

# rsdsa community update

VOLUME NO. 4

ISSUE NO. 5

WWW.RSDS.ORG/NEWSLETTER

Summer 2018

## A DAY IN THE LIFE *by Caroline Bert*

<https://rsds.org/professional-patient-photographer/>



INSIDE  
THIS  
ISSUE

**INTRAVENOUS KETAMINE INFUSION FOR COMPLEX  
REGIONAL PAIN SYNDROME (page 7)**

# INSIDE THIS ISSUE

	Page
Healing from Within .....	5
Intravenous Ketamine Infusion for Complex Regional Pain Syndrome .....	7
Virtual Reality for CRPS .....	8
Hope on the Horizon .....	9
Fight the Flame .....	11
Needle Stick Can Cause CRPS/RSD – What You Need to Know.....	12
Rehabilitation of CRPS/RSD .....	13

## Find Us Online

### Blog

[www.rsd.org/blog/](http://www.rsd.org/blog/)

### Twitter

@rsd

### Facebook

[www.facebook.com/rsd](http://www.facebook.com/rsd)

### YouTube

[www.youtube.com/user/RSDAofAmerica](http://www.youtube.com/user/RSDAofAmerica)

### Instagram

@rsd\_official

### Editor

Lauren Bentley

[laurenbentley93@gmail.com](mailto:laurenbentley93@gmail.com)

## 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 RSDA Community Update? We would love to hear from you. Please email your thoughts to [info@rsd.org](mailto:info@rsd.org).*

## SPECIAL THANKS

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

# The Director's Letter - A Summer Update

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

## JENKINS AWARDS TOP \$100,000

Since 2012, RSDSA, with the financial assistance of the RSDSA community, has awarded over \$100,000 dollars in grants via our Brad Jenkins Patient Assistance Program. We have directly helped 167 individuals and families struggling with the financial devastation caused by having CRPS. Weekly, we receive desperate calls to help pay for utility cut-off notices, transportation to out-of-state consultations with CRPS specialists or travel to treatment programs, emergency grants to individuals whose SNAP benefits have been cut, car payments to stop repossessions, help pay for scooters and power wheel chairs, and much more. Just last week, we purchased a used power wheelchair on Craigslist and then purchased a battery & van ramp on Amazon and I personally delivered it to a local family. Need emergency financial help? We will send you an application. Call toll-free 877-662-7737. Every dollar donated to our Jenkins fund is invested directly in helping individuals. Please consider making a gift to our Jenkins Fund by mailing a gift to RSDSA, PO Box 502, Milford, CT 06460 or by clicking here, <https://rsds.org/donate/>



## TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS CONFERENCE IN CHARLOTTE, NC ON SEPTEMBER, 29,

RSDSA is returning to our southeast coast this September. We are partnering with the Stillitano family, founders of Fight the Flame 5K to sponsor an exciting full-day conference: Amberly Largo, author of *True Grit and Grace* will share her inspiring journey of survival and transformation after a horrific motorcycle/SUV accident. Jenny Picciotto's riveting interview of Ms. Largo is on page 5. Dr. Robert Schwartz of the Piedmont Physical Medicine and Rehabilitation in Greenville, SC will share his out-of-the box innovative insights which guide his treatment of complex cases of CRPS. Phil Parker, founder of The Lightning Process is will be traveling from England to talk

about his three-day program which is helping many people with CRPS (watch Amanda Ashley present about the program at our Arkansas conference: <https://www.youtube.com/watch?v=8mDPT-g6bxo> Our San Jose conference videos are now posted on our website: <https://rsds.org/educational-presentations/>

## RSDSA COMMUNITY UPDATE

We hope that you enjoy the summer issue of the *RSDSA Community Update*. Michael Sullivan of the Bay Pain & Wellness Center has written an excellent, helpful article, Rehab of CRPS on the neuroscience of pain and the critical importance of movement. His goal is, "In writing is to convince you that movement, while it may be painful, is good, and to share some strategies for restoring function. His guiding principle is "that if you can do tomorrow what you did today, you are heading in the right

direction. If you can't do tomorrow what you did today then you did too much. Adjust your activity level accordingly." Tracy Coral's interview with Cornell University's Professor Won highlights a promising virtual reality pilot study in CRPS. Jenny Piccotto's interview with Dr. Xu of the Cleveland Clinic reports on RSDSA's international survey on use of IV ketamine to treat intractable CRPS and the development of reference protocols which can be utilized to prove the safety and efficacy of IV ketamine for CRPS treatment.

### 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.

### RSDSA'S ACCREDITED

### MEDICAL EDUCATIONAL

### PROGRAMS

Too many health care professionals have no clue about CRPS and how to treat it. Please help us change this distressing situation. We have developed three free accredited courses on the diagnosis and treatment of pediatric and adult CRPS. Please help us educate health care professionals about CRPS. We can provide you with flyers promoting these courses for distribution in your community. Here is an online link to the courses, <https://rsds.org/rsdsa-pediatric-crps-accredited-online-course/> and

<https://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/>

### 3RD ANNUAL LONG ISLAND AWARENESS WALK EVENT

I invite all metro New Yorkers to gather with RSDSA on September 15 at Eisenhower Park in East Meadow, New York for our third annual fundraising walk event. This year's walk will take place from 8:00 a.m. until 2:00 p.m. at Eisenhower Park's 1K and 2.5K paths, which will be reserved for this event. Last year's event attracted nearly 450 walkers and 50 volunteers and raised \$56,000 for RSDSA. Please come and meet others with CRPS and their family members. We will have food, crafts for children, educational exhibits, an incredible raffle, and much more. For more information, register, or to donate, please visit <https://rsds.org/event/3rd-annual-long-island-crps-rsd-awareness-walk-event-east-meadow-ny/> or call us 877-662-7737.

