

# rsdsa community update

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This issue was funded by a donation in memory of Ronni Jill Zager by her parents Lawrence and Judy Zager.



INSIDE  
THIS  
ISSUE

Join us in the Big Easy this June for our  
Young Adult Weekend *(page 14)*

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## CALL FOR AUTHORS & IDEAS

Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? Is there a special topic you would like to see included in the RSDSA Community Update? We would love to hear from you. Please email your thoughts to [info@rsds.org](mailto:info@rsds.org).

## SPECIAL THANKS

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Aetna, Arkansas Pain Center, LTD, Baker Family Charitable Trust, Center for Pain Management, Edelman, Krasin & Jaye PLLC, Grünenthal, Neurologic Relief Center, NoPainHanna, Oska, Pope/Taylor National CRPS/RSD Lawyers, Shirley Ryan Ability Lab, Vitalitus.

# Opinion: Optimism for Better Days for the CRPS Community

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

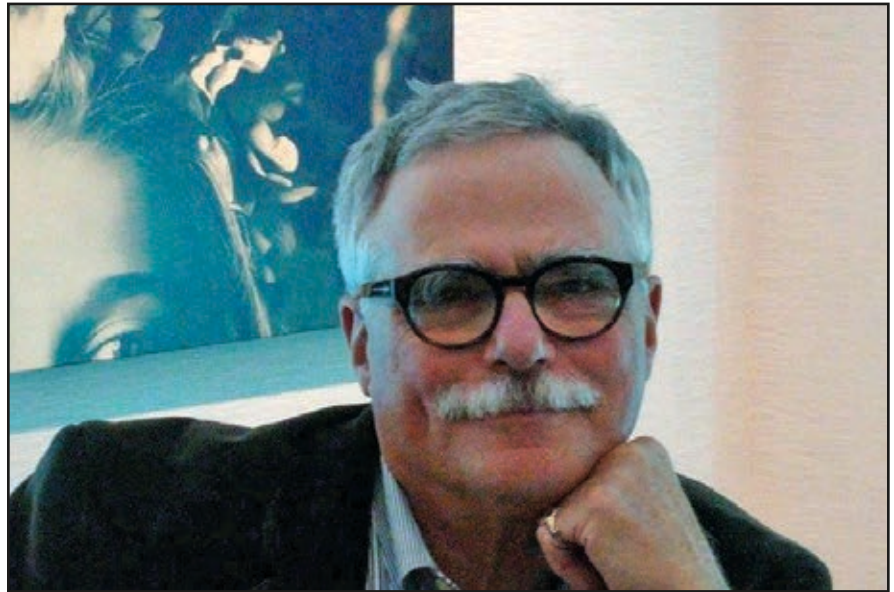
*In November, **The National Pain Report** asked RSDSA Executive Director, Jim Broatch, to share progress the organization has made towards spreading awareness and finding a cure for CRPS.*

I'm very optimistic about the current and future prospects of the CRPS community.

For the past several years, RSDSA has been involved in creating the necessary infrastructure for an expected increase in CRPS international clinical trials. We have provided the seed and ongoing funding for the **International Research Consortium** (IRC) for CRPS.

The creation of the IRC was a prerequisite; although there have been significant strides in CRPS research during the last 20 years, there still is no solid information or Randomized Clinical Trials (RCTs) treatment or even definitive information about mechanisms and treatment responsive phenotype because:

- CRPS is a relatively rare condition and treatment trials have generally been small number (N) single site pilot studies. Federal agencies that approve treatment (e.g., FDA in the US) and insurance payers do not consider preliminary, pilot, or case series type evidence.



Definitive trials are needed.

- Funding levels for basic and clinical research are at historic lows. (Remember that only 2% of research health care dollars are invested in pain research).

Large, multi-site studies with appropriate numbers are needed to advance research and the IRC will accomplish this through pooling of resources internationally for rapid and conclusive studies.

Since CRPS was designated as a rare disease (prevalence of less than 200,000 in the United States), a number of pharmaceutical and medical device manufacturers have signaled their intention of sponsoring CRPS clinical trials. Prior to this designation, I could only cite two major RCTs during

the last twenty years. A number of corporations have approached me or members of our scientific advisory committee to discuss the feasibility of sponsoring trials now because CRPS has the rare disease moniker.

Currently, Grunenthal is sponsoring a clinical trial in the US of neridronic acid, to test its efficacy and safety in people with CRPS. Some individuals with CRPS have traveled to Italy to bypass the trial since individuals who have had CRPS for more two years are excluded from the trial. The other part of the necessary infrastructure we are helping to fund is the finalization of COMPACT- **Core Outcome Measures** for Complex Regional Pain Syndrome Clinical Trials. Historically, a wide range of different outcome measures have been used to capture the

multidimensional nature of CRPS which was a significant limiting factor in the advancement the understanding of the mechanisms and management of CRPS. In 2013, an international consortium of patients, clinicians, researchers and industry representatives was established to develop and agree on a minimum core set of standardized patient reported outcome measures for use in future CRPS clinical studies in an adult population (COMPACT). This work was completed and published in 2017.

