it wasn't a frequently mentioned side effect of taking the fluoroquinolones. However, many websites across the internet bear the testimonies of those who either had their CRPS symptoms worsened by a fluoroquinolone or, in some cases, of developing CRPS after taking a fluoroquinolone. Yet, without scientific studies specifically designed to look at any relationship between CRPS and fluoroquinolones, we cannot categorically state that fluoroquinolones cause or worsen CRPS.

Unfortunately, as we all know given the rarity of this disease, any such study will in all likelihood never be done.

So what advice can be given to those of our community as it relates to fluoroquinolones?

Firstly, for the types of infections listed above and even for other community-based infections not serious enough to require hospitalization, it would be wise, in most cases, to avoid taking fluoroquinolones. If your provider prescribes or recommends one for an infection, you should ask them if there are viable alternatives and, if so, strongly advocate and ask for one of the alternatives. Though there are certainly many factors that are weighed as a provider decides which antibiotic to give for an infection (or if an antibiotic is even needed given that many of these infections are caused by viruses and not bacteria), it is helpful to understand that in our current medical environment, providers commonly choose “high-powered” and broad-spectrum antibiotics over older antibiotics that cover more specific bacteria in order to decrease the likelihood of missing a bacteria not covered by an older antibiotic. As part of the discussion with your provider, point out that CRPS is a disease in which the neurological system has gone awry for unknown reasons, that the FDA has a black box warning about neuropathy, and that many others have documented their adverse (and sometimes extreme) reactions to fluoroquinolones as your main concerns about taking a quinolone.

This preference for “high-powered” and broad-spectrum antibiotics is true in hospital medicine as well. Thus, if hospitalized for a serious bacterial infection, patients should also have a thorough discussion with providers about the reason for recommending a fluoroquinolone and viable alternative antibiotics to use for treatment. Thankfully, in the majority of cases, this simple conversation will lead providers to offer alternatives that could be used. However, in some cases, providers will explain why a fluoroquinolone is needed (for example, in the event that a culture reveals a strain of bacteria that is resistant to multiple antibiotics, but sensitive and susceptible only to a fluoroquinolone). Though these cases will arise, thankfully they are rare.

It has been my desire in this article to equip those in our community with some knowledge of fluoroquinolones to help them and their provider choose the best antibiotic in the event of bacterial infections.

Should this article raise questions among us, please respond at info@rsds.org and we will try to answer them in upcoming newsletters.

Billy Alexander, MD

Works Cited.

- ¹ [Br J Clin Pharmacol](#). 2011 Sep; 72(3): 381–393

Lana Santoro: Teacher Turned Student

BY LANA SANTORO

Lana Edwards Santoro, Ph.D., is a teacher, educational consultant, writer, and amateur photographer. She also lives with Complex Regional Pain Syndrome (CRPS). Embracing CRPS turned this teacher back into a student.

Lana's interest in education began when she was in elementary school. She loved reading and never passed an opportunity to visit books in the library. She remembers setting up a "school" at home in her living room while her grandfather lovingly subjected himself to her improvised reading lessons. Lana's early interest in teaching and learning became her professional work. With an interest in multidisciplinary, integrated approaches to education and health, she taught in a residential treatment program, psychiatric hospital, and a center for children and adults with medically complex, developmental and intellectual disabilities.

Lana continued her work in education and obtained advanced degrees in special education and research. She taught pre-service teachers at the undergraduate and graduate level, consulted with state, local, and private agencies on a variety of projects, and presented extensively about how to apply research-based, instructional strategies in the classroom. Lana also served as principal investigator on a series of federally-funded research

As someone dedicated to "what the research says" about best practices in education, Lana was overwhelmed by the lack of research for CRPS at the time. She was haunted by what seemed missing and the research questions that weren't being asked"

studies on comprehension where she and her colleagues developed a widely-used intervention and curriculum for struggling readers.