### 5TH ANNUAL COLOR THE WORLD ORANGE DAY IS NOVEMBER 5, 2018

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 last year.

Want to get involved. Visit Color The World Orange on Face Book: <https://www.facebook.com/ColorTheWorldOrange/>

*James W. Broatch*



**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@rsds.org](mailto:info@rsds.org).**

---

# Healing From Within

## Amberly Lago's recently released book

BY JENNY PICCIOTTO

*True Grit and Grace: Turning Tragedy Into Triumph* chronicles her journey following a severe motorcycle accident in 2010. Her life as a professional dancer, fitness trainer, and athlete was shattered when she was stuck by an SUV. The impact broke the bones in her right leg and severed her femoral artery. She was placed in an induced coma while the doctors considered amputation. After months in the hospital and extensive surgeries, she was diagnosed with Complex Regional Pain Syndrome. Her story is one of inextinguishable hope, overcoming insurmountable pain and suffering. She now devotes herself to inspiring others by sharing the lessons she learned on her path toward accepting herself, her scars, and her new normal.

I was honored to have the chance to talk to Amberly, who still appears young, athletic, vibrant, and healthy. She had just finished teaching a fitness class and was recovering in the parking lot with her shoes and socks off, her foot propped up on the dashboard, throbbing and swelling. As anyone who lives with CRPS/RSD has can affirm, we learn to put on a brave face and mask the pain inside our bodies. She told me about her road from denial and desperation to claiming her resilience. It is a message she shares with as many people as she can, through social media, her book, interviews, articles, and as a motivational speaker.

Amberly, a mother of two, spent 3 ½ months in the hospital fighting to save her leg. She drew strength from her Texan upbringing, which taught that showing vulnerability equaled weakness. So, she did her best to



“cowgirl up.” She stuffed it down and worked hard to regain the use of her leg, motivating herself with the athletic mantra: “No pain no gain.” That approach would only take her so far.

After being diagnosed with CRPS, she would have to unlearn these attitudes and embrace self compassion. “Vulnerability does not mean you are weak,” she tells me. “It shows that you have courage and the ability to grow.” However, arriving at a place of acceptance was a path through darkness and self doubt.

Today Amberly describes herself as a “dignified disabled person.” Learning how to live with CRPS was the most challenging transformation of her life.

Elisabeth Kubler-Ross, a psychologist working with terminally ill patients, pioneered the concept of five stages of grief - denial, anger, bargaining, depression, and acceptance. Her work has subsequently been broadly applied to any major life loss. I asked Amberly how she navigated her path to acceptance, and why it is important to her to share her story with others.

*The ultimate lesson all of us have to learn is unconditional love, which includes not only others but ourselves as well.*

*– Elisabeth Kubler-Ross*

Amberly's first response to the diagnosis of CRPS was denial. She searched for a doctor who would give her a different diagnosis. It was inconceivable that she had survived the crash and all of those surgeries only to be facing a life of unrelenting pain. Desperate for relief, she tried anything and everything the traditional and alternative medical communities had to offer including spinal blocks, radio frequency ablation, pain medications, spinal stimulator trial, ketamine infusions, Chinese medicine, dietary changes, and homeopathic medications. The family took out a lien on their home and borrowed money from friends to help cover the costs of her treatments.

When nothing helped, she began a downward spiral. Although she never seriously considered suicide, she found herself thinking that her children could find a better mom; her spouse could find a different wife, one like she used to be, when fitness was her life. Her leg, scarred, riddled with unexplainable pain, no longer felt like it belonged to her. She dissociated from her physical body, and began to hate her leg, the pain, muscle spasms, and scars. She covered it, and tried to ignore the way it looked, the way it felt. “I was in denial for 2 years,” she tells me. “I couldn't wrap my mind around it.”

The road to acceptance ran through a deep, dark valley. As she tried to tough it out, Amberly sank into

depression and began isolating. She cut herself off not only from her body, but also from the people and activities that had brought meaning and purpose to her life. She found that a glass of wine relaxed her, and began drinking more than normal. It took yet another tragedy for her to realize that she would have to rearrange her mindset and embrace a new world view to begin the process of healing from within.

*When we meet true tragedy in life we have two choices; we can either give up and give in to the pain or use the challenge to claim our innermost resilience and thrive.*

*– Amberly Lago, “True Grit and Grace”*

A couple of years into her struggle, Amberly developed pain in her back, pain that she ignored. It eventually became so severe that it masked her CRPS. Not taking her condition seriously, she nearly paid the ultimate price.

When she went into convulsions, her husband took her to the Emergency Room for treatment, but they immediately redirected her to the Intensive Care Unit. She was diagnosed with sepsis, a life threatening toxic infection, secondary to the kidney stone that had been causing so much pain in her back. The doctors told her that if she had delayed treatment even another day, she could have died.

Amberly describes this moment as her turning point: “It was a huge wake up call. I was scared.” She recognized that covering over her emotional and physical pain, ignoring the messages her body was sending, was not a solution.

Still in the hospital bed in the ICU, she began to adopt a new outlook. Her first step was readjusting her attitude toward her leg, accepting the fact that she was going to have to find a way to love and respect her body. She started a gratitude practice,

replacing each negative thought with a positive one.

