

rsdsa
community update

VOLUME NO. 2

ISSUE NO. 3

WWW.RSDS.ORG/NEWSLETTER

Fall 2015

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without medication



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CALL FOR AUTHORS AND IDEAS

Do you have a personal story, art, or knowledge to share with the CRPS community? Is there a special topic you would like to see the RSDSA Community Update include? We would love to hear from you. Please email your thoughts to info@rdsd.org.

SPECIAL THANKS

Thank you to everyone who contributed to this newsletter, including four captivating volunteer writers and advocates for the CRPS community. We would like to acknowledge our Corporate Members whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate members include Axsome Therapeutics, Boston Scientific, Grunenthal, Lilly, Medtronic, and Purdue Pharma. For more information about becoming an RSDSA Corporate Member, please contact Jim Broatch at info@rdsd.org. Thank you also HDMZ, a life science marketing agency, for helping to edit and produce the newsletter.

THE DIRECTOR'S LETTER

Current and Future RSDSA Initiatives on Behalf of the RSDSA Community

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

Much good has happened in the CRPS community this summer.

Last month, the RSDSA partnered with The Coalition Against Pediatric Pain and the U.S. Pain Foundation to co-sponsor a free camp for children living in chronic pain at The Center For Courageous Kids in Scottsville, Kentucky. The camp was held July 14-17, 2015 for children ages 7-17. The goals of the summer camp were FUN, FUN, and more FUN! It is the first time we have ever found a camp for children living in pain. The camp was entirely free for all participants and a parent or guardian who stayed at the camp with his/her child. Special thanks to generous donors Ian Ferry, Dr. Alden Ferry, the Marin Community Foundation, Sue Pinkham, Art Rosenberg and Cheryl Wexler. If you did not attend this year, we plan on making the camp an annual event!

In June, we held an Integrated Conference for CRPS, our semi-annual conferences for people with CRPS and their caregivers. These are one of our most important educational initiatives and the recent June conference in Denver was an outstanding success. Our attendance topped 110 individuals and caregivers. One couple drove 14 hours from Arkansas to become more educated about current treatment options. Another traveled from Massachusetts! We are currently editing the conference presentations for viewing on our YouTube channel. Please visit, <https://www.youtube.com/user/RSDSAofAmerica>. We've uploaded 78 videos with more to come!

Plans are underway to host the Integrated Solutions to CRPS in Cherry Hill, New Jersey on September 11, 2015 (with a fundraising walk on the following day) and in Long Beach California on February 27, 2016. If you have any questions, please email Samantha Barrett at SBarrett@rsds.org. Special thanks to our major sponsors: Dale and Linda Baker, Grunenthal USA Inc., Nelson Ball, Mountain View Clinical Research, Fila Paragas, Allsup, Genelex Corporation, Joel Server, and Craig and Elizabeth Nielsen.



JIM BROATCH AND HIS GRANDDAUGHTER CORA MARIE.

If you have an event that you would like to plan, email Samantha Barrett at SBarrett@rsds.org and she can get you started!

Bob Lane, a member of the RSDSA's Board of Directors has pioneered the development of a 1-credit hour CEU for nurses on Complex Regional Pain Syndrome (CRPS): Causes, Diagnosis and Treatment. If you are interested in teaching the course in your area, or want to see where a course may be coming next, please contact Bob Lane at rlane183948@comcast.net. We hope to develop CMEs for physicians, physician assistants, and nurse practitioners in the near future.

The RSDSA is also tackling the thorny issue on how individuals with CRPS are treated by Emergency Department (ED) staff when they go to obtain pain relief for an unbearable pain flare. The answer may be intravenous (IV) ketamine. ED staff are very familiar with ketamine, but not as a rescue agent for breakthrough neuropathic pain. To raise the profile of this intervention, we are sponsoring an article on the use of IV ketamine for neuropathic pain flare-ups in the Journal of the American College of Emergency Physicians. We will also exhibit at the American College of Emergency Physicians Scientific Assembly in October. The RSDSA is also exploring an educational initiative to develop guidelines for the use of IV

ketamine for CRPS in outpatient and inpatient centers. At this point, there are no guidelines and people with CRPS are treated differently depending on where they seek treatment.

In the CRPS research arena, the RSDSA via its International Research Consortium (IRC) has recruited over 35 established and productive CRPS clinics around the world to join the IRC. The IRC wants to encourage multi-center clinical trials of novel therapies. (Just planting a seed of hope!)

This May, the RSDSA Board of Directors approved a pilot genetic study of CRPS with Vanderbilt University Medical Center Professor Stephen Bruehl. This project will address a fundamental question regarding CRPS: Why do some individuals develop CRPS and others do not despite experiencing similar injuries? The project utilizes genetic, proteomic, and metabolomic data from 116 military veterans. You can read more about the study on page 15 of this issue.