A 2006 tennis match led to a ruptured gastrocnemius muscle, dozens of visits to medical professionals, and—four years later—a CRPS diagnosis. As someone dedicated to "what the research says" about best practices in education, Lana was overwhelmed by the lack of research for CRPS at the time. She was haunted by what seemed missing and the research questions that weren't being asked. Struggling to sort through what was known and not known, Lana became a student again as she applied her interest in education to her experience with CRPS. CRPS became an excuse, of sorts, to return to the library



(or, more frequently these days, Amazon.com) to read what she could find on pain management, treatment, and mindful living. Those hours of study culminated in the development of her personal CRPS management curriculum. Because best practice suggests an individualized, multi-disciplinary approach to CRPS treatment, some of the main components of Lana's management have included:

- collaboration with her medical team on appropriate interventions
- on-going work with a personal trainer to design and implement a physical training program, (e.g., the application of graded motor imagery strategies and principles of explicit instruction—including the use of models/ demonstrations, scaffolding, and strategic integration)
- the use of a variety of self-management strategies to support daily living

(e.g., the University of Massachusetts Medical Center's Mindfulness-Based Stress Reduction program by Jon Kabat-Zinn and Open-Focused Training by Les Fehmi and Jim Robbins)

Lana currently works part time from her home in Alexandria, Virginia as a Research Associate and Curriculum Developer with the Center on Teaching and Learning at the University of Oregon. She continues her consultation with local and state education agencies and loves working with in-service teachers. Lana is excited to share some lessons learned and a few strategies from her CRPS management toolkit:

MY SELF-MANAGEMENT TOOLKIT

LANA EDWARDS SANTORO

As those with a CRPS diagnosis know, nothing prepares you for CRPS. When I first received my diagnosis, I looked everywhere for a roadmap. I searched all kinds of sources for information that would tell me what to do, what steps to take. I knew that I didn't want to just live with CRPS. I wanted to be *living with* CRPS in a full, active way—regardless of whether I was using a wheelchair, crutches, walking without assistance, sitting in a hospital waiting room, spending time in bed recovering from a flare, or enjoying activities with my family. I've often viewed my professional life with two distinct emphases: practitioner and researcher. In many ways, my experience has required me to draw fully from both—the research and the application to practice. Here are a few of the “research-to-practice”

lessons I've discovered on my CRPS journey:

1. **Take a research-based approach to CRPS management.** To the greatest extent possible, use research on CRPS to guide treatment and self-management decisions. Since research on CRPS continues to evolve, I admit to shamelessly borrowing research-based strategies from other related disciplines. For example, while not entirely specific to a CRPS population, there are research-based strategies that can be applied and adapted from the literature on chronic pain and illness. I've also incorporated research on resilience, coping, mindfulness, healing spaces, special education, and neuroplasticity to inform how I approach self-management.
2. **Find something interesting that you can apply to your CRPS management and learn about it (. . . then share what you're learning).** Approaching CRPS from a learning perspective has helped me tremendously. While I'm interested in topics related to education and psychology, you may have other interests and experiences in other disciplines that can help you (and the rest of us) learn more about how to interact with CRPS. Therefore, start your own independent study. Whether you want to explore more about how people with chronic pain are represented in film, how technology applications can

improve the lives of people with disabilities, how an interest in cooking could be applied to the development of anti-inflammatory recipes and the preparation of delicious, nutritious meals, or how a sports obsession could be transformed into documenting the lives of athletes who have overcome personal challenges. The key is: just do it!

Also, think about how a favorite hobby, like gardening, woodworking, word study, listening to music (without other distractions), or photography could be used to help with coping. In other words, give yourself a learning project, see how it might apply to living with CRPS, and “geek-out.” (Here's a note that my reading comprehension research-self would like to share: This self-study approach to CRPS builds comprehension and can add layers of meaning to your CRPS experience. Our ability to cope with difficult challenges often improves when we find ways to connect more meaningfully).