“My light was so dim,” she told me, “but when I stopped fighting it and learned to surrender and accept that this is what I have and figure out what I can do to make the best of it, I was able to truly begin to grow.”

*Gratitude turns denial into acceptance, makes sense of our past, brings peace for today, and creates hope for tomorrow. ~ Amberly Lago*

“I am grateful I have my leg,” she says. “I decided I will love it until it feels better. Our bodies converse with us, whisper, talk, and if ignored, finally they scream. I let my body go until it screamed. I was in the ICU for 3 days and realized I have to listen to my body and have compassion for myself. If my daughter had pain, I would not ask her to ignore it and suck it up. Today, I stop and rest when I need to. I have learned to be gentle with myself. I celebrate the small victories. If I have to stop, that doesn’t mean I can’t, or that I am not successful, it just means I am taking care of myself.”

Amberly describes this experience as the moment she began to embrace her pain and reclaim her passion for life. She searched her heart for the little light that flickered in the shadow of nearly losing her life. She fed that flame by focusing on what she could do, rather than what she was no longer able to do. She began to write exercise and diet plans for friends and family from her hospital bed.

Accepting her new normal meant allowing herself to be vulnerable, giving herself permission to take recovery time, develop her pain management toolbox, and cultivate a strong support network. “When I admitted to myself that I had CRPS I was able to talk about it, to reach out and ask for help.”

Expressing and acknowledging what she was going through felt like a relief from the struggle to bury the painful reality of living with CRPS. In the process, she developed new coping skills such as mindfulness, meditation, self-love, and self-compassion. She began journaling and sharing her experiences on social media and, later, as a motivational speaker. She also returned to the gym and her work as a fitness trainer while still in her wheelchair.

“Working with people is a gift,” she says. “Being of service has given my life purpose, pulled me out of depression. I have a different mindset now. Helping others is the key of happiness.”

These days, Amberly inspires hope and encourages others to claim their own resilience. Her powerful story illustrates the possibility of enjoying life despite living with chronic pain. She encourages everyone to start where they are, be grateful for what they have, and do what they can; to resist the urge to isolate, build community and a support team, and to be gentle to themselves.

She continues to suffer from the swelling, color changes, flares, and fluctuating pain levels that accompany living with CRPS. She still needs to stop, rest, and listen to her body. She counts her blessings every day, practices mindfulness, engages in prayer, surrounds herself with positive people, eats an anti-inflammatory diet, and continues to work with her pain management doctor. She has not found a cure for her CRPS, but she has found that by embracing her pain, she rekindled her love of life, and discovered a path to healing from within.

---

You can learn more about Amberly Lago at [amberlylago.com](http://amberlylago.com)  
By Jenny Picciotto

# Intravenous Ketamine Infusion for Complex Regional Pain Syndrome

BY JENNY PICCIOTTO

RSDSA is pleased to announce the publication of Intravenous Ketamine Infusion for Complex Regional Pain Syndrome: Survey, Consensus, and a Reference Protocol, which was published March 9, 2018 in *Pain Medicine*, a multidisciplinary pain journal. This original research, which was funded by RSDSA, studied the usage of intravenous ketamine for the treatment of CRPS and developed reference protocols for use in future comparative studies.

The first phase of the study was a survey to gather data about what protocols are in use among physicians who currently offer ketamine infusion therapy to their CRPS patients. Then a team of experts convened for a professional conference entitled “Ketamine: The State of the Art and the Science.” Presentations covered the history and pharmacology of ketamine, its use in the treatment of CRPS, a panel discussion, and a day of break-out sessions which kicked off the development of two reference protocols through a process of consensus among clinical experts.

According to their paper, “Ketamine is being used increasingly in intravenous (IV) infusion clinics to manage CRPS pain, but without guidance, standard protocols, or guidelines.” Although “many case series have suggested that IV ketamine infusion is effective in reducing pain in CRPS/RSD,” the lack of rigorous controls and the small size of the studies, in addition to the various protocols followed, have

not produced high quality evidence. “The current level of evidence is 2B (i.e., moderate evidence, positive but weak recommendation).”

Complex Regional Pain Syndrome, previously known as Causalgia and Reflex Sympathetic Dystrophy, is a poorly understood, severe pain disorder. According to the National Institutes of Health:

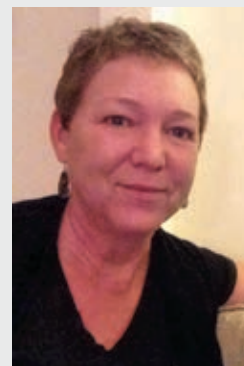
The exact trigger of CRPS after an injury is not known, but it may be due to abnormal interactions between the central and peripheral nervous systems, and/or inappropriate inflammatory responses.... Unfortunately, published research studies validating the efficacy of these treatment options are limited and no single drug or therapy (or combination) has shown consistent, long-lasting improvement.

CRPS patients face a complicated array of treatment options, most of which are not FDA approved and/or have been borrowed from other conditions. Because few evidence-based studies have been done, care providers and patients rely on a trial and error approach to treatment. “Formulating an evidence-based approach to CRPS management is difficult given the lack of high-quality evidence supporting efficacy of most available therapies.”

This research is a critical step in the right direction. The “reference protocols, one for inpatient ketamine treatment and one for outpatient ketamine treatment, do not represent guidelines for

ketamine infusion for CRPS; rather, they are a reference/orientation by which practitioners can access the consensus of highly experienced practitioners. Importantly, this consensus result can provide a starting point for statistical validation of formal guidelines and a more uniform approach to research protocols that will validate the safety and efficacy of ketamine through controlled clinical trials.”

