

# rsdsa community update

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## GETTING BACK ON (THE) TRACK: MY BATTLE WITH CRPS

By **HENRIETTA MIERS**

On August 25, 2010, five days before my first cross country pre-season at Princeton, I entered the East Hampton Woods in the best shape of my life. Never did I think I'd end up leaving those woods in an ambulance.

My parents and I were visiting our family friends out in East Hampton the week before I left for college. All summer my dad, who also doubles as my training partner, and I had been finishing our runs just as the sun was setting. On this day, we began our 70-minute run around 7:15pm. Before starting, we asked two bikers leaving the woods how much light they thought we had left. They said 45 minutes tops and we thought, "we've been fine all summer, what could go wrong?"



Pictured here: 800-meter prelims of the Ivy League Championships (2013).

The first half of the run felt great. I was happy, fit, chatting away with my dad. However, the conversation quickly turned into an argument about my wanting to leave East Hampton a day early so I could say goodbye to my friends. The argument was soon curtailed by cries of pain as I lit up the face of my watch to see what had happened. I had turned my ankle on a rock and that was the end of that run. Thank goodness for my dad, who carried me through the pitch-black woods to the first house we could find. Once we showed them my ankle, they immediately called an ambulance. As we waited, the children at this house were determined to cheer me up. This is a moment that still brings a smile to my face. Five hours later, I was in bed with three torn ligaments and enough Vicodin in me to fall asleep.

*Continued on page 18*

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This newsletter was sponsored by R. Steven Shisler, Esquire is an attorney whose practice concentrates on representing people who suffer from CRPS caused by the negligence of others. He is a member of, and secretary of, the board of directors of RSDSA. He has suffered from reflex sympathetic dystrophy/complex regional pain syndrome and the partial paralysis of his left arm for 47 years as the result of a motorcycle accident. Steve can be reached at 215-564-4080.

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

### **SPECIAL THANKS**

*We would like to acknowledge our Corporate Partners whose generosity helps to underwrite issues of the RSDSA Community Update. Our Corporate Partners include Abbott, Baker Family Charitable Trust, Grünenthal, Vitalitus and Michael & Lynn Coatney.*

# Director's Report

BY JAMES W. BROATCH, MSW • RSDSA EXECUTIVE VICE PRESIDENT, DIRECTOR

## Working Virtually During a Pandemic

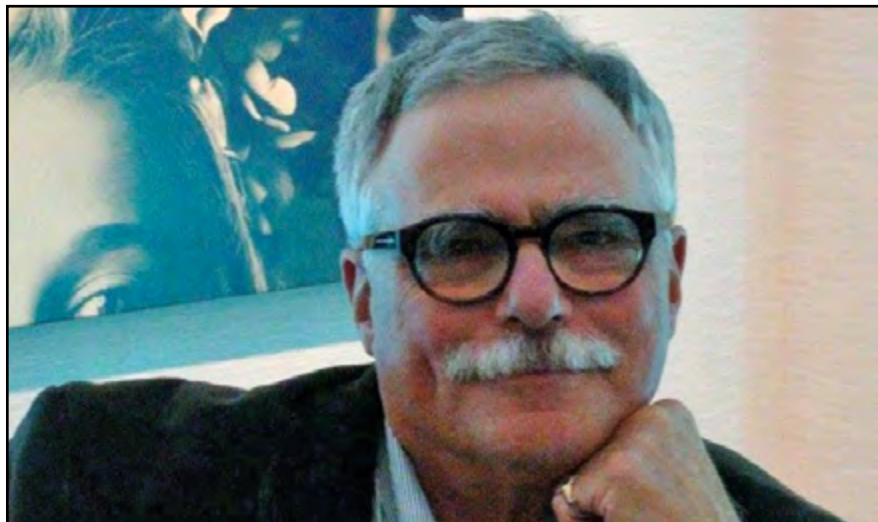
Since the start of the pandemic, RSDSA staff have been working virtually. We are retrieving telephone calls, answering emails, monitoring our social media platforms, providing crisis interventions, mailing masks and information packets, conducting staff meetings via Zoom and much more. We were so disappointed to cancel many educational, awareness, and fundraising events.