3. **Create your own individualized action plan.** Create an action plan just like someone in education might develop an individualized education plan (IEP) for a student receiving special education. Your action plan should be dynamic and evolving. Around the time of my diagnosis, my action plan initially focused on medical intervention and the physical training work required to help me transition from wheelchair

use to walking. Currently, my action plan has more of a functional restoration focus and emphasizes activities of daily living (I admit that if I take the time to write things down, I'm more likely to follow my plan and even meet some of my envisioned goals).

4. **Pay attention to pain like you are carefully reading a complex text.**

I find working with pain is a little like reading comprehension. It requires ongoing attention and interaction. I've learned that paying attention to subtle details, hard-to-ignore themes, and changes in what the "pain story" communicates overtime, helps me manage and work with pain (somewhat) better. Overall, try to understand and get to know your pain; specifically, learn the micro- or macro-level patterns that cycle through your own "text."

5. **To the greatest extent possible, get moving, even if your path toward movement is infinitesimally slow.**

Even though it might feel counterintuitive from the body's chronic pain perspective, working on movement has an eventual pain management payoff. Of course, there are many other benefits to movement too.

6. **View CRPS challenges from different perspectives.**

My photography hobby has taught me the important practice of perspective shifting and re-framing the same shot from different angles. Re-framing allowed me to experience the joy of movement in my wheelchair. As I continue to

improve my walking skills, I've yet to experience the fluidity, agility, and opportunities for self-initiated acceleration and speed that I learned to appreciate when I went wheeling.

7. **Incorporate less as more when scheduling.**

Many others living with CRPS discuss the importance of pacing and careful scheduling too. I'll add my voice to this chorus. Like many of you, I admit I can be an over-doer. Learning to be mindful of my body and the potential subtleties and dynamics of underlying pain (see #3), help me pace within my optimal range of functioning.

8. **Change.** One of my hardest lessons was learning that I had to be open to how CRPS would change my life. When I figured out that I couldn't continue to do the same things in the same way (ranging from small daily tasks to my job in academia), I started to make the time consuming, and often very difficult, "all in" changes to my schedule and daily routines. When I started to make these changes, and adhered to my new routines, I discovered gradual improvements in my overall functioning. I also learned the profound lesson that change often signals that you're heading on the path to acceptance.

9. **Return to "the library," whether brick-and-mortar or virtual, and use stories of hope to help chart your CRPS journey.**

When I first received my CRPS diagnosis, I read, watched, and listened to every story of hope I could

get my hands on. I wanted to know how other people lived with CRPS, and how others with chronic illness faced challenges and celebrated life. What I learned from other stories of hope gave me my roadmap for how I wanted to approach life with CRPS. In their wide-ranging perspectives and diversity, these stories are great teachers for how to live resiliently (as a start, read any Linda Lang essay written for RSDSA, if you haven't already).

While I try to take a proactive, positive approach to my self-management, the reality of living with CRPS dictates that pain is an inescapable part of the trip. Simply put, despite Lessons #1-9, we know a CRPS journey can be miserable, exhaustingly disheartening, and even tragic. Just like any hero's journey, there's time spent with darkness.

Therefore, look for the darkness, pain, and struggle in stories of hope -those themes can equally inform your roadmap. To me, stories of hope aren't always glossy, or about a victory, or a cure in the traditional sense. Rather, **the best stories often highlight the simultaneous acceptance of limitations and determination to overcome them.** These

narratives are fundamentally about the struggles and setbacks that lead to compassion, enrichment, and complex perspectives. I especially look to others who were diagnosed with CRPS at earlier times when less was known about treatment. Here I find hope through remarkable courage and raw authenticity.

The Importance of A Walk

BY **BETH SEICKEL, BSN**

Many of us attend or get involved with a walk to support a family member or friend challenged by a specific diagnosis or condition hoping the fundraiser will help to create change.

So how can a RSDSA event be any different? Who participates? What can one expect? Where is it held? Do you have to walk to attend? Is it accessible?