Now, RSDSA is funding the addition to COMPACT of an internationally agreed core **clinical** outcome measurement set that will be collected alongside the patient reported outcome measures and stored on an electronic data capture system.

Speaking with and corresponding daily with members of the RSDSA community, I'm heartened by the increased clinical use of medical cannabis, ketamine, low-dose naltrexone (LDN), and graded motor imagery (GMI) and mirror box therapy. But significant problems remain with the refusal of most insurers to pay for medical cannabis & ketamine and the lack of trained therapists in GMI.



# Autoimmunity and Complex Regional Pain Syndrome

BY **DAVID J. CLARK, MD, PHD**

## **RSDSA APPROVES \$129, 093 GRANT TO INVESTIGATE AUTOIMMUNE DETERMINANTS OF COMPLEX REGIONAL PAIN SYNDROME**

In December, the RSDSA Board of Directors unanimously approved David J. Clark's, MD, PhD grant application. According to Dr. Clark, the principal investigator, the goal of the study is "to identify the targets of CRPS-related autoimmune antibodies using blood and tissue samples from people with CRPS. In addition to helping establish autoimmunity as a process supporting CRPS, knowledge of the autoimmune targets will enable us to design testing, allowing caregivers to identify those individuals with CRPS who might respond to immune system modulating therapies, and to gauge disease activity."

I asked Dr. Clark to explain this study's relevance for people with CRPS. Here is Dr. Clark's reply:

From the time of the first descriptions of the burning pain, swelling, warmth and other findings of what we now call Complex Regional Pain Syndrome (CRPS), physicians and scientists have been stymied to explain what causes the condition. Popular hypotheses include dysfunction of sensory nerves, dysregulation of the autonomic nervous system and altered functioning of the brain. Each of these guesses has some merit,

but none completely explain why some people develop CRPS after even minor injuries while most people recover with no residual problems. Regrettably, our lack of ability to effectively treat CRPS is related to this lack of understanding of the causes. Both the shortcomings of existing explanations and our rapidly expanding understanding of the immune system have led to new theories of how CRPS is initiated and maintained. Excitingly, if these new ideas prove to be correct, new therapies might be found.

Autoimmunity is defined as an immune response of an organism against its own tissues. The field of medicine has been witness to the discovery of an autoimmune basis or at least contributions of autoimmunity to many diseases, including ones long believed to be due to other causes. Type 1 insulin dependent diabetes is an example where we now understand the immune-mediated destruction of pancreatic beta cells to be a critical event. Slowly accumulating evidence suggests such contributions to CRPS. For example, genetic studies have linked changes in immune-related human leukocytic antigen (HLA) gene sequences to certain forms of CRPS. Additional observations have shown that CRPS is more common in people with strong antibody responses to chlamydia, parvovirus and campylobacter

infections, suggesting some of those antibodies might cross-react with normal tissues. Other reports show that the numbers of antigen presenting cells, important for immune reactions, are present in large numbers in the skin of patients with CRPS. In fact, laboratories working independently in different parts of the world have shown that antibodies in the serum of CRPS patients can interact with normal structural proteins like keratin found in skin, proteins expressed in the nuclei of cells and receptors for neurotransmitter molecules expressed on neurons.

Building on these observations, some clinician-scientists have attempted to control the symptoms of CRPS using techniques that reduce the activity or abundance of autoantibodies. For example, encouraging results have been obtained in treating CRPS patients with plasmapheresis, a technique in which autoantibody-containing plasma is separated from blood and the blood cells are then returned to normal circulation. The use of stronger immunosuppressive drugs is also underway. However, after encouraging initial studies with small numbers of patients, a larger clinical trial using intravenous immunoglobulin (IVIG) unfortunately failed to provide more relief to CRPS patients than did a control infusion. While some of these treatments are promising, each of these techniques involves variable levels of expense, sometimes quite high, and risks from unintended suppression of normal immune function. Unfortunately, none of these

approaches works for every CRPS sufferer making it important to carefully select patients.

One of the main challenges, therefore, has been to identify who will benefit from immune therapies, and who is unlikely to benefit and can therefore be spared the risk and expense. We do not yet know how to do this, leaving patients and providers in the position of having to use a trial and error approach. On the other hand, there are some potential approaches under development. One of the most promising is to assess a patient's serum for the presence of autoantibodies. Investigators have shown that the presence of autoantibodies can be measured using in vivo (animal model), in vitro (cell culture) and biochemical (immunoblotting) procedures.

The RSDSA is now supporting an effort that would make the detection of autoantibodies in CRPS sufferers a reality. Using the antibody containing serum of CRPS and pain-free controls, we will attempt to identify the proteins targeted by the autoantibodies that are associated with pain. Hopefully this will result in the identification of proteins that can serve as a test panel for diagnosing CRPS supported by autoimmunity. In addition, having this type of immune testing available will help select patients for autoimmune therapies and allow doctors to follow the responses of patients receiving those therapies.