A new clinical trial has started enrollment. Axome Therapeutics has begun a phase 3 trial to evaluate the efficacy and safety of AXS-02 (disodium zoledronate) for the treatment of CRPS. To learn more about the company's trial and eligibility requirements, visit www.CRPSTrial.com or www.clinicaltrials.gov.

It is a very exciting and hopeful time for the RSDSA and the CRPS community. Stay tuned, much more is to come this year! Don't forget to follow us on all of our social media platforms for live updates:

Twitter: @rdsda or <http://www.twitter.com/rdsda>

Facebook: <http://www.facebook.com/rdsda>

Instagram: @rdsda_official

YouTube: <https://www.youtube.com/user/RSDSAofAmerica>

Best of health,

James W. Broatch



We understand how CRPS feels.

Non-stop, unbearable pain could be a medical condition called Complex Regional Pain Syndrome (CRPS). Learn more about a new clinical trial we're conducting to evaluate an investigational treatment.

While there are no approved treatments for pain associated with CRPS, doctors and researchers are working to find pain relief treatment options. Currently, local doctors are conducting a clinical trial of a trial pain medication for people diagnosed with CRPS-I.

They want to evaluate the safety and effectiveness of this trial medication, which is administered by a series of infusions.

To pre-qualify for this trial, you must:

- Be between 18 and 80 years of age
- Have a medical diagnosis of CRPS-I
- Be receiving stable treatment for CRPS-I for at least 1 month prior to the trial

The trial doctor will review other eligibility criteria with you. All trial-related visits, tests, and medications will be provided to you at no cost. In addition, reimbursement for trial-related time and travel may be provided.

To learn more about this trial, please call **888-641-4961**, visit www.studyCRPSnow.com

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UPCOMING EVENTS

Integrated Solutions to CRPS is Coming to Cherry Hill, New Jersey!

Due to popular demand, we are bringing our Integrated Solutions to CRPS conferences to the upper East Coast!

On Friday, September 11, 2015, RSDSA will be hosting this conference at the Crowne Plaza Philadelphia-Cherry Hill. This all-day conference will feature presentations by Philip Getson, DO, Stephen Boyajian, DO, Mr. Mark Butler, PA, Ms. Liesha Getson, H.H.C., and Ms. Sharon Weiner. They will be speaking on everything from the basics of CRPS to Graded Motor Imagery. Breaks during the conference will allow conference attendees to network with each other and some of our speakers.

Our weekend together in New Jersey will continue on Saturday, September 12, 2015, with the 2015 CRPS/

RSD Walk for Awareness in Cooper River Park. Dr. Philip Getson is hosting the walk again this year.

We hope that you will join us during our weekend in New Jersey. For more information on the conference, please contact Samantha Barrett at SBarrett@rsds.org or at (508) 942-2141. To learn more about the walk, please contact Dawn Hesser at crpsrswalk@gmail.com or at (877) 662-7737.

To register, visit rsds.org/events and bring the calendar to September of 2015. By clicking on the day of the event, you will be directed to an online registration page for both the conference and the walk. We hope to see you there! ■



A PICNIC TABLE ON THE COOPER RIVER.

Dance is Exercise in Disguise for CRPS and Chronic Pain

BY LUCRECIA MARTINEZ, CPT, CES, FMT

In 2010, I received a difficult diagnosis: a left hip labrum tear with hip impingement. I was now not only a personal trainer specialized in working with patients with chronic pain, but also a patient and chronic pain sufferer myself. I would also face, like my patients, big decisions about how this pain would alter my life.

Until then, my passion in life had been dancing. My husband and I met dancing. We loved to escape on date nights to dance salsa, cumbia, merengue, and any other Latin-infused music.

At first, I denied that pain could rob me of my passion. I would grit and push myself through the pain. I feared that, if my husband and I could no longer dance, he would feel sad. All of this dancing in denial, however, would cause flare-ups that lasted for days.

Some years later, while working with my patients, I realized that neither dance nor pain needed to dictate my life, that my life was mine alone. I taught patients how to modify and pace their activities, helping them to manage pain, regain function, and reach personal goals. Why not do the same for myself? Why not modify dance?

I then trained to be a Latin dance instructor. Together with my husband, we choreographed our own unique and modified dance moves to go with high beat, energetic and fun music. Those moves created the first Latin Dance Fusion class that I taught for those who suffer from chronic pain.

At first this was a hard class to sell! For a few weeks, I found myself alone with no participants. As we all know, chronic pain leads to fear of movement, fear of pain, and fear of re-injury. "No thank you, Lucrecia. I think I'll pass on dancing!"