RSDSA is in the forefront of CRPS research. We are dedicated to funding studies for treatment and a cure.



## ABOUT THE AUTHOR

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

# Virtual Reality for CRPS

BY TRACY CORAL

What would you think if there were a treatment modality which combined virtual reality with relieving acute pain? Meet Andrea Stevenson Won, a researcher who believes that a facilitated environment, like that provided by virtual reality, offers real hope for those in pain. She is the Director of the Virtual Embodiment Lab at Cornell, where she is an Assistant Professor of Communications with the College of Agriculture and Life Sciences at Cornell. She holds a Masters in Science in Biomedical Visualization from the University of Illinois at Chicago and has completed a PhD in the Virtual Human Interaction Lab in the Department of Communication at Stanford.

Professor Won became interested in virtual reality and how it could be used as a treatment modality for patients living with physical pain. In pilot studies, encouraging results show that virtual reality can help with both acute pain and Post Traumatic Stress Disorder (PTSD). Of particular interest to readers of this newsletter is that Dr. Won's own pilot studies on pain dealt with the use of virtual reality to treat Complex Regional Pain Syndrome (CRPS) and Persistent Idiopathic Facial Pain. I had the opportunity to speak with Professor Won, and to learn more about her work. I was anxious to discover what had influenced her to study CRPS. Dr. Won explained that CRPS was a condition close to her heart, as she has a family member who was diagnosed with it at a young age. She also spoke about

her mother, a nurse practitioner, whose work focused primarily on non-opiate options to treat pain. Ms. Wong stated, 'they are my two motivators'.

In essence, virtual reality is a computer gaming system, in which a person can be completely immersed in a three-dimensional environment, and engaged in specific settings during the game. In her lab at Cornell, Professor Won is exploring how physical and social exchanges in facilitated environments affect the perceptions of individuals. In regards to physical pain, virtual reality will distract the mind. The individuals using virtual reality are performing movements during the course of the game which may be extremely difficult to do on a typical day. Won stated "when patients see themselves moving in ways they can't in real life, their brains use that feedback to create their body image." Won has stated in a previous article that "visual feedback can effectively change the way people with chronic conditions move. By tricking the brain with virtual experiences, the results could prompt lasting relief in the real world" (Kelly, 2018).

When speaking with Dr. Won, she opened up about how she speaks to her students about CRPS, and the future for virtual reality. "When I am describing CRPS to students, I say that it is a difficult-to-treat chronic pain condition. I explain the reason why we think it might be a target for virtual reality therapy is

that it has some things in common with phantom limb pain, which have made both targets for mirror visual feedback. In particular, there are similar changes in the brain that might indicate visual feedback on movement could be helpful. The future for virtual reality is broad, but we really need systematic research before making recommendations.



## ABOUT THE AUTHOR

*Tracy Coral has lived with CRPS for 15 years, as well as Dystonia and Ehler-Danlos Syndrome(EDS). She is a committee member for the Jenkins Patient Assistance Fund. When she is not doing work for the grant, she is advocating and educating others about cannabis, and how it can be a beneficial treatment option for individuals living with chronic illnesses. In her spare time you can find her painting, spending time with her family and friends, and two dogs.*

# Hope on the Horizon

BY **KAREN E. BINKLEY, MD, FRCPC**  
**BINKLEYK@SMH.CA**

I would like to see it reach the point where it could be easily and cheaply deployed in homes.” As Professor Won and I were wrapping up our interview, I asked my final question: ‘Is virtual reality currently available for patients who are interested in trying it?’ She responded, “This depends where you live, and what your condition is. Weill Cornell has the PATSS clinic; Stanford has a virtual reality clinic in Psychiatry running a trial for Functional Neurological Disorder (FND); I hope to follow up on a pilot study with Stanford Neuroscience and Pain to run a RCT shortly. There are a lot of people exploring virtual reality, but – it’s not a standard care yet for many conditions, just a promising area of investigation.”

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.

Basic scientific research into the cause and mechanism of a condition is important so that appropriate treatments can be devised. Thanks to such research, it is now known that CRPS is caused by inflammation in the nervous system, resulting in increased transmission of pain signals. This knowledge has led to the use of various anti-inflammatory treatments for CRPS; these corticosteroids, high dose intravenous immunoglobulin, anti-tumor necrosis factor, plasma exchange immunosuppressants, such as mycophenolate. Still, these treatments are not universally effective.

## **GETTING ACCESS TO THE BRAIN AND SPINAL CORD WITH ANTI-INFLAMMATORY BIOLOGIC AGENTS.**

One of the problems with treating CRPS is that there is inflammation in the central nervous system (i.e., the spinal cord and brain), and many agents cannot reach these areas because of the blood-brain barrier, which prevents entry of certain

*A group in France has come up with a different way that may predict ketamine response, involving a test that is generally available, known as three phase bone scintigraphy. This type of bone scan was used in CRPS patients and it was shown that ketamine response correlated with the ratios of fixation of tracer compound in the second and third phases versus the first phase of the scan.*

substances into the brain. Normally, this is a good thing as it protects the brain from noxious chemicals, but it also prevents therapeutic agents from entering the brain as well. In previous columns, I have outlined some novel ways that are being investigated to overcome this challenge.