Thinking optimistically, the ability to identify CRPS patients with active autoimmunity opens the door to trials of treatments seldom, if ever, used to control the condition. Some classes of

medications not usually used to control CRPS (and not FDA approved for this purpose) include anti-B cell medications used to control rheumatoid arthritis, calcineurin inhibitors used to reduce rejection of transplanted organs and other immune system modulating therapies. While it needs to be stressed that these are not currently accepted approaches to controlling CRPS, the immune system may represent a new target for the prevention of CRPS and possibly the reduction of the severity of the pain, disability and other features of this syndrome.



#### **ABOUT THE AUTHOR**

*Dr. Clark is the Director of the VA Palo Alto Health Care System's Pain Service. One common scenario he has seen in his clinic is for a patient to report a specific injury or trauma, e.g. a surgery, war-related injury or motor vehicle accident, followed by pain which did not resolve along the predicted time course. The advent of effective body armor and the armaments of modern warfare have produced a large number of veterans with non-resolving pain in their limbs. Drs. Clark and Kingery have for many years co-supervised a laboratory focused on the study of pain occurring after trauma and surgery including complex regional pain syndrome (CRPS) using animal models and, more recently, human subjects. His laboratory studies has helped them to understand the role of peripheral pain mediators in supporting not only acute pain, but in fostering the transition of acute pain to a more chronic disabling form. Regarding our most current work, they have joined forces with an expert in immunology to explore a very novel autoimmune-related hypothesis. The current studies are key for the field as they will provide a platform from which to design both focused investigations into mechanisms linking peripheral injury to autoimmunity, and hopefully clinical studies where investigators target specific immune system components with rationally selected therapies in order to achieve the optimal outcomes.*

# CRPS Community

BY JENNY PICCIOTTO

Bob Lane has a passion for community. He is a member of the RSDSA board of directors, founded the Maria Fund in his wife Maria's honor, and is the facilitator of the Denver Metro Complex Regional Pain Syndrome (CRPS) Support Group.

As Chair of the RSDSA Communication and Education Committee, Bob pioneered the development of a continuing education course for the American Nurses Association: "Causes, Diagnosis and Treatment: Introduction to CRPS." His objective is to continue to create and promote more accredited courses for physicians and pharmacists. He also helps with the organization and planning of RSDSA patient education conferences and is working on plans for the September conference, which will be held in Denver. Stay tuned for details as this conference shapes up!

Although he contributes to the community in many ways, facilitating the Denver support group has been both personally rewarding and where he feels he has the most direct opportunity to help patients and caregivers navigating the challenges of living with CRPS. "The personal contact is where I feel my feet on the street," he says. "It's where my heart is, where we share our experiences and keep the hope alive."

Bob's journey with CRPS began when his wife Maria developed a severe case of CRPS following

a bunionectomy (a surgical procedure to remove a painful inflammation at the base of the big toe which makes walking and weight bearing difficult). Everyone expected that after the procedure, Maria would recover within the usual four to five weeks. However, two to three weeks after the surgery, the pain was worse, not better. Her surgeon encouraged her to give it time, but she did not improve. It wasn't until seeking a diagnosis from several doctors that a resident who was assisting the attending surgeon finally suggested that her symptoms could be CRPS.

At the time, Bob was working with hospitals in post-surgical pain management as a medical device representative. He knew CRPS was a challenging diagnosis, but was hopeful that his contacts with professionals in the field of pain management would ensure that Maria received the best treatment available. It was the beginning of a tortuous and life changing journey.

Despite aggressive care including medications, nerve blocks, and ketamine, Maria developed degenerative CRPS. It progressed to affect her entire body, including her vision, lungs, and internal organs. As Bob describes in his blog for CRPS Awareness in 2017:

*"At the time, we tried every treatment available and even considered flying to Germany for a ketamine coma, before they were banned. All of these treatments offered no relief and only added medication*



*side effects as an additional complication. Eventually, Maria developed full body CRPS, an uncommon progression of CRPS. My goal at the time was to continue to offer hope to my wife. Severe depression was becoming very obvious. The constant pain and social isolation only contributed to her depression. Nobody, including family and friends, understood. Eventually, Maria succumbed to her battle with this horrible disease after an intense 3 years of fighting."*

Maria was a loving wife and mother to their four children. In her honor, Bob founded Maria's Fund, a charity devoted to CRPS education and suicide prevention.

As Maria's partner, Bob has seen the deep despair that afflicts people suffering from CRPS. He has also experienced the guilt and frustration of being a caregiver, struggling to make things better. His experiences led to his drive to make information about CRPS more available to medical professionals, patients, and

caregivers. “It created a passion,” he says, “just how crazy it was trying to find information and get treatment made me want to get involved.” The RSDSA website became a source of guidance.

For several years Bob has been creating community through the Denver Metro Support Group where everyone is welcome including patients, family members, and friends. “The support group is hands on face time,” he says, “where people can learn about the concept of CRPS, learn how unique it is for each person, and share tips and tricks on how to care for themselves.”

Taking care of yourself is a theme not only for patients, but is also important for caregivers, who Bob refers to as the “unsung heroes” in the CRPS picture. While the person who has CRPS fights a daily battle with the pain while juggling the emotional consequence; the caregiver or significant others in their lives also experience a spectrum of emotions and losses as they come to terms with their new reality.