As I talked to more patients, I explained how the moves could be modified to honor their own individual needs. I encouraged patients. I made each

LUCRECIA'S BEST 3 RYTHMS OF THE NIGHT PLAYLIST

We enjoy these songs because they have easier beats for adapting dance moves.

1. I like it like that (Mambo/ Cha Cha Cha) By: Ballroom Orchestra & Singers
2. Bailando (Spanish Version) By: Enrique Iglesias
3. Techno Cumbia By: Selena

patient feel welcomed and helped modify moves according to their respective injury or pain location. They were brave! They conquered their fear!

What began as a class of zero has grown to ten or more of us two to three times a week! I can proudly say at least 5 of the dancers are CRPS patients!

You may ask, "How in the world can you modify dancing?" That's the fun, liberating question.

First, the moves are modified for specific muscles. We leave out the jumping, twisting, and other high-impact triggers. Second, there is no rule that says we must stand while dancing. For people with lower extremity injuries, we can groove while sitting down with just arms. For upper extremity injuries, we can choreograph footwork and limit or modify arm movements. Third, people with full body pain can come enjoy the music, watch, and laugh with good people who understand each others' lives. Guess what? Just by doing that, they have begun the biological healing process of releasing endorphins!

Therein lies the beauty.

Exercise is medicine. It is needed to keep our hearts healthy and decrease the risk of diabetes, high blood pressure, high cholesterol, and many other chronic ailments. Dancing is simply exercise in disguise! Our Latin Dance Fusion classes secretly integrate

exercises for the entire body, as willing, in 45 minutes of dancing.

In 45 minutes, we are sweating, our hearts are pumping, we are smiling, we are laughing, and we follow movements guided by a trainer specialized in working with patients in pain.

I asked what some of my patients turned dancers had to say about the experience. One regular, Lisa, who has lived with CRPS for the past 11 years, said, “Dancing gives me energy. It is fun to dance with friends who understand what it is like living with pain. It helps me to feel normal and allows me to focus on the dance steps instead of focusing on the pain!”

Another regular, Eric, recently started to teach the class, too. “Dancing brightens my day and since I began teaching, allows me to help brighten the day of others who suffer with pain just as I do,” he said. “See, I always wanted to teach. I never thought I would teach dancing! Dancing has increased my confidence to a level it has not been in for years!”

Indeed, Eric, spreading hope is a precious joy. Hearing those words from each of the dancers, moreover seeing their smiling faces together with mine throughout the week, has been priceless. If you think modified dancing may be for you, talk to your primary doctor about whether such dancing could be something for you to start! ■



ABOUT THE AUTHOR

Lucrecia Martinez, has been a certified personal trainer at the Bay Area Pain & Wellness Center for close to 10 years and within the last year started teaching free dance classes for people with chronic pain. One of the many ways she treats pain at the center is through a multidisciplinary, six to eight week Functional Restoration Program (FRP). The program includes typical research-based exercises designed for CRPS patients, including desensitization, mirror therapy, strengthening, stretching, relaxation techniques, psychological support, art therapy, and many others.

ADAPTING YOUR GROOVE

Our Latin Fusion Dance Class for Chronic Pain avoids jumping, twisting or bending. We take traditional exercises, modify to fit the need of each person (e.g., sitting or by limiting movement to injured area if pain increases). We are non-judgmental and promote pacing and modifications! Each person adds their own flavor to their dance, making it their own.

As shown in these pictures, the participants are working on:



Shoulder range of motion with a side step.



Cross punching with abdominal muscle activation and hip rotation. Hip rotation is a movement that can be confused with a twist, but it is actually rotating from the foot through the hip so the full body is turning. We call it “side punching”.



Hip flexor march with abdominal activation. The hip flexor is the muscle responsible for raising our leg above our quadriceps. We can do this move while standing, sitting, or marching.

COVER STORY

THE TIME IS NOW

BY JENNY PICCIOTTO

“WHEN YOU ARE DOING SOMETHING YOU LOVE, YOU CAN DISTRACT YOURSELF FROM PAIN. ENGAGING IN ACTIVITIES THAT DECREASE STRESS AND INCREASE JOY NATURALLY BOOSTS ENDORPHINS, WHICH REDUCES PAIN.”

Jennifer Jones is no amateur when it comes to pain. She has lived with Complex Regional Pain Syndrome since 1997, when she was stopped in traffic and rear ended, crushing her knees into the dashboard. The former EMT, trapped in her car, called dispatch and waited for rescue.

After 18 years, pain is a part of who she is. Her story is one of incredible courage, dedication, and the will to live.

When Jennifer was diagnosed with CRPS, she was unable to walk. She relied on her wheel chair and walker, waiting for her mother to come home to help her to the bathroom. Her legs

were too weak to support her, and she experienced uncontrollable muscle spasms. She spent the next ten years in bed.