Simply stated, **RSDSA's Long Island Annual CRPS/RSD Awareness Walks** reflects the organization's mission statement by creating:

- Awareness and Advocacy
- Education and Resources
- Comradery and Networking
- Validation and Support
- Hope and Encouragement

In 2016, the RSDSA **"1st Annual Long Island CRPS/RSD Walk"** hosted 225 kids and adults, raising \$25,000, despite the heat and humidity at Eisenhower Park in East Meadow, NY. This was an impressive turnout, as CRPS is considered a "rare condition" under the National Organization for Rare Disorders (NORD), a 501(c)(3) organization.

Imagine not only meeting another individual living with CRPS for the first time but actually having a conversation about the medical, social and personal challenges with somebody who *actually understands*. To realize you are NOT alone is an awesome realization brought forth by a **RSDSA** walk event.

Now jump to **September 9, 2017**. Despite the walk committee co-chairs living with CRPS, numerous flares and hospitalizations, **RSDSA's "2nd Annual Long Island CRPS/RSD Awareness Walk"** came to fruition, attracting some 450 participants from NY, PA, NJ, RI, CT and Italy, raising \$56,000.

The RSDSA reached so many people through the tireless efforts of Stacey Udell, a CRPS patient and volunteer walk co-chair, whose media outreach linked RSDSA with Sandy Hillman Communications, News 12 Long Island, WBAB, WRHU, Newsday and East Meadow Herald, among others to help create awareness about CRPS and the event.

Links and pictures for articles:

<http://liherald.mycapture.com/mycapture/folder.asp?event=2157908&CategoryID=56065>

<http://liherald.com/.../hundreds-raise-funds-for-rare-conditi...#RSDSA #CRPS #RSD #chron-icpain>

Jim Broatch, RSDSA Director and VP, opened the event by welcoming all who travelled from near and far. After a few housekeeping points, Jim shared the origins of RSDSA, noting the organization's incredible growth since its humble beginning back in 1984 from the kitchen table of 2 determined NJ moms. What an evolution!

After thanking all the volunteers and event sponsors, Jim encouraged everyone to visit the raffle

All Event Sponsors:

Titles: Abbott (St. Jude Medical), Grunenthal, Relax Release Relief

Platinum Sponsors: Pain Institute of Long Island, Looking Above and Beyond

Gold Sponsors: Town Total Compounding Center, Ketamine Treatment Centers, Stony Brook Center for Pain Management, Edelman, Krasin, & Jaye, PLLC, Vitalitus LLC

Silver Sponsors: Basics Landscaping, Medtronic, NSPC Brain and Spine, CRPS Treatment

Bronze Sponsors: Distinctive Dental Services of New York, Dr. Lynn Webster, Zwanger Pesiri, Vireo, Farmingdale PT East, Melaleuca, Medical Arts Radiology

Orange Sponsors: PPT Management, LLC, Cookies United, Pain Pathways, Sore No More, St. Catherine of Siena Medical Center

tables and take advantage of the wealth of information found in the **"education and exhibit"** tent.



Jim recognized Amanda from Illinois as the winner of the tee shirt contest. Her design brought cohesion to the event by depicting how so many people, including her mom, feel while living with CRPS.

Jim also introduced Sarah, daughter of co-chair Debbie, who spoke about living with a CRPS parent. Her speech brought many to tears. Our "special honored guest" was Dr. Brian Durkin, a board-certified anesthesiologist with Pain Institute of Long Island.

To commemorate the day, a group photo was taken highlighting teams decorated in colorful team shirts, hats, wheelchairs, canes, scooters, crutches and painted faces. All stood together celebrating they are NOT alone.



With spirits filled with hope, the walk kicked off. Whether with a walker, as a roller in a wheelchair or scooter, or with a cane/crutches, all were surrounded by a large group of support as they traveled around either the 2K or 5K paths with family and friends.

Participants were encouraged to read as many educational signs they could find around the paths, while stopping at water stations welcomed by volunteers cheering them on. All were congratulated with an event medal at the finish line, which for many was an incredible sense of accomplishment.