From Bob’s perspective, for people coping with CRPS, there are two elephants in the room - that is, two topics that are often overlooked. One is the tremendous emotional trauma of living with CRPS that can lead to loss of hope and the risk of suicide in the case of the patient. The second is the stress experienced by caregivers who can feel overwhelmed and powerless in the face of their loved one’s suffering. As is the

case with any serious health challenge, both patients and caregivers alike can experience depression, anxiety, guilt, frustration, loneliness, and grief.

That’s why his meetings are inclusive; to help patients learn about CRPS, share ways of coping, and learn about treatments *and* to help caregivers better understand the often confusing symptoms of CRPS, make connections with other caregivers, and recognize the need to also take care of themselves.

“The door swings both ways,” Bob explains, “Patients and caregivers can experience deep despair. It is not unusual for me to be approached by patients who are on the verge of suicide or have considered it. It’s important to know the signs of despair and possible suicide, and know how to respond. It’s also important to support those who are supporting people with CRPS. Caregivers can feel guilt because they want to do more or are struggling to meet physical and emotional needs. They may be frustrated because they can’t fix it, and are at risk of compassion fatigue.

<sup>iii</sup> If the person who is doing the supporting emotionally collapses, or the spouse leaves, then there is no support. I want to help prevent that.”

Bob’s experiences have fueled his passion for community and his commitment to CRPS education and suicide prevention. It is his hope that one day there will be a cure or treatment for everyone. Meanwhile, he says,

“It’s important for people to gather together and discuss living with CRPS, treatments, flares, surviving the day. When we share information, we internalize new knowledge and that helps us relate to one another. We develop connections and a network of support. We help each other and that helps us all keep hope alive.”

*You can access information on suicide prevention here:*

<https://rsds.org/stories-of-hope-the-taboo-of-suicide-by-linda-lang/>

i <https://rsds.org/crps-awareness-day21-different-perspectives/>

ii <https://www.facebook.com/MariasFund/>

iii <http://www.compassionfatigue.org/pages/compassionfatigue.html>



#### **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.*

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# Kim's Story

BY MARY ANN BAREFIELD

I am writing to you about my wife Kim and the story of the day that changed our lives as we knew it.

October 25, 2012 changed her life, and mine, forever. She was out visiting her horse at the stables when another horse got loose and did a double barrel kick in excitement from being free. Unfortunately, Kim was at the other end of the kick. Her right hand was pinned against her hip and broken from the blow of the kick, while her left shoulder (the good shoulder) took the other kick. Her hand was casted but she could barely stand it because of the burning and swelling. I'll spare you the details on what all transpired from that time, but her hand was not healing and she knew immediately what was wrong. She was one of the lucky ones to know about RSD/CRPS because she has a patient that suffers from that as well. My only knowledge of RSD/CRPS at the time was from her patient who was wheelchair bound from a hand injury, so I thought that would be Kim's fate. You see, she is a Chiropractor and makes her living with her hands. She was out of work for a year after that accident. In a previous accident in 2012, she was cycling and was hit by a car where she broke her leg and tore her right shoulder. She had shoulder surgery and we had no way of knowing that

the surgery would not be done correctly and would have to be re-done by a different doctor.

We made an appointment with Dr. Kirkpatrick in Tampa at the RSD Research Center where he confirmed her diagnosis. She eventually had a ketamine ganglion block, as the RSD had spread to her mid forearm. Luckily the first block stopped the RSD in its place. She has since had 3 other blocks but they have been less effective and more traumatic each time.

Although that was the hardest and most challenging year of our relationship, she powered through it. During that time, she completed her 600 ABN hours to become a Certified Functional Medicine Practitioner and re-invented herself. She became a panel speaker and webinar presenter for Standard Process, the supplement company she exclusively uses in her practice. She got trained in transcendental meditation and meditates 1-2 times a day. She fine-tuned her diet to eliminate inflammatory foods. She even learned to eat and write with her left hand since using her right hand flares up the beast. She is now a converted "lefty."

Her hand was becoming disfigured from the tendon and

ligament damage, so we went to a hand and shoulder specialist. We knew she would eventually have to have surgery to fix her hand but had put it off because of the fear of the RSD/CRPS spreading. We didn't dream her shoulder would need to be re-done until the Dr. said "so, what's up with the shoulder?" Upon examination and new x-rays, it was obvious there was a problem that needed to be fixed. Since she had to have surgery to re-fix her shoulder, she decided to have her hand done at the same time. So, on August 23, 2013, she had shoulder surgery and 10 days later on September 3, 2013, she had her hand repaired. Dr. Kirkpatrick and the anesthesiologist worked together on her case and she came through without flaring up the RSD/CRPS.

Kim has always been active, athletic and healthy. In her younger days, she was a competitive weight lifter, bodybuilder, runner and avid cyclist. After the cycling accident, she still went to the gym every day, broken leg/torn shoulder and all. She claimed "I still have one good leg and one good shoulder." After the horse accident, you would think that going to the gym would have stopped. In fact, it did for a few weeks in the beginning, as she was dealing with pain, depression

and a new way of life. One day, I gently suggested she might want to think about getting on an anti-depressant. At that moment, she realized she had to snap out of her "mood" and do something about it! Being depressed was not going to help her. She went back to the gym and learned new ways to hold the weights. She tried to run again but could not because of the jarring and the pain to her hand, so she started walking... a lot.