Flash forward 18 years later. This determined woman has discarded the 150 lbs she gained while self medicating with Ben and Jerry’s ice cream, along with the 1,104 bottles of medication that sustained her through the first ten years of coming to terms with living with CRPS.

Today, Jennifer has new tools to help her manage her condition. She struggles to adapt to her body’s new needs, but she has the willpower and the skills to balance her mind and body despite the ongoing challenges of living with CRPS.

Jennifer’s condition began in her right leg, ankle and foot. It quickly spread to her left leg and thighs, complicated by herniated and bulging disks.

THIS DETERMINED WOMAN HAS DISCARDED THE 150 LBS SHE GAINED WHILE SELF MEDICATING WITH BEN AND JERRY’S ICE CREAM, ALONG WITH THE 1,104 BOTTLES OF MEDICATION THAT SUSTAINED HER THROUGH THE FIRST TEN YEARS OF COMING TO TERMS WITH LIVING WITH CRPS.

Eventually, the condition spread to her face, mouth, breast, arms, legs, and digestive system. She suffered from stomach pains, cramps, constipation, and loss of peristalsis. This condition, called gastroparesis, affects many CRPS patients and may cause vomiting, bowel changes, and malnutrition.

Jennifer reentered the world in 2007 with new determination.

“YOU NEED TO GO BEYOND THE WALLS OF YOUR COMFORT ZONE, BEYOND FEAR. WE NEED TO PUSH BEYOND THE KNOWN INTO THE UNKNOWN. THAT IS WHERE THE ANSWERS ARE.”

She recognized that she was defeating herself lying in bed, smoking, and eating junk food. As Albert Einstein once said, “No problem can be solved from the same level of consciousness in which it was created.”

Inspired by his words, she shifted her focus and began the process of reclaiming her life.

Having learned of an Ayurvedic integrative practice in Arizona, Jennifer moved there for a month in order to undergo intensive personalized treatment. She gradually reduced her dependency on the numerous medications she relied on for pain relief.

Placing her faith in the multi-disciplinary practice of Ayurveda, an ancient method of natural healing developed in India over 5,000 years ago, she underwent treatments involving food, herbals, yoga, and meditative modalities. “It went beyond the physical,” she says. “You need to go beyond the walls of your comfort zone, beyond fear. We need to push beyond the known into the unknown. That is where the answers are.”

As her body detoxified from the complex combination of medications she had been consuming for ten years,



she began to experience balance in her mind and body, taking her first steps in her return to walking. As she gained strength, she went from a walker to crutches, remembering the many nights she lay in bed in her parents’ home, eating and crying. This was a whole new experience.

She learned new methods to deal with the disabling pain of CRPS. Meditation and breathing practices taught her to encourage circulation in

“CREATIVITY IS KEY TO PAIN REDUCTION. CREATIVE ACTIVITY CROSSES THE HEMISPHERES OF THE BRAIN, REROUTING NEURAL PATHWAYS.”

her limbs. Visualizing healing and physical touch, she desensitized the hypersensitive areas of her body. She reprogrammed her mental and emotional state by visualizing new life dreams and goals such as walking, driving and working. “Meditation, envisioning health, and researching alternative practices has helped me develop a sense of self empowerment. By focusing on simple goals and celebrating accomplishments, confidence accumulates, displacing negative thought patterns.”

“BY FOCUSING ON SIMPLE GOALS AND CELEBRATING ACCOMPLISHMENTS, CONFIDENCE ACCUMULATES, DISPLACING NEGATIVE THOUGHT PATTERNS.”

Jennifer has managed her CRPS without medications for three years. She attributes her success to a daily routine grounded in Ayurvedic, nutritional, and movement therapies. These include prayer, meditation, massage, yoga, dance, proper nutrition, visualization, creative expression, and consuming food as medicine.

She has also creatively adapted her life style to the limitations of CRPS. To address the pain she faces on a daily basis, she routinely uses wraparound sunglasses, wears construction ear muffers, and uses a pain cream she designed herself. She engineered a shield to prevent the air conditioner in her car from blowing on her lower body. She also plans for recuperation periods after periods of activity. “It is a matter of problem solving. How can I make this situation work for me with the limitations I have?”

She talks about neuro-linguistic programming, hypnotherapy, ritual, and remembering — a practice of literally memorizing moments of feeling whole, of feeling the wellness in the body, so she can recall them and change physical sensations when CRPS flares. “Lock the memory in so you can remember what it feels like to be pain free, calm, and not depressed.”

ALTHOUGH SHE HAS NOT CURED HER CRPS, SHE IS NO LONGER DEFINED BY IT.