Interesting work from the lab of the late Dr. Ben Barres at Stanford shows that microglial cells (which have been shown to be activated

## **SAVE THE DATE**

**Join RSDSA**

*in*

**Charlotte, NC  
on September 29**

*for*

**Treating the  
Whole Person;  
Achieving Wellness**

in CRPS) secrete factors that increase inflammation, including interleukin 1 (IL-1), tumor necrosis factor (TNF) and one of the first complement components, C1q. They show that it is possible to block the inflammation by treating with antibodies to all three of these substances (anti-IL-1, anti-TNF and anti-C1q) in the lab. Excitingly, antibodies to IL-1 and TNF are already approved for clinical use and are readily available, often referred to as “biologics” that are often used to treat autoimmune disorders like rheumatoid arthritis, and Crohn’s disease. At present, there are no clinically available antibodies to C1q, however.

The problem with administering these antibodies to CRPS patients is that they are fairly large molecules, and do not readily pass the blood-brain barrier. It has been shown in rodents, for example, that if one gives anti-IL-1 systemically in the acute phase of CRPS, there is reduction in pain, but that is not the case in the chronic phase. That is likely because initially, the inflammation occurs outside, in the periphery. By the time CRPS becomes chronic, the inflammation has spread to the central nervous system, where the antibodies cannot reach. However, if the anti-IL-1 is given intrathecally (directly into the central nervous system) in the chronic phase, then there is reduction in pain.

So why not just administer the antibodies intrathecally to CRPS patients? This does involve some risk, including introduction of infection and damage to the spinal cord. However there may be a less invasive way of getting substances into the brain by administering the substances by peri-spinal injection. There is some evidence that this can be done safely, and

it has been shown to be effective in treating stroke, and one case of post-operative dementia. This technique has been used only by a few investigators, and is not universally practiced. There are still risks, including infection, which may be heightened since neutralizing IL-1 and TNF impairs the immune system. But if it is proven to be effective and relatively safe, it may open up the possibility of new treatments for CRPS. Would a single agent, like anti-TNF be sufficient, or would there need to be both anti-TNF and anti-IL-1? Would just these two work, as there are no currently available antibodies to C1q? Only further research will tell.

### **A BETTER WAY TO PREDICT KETAMINE RESPONSE?**

Not all CRPS patients will respond to ketamine. Ketamine infusions are time and resource consuming, expensive, and can have unpleasant side effects (but may be worth it if it helps your CRPS). In a previous column, I outlined work done by the Philadelphia group that showed they could predict which patients would respond to ketamine by analyzing the pattern of micro-RNAs in their blood. Micro-RNAs are small molecules that help control the expression of proteins in the cells. However, this type of analysis is not widely available. A group in France has come up with a different way that may predict ketamine response, involving a test that is generally available, known as three phase bone scintigraphy. This type of bone scan was used in CRPS patients and it was shown that ketamine response correlated with the ratios of fixation of tracer compound in the second and third phases versus the first phase of the scan. If this result can be replicated and verified, it is a relatively simple

way to predict response to ketamine. It may spare some patients the unnecessary time, expense and side effects of ketamine infusions if they are not going to be effective for them. And for others, it will give them some reassurance that they will likely benefit, and the time and expense will likely be worthwhile.

### **References.**

- Neurotoxic reactive astrocytes are induced by activated microglia. Liddelow SA 1,2, Guttenplan KA1, Clarke LE 1, Bennett FC 1,3, Bohlen CJ 2, Schirmer L 4,5, Bennett ML 1, Münch AE 1, Chung WS 6, Peterson TC 7, Wilton DK 8, Frouin A 8, Napier BA 9, Panicker N 10,11,12, Kumar M 10,11,12, Buckwalter MS 7, Rowitch DH 13,14, Dawson VL 10,11,12,15,16, Dawson TM 10,11,12,16,17, Stevens B 8, Barres BA 1. *Nature*. 2017 Jan 26;541(7638):481-487.
- Acute versus chronic phase mechanisms in a rat model of CRPS. Wei T 1, Guo TZ 2, Li WW 3, Kingery WS 4, Clark JD 5. *J Neuroinflammation*. 2016 Jan 19;13:14.
- Perispinal Delivery of CNS Drugs. Tobinick EL. *CNS Drugs*. 2016 Jun;30(6):469-80. Review.
- Treatment of post-anesthesia dementia with perispinal etanercept injection and hyperbaric oxygen therapy: a case report. Steve Best 1 and Dan G. Pavel. *J Med Case Rep*. 2017; 11: 105.
- Three-phase Bone Scintigraphy Can Predict the Analgesic Efficacy of Ketamine Therapy in CRPS. Sorel M 1,2,3, Beatrix JC 1, Locko B 1, Armessen C 1, Domec AM 1, Lecompte O 1, Boucheneb S 4, Harache B 4, Robert J 4, Lefaucheur JP 2,5. *Clin J Pain*. 2018 Mar 13. doi:10.1097/AJP.0000000000000607. [Epub ahead of print]

# Fight the Flame

BY SYDNEY EDEN

Five years ago, a group of Charlotte teenagers started an organization that was dedicated to promoting awareness of and raising funds for CRPS. Twelve-year-old Landon had no idea that what he started in 2013 would turn into an annual event that would be ranked as the second largest CRPS fundraising event in 2017. Thanks to our amazing sponsors we had an extremely successful day.

We would like to thank our ...