Kim had not ridden her bicycle since the cycling accident in 2012. She missed it like crazy but just had not been ready to get back out there. When the RSD spread to her left toe, she was no longer able to walk for exercise, so she knew she'd have to get back on that bicycle. Finally in 2017, I reluctantly (for the safety factor) encouraged her to get back to cycling. She did and said it was the only thing that took her mind off her hand. She has found groups to ride with and has made lots of new friends. One day she mentioned training for the Senior Olympics. I said "Go for it! When can you sign up?" Within a month, we were traveling to Gainesville, where she qualified for the Florida State Games. On December 6th, she entered the FSG in the 60-64 age group and took first place in the 5k and 10k Time Trials and the 20k and 40k Road Race and will be going to Albuquerque, New Mexico for the National Senior Olympic Games in June 2019.

I am writing in hopes that her story gets picked up to help create awareness of this debilitating condition. It is so

frustrating when we explain to someone why she shakes hands with her left hand and then they still want to touch her right hand and "see." People don't understand that her skin feels like it is being ripped off her bones when even the slightest breeze from the fan blows on it. I am writing in hopes that this gives someone else with RSD/CRPS encouragement and hope and that taking care of yourself mentally, emotionally and physically helps deal with the constant pain. I am writing in hopes that someone who knows something is wrong with them but all the doctors say "it's in their head," may realize that RSD/CRPS could be what they have. I am writing in hopes that another caretaker, spouse or child of an RSD/CRPS sufferer sees that life can go on with RSD/CRPS. It's hard, but we take one day at a time.

Kim is a true inspiration to everyone she meets. She rarely ever complains of her pain and not many people realize her struggles. Those of us that do know what she's been through almost forget about it because she is just such a trooper! I see the toll it takes on her, but she keeps her head up, her attitude positive and her body moving to combat it.

She is my hero!

Sincerely,

Mary Ann Barefield

## 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).

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# CRPS and The Dentist *"You Don't Have to Be Afraid"*

BY GLENN L. GITTELSON, DDS

Complex Regional Pain Syndrome (CRPS) is a disease of the sympathetic nervous system and can therefore affect any part of the body receiving a sympathetic nerve supply, which is to say CRPS can affect any part of the body. The sympathetic nervous system is charged with regulating and maintaining all bodily functions and when under duress, the so called "*flight and fight*" response occurs. The sympathetic nervous system controls blood pressure, pulse, respiration, body temperature, and all immune system and body glandular function. If the sympathetic nervous system becomes dysfunctional, no matter the reason, the resultant symptoms of the CRPS disease process can become horrific and devastating to the sufferer. Symptoms such as high-level pain, swelling, muscle spasm, and skin changes can follow a dermatomal distribution (see diagram#1) and/or involve any of the internal organs. Symptoms can change in location, presentation and intensity. Due to this, CRPS is often referred to as "*the disease with a mind of its own.*"

Early diagnosis is critical, as the potential for extended abatement and remission of symptoms is possible if CRPS is diagnosed and properly treated with in the first few months of

onset of symptoms. Subsequent to this, treatments are often geared toward potential attempts at abatement of symptoms, with the risk being ongoing flare ups and exacerbation of any CRPS based symptoms. This is what makes CRPS such a horrible disease. The goal of treating the person with CRPS then is to recognize, eliminate, minimize and/or prevent the spread of this disease process.

The definitive literature on CRPS dates back to 1864, with the definitive diagnostic guidelines for CRPS most recently organized and published in 2007 and 2013 and known as "The Budapest Criteria for CRPS". (References available upon request).

An excellent reference book for CRPS is Hooshmand H. Chronic Pain-Reflex Sympathetic Dystrophy Prevention and Management. Boca Raton, CRC Press, 1993.

People who have CRPS are aware of the potential for acute flare ups of their symptoms secondary to any inciting event. Specifically, going to the dentist can be viewed as a stressful, uncomfortable and possibly painful experience. These concerns do have merit. Going to the dentist for any procedure whether it be a routine dental

cleaning and check- up, filling a cavity, the cosmetic bonding of a tooth, orthodontics, root canal, extraction or an implant can lead to a CRPS flare up which can cause new CRPS symptoms or make existing symptoms worse. It must be understood, however, that it is not so much the procedure being done, but rather the CRPS patient's reaction to the procedure that can cause an exacerbation of new or existing symptoms. CRPS to the head, neck, face and mouth is also well documented in the literature. (References available upon request)

Another concept that must be understood is that mechanical injury and sensory-based pain input into the brain is what triggers the body's sympathetic response. Therefore, it becomes critical to identify all potential sources of injury, discord and pain when treating the CRPS patient. It is the author's adage that "*all pain can be traced to its source.*" If one is able to eliminate, minimize or control source pain, the body's sympathetic responses should also be able to be controlled and/or minimized. However, the longer the CRPS patient has symptoms and the more centralized the sympathetic symptoms, the more difficult it becomes to try and abate those symptoms. Early