“Creativity is key to pain reduction. Creative activity crosses the hemispheres of the brain, rerouting neural pathways.” Her daily routine is a process of rewriting her mental programming. It has rewired her brain so that pain no longer has the same defeating meaning it once did.

Jennifer is the consummate CRPS warrior. She spent ten years bedridden, has consumed 70,975 pills, gained 150 lbs, lost 177 lbs, and developed new mental and physical skills to reclaim her life. Although she has not cured her CRPS, she is no longer defined by it. ■

You can hear more from Jennifer Jones directly as she blogs about her life, her condition, nutrition and living joyfully in the moment on Instagram and Facebook. http://websta.me/n/the.time.is.now_jjwa You can reach her by email at TheTimelsNow.jjwa@gmail.com.



ABOUT THE AUTHOR

Jenny Picciotto is a CRPS patient, yoga instructor, massage therapist, and writer. She currently lives in Hawaii, where she leads the Oahu CRPS Support Group, and is active in the online support community.

Tips For Traveling With Chronic Pain

BY AUBREY HALEY

Traveling with chronic pain and disabilities is completely “doable”! With the right tools, a bit more planning and an unwavering commitment to go at your own pace, a satisfying experience can be had by all. The following is a list of things to remember as you prepare to venture away from home.

BOOK YOUR TRIP THROUGH A TRAVEL AGENT

Use an agent when possible, especially if you are traveling in an unfamiliar area. Plan your trip as far in advance as possible. Agents will discuss the best modes of travel for you, can arrange for transfers and ensure as much ADA accessibility as possible. Agents are often privy to insider information about the places they send you and have negotiating powers. Be sure to ask about hotel shuttles and transportation in addition to lodging. Using a travel agent insures you have someone to call if things don’t go as planned; they can make alternate arrangements for you on the spot. Be specific and clear when describing your disability. Not all service providers know the “lingo” of accessible travel, or the medical terms for certain conditions. Give as many details as you can about what you can and can’t do, and don’t downplay the severity of the disability. The more information a service provider has, the better they will be able to accommodate you.

USE A PACKING APP

“Pack The Bag Pro” (\$1.99 in the app store) and similar apps are sanity savers! Chronic pain and associated medications tend to cause foggy, tired brain; cut yourself a break and let the app do the remembering for you. The app allows users to list everything they will need and check each item off as it goes in the bag. After checking your destination’s weather report, spend a few days working with the app before packing your bags. Reminders can be set within the app to keep you on track.

CONTACT THE TSA

Per the TSA website, TSA.gov: “TSA Cares is a help line to assist travelers with disabilities and medical conditions. TSA recommends that passengers call 72 hours ahead of travel for information about what

to expect during screening. Travelers may call TSA Cares toll free at 1-855-787-2227 prior to traveling with questions about screening policies, procedures and what to expect at the security checkpoint. When a passenger with a disability or medical condition calls TSA Cares, a representative will provide assistance, either with information about screening that is relevant to the passenger’s specific disability or medical condition, or the passenger may be referred to disability experts at TSA. Passengers can use TSA’s Notification Card to communicate discreetly with security officers. However, showing this card or other medical documentation will not exempt a passenger from additional screening when necessary.” *TSA recommends that passengers call approximately 72 hours ahead of travel so that TSA Cares has the opportunity to coordinate checkpoint support with a TSA Customer Service Manager located at the airport when necessary.”*

OPT FOR E-TICKETS

No more paper airline tickets! Your itinerary and boarding pass go straight to your smartphone, producing a barcode the airline will scan as you board the plane. Passbook on Apple iPhones, iPads and iPods will store e-tickets (like a virtual folder), keeping everything together and easier to access. Check for e-tickets when planning other activities and consider using Open Table (or similar apps) as you make reservations for your vacation, they make life much simpler.

REQUEST A WHEELCHAIR FROM THE AIRLINE

This needs to be done when the airline tickets are purchased. There is no additional cost incurred by the traveler. The wheelchair should be mentioned at the airline counter immediately upon check in with your airline. Wheelchairs can also be requested for your destination airport (during the booking process). Prior to landing and disembarking, confirm with a member of the flight crew. You may also request a golf cart shuttle between gates and baggage claim. Even if you think you can walk, opt for the extra help! Airports are vast, congested spaces. Carrying bags can be cumbersome and out of the norm. Your body will thank you!

UNDERSTAND REQUIREMENTS FOR SERVICE DOGS AND ASSISTIVE EQUIPMENT

Before you travel, contact your travel agent, airline, the embassy or consulate for your destination concerning information on possible restrictions for service dogs and assistive equipment. If service dogs are permitted, find out about requirements for quarantine, vaccination, and documentation. Talk with your vet about tips for traveling with a dog, and make sure your hotel will accommodate your service dog. Find out if there are specific policies for devices such as wheelchairs, portable machines, batteries, respirators and oxygen.