We'll be conducting a fall virtual "Treating the Whole Person: Optimizing Wellness" conference over the course of a week. Next month, we're conducting an inaugural virtual walk on Aug ust 22. To register, please visit <https://secure.qgiv.com/event/rsdsa-crps-walk>.

RSDSA, like other not-for-profits, has been adversely financially impacted by the COVID-19 pandemic, yet we are still accomplishing our mission of supporting, educating and providing hope to the CRPS community. Please consider making a donation, no matter what size, to help us serve the CRPS community. Please visit <https://rds.org/donate/> to donate now or to start donating monthly.

## Facebook BeLive Presentations

During the pandemic, RSDSA has been hosting BeLive presentations for the CRPS community. With each subsequent presentation, our attendance has soared. The



first BeLive with Dr. Melanie Levine had 1,148 unique viewers. The top audience members were women aged 55-64 and the top viewing location was New York. Our second BeLive with Dr. Peter Abaci attracted 1,556 unique viewers and the top audience members were women aged 55-64 and the top viewing location was California. Our third BeLive with Dr. Scott, Dr. Fass, and Brendan Pitcairn had 1,990 unique viewers. The top audience members were women 55-64 and the top viewing location was Pennsylvania.

The presentations are archived on our website: <https://rds.org/educational-presentations/>

All of our recent conference videos are archived on this page too.

## Sponsorship of this Electronic Issue of the RSDSA Community Update

This issue is sponsored by R. Steven Shisler, Esquire, an attorney whose practice concentrates on representing people who suffer from

CRPS caused by the negligence of others. He is secretary and a member of the board of directors of RSDSA. He has suffered from Reflex Sympathetic Dystrophy/Complex Regional Pain Syndrome and the partial paralysis of his left arm for 47 years as the result of a motorcycle accident. Steve can be reached at 215-564-4080.

**If you are interested in sponsoring an upcoming issue, please contact me at 203-623-4415.**

## Publication of the 5th Edition of Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines

RSDSA is funding the publication of the fifth edition of the Treatment Guidelines, last updated in 2013. Dr. R. Norman Harden is our editor and we hope to complete the project this year. The Guidelines have been cited in 55 subsequent peer-reviewed journal articles.

*James W. Broatch*

## 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 [jkrassner@rds.org](mailto:jkrassner@rds.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 with TV or newspapers (we can help you).
- ✓ Share your story of hope. Inspire others who are struggling as you have.

# Dermoneuromodulating

BY **DIANE JACOBS, PT** • DFJPT2009@GMAIL.COM

## Introduction

It is my pleasure to provide the RSDSA some information about the hands-on work I call dermoneuromodulating, or DNM. Done well, physical contact by a practitioner should feel good, relieving. The hands of a practitioner should be clean, slow, steady, light, warm, sensitive, responsive, kind, intelligent, effective, and above all, never uncomfortable.

The human brain has been described as the most complex object in the known universe, with its 86 billion neurons (plus another couple hundred million for the peripheral nervous system), each having up to 10,000 connections to other neurons, the sum total of which amount to as many possible nodes of connection as there are stars in the sky, or some astronomical number like that.

I like to argue that the only thing that might be able to help such a complex human nervous system is another equally complex human nervous system, a person who has good boundaries, focused attention and rapport with the person who has hired him or her to help with a pain problem.

A dermoneuromodulating encounter consists of two people who contract how they will work together, and two nervous systems, all four of these entities working together for improved

pain management capacity in one person and their nervous system.

## If you are the person with pain:

Assume control of any hands-on session by being the translator. You have hired this person to help you and, therefore, you have control. You know your own nervous system and that it has been freaked out about ... something, even though your doctor told you they can't find any cause. Pain itself can feel so overwhelming and.... just plain wrong. You know how you feel – you can feel what's going on inside yourself way better than somebody else can, so don't be timid about offering feedback.