## Hooshmand and Hashmi: Complex Regional Pain Syndrome

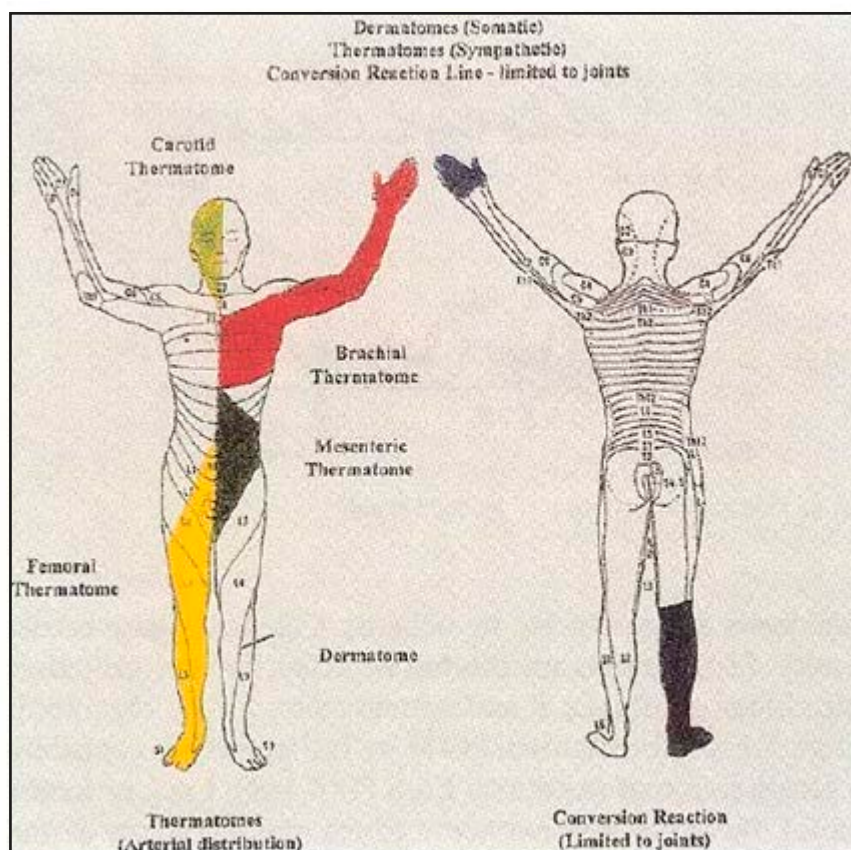


DIAGRAM #1

Any of the symptoms listed can occur in any combination in one or more of the four color diagramed thermatomal areas. All symptoms can change location, intensity, and duration in any given thermatome on any given day without warning or reason. As such, CRPS/RSD is often referred to as "THE DISEASE WITH A MIND OF ITS OWN."

recognition and proper diagnosis of the CRPS patient is critical, as is the initiating of treatment and therapy.

Knowing that early diagnosis of the CRPS patient is important and proper routine dental care is essential to one's overall health, the questions now become *"what can the dentist do to identify the CRPS patient, and what can the dentist do to minimize, control and/or eliminate the CRPS patient's sympathetic response to any dental procedure?"*

Patients who present with high level disproportionate pain, non-resolving pain, muscle dysfunction, (tightness, spasm to jaw muscles), unexplained swelling to the face, heat and/or cold intolerance, color changes to the skin, thermatomal distribution of symptoms, inflammatory responses such as unexplained rashes or inflammation in the mouth or face should alert the patient and dentist to the possibility of a CRPS diagnosis.

Any history of or presentation of trauma or injury to the Temporomandibular Joints, (TMJs) and/or cervical spine is cause for concern for the CRPS patient, as these injured or damaged areas can be ongoing triggers to the sympathetic nervous system. Further investigation of the TMJs and cervical spine with advanced imaging, the standard of care being an MRI is called for. Only with an MRI can all hard and soft tissue anatomy be properly visualized for structural damage and/or alteration. There is a tremendous sensory and sympathetic communication between the TMJs, the trigeminal nerve that innervates it and the cervical spine. Pain patterning can be overlapping from neck to jaw and face and vice versa.

It must also be realized that the absence of pain does not mean there is no problem with the TMJs. Distorted growth of the face in a growing child, facial skeletal distortions and facial skeletal changes occurring in the adult, changes to the bite and how the teeth align are all potential signs of jaw joint (TMJ) issues. The significance of this is that the disruption of normal function as it relates to the jaw joints and bite can be a trigger for ongoing sympathetic dysfunction. Misalignment of the cervical spine can be a trigger for various types of headaches and facial pain which can then be a trigger for further ongoing sympathetic dysfunction. More often than not, TMJ and cervical spine issues go hand in hand, as

the two are often injured together and therefore must be evaluated together and treated together.

Any and all potential dental-related pathology should always be identified and treated. Knowing that there is a tremendous sympathetic nerve supply to the mouth and structures contained therein, how then can the dentist minimize, if not negate, the sympathetic response to any dental procedure?