#### Platinum Sponsors:

Bojangles', Ayers, Whitlow, & Dressler, Connolly Orthodontist, Southeast Pain & Spine Care

#### Gold Sponsor:

Omega Sports

#### Silver Sponsors:

Abbott, Hendrick Honda, Dennis Coffey & Silver Investments

#### Bronze Sponsors:

McKee Dental, Stacks Kitchen, Performance Growth Advisors, Bullard Realty Group, Metrolina Pain Relief, European Wax Center, Stanley Specialty Pharmacy, Waltonwood Senior Living, Honest Auto-1, Pyramid Printing & Healthy Home Market

Mile Markers: Kids First Pediatrics, Shelf Genie & Camp Gladiator

As of today, Fight the Flame has raised over \$110,000 for the RSDSA. Fight the Flame has worked hard to become an active voice in the Charlotte community. They organize and sponsor a local support group for families and individuals in the Charlotte area who are living with

*Sydney Eden was a Fight the Flame intern. She just graduated from University of North Carolina at Charlotte with a degree in Health Communications and minor in Psychology. She will be continuing her education at UNC-Charlotte pursuing a Master's Degree in Hospital Administration.*

CRPS. In addition, every year Fight the Flame awards a CRPS Awareness college scholarship to local high school student. Applicants for the scholarship must educate others about CRPS to be considered for the award.

This year, Fight the Flame will be hosting its 6<sup>th</sup> annual Fight the Flame 5k Race and 1k Roll & Stroll on Sunday, September 30, 2018 at the McAlpine Creek Park in Charlotte, NC. Those who will not be in the area for the event can also participate as a virtual walker.

Please consider helping us Fight the Flame. You can register for the race, the virtual walk, or make a donation to RSDSA at <https://runsignup.com/Race/NC/Charlotte/FightTheFlame>.



# Needle Stick Can Cause CRPS/RSD – What You Need to Know

BY **BRIAN POPE, ESQUIRE**

**POPE/TAYLOR - NATIONAL CRPS/RSD LAWYERS**

As an attorney who has been reviewing potential CRPS/RSD liability cases for the last 20 years, I have a pretty good feel of trends in the causes of CRPS. Unfortunately, I have noticed a growing number of people who have contacted me complaining of developing CRPS as a result of an IV needle stick. There are very few actual cases of nursing/medical malpractice that can be brought as a result of developing CRPS from a needle stick.

First, it is always foreseeable that if you are getting a needle stuck into a part of your body, you may develop CRPS as a result. The nurse could do everything by the book in a correct needle stick procedure and you could still develop CRPS. In this case, there is not a potential nursing/medical malpractice case to be pursued. The vast majority of cases I review fall into this category.

However, if a nurse violates the standard of care during a needle stick procedure, then it is a different analysis. The most common needle stick injury I see is when a nurse sticks the needle directly into a nerve, such as the median nerve, and damages the nerve. Usually, when this happens, the patient feels an immediate jolt of “electric” pain and reacts by crying out in pain. Unsurprisingly, there are very few medical records I have reviewed where this reaction is documented, allowing for plausible deniability if there are any subsequent complications from the needle stick.

If there is direct nerve damage due to a careless needle stick, usually the person will follow up with a doctor. The doctor may then do exploratory surgery to determine the extent of damage to the nerve. I have had a few cases where the subsequent treating doctor will take pictures and document the damage done to the nerve. Obviously, these are the best legal cases as the documentation and pictures provide compelling evidence of the damage done to the nerve. This also helps with proving causation in that the needle stick caused direct damage to the nerve, which resulted in the development of CRPS Type II.

Our law firm reviews potential CRPS/RSD cases, whether the CRPS is caused by a trauma (car accident, workplace injury, slip/trip and fall) or medical/nursing negligence (unnecessary surgery/procedure performed incorrectly that damages the nerve). If you have any questions regarding what you think may be a potential CRPS/RSD legal case, please contact our office for a free consultation.

## 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@rdsd.org](mailto:info@rdsd.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).

---

# Rehabilitation of CRPS/RSD

BY **MICHAEL SULLIVAN, PT - DIRECTOR OF FUNCTIONAL RESTORATION PROGRAM**  
**BAY AREA PAIN AND WELLNESS CENTER**

How important is movement to our health and wellbeing? A dark lesson starting in medieval times and running into the mid-1800s is provided by the numerous inquisitions, the most famous being the Spanish Inquisition. For over 700 years torture was used to induce people to confess to their heresies, recant their heathen ways and profess their faith in God. Torture was used to speed up the process. One of the most effective means of torture was the use of constraints to restrict a person's ability to move. Stocks, barrels, metal cages, ropes and chains were used to prevent movement. The tighter a person is bound, the less they can move, the greater the pain. Complete restriction of movement can lead to excruciating and unrelenting pain within twenty-four hours. People were known to go mad in a matter of days. My apologies if the thought of this alone is enough to make you cringe or feel discomfort (you can thank the mirror neurons in your brain) but this illustrates the importance of movement and highlights that pain is a consequence of immobilization.

One of the many issues that people with Complex Regional Pain Syndrome struggle with is that movement is painful, to the point where they don't feel they have the choice to be active. Essentially, pain itself becomes the constraint that restricts movement resulting in more pain. As a result of this vicious cycle,

CRPS sufferers can get into a downward spiral of functional decline that not only exacerbates their pain but seriously diminishes their quality of life. Fear of movement as a result of pain leads to avoidance of movement. My goal in writing today is to convince you that movement, while it may be painful, is good, and to share some strategies for restoring function. First, let's look a little more closely at the pros and cons of not moving.