By that I mean, communicate with your therapist – if they are touching you in some way that hurts, say so. The therapist should immediately stop whatever they are doing that feels uncomfortable and try from another angle. This is called keeping "locus of control." Remember, they DO NOT have to hurt you to help you. Far from it!

You should always feel that you can relax and allow the touch to be whatever it is and do whatever it does. To get that far, you will need to establish trust with said practitioner first. If you do not fully trust him or her, there will be some part of your nervous system, conscious or

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unconscious, that will hold back and won't be able to permit change. So, take control of the relationship.

Nervous systems cannot be changed by any outside person or force in a physical therapy setting. Nervous systems can change themselves however, for the better.

Nervous systems will change themselves only when they are darn good and ready to change, not before.

Much of the nervous system operates well below your own level of awareness. It will self-correct at that level as well. When it does, it can feel kind of amazing. Then you will think your therapist is a magician. But know that they aren't - it was you all along, and your amazing nervous system.

### **If you are the therapist:**

Explain to your patient that only they can get themselves better, but you will help as much as possible. Set up communication so that the patient feels they can tell you anything and you'll be there to help them. There may well be tears, so keep a box of tissues handy. Listen, listen, listen.

Don't say very much. Especially, don't burden your patient with any comments that could well be noceboic. Noceboic means harmful or threatening to their ears, like any talk about degenerating discs in the spine, or degenerating joints, or ANY orthopaedic situations commonly seen on visual imaging. Bennedetti showed that with noceboic input, cholecystinin is released in the brain, which is antagonistic to endogenous

opioids. We want our people with chronic pain to make all the endogenous opioids they possibly can. So instead, if a patient coming to see you is convinced that something somebody found on an MRI is the cause of their pain, you can simply remark how it has been found that those sorts of things commonly appear on MRIs in completely asymptomatic people too, like grey hair and wrinkles on the inside of the body. Then move on.

Several visits may ensue before you even get around to suggesting any hands-on work. They may tell you that unsuccessful attempts have been made in the past by well-meaning practitioners or even that their pain has been made worse. You will have to have earned their trust before you propose another try. Heraclitus said, you never stand in the same river twice. This time things could turn out different.

Before you ever touch someone, it is very good manners to make eye contact and ask out loud for permission. Assume nothing. Tell your patient you will not hurt them, and if you do, by mistake, immediately change whatever you are doing and thank them for telling you.

As a therapist, you are not responsible for any changes that do or do not occur in another person's brain. You do not have magic hands. You are a catalyst only. Like any catalyst, for example in a chemical reaction, you will help to speed up a reaction but precipitate out, leaving nothing of yourself behind in the process except a fond memory perhaps (we all hope).

You are important in that you and your desire to help, evident through your words, body language and interaction, are providing a person in pain with a containment system, a context within which they can feel safe and trust you to not hurt them more.

But they, and their own nervous system, are creating the desired change, not you. When you touch them, you are merging your nervous system with theirs for awhile. A non-verbal kinesthetic conversation will take place, and both parties will gain much more insight into the problem facing the person with pain. Both of your attentions will drift back and forth between exteroception and interoception. Some verbal conversation may occur, but a lot of time, changes take place in sort of quiet, non-verbal interaction zone.

Take advantage of a couple built-in features that nervous systems have, called temporal and spatial summation. This means that your innocuous input signal will build over time. Some parts of the nervous system will get excited and nervous and check you out for any threat you may pose. Just don't hurt it, and you'll be fine. Eventually it will come over, wag its tail like a puppy, and want to play. The signal will reach deep into the brain and the person's cortex will check it out, then exploit it, if possible. That is what predictive brains do.