LIMIT CLOTHING TO ONE OUTFIT PER DAY

Don't be afraid to make pieces pull double duty. Clothing should be very comfortable and require no extra care (e.g, ironing or special hanging bags). Most tourist destinations are relatively casual, especially in the summer months. Jersey and cotton fabrics are fantastic choices for travelers because they can be rolled for packing, don't wrinkle much and look dressier than denim. Both are comfortable and easy to care for. If need be, wash in a hotel sink and hang to dry overnight. They will still look great. Pick loose, breezy clothes that can be layered for changing temperatures. I like to pick a color theme for my travels such as black and white with various colored tank tops or t-shirts. That way, everything coordinates and if something needs to be worn twice, nobody can tell. Remember to throw a stain stick in to treat stains immediately. Keep jewelry simple. Most importantly, take a very limited number of shoes; a pair of black flats and tennis shoes or sandals.

DOWNSIZE YOUR PURSE/PERSONAL BAG

Cross body bags may limit you to lip gloss, smartphone and wallet, but they reduce the stress on your neck and shoulders, as well as make things easier to access — leaving hands free for your mobility aids and balance. A smaller bag is also easily placed in a hotel safe if you plan on leaving it behind as you venture out. Likewise, men should consider wearable bags or waist packs. Backpacks also make great carry-ons, leaving hands free. They will easily accommodate a cross body bag/wallet and allow room for a snack, small electronics, charging cables, a jacket, medication and small makeup bag—in case other luggage is lost.

DOCTOR'S NOTE AND MEDICATION

Travel with a statement from your doctor covering your

condition, medications, potential complications, special needs and other pertinent information. All pills should be kept in a weekly sorter so each dose is readily available, including a few extra doses. Using your smartphone, photograph the travel statement and prescription bottle labels showing your name, Rx number, doctor's information and pill description. Should you need to show any medical or TSA personnel your Rx while traveling, you will have information handy. If you will be running out of a controlled substance while gone, don't forget to make arrangements with your doctor ahead of time. Keep breakthrough pain medications on your person and readily available at all times during your trip.

PERSONAL MEDICAL INFORMATION

iPhones have a "Health" app, allowing you to keep all medical information handy, including blood type, medications and dosage, treating doctors, diagnosis and other pertinent information. Emergency Personnel have been trained to look for such information. From the "Lock" screen on the iPhone, pressing "Emergency" in the lower left corner will take emergency personnel to the screen allowing "Medical ID" access — even if the person using your phone doesn't know your lock screen code. Make your travel companions aware your health information is accessible from your phone.

SET ALARMS/REMINDERS FOR EVERYTHING!

You are out of your element, it is critical to maintain your medication schedule to avoid a pain flare. Alarms will keep you on schedule for all travel activities and time zone changes. Let your smartphone do the work!

KEEP A SMALL SNACK AND WATER WITH YOU

Medication shouldn't be delayed because you don't have something to take it with. Hungry travelers tend to be cranky travelers, too.

YOUR FAVORITE PILLOW!

Everyone has one. Make sure your favorite pillow makes the trip. With space a premium in cars and airplanes, consider a U-shaped or travel size pillow. If needed, be sure to request extra pillows from the hotel to prop yourself into the most comfortable sleeping position. Travel requires extra energy. Rest is paramount for a great trip—and hotel beds are not always conducive to a good night's sleep!

BUILD IN EXTRA TIME FOR ACCLIMATION TO A NEW ENVIRONMENT AND PACE

Be sure to afford yourself the time needed to acclimate to a new schedule. If you must have a layover, a minimum of 90 minutes is recommended between flights. Planning an extra day to acclimate when you arrive and scheduling a day of rest upon returning home will help you to be more comfortable. As well, allow yourself extra time in the morning to get up, take meds and get moving. Everything takes a little longer in an unfamiliar environment, especially when living out of luggage. You may need to select to participate in only the most important activities on your itinerary and opt out of the less important ones to save energy. Make no apologies for taking a mid afternoon nap, going to bed early or changing plans because you're not feeling well. If you are traveling to a higher altitude, the oxygen is thinner and the body requires more blood. Medication and alcohol can intensify altitude sickness. Discuss the best way to prepare for a different environment with your health care provider. Overall, be prepared for changes in pain levels, but don't dwell on the negative. A relaxed, flexible attitude makes all the difference!