It must be realized that the sympathetic nerves that supply the mouth have their origins in the upper cervical spine. These nerves branch out from the cervical spine and ultimately are located on either side of the neck, below the lower jaw or just under the skin in a specific location. These nerves are identified as the Greater Auricular and Transverse Cervical nerves, (GA, TC). They are easily reached and can be easily blocked with the use of local anesthetic while the patient is in the chair prior to any dental procedure thereby preventing any sympathetic awareness or response to the dental procedure. These nerve blocks take effect within minutes, last for several hours, can be repeated when necessary and have minimal risk associated with them. The author has used these nerve blocks successfully for many years to treat the dental needs of the CRPS patient.

The author uses these nerve blocks to prevent sympathetic responses to dental procedures

as described and also to treat CRPS patients who present with CRPS symptoms previously described to the Carotid and Brachial Thermatomes (Diagram #1).

In particular, the author has had much success in treating sympathetic maintained symptoms such as pain, muscle spasms, edema and skin alterations to the head, neck, face and upper torso with the use of these nerve blocks. As the treatment of the CRPS patient must be multifactorial, often these nerve blocks are supplemented with the use of certain medications, physical therapy and CRPS diet modification to maximize control over the dysfunctional sympathetic nervous system.

The two main sympathetic nerve blocks that can be administered to allow treatment of the mouth, head and face are the Greater Auricular nerve blocks, (GA) and Transverse Cervical nerve block, (TC). It is the author's contention that any practitioner who is licensed to administer injections can be trained to administer these types of nerve blocks to help and better serve the CRPS population in an easy and ongoing manner.



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*Dr. Gittelson has been in private practice for more than thirty five years as a restorative dentist. For the last eighteen years, his practice has focused primarily on diagnosing and treating TMJ related disorders, as well as head, neck, facial pain and CRPS/RSD disorders in children, adolescents and adults.*

*Dr. Gittelson has extensive and ongoing training in the science of jaw joint and facial pain diagnostics, as well as TMJ MRI and Maxillo-Facial CT interpretation. He received this training at the prestigious Piper Education and Research Center, in St. Petersburg, FL under the direct tutelage of Mark Piper, M.D., D.M.D.*

*Dr Gittelson offers educational seminars to the general public on CRPS.*

*Dr Gittelson also offers courses to doctors and qualified practitioners on the science of CRPS diagnostics and treatment including nerve blocks.*

# A Walk in the Park for Courageous Kids

BY LINDA J. HORAN AND RUSS A. MAUK

In June, 2018, I felt led by God to start Door of Hope, a RSD/CRPS support group for the state of Delaware and tri-state area. I formed this group because there are no support groups within 100 miles of where I live. It is through this group that Russ and I were brought together. December was a busy month for Door of Hope. Cornerstone United Methodist Church invited us to do a fundraiser the weekend before Christmas. As pictured, we enjoyed this opportunity. They also agreed to give us a substantial contribution towards one child attending camp. At the fundraiser we met a few people with CRPS who we invited to our monthly meeting. As a sign of their support, they invited the group including Leanna, our youngest member, to do a video to help raise funds for "Coins for Courageous Kids Camp." In addition to the camp, the proceeds will go towards scholarships for medical treatment and, most importantly, a search for a cure.

As CRPS Warriors, we are preparing for our first walk to directly benefit the "Courageous Kids Camp" by raising funds and awareness of this disease. This summer up to 58 children and their families will experience a fully handicap-accessible camp in Scottsville, Kentucky. Tremendous strides have been



made to the fundraising by contacting doctors, medical practices, law firms and large corporations to consider becoming a sponsor for this important cause. Starbucks and Salon Rispoli have committed to provide gift baskets that will be raffled off at the walk. Meetings are open to all CRPS sufferers, caregivers, and medical personnel. For more information, see support groups under RSDSA.

Linda and I have learned that there is no proverbial "I" in the word "team." Utilizing radio and local television over the next several months, we will assemble our dream team by tapping the community resources from churches, local businesses, and the young people in our schools. This is all to make a difference in the life of a child suffering from such a rare and painfully debilitating disease. In spite of our small numbers, with God's Help we can successfully complete our inaugural walk.

Please follow our walk preparations and progress on Door of Hope's Facebook page.

## Carolyn's Cards

Carolyn's Cards is a program that sends cards and other small surprises through the mail to individuals with Complex Regional Pain Syndrome (CRPS) and to their caregivers. The purpose is to help those feeling isolated or down because of CRPS by sending them a card to help them not feel alone, provide encouragement, provide support, help them feel part of a community, and most importantly to give them a smile. I received the inspiration from my Mother who would send me cards when I was down, in a lot of pain, or recovering from surgery. These cards would help to brighten my day. I thought it would be great if I could reciprocate that feeling for others. I started sending cards to the attendees of the first Young Adult Weekend as a way to stay connected to them and show support. I was surprised to hear how much they genuinely enjoy the cards. I have continued to add names to my list after each Young Adult Weekend.