### **Pain**

A revolutionary idea about pain emerged in 1965 with the publication of Ronald Melzack and Patrick Wall's paper, Pain Mechanisms: A New Theory. This

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new idea was that the central nervous system had opinions about, and options for interacting with, even for dampening down, spinal cord mechanisms for transmitting nociceptive input to our conscious awareness. This new idea overturned 400 years of dogma that in essence had created a belief system that pain was something that traveled to the brain along nerves from the body. A great deal of neuroscience research has been done since then. Some of it has to do with understanding pain, but most of it has been to try to solve the mysteries of how the brain works, period.

Currently a popular notion is that the brain is predictive, constantly referring to what it already knows, and projecting that outwards onto the rest of the world. This is important for DNM practitioners to consider. It means that if you can supply a carefully prepared person's brain with just a tiny bit of unexpected, carefully titrated novel sensory input, the whole pain experience may turn on a dime, dissolve, even if that pain has been around for a very long time.

Another feature that people have known about for a long time that has to do with sensory systems is the Weber Fechner law. It was first worked out with the visual system. If you are in a completely dark room, and you light one candle, you'll be able to see a lot better. If there are 99 candles burning in a dark room, and you light one more candle, you won't notice any difference. This is why less is often more. The novel sensory input has to be able to get to whatever part of the brain

it needs for things to be able to change inside the entire nervous system. This novel input may be visual, as with mirror boxes or graded motor imagery, or somatosensory as in movement therapy or manual therapy like DNM.

### **The nervous system**

It is important to realize that a human nervous system has no idea that we use different names for different parts of it. It thinks it is a seamless whole, from skin cell to sense of self.

So, what is the nervous system? It is a highly excitable communication system comprised of brain, spinal cord, and about 45 miles, or 72 kilometers of peripheral neural tree in the body, much of which is in the skin organ. Really, this system is more of a verb than a noun. It is always busy, impulses racing around at speeds of up to 200 miles per hour. If something is amiss in one part of it, the entire system will know about it within milliseconds. Same with when something self-corrects.

Even though human brains are large compared to other primate brains (about three times larger than our closet cousin, the chimp, and five times larger than most other mammals our size and weight) it is still pretty small. The entire human nervous system is only about two percent of our body, but it's the boss of us. It runs us. It runs the entire show because it is so excitable and communicative. It is constantly working, day and night, 24/7, keeping us alive. When we are asleep, it keeps our lungs breathing and our hearts beating. It rolls us over without waking us up (hopefully). In the morning it

wakes us up, because it wants us to go void its bladder and get it something to eat or drink. There is an interesting relationship between the brain and the spinal cord. Both are the central nervous system.

### **Spinal cord**

The spinal cord is the oldest part of the central nervous system. I like to think that because it is the oldest, the spinal cord thinks it should have seniority. One of its main jobs is to move motor information from the brain out into the body. The brain constantly modulates motor output to make it refined and smooth and just the right amount so that we don't knock over our coffee cup all the time. What happens when this pathway from brain to body is interrupted, as in a spinal cord injury for example, is that there will no longer be control by an individual over their movement. Their legs will still move in spasmodic contractions, which will be spinal cord behaviour, but the person won't be able to stop it – it will have to stop all by itself.

My point in bringing this up is to say it seems that as the brain evolved at the front end of the spinal cord, one of its main jobs was to inhibit and smooth out unwanted and unnecessary motor output generated by the spinal cord itself. Even in people without spinal cord injuries, the spinal cord can take over the body with its withdrawal reflex. This is an extremely protective mechanism which can make your hand fly up off a hot stove before your brain can even register that it felt hot. It operates completely independent from the brain, in response to any phasic burst of nociceptive

input. The spinal cord is like a first responder. Then what happens? If the burst of nociception is coming from inside the body somewhere, the spinal cord won't know the difference and will tighten up the body somewhere in response. What will that do? Probably the tightening will squeeze peripheral nerves somewhere, which may well increase nociceptive input, producing an amplification of "danger signal" to the brain. Like we really need more threat signals, right?