WALKING/HIKING POLES

Using two hiking poles allows you to walk balanced and more upright than a cane, preventing achy muscles and joints. They are a fantastic walking aid if you will be navigating uneven terrain or doing a lot of walking during your trip. I've hiked hundreds of miles with mine since my diagnosis. You will be able to take a cane or walker on the airplane if needed, however, walking/hiking poles with a tip — even if they have rubber covers — are not allowed in the airplane cabin. TSA requires them to be checked with baggage. Most hiking poles telescope, making them collapsible for packing.

EYES AND EARS

Many chronic pain patients are light and sound sensitive, do whatever you can to create a serene environment on the airplane, in the hotel, and on public transportation. Don't forget to have gum handy to help your ears adjust to cabin pressurization.

BUILD A PLAYLIST

Keep your smartphone stocked with your favorite soothing music. Listening to calming music or guided meditation is an easy way to relax and create a sense of familiarity. Music, guided meditation or binaural beats

(available for free in the App Store) help reduce anxiety on the plane or long car rides. They can also be used to eliminate unsettling noise or as a sleep aid. Later, when you return home, that same playlist will help transport you to happy travel memories on high pain days.

CAMERA

If you are fortunate enough to travel, make sure to take the extra few minutes necessary to snap pictures everywhere you go. Pictures are precious reminders of good days with family and friends, be sure to take lots of them and put them in an album when you return. They are especially nice to revisit on high pain days.

HYDRATE!

Flying, riding in a car, and hotel air conditioning can all lead to dehydration. Not only should water intake be increased (starting the week prior to travel), don't forget chapstick, lotion for skin, and ointment in case of a nose bleed. Prescription medication can increase these symptoms, especially in higher elevations. Discuss your travel plans with your doctor to find out how to prepare for your destination.

YOUR BEST POSITIVE ATTITUDE!

Regardless of your reason for travel and the destination, taking a trip requires a flexible attitude and an explorer's mindset. The more positive you are, the more positive the people around you will be. The purpose of travel is to have new experiences, visit family and friends, and make memories. If you come across someone's negative attitude, let it roll off your back like water off a duck. Enjoy yourself! ■



ABOUT THE AUTHOR

Aubrey Haley was diagnosed with CRPS in her neck and left arm after a car accident in 2009. Over the next year, her CRPS spread body wide. After trying a long list of treatments and medication, she has found a way to manage her CRPS using a combination of Western and Eastern medical techniques. Aubrey is a wife and mother to 4 daughters, in addition to being a writer and Certified Massage Therapist. Follow Aubrey's blog, "Fighting With Flare" at <http://fightingwithflare.blogspot.com> to read more about her adventures with CRPS, managing a healthy lifestyle and a family.

Hope on the Horizon

BY KAREN E BINKLEY, MD, FRCPC

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. That research is ongoing and has led to several new developments in our understanding of CRPS and implications for treatment.

After an injury or trauma, the body responds with inflammation. This helps to bring blood and nutrients to allow tissue repair. When no longer required, this process is normally shut down. In CRPS, it is thought that there is damage to nerve cells called neurons. The cells that support neurons, called microglia, release substances to cause inflammation and start the healing process. For reasons not completely understood, in CRPS the process of inflammation is not turned off as it normally should be.

Dr. Yves De Koninck, at Laval University in Québec Canada, studied animals and found that after injury, microglia release a signal that causes the nerve cells in the spinal cord to reduce the amount of a molecule on their surface that transports ions, in this case, potassium chloride. This upsets the balance of chloride ions between the inside and the outside of the neurons. Since this balance is required for neurons to function normally, the neuron starts misfiring and creates interference in the regulation of pain signals. A simple light touch can trigger severe pain under the circumstances. It is thought that a similar problem occurs in CRPS.

Dr. De Koninck and his colleagues are developing compounds that increase chloride transport through this affected ion transporter molecule on neurons' surface. In animal studies, they have found a compound that brings more of this important transporter to the surface of the neurons. The compound was able to restore the chloride gradients and the normal function of nerve cells in the spinal cord. It reduced signs of neuropathic pain in rats and appeared to be safe and well-tolerated. It is hoped

that eventually similar results can be obtained in human patients.

If you are interested in learning more about this exciting research, check out the December 2014 issue of Scientific American: "Pain That Won't Quit". There is a second interesting article, titled "Taking the Sting Out Of Pain", in that issue in which the authors explain research that is being done on endotoxins that can block another ion transporter on the surface of neurons, in this case for sodium, that also contribute to pain.

Dr. Linda Watkins and her group in Colorado are looking at other ways to reduce the inflammation associated with CRPS and other forms of neuropathic pain. In CRPS, it appears that there are reduced levels of an important anti-inflammatory substance called interleukin-10 (IL-10). They are developing a compound, that when injected around the spinal cord, will produce IL-10 and reduce inflammation. It has been shown to reduce neuropathic pain in animal models, and appears to be safe. The effect of the injection is expected to last about 3 months. The first trials in human patients should start later this year. Dr. Watkins spoke about this promising research at the RSDSA-sponsored "Integrated Solutions to CRPS" conference on June 14, 2015 in Denver, Colorado.