Throughout the event, attendees were able to gather a plethora of educational and other resources material in the "Education and Exhibit Tent", including:

- Abbott (St. Jude Medical) DRG stimulator
- Pain Institute of Long Island, Dr Brian Durkin
- WBAB broadcasting at event
- Stony Brook Center for Pain Management
- Edelman, Krasin and Jaye PLLC
- Town Total Compounding Center LLC
- Vitalitus LLC

- Medtronic (SC stimulator)
- NSPC Neurological, Brain & Spine Surgery
- CRPS Treatment Center of Italy
- Distinctive Dental Services of N.Y.
- Zwanger and Pesiri Radiology
- Farmingdale Physical Therapy East
- Medical Arts Radiology
- Vireo Health (Medical Cannabis)
- TCAPP (The Coalition Against Pediatric Pain)
"A national non-profit committed to improving quality of life for children living with chronic pain from rare diseases."
<https://tcapp.org/about-tcapp/>
- Educational Boards



We were so grateful to receive support from:

- Levittown Fire Department for volunteering to BBQ
- Medical tent coverage: EMT Ryan, and nurses from local hospitals
- Family and friends assisting with setup, running and clean up
- Massapequa Girl Scout Cadette Troop cheering on walkers while manning a water station and handing out orange necklaces, hand clappers, etc.
- Sorority Sisters from Alpha Epsilon Phi from Hofstra University including student producer Marci Delaney accompanied by Fran Spencer, producer of WRHU's "A League of Our Own"

Food donations were received from:

- Seafood Bagels
- Uncle Giuseppe's of Massapequa
- Costco and BJ's
- Cookies Unlimited
- BBQ food provided by RSDSA
- Hamburger buns by Team Marni
- Water, Ice and Stickers by Team Drew

Event Items included:

- Shirts, Medals and ChapSticks® by The Vernon Company
- Raffle baskets from Team Tiffany
- Pain Pathways donated magazines
- Sore No More samples
- Melaleuca® energy bars
- RSDSA brochures, cards

However, none of this would be possible without the constant support of Jim Broatch, Executive VP & Director RSDSA, and Samantha Anderson, RSDSA's Special Event Coordinator.

If anyone was not mentioned, please know we are so grateful! And as the walk committee still recovers, ALL of us, including the 450 participants and sponsors, took a huge stand together to create CRPS awareness which is: "A Real Medical Condition."

Stay tuned for information on **RSDSA's "3rd Annual CRPS/RSD Awareness Walk"** in September 2018. But until then, THANK YOU to everyone!



Emergency Outreach: Dr. Billy Alexander

BY JENNY PICCIOTTO

Dr. Billy Alexander is soft spoken, heartfelt, and understands the issues patients face when they seek emergency care for CRPS. With over a decade of experience as an emergency room (ER) physician, he understands the pressures and mindset of ER providers. It's also personal. He has faced the daunting task of researching what is known about CRPS, exploring treatment options, and seeking knowledgeable help for his daughter. That process was made a little easier when he attended an RSDSA patient education conference about a year after her diagnosis. He soon joined the RSDSA Board of Directors, where he spearheads a campaign to improve outcomes for CRPS patients who go to the ER for help during flares.

Not only is CRPS a rare condition seldom recognized by doctors, pain patients who show up at an emergency room seeking relief from an acute flare also face a credibility challenge. Despite the heightened public awareness of opioid abuse, Dr. Alexander says the problem has always existed. ER doctors resist giving narcotics. While the patient may know what they need because it has helped them before, asking for narcotics can be a red flag. Instead of diagnosing the problem and working out a treatment plan, the patient may be perceived as a drug seeker rather than a legitimate emergency victim.

Dr. Alexander's mission is to increase awareness of CRPS within the medical community.

"The most important thing," he says, "is to expose more doctors to information about CRPS, and help physicians understand treatment options."

Ketamine is an option for treating acute flares. Not only is it commonly used during emergency procedures as an anesthesia, but ER doctors are also familiar with this medication. The most common protocol is a four-hour infusion, which may be more attractive than offering opiates, but also means a longer than average ER visit. The key is to make the diagnosis and know what interventions are available.