One of our responses to pain is to avoid movement to protect the injured area from further harm. In the early stages of injury this type of guarding is an adaptive response that helps us to heal. Depending on the injury, your doctor may even use immobilization to set up the conditions under which the damaged tissues heal. The simplest example would be casting a broken bone. In deciding how long to immobilize an injury there is always a tradeoff between the time that is needed for the tissue to heal and the deleterious effects of immobilization. Not only can immobilization be painful in of itself, it also is not healthy for many of our tissues. Muscles need to move and work to remain strong and flexible. Moving joints distributes synovial fluid that helps to lubricate and provide nutrition to joint surfaces. Nerves elongate and glide relative to the surrounding tissues when we move. Movement and interaction with our environment activates

nerve endings, sending a constant stream of information to our brains for processing that are essential to brain health. Part of the healing process is the laying down of scar tissue as a means of repairing damage. Unfortunately, scar tissue is not very smart and while it strengthens the damaged tissue, it also can form cross-links to tissues that need to move in relationship to each other. The longer these cross-links remain in place the stronger they get and the more they can restrict normal movement. Importantly, movement is also necessary for the final phase of healing, a remodeling process that allows injured tissues to reorganize and gain maximum strength. When we continue to guard against movement after the initial healing process is complete, we are doing more harm than good, and the protective response becomes maladaptive. It is no longer helping us to heal. In short, our muscles, fascia, joints, nerves and brain all need movement to remain healthy and any immobilization, even of an isolated body part, beyond the minimum required for healing is not good for us. The consequences are most extreme when people take to bed rest to cope with their pain. We then add cardiovascular deconditioning, arterial constriction, blood clots and the possibility of pressure sores to the list of adverse consequences. Studies demonstrate that there is no known medical condition that is helped by prolonged bed rest<sup>1</sup>.

When faced with the dilemma that it 'hurts' to move and accepting the fact that it is bad for your health and exacerbates pain to not move, I am hoping you will choose the latter. I recognize that this is no small task. So how should you proceed?

### **ARM YOURSELF WITH KNOWLEDGE;**

pain neuroscience education is key. Know that pain is not synonymous with tissue damage. In a normal functioning nervous system, pain is an early warning system of potential tissue damage. With CRPS both the peripheral and central nervous system function can become sensitized resulting in pain with non-painful stimuli (allodynia), exaggerated pain with a painful stimulus (hyperpathia) or pain in the absence of any stimulus, i.e. spontaneous pain. To use a smoke alarm analogy, this is the equivalent of every smoke alarm in your house going off when you blow out a single birthday candle in addition to your smoke alarms going off randomly all day and night. With the smoke alarm, eventually you would come to the conclusion that the system is malfunctioning, and if you are anything like me, you would start cleaning them off the ceiling with a broom stick. The smoke alarm is no longer providing you with useful information. The same could be said of the sensitized nervous system. Common sense tells you that touching your hand lightly should not result in a burning sensation, but it does and patterns of activation in the centers of the brain that process this information look

about the same as if you were touching a hot burner on your stove. There is nothing imagined about this, it is real. The good news is that you can change this experience.

### **LEARN WAYS TO MODULATE YOUR PAIN.**

While knowing how pain is processed is not an absolute requirement to learn pain modulation, most people just don't take our word for it when we tell them they can make their pain better or worse. The receptors in our body that collect information about actual or potential tissue damage are called nociceptors and the process whereby information about unpleasant stimuli is transmitted to the brain for processing is called nociception. Your brain takes this information, puts it into context of your past experiences, psychosocial factors, your personal beliefs, your cultural identity, your current health and demographics and your spiritual beliefs among other factors and does a threat assessment. **Your brain will produce pain in proportion to the perceived threat not necessarily in proportion to the actual threat.** If your conclusion is that what you are experiencing is not very dangerous then you will experience less (or no) pain. Thoughts and expectations do matter. If you have catastrophic thoughts and expect that you will never get better your pain will be worse. Your brain will ratchet up the threat assessments unless these thoughts are addressed. A psychologist with experience in chronic pain management is most helpful in addressing these issues.

Nociception need not be present to experience pain. Emotional and cognitive stressors can both produce pain responses in areas of the brain identical to those produced by the nociceptive process. Learning techniques to manage these stressors can down regulate pain. Meditation and relaxation exercises quiet activity in areas of the brain that process pain. Conversely, you can have nociception but not experience pain. There is an abundance of functional magnetic resonance imaging studies that allows observation of brain activity in real time that support these assertions.

### **IT'S TIME FOR GRADED MOTOR IMAGERY.**

The ground breaking work being done by Butler and Moseley with the Neuro Orthopedic Institute (NOI) addresses the neuroplastic changes that occur in the brain as a result of the central nervous system being bombarded by nociceptive information. Brain health is promoted through a series of three activities: laterality tasks, imagining/thinking about movement and mirror box therapy. These activities can help to reduce pain and increase motor control for better quality movement. NOI has many good online resources that can help get you started. We generally recommend five minutes of GMIB-10 times per day spread out across your waking hours. If you are going to be working with a physical therapist, make sure the person you are working with has experience with these techniques. Pairing these with desensitization exercises can help with allodynia.

## ADDRESS THE BUILDING BLOCKS OF FUNCTION.

Once you have developed some skills to better manage your pain, you are more likely to have success progressing into the active portion of your treatment program. Our goal up to this point in addition to understanding and reducing pain has been to reduce the fear associated with movement by better understanding pain. Given that you will be able to down regulate pain in the event that it increases you will be able to look past those previous experiences of trying to increase your activity level that did not go so well. Gentle exercises to improve joint mobility, improve muscle flexibility and increase cardiovascular endurance are key. Start slow, increase slowly but don't be deterred by discomfort that you are likely to experience in the moment. As you add more. Activities to your program, the guiding principal is that if you can do tomorrow what you did today, you are heading in the right direction. If you can't do tomorrow what you did today then you did too much. Adjust your activity level accordingly. Once you have established a baseline you can start slowly increasing the duration of your cardiovascular activities. Studies demonstrate that cardio above all other forms of exercise helps to regulate health in the nervous system, decrease depression, and reduce stress in addition to promoting cardiovascular health.