Again, the brain's job seems to be to inhibit most of somatosensory information from coming *in* usually. You put your clothes on in the morning and you feel them, then later you don't feel them anymore. Same with nociceptive input, or danger signalling from the body. Nociceptive input is happening all the time, but generally, we aren't aware of it. We have what is called "descending modulation" by the brain. This is a wonderful intrinsic automatic system of dampening, mostly to do with inhibition substances the brain makes and puts into the synapses in the spinal cord to dampen the crossover and ascent of nociceptive information up the cord to the brain. Good system. Works really well. Until for some reason it doesn't.

### **Back to the whole nervous system in general**

In order to do its job of keeping us alive and keeping our physiology functioning properly, the nervous system uses a staggeringly *huge* amount of energy compared to its proportional size, as a body system. This amazing system that amounts to only two percent of the body uses up to 25 percent of all available oxygen and glucose

ALL THE TIME. Day and night, 24/7. These two substances are delivered to the nervous system by blood flow.

If any part of a nervous system doesn't get what it needs, it will complain to you, the person within your own nervous system. A lot of pain seems to have something to do with what I affectionately call "crabby nerve syndrome." Remember there are 45 miles of nerves in there. That is a lot of nerve length to keep fed, oxygenated, and drained by the vascular system.

Nerves are long sensitive physical noodles that can't move by themselves – they depend on you to move the containment system around them, within which they can slide a bit. Peripheral nerve entrapment literature is extensive, and at this point in my life, I figure most pain might boil down to some nerve somewhere feeling oppressed within its containment tunnel. I say most, not all. Obviously, there are some types of chronic pain that are more mysterious. For example, Phantom Limb Pain can occur in a person with, say, amputation of a leg, where there really aren't any nerves to be entrapped, yet the person can feel pain in a foot that is no longer there. But where there are nerves, a person can often physically affect them somewhat for the better.

Michael Shacklock has done extensive work and research with what he calls "neurodynamics." The term refers both to the way nerves move within the body as we move about in life, and the treatment approaches he and others have devised as ways to treat people with pain. These involve special movements to

slide nerves back and forth within the body, by say, extending the arm out, bending the head to the side while bending the hand at the same time. Most physiotherapists have learned how to teach these moves to people with pain. The idea is "feed the nerve." By sliding a nerve within its tunnel by a small amount frequently, you are "feeding" it by activating mechanically sensitive blood flow into and out of the nerve. Imagine the crabby nerve is a sick puppy. It's too weak to eat by itself, but you know it must be hungry and without food, it could die. So, you give the puppy an eyedropper of food every couple of hours. Not too much, because you want that food to stay down. But you know it needs help to recover, and that means adequate nourishment.

Neurons have things called receptors all along the length of their membranes. These are proteins that the neuron makes that initiate an impulse to move along the neuron. They are constantly turning over, taken out and replaced. The idea is that by doing small neural glides or slides, feeding the sick puppy little by little, the neurons will get better. They will make fewer receptors and the new receptors will be receptive to more appropriate stuff. They will become less sensitive, in other words. The puppy recovers, starts to run around and wag its tail again. Nerve slides or glides could be thought of as "move better pills." You take a set dose, without missing any doses, and complete the entire prescription. It takes about 72 hours for receptors to completely turn over in nerve membranes. By day four,

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there should be some sort of improvement in perception of one's pain.

### The skin organ

This is my favorite organ right after the nervous system. It has different layers and tissue types in it and lots of different glands, blood vessels and neurons, which makes it very complex. The outermost layer of it, the epidermis, is comprised of cells derived from the exact same layer in an embryo that turns into the entire nervous system. It is as if the skin is the outside of the brain!

The skin organ is actually quite thick: on the back of the hand, it may only be a few millimeters thick, but around the trunk, hips and upper thighs, it can be inches thick. It is also heavy, weighing as much as the skeleton.

We don't usually notice how heavy our skin organ is though, because it is held onto the body by thousands of small skin ligaments, which distribute its weight. Some of those skin ligaments are tubular, and through them pass nerves and vessels that supply the skin organ itself.

Nerves that pass into the skin organ are called cutaneous nerves. They contain autonomic motor neurons that control