Outreach to doctors is accomplished by setting up educational booths at the annual conferences of medical associations such as the American College of Emergency Physicians, the American Academy of Family Practitioners, and the American Academy of Alternative Pain Management. Dr. Alexander and RSDSA Director, Jim Broatch, have the opportunity to interact directly with the doctors in attendance. Because he is a practicing hospitalist with many years of ER and family practice experience, Billy shares the physician's perspective and can speak to doctors as a peer. "If ketamine is not available," he encourages doctors to "consider narcotics."

"ER doctors are willing to treat acute flare ups for chronic diseases such as COPD, so why should we not expect them to treat acute pain flares?" he says.

"You can overcome the opioid/drug seeker bias with reasoned argument and by proving your case."

These are his recommendations:

1. **Bring a letter** - Ask your care provider to write a letter explaining that you are under their care for a chronic pain issue, which is managed, but that you may have a flare from time to time that requires emergency intervention.
2. **Stay calm** - Understand the pressures the ER doctor is facing. Although you are in a lot of pain, you need to be able to communicate effectively.
3. **Explain** - Make it clear that you are not doctor shopping or drug seeking, and that you have a stable relationship with your doctor. Explain your treatment regime, how you are taking medications as prescribed, and that you are having an acute flare up.

CRPS patients are by definition self-educated and often discover that their care providers don't know anything about their condition. According to Dr. Alexander, "The bottom line is to be prepared to educate all doctors you interact with."

(Additional resources are available on the RSDSA website).

¹ <http://www.acepnow.com/article/tips-for-managing-complex-regional-pain-syndrome/>

² <https://rds.org/wp-content/uploads/2016/04/Emergency-protocol-4-04-16.pdf>

RSDSA Launches Support Group Facilitator Support Group

Beginning in late 2017, RSDSA launched an outreach program for facilitators and leaders of support groups working in communities across the United States. Goals for the Facilitator Support Group (FSG) include helping new group leaders get up and running, monthly chat support and advisory meetings, and an online resource guide for facilitators. A tool box of how-to publications, leader's conference retreat, and a grant program round out the team's vision of building a support network for these valued community leaders.

Sharon Weiner, a member of the RSDSA Board of Directors, founder of Living with RSD, Inc.¹, and Chair of the Young Adult Weekend, is spearheading the campaign. With decades of experience as a patient advocate and support group leader, she is aware of the challenges and rewards of stepping into a leadership role. Helping others gives us a sense of purpose and meaning, she says, while staying active and engaged is a distraction from CRPS pain. Coming up with ideas for meetings, building community, how to be an effective leader, and avoiding burnout, are common concerns for both established and new support group leaders.

FSG is laying a foundation for a vibrant support group network offering peer interaction, resource development, problem solving, encouragement, and funding for these groups so they are better able to serve their members.

In addition to ongoing monthly phone sessions, FSG is developing a meeting guide for National Safety Month in June. This guide will be made available to all interested FSG leaders and will cover safety and emergency planning, including practical tips, and special considerations for staying safe while living with CRPS.

The FSG grant program offers financial assistance with the costs of establishing a new support group and facilitating an existing CRPS support group. Groups registered with RSDSA can submit an application for aid with expenses such as the costs of renting a space for meetings, postage, printing, and supplies related to support group meetings or events. Funds are available for support groups who wish to hold a fund raising, advocacy or awareness event, including permit costs for events and approved promotional materials.

If you are a support group facilitator and would like to join FSG or apply for a grant, please contact Jim Broatch, 877-662-7737 or info@rsds.org. If you are interested in joining a support group, read on. We hope to see you at a meeting soon.

Support groups are a good way to break out of the isolation and loneliness that accompanies living with CRPS. Some meet in person at a member's home or other local venue. Others meet online or via conference call. You'll find the groups welcoming to new members. They understand what you're going through. The environment is generally positive and solutions-oriented. You'll learn new coping strategies and benefit from the experience of others. You'll also likely find that you have much to contribute the group in return. You may also want to consider starting a group in your area. You can find a list of RSDSA registered support groups at: <https://rsds.org/find-a-support-group-near-you/>

¹ <http://www.livingwithrsds.com/>

Edamame Salad

This edamame salad is bursting with flavor. It is great served over a bed of lettuce or your favorite pasta. I love it as a salad over kale or with farfalle pasta (gluten-free of course). Edamame is an excellent source of protein and this dish is a wonderful compliment to any anti-inflammatory diet.

You will need:

1 lb. frozen shelled edamame
10 oz. bag frozen sweet corn kernels
1 red bell pepper, diced
¼ cup green onion, sliced
½ cup red onion, finely chopped
¼ cup Italian fresh parsley, chopped
2 tbsp. basil, chopped
Lettuce options - Arugula or chopped kale
2 oz. cubed cheese, optional (dairy-free or grass-fed)

Dressing:

½ cup fresh lemon juice
2 tbsp. Dijon mustard
2 tbsp. olive oil
Salt, to taste
Pepper, to taste



Directions:

1. Prepare edamame according to package directions. Drain and rinse with cold water. Set aside.
2. Prepare corn according to package. Drain. Set aside.
3. In a large bowl, combine edamame, corn, diced red bell pepper, chopped green onion, chopped red onion, chopped parsley and chopped basil. Add cubed cheese (optional).
4. In a small bowl, whisk together lemon juice, mustard, olive oil, salt and pepper. Pour dressing over edamame salad mixture and toss to coat.
5. Refrigerate to marinate the flavors together or until ready to serve.
6. Serve over a bed of lettuce or your favorite pasta.

Tip:

Pace yourself: Freeze a portion or two for a quick meal on a bad pain day. Skip the bed of lettuce and serve over pasta.

Reduce prep time: Use pre-squeezed fresh lemon juice instead of squeezing your own juice from a lemon.

Reminder: Use organic gluten-free, dairy-free and grass-fed options when possible.

Bon Appetit. Let Food Be Thy Medicine.



2018 CRPS Young Adult Weekend: Taking Care of Us! RSDSA is excited to announce the 2nd CRPS Young Adult Weekend! After the success of the first event and the expressed need, we have decided to head down south! This event is for young people with CRPS from the ages of 18 – 29. Come spend the weekend in Music

City with people who understand what you are going through to the fullest extent. We have limited space, so please let us know as soon as possible if you wish to attend.

- Date: Friday, June 15 – Monday, June 18, 2018.
- Time: Starts Friday at 3:00 and ends Monday at 12:00 (EDT).
- Location: **Holiday Inn Nashville-Vanderbilt**, W. End Avenue, Nashville, TN 37203.
- Fee: \$250.00. You may make a \$50.00 non-refundable deposit which will reserve your spot, but you may also pay in full (\$200.00). Final payment is due on or before May 1, 2018.
- To Register or for detailed information please contact RSDSA YA Weekend Committee at rsdsayawkend@gmail.com.
- Plan an event with the help of RSDSA by emailing us at info@rdsd.org.



rsdsa
SUPPORTING THE
CRPS COMMUNITY

Easy Ways to Give

- **Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.**
- **Use AmazonSmile.com. and make RSDSA your charity of choice while shopping online.**
- **If you're selling things on eBay, you can give a portion of the profits straight to RSDSA.**
- **Set up a collection canister in your local grocery store.**
- **Plan an event with the help of RSDSA by emailing us at info@rdsd.org.**

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WWW.RSDS.ORG

THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

VOLUNTEERS:

If you wish to volunteer, please do the following.

- **Please contact LindaLang@rsds.org**
- **Please tell Linda something about yourself and your experience with RSDS.**
- **Please include your email and a phone number where you may be contacted.**
- **We especially need teens and parents of children with CRPS to volunteer.**

THOSE IN NEED OF SUPPORT:

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