If you or a loved one has CRPS, it's hard to be patient and wait for better treatments to become available. But it should still be comforting to know that there are brilliant and dedicated individuals who are devoting their lives to this effort. They are working as hard and as fast as they can to help. We should all do whatever we can to support their efforts. ■

ABOUT THE AUTHOR

Dr. Binkley is an Associate Professor, Department of Medicine, Division of Clinical Immunology and Allergy, University of Toronto, Toronto, Ontario, Canada. She developed CRPS in 2007 after an otherwise trivial fracture.

An Exploratory Study of Genetic, Epigenetic, Proteomic, Metabolomic, and Gene Expression-Related Factors in CRPS



PROFESSOR STEPHEN BRUEHL

In June 2015, the RSDSA awarded a \$57,000 grant to Vanderbilt University Medical Center Professor Stephen Bruehl to conduct a study to discover possible genetic and molecular factors related to CRPS.

CRPS is believed to have multiple underlying mechanisms. Previous research has documented a likely contributory role for central and peripheral nervous system changes, autonomic nervous system influences, elevated inflammation, and immune system alterations.

While it has long been assumed that genetic-related factors also contribute to CRPS, there have been few research studies on this topic. The little research conducted in this area to date has focused on a limited number of specific genetic differences (small differences in the DNA sequence), while ignoring the possible contributions of thousands of other genetic differences. Virtually unexplored are differences in how genes are expressed in the body, which is important because genes can be turned on or off by environmental and other factors. Similarly, little prior research has considered the possibility that CRPS risk may be influenced by differences in certain proteins (the building blocks for all tissues in the body) and how individuals metabolize (process) chemicals within the body.

This project will address a fundamental question regarding CRPS: why do some individuals develop

CRPS and others do not, despite experiencing similar injuries?

To do so, Dr. Bruehl will analyze a vast amount of highly detailed genetic, protein-related, and metabolism-related information collected as part of a previously completed Department of Defense research study of 116 military veterans experiencing CRPS and non-CRPS pain following traumatic injuries that required limb amputation. This information has never previously been examined.

Specifically, Dr. Bruehl and his team will study whether development of CRPS rather than non-CRPS limb pain (or no pain) after amputation is linked to differences in:

- genetics (particularly in genes not previously explored for CRPS risk)
- gene expression (whether certain genes are turned on or off)
- epigenetic regulation (nonpermanent modifications to genes that govern their activity)
- the proteins that make up the body
- and how chemicals are metabolized (processed) by the body.

Dr. Bruehl's team will also test whether severity of CRPS symptoms is associated with these factors.

The analysis will provide highly detailed information on a range of potential risk factors for developing CRPS that have never previously been examined. Results may help provide new directions for future research seeking to understand the mechanisms of CRPS and potentially suggest new possibilities for treatment of CRPS. ■

**REFLEX SYMPATHETIC DYSTROPHY
SYNDROME ASSOCIATION**

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



TEL: 877.662.7737
FAX: 203.882.8362
WWW.RSDS.ORG

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

EVENTS CALENDAR 

AUGUST 29

MACY'S SHOP FOR A CAUSE, Your Local Macy's
First Annual Walk of Hope, Erie, PA

SEPTEMBER 7
LABOR DAY

SEPTEMBER 11
INTEGRATED SOLUTIONS TO CRPS CONFERENCE, Cherry Hill, NJ

SEPTEMBER 12
CRPS/RSD WALK FOR AWARENESS, Pennsauken, NJ

OCTOBER 12
COLUMBUS DAY

NOVEMBER 1
FIGHT THE FLAME 5K, Charlotte, NC
THE 2ND ANNUAL CENTRAL NJ WALK OF HOPE FOR A CURE,
Lincroft, NJ

NOVEMBER 2
COLOR THE WORLD ORANGE, Worldwide
BELLARMINE UNIVERSITY RSD/CRPS AWARENESS DAY,
Louisville, KY

NOVEMBER 7
FREEZE THE BURN 1K/5K FUN RUN/WALK, Billings, MT

NOVEMBER 14
THE ANNUAL SAN DIEGO WALK FOR AWARENESS AND A CURE,
San Diego, CA

Don't see an event near you?

Contact Samantha Barrett (sbarrett@rds.org)
to discuss planning an event in your area!

PEER-TO-PEER CONVERSATIONS 

The rdsda Support Committee proudly presents a new peer support program.

VOLUNTEERS:

If you wish to volunteer, please do the following.

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