The cards can be sent for birthdays, holidays, other celebrations, after medical procedures, or when we receive notification that someone is having a difficult time. Carolyn's Cards will receive names and addresses via recommendations provided by RSDSA or directly emailed to carolyns.cards2@gmail.com.

# RSDSA YOUNG ADULT WEEKEND

June 7-10, 2019



RSDSA is excited to announce this first Young Adult Weekend of 2019 will be held in "the big easy"-New Orleans, LA!

After the success of the previous events and the expressed need we will continue to schedule this event across the country! This event is for young people 21-31 with CRPS. You are invited to attend a weekend of workshops, free time to sightsee, group excursions and spending time with people who truly understand what you are going through to the fullest extent.

**Date: Friday, June 7-Monday, June 10, 2019**

**Time: Starts Friday at 3:00 PM and ends Monday 12:00PM**

Hotel details to follow.

Fee: \$250.00 with a \$50.00 non-refundable deposit which will hold your spot. Final payment is due by May 10, 2019

To register or for more informations please contact RSDSA YAW Committee at: [rsdsayawknd@gmail.com](mailto:rsdsayawknd@gmail.com)

Thank you to the Coatney Family for sponsoring this event.



## Easy Ways to Give

- Make RSDSA your charity of choice on [GoodSearch.com](http://GoodSearch.com) and use that instead of Google.
- Use [AmazonSmile.com](http://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).

# Make Your Own Pizza Night

**MAKES** 2 (10-inch) pizzas or one larger pizza. Serves 4.

## INGREDIENTS

- 1 pound pizza dough, at room temperature for at least 1 hour
- 1/2 to 1 cup of your sauce of choice
- 2 to 3 cups of other toppings including sautéed mushrooms and onions, pepperoni, sausage, bacon, or anything else you enjoy.
- 1 to 2 cups shredded or sliced cheese (4 to 8 ounces) such as mozzarella, Monterey Jack, provolone, fontina, or any other favorite
- Cornmeal or all-purpose flour (optional)

## INSTRUCTIONS

- 1. Heat the oven to 550°F or higher.**
- 2. Roll out the dough.**  
*Pizza Baked on a Baking Sheet:* Brush a thin film of olive oil on a baking sheet. Working with one piece of the dough at a time, form it into two small discs or one large disk with your hands and place it on the baking sheet. Use your hands or a rolling pin to flatten the dough until it is 1/4-inch thick or less. If the dough starts to shrink back, let it rest for 5 minutes and then continue rolling.
- 3. Top the pizza.** Spread the sauce evenly over the surface of your pizzas. Continue with cheese, and then your other toppings. Have fun to make it the way you want it!
- 4. Bake the pizza.** Using a pizza peel or the back side of a baking sheet, slide your pizza (with the parchment or with the cornmeal) onto the baking stone. If you don't have a baking stone, bake the pizza right on the baking sheet. Bake for 5 minutes, then rotate the pizza. Bake until the crust is golden-brown and the cheese is melted and browned in spots, 3 to 5 minutes or more.
- 5. Slice and serve.** Transfer the pizza to a large cutting board and let cool slightly, just until you're able to handle it. Slice, serve, Enjoy!

**Storage:** Leftovers can be stored in an airtight container in the refrigerator for up to 4 days. Reheat slices in the oven.

Submitted by Kyle Vorchheimer <[kvorchheimer@gmail.com](mailto:kvorchheimer@gmail.com)>



## POETRY CORNER

# Reflex Sympathetic Dystrophy Can Take

RSD may take my walk  
but it will not take my talk.  
I will be vocal I will be bold.

I will never give in  
and I am never too old.  
RSD may take my hair  
but I don't care.  
I will keep my head up high.  
Hair is nothing  
between you and I.

I will never give in  
and I am never too old.  
RSD may take my speed  
that's OK I didn't really need.  
All things will come in time,  
patients is a state of mind.

I will never give in  
I am never too old  
RSD has made me bold.

~JRC -19

**REFLEX SYMPATHETIC DYSTROPHY  
SYNDROME ASSOCIATION**

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

Non-Profit  
U.S. POSTAGE  
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Graphic Image  
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THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

## RSDSA 2019 EVENTS CALENDAR TO DATE

MARCH	
3/15/19	4th Annual CRPS Awareness Night with the Colorado Avalanche
APRIL	
4/27/19	3rd Annual Tame the Pain Golf Event, Galena, OH
MAY	
5/12/19	3rd Annual Stomping Our the Flame, Manassas, VA
5/18/19	Treating the Whole Person, Optimizing Wellness, Houston, TX
JUNE	
6/1/19	1st Annual Walk in the Park for Courageous Kids, Newark, DE
SEPTEMBER	
09/07/19	4th Annual Long Island Awareness Walk Eisenhower Park, Long Island, East Meadow, NY
9/22/2019	1st Annual Walk in Ocean Township New Jersey
9/29/2019	6th Annual Fight the Flame 5k, Charlotte, NC - Beth and Steven Stillitano
9/29/2019	4th Annual Knock Out Pain 5k - Easton, PA - Sarah O'Steen
NOVEMBER	
11/4/19	Color the World Orange, Worldwide

## PEER TO PEER

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!