In addition to neuropathic pain associated with dysfunction in the nervous system people with CRPS experience a combination of orthopedic consequences associated with the original injury or disuse. Almost universally,

one of these consequences is myofascial pain associated with guarding the injured area and adjacent areas. Learning skills to self-manage myofascial pain are essential to reducing pain in the periphery. Releases and stretches are essential to managing flare ups.

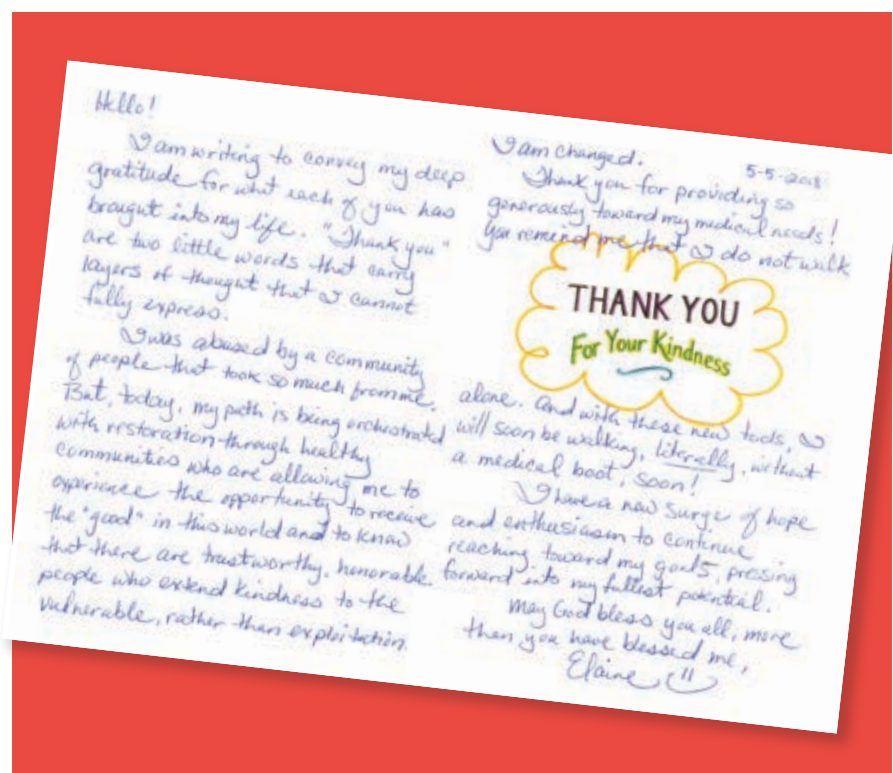
When you are experiencing some success with the above it is time to move on towards addressing specific deficits identified on your physical therapy evaluation. Exercises for building strength, addressing postural imbalances, improving balance, practicing good body mechanics are a good lead in to functional training.

## PUTTING THE FUN BACK IN FUNCTIONAL:

Ultimately, everything up to this point is pursued with individual functional goals in mind. What are the most important activities for you to regain quality of life? For some, self-care and the ability to

live independently is the most important thing. For others it is playing with their children or dancing with their partner. For some, it is getting back to work and regaining financial independence. Getting back into your normal daily routine involves sitting and standing tolerance, safe ambulation, the ability to transfer from standing to floor and back and may involve components of lifting, carrying, pushing and pulling, fine and gross motor skills. These should all be incorporated where appropriate to meeting your functional goals. Engaging in activities that you enjoy unlocks your body's natural pain relieving ability and is another step towards a more healthy life.

1. Allen. C; Glasziou, P; Del Mar. C (9 October 1999). "Bed rest: a potentially harmful treatment needing more careful evaluation." *Lancet*. **354** (9186): 1229-33).



**REFLEX SYMPATHETIC DYSTROPHY  
SYNDROME ASSOCIATION**

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

Non-Profit  
U.S. POSTAGE  
**PAID**  
Graphic Image  
06460



TEL: 877.662.7737  
FAX: 203.882.8362  
[WWW.RSDS.ORG](http://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



### 2018 CALENDAR OF EVENTS THROUGH NOVEMBER

**August 25-** CRPS Awareness Day At Dodger Stadium -  
Los Angeles, CA

**September 15-** 3<sup>rd</sup> Annual Long Island CRPS/RSD  
Awareness Walk Event- East Meadow, NY

**September 23-** Knock Out Pain 5K- Easton, PA

**September 29** Treating the Whole Person: Achieving  
Wellness, Charlotte, NC

**September 30-** Fight The Flame 5K 2018- Charlotte, NC

**October 21- 2018** CRPS Awareness Walk- Pennsauken, NJ

### NOVEMBER IS CRPS AWARENESS MONTH

**November 3** Thompson Park Walk Lincroft, NJ

**November 4** Zumbathon Charity Event in Freeport, NY

**November 4** Fight the Flame 5K in Mentor, OH

**November 5** 5th Annual Color The World Orange

## PEER-TO-PEER THOSE IN NEED OF SUPPORT:

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

- **Please contact [LindaLang@rsds.org](mailto: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](mailto:info@rsds.org)  
to discuss planning an event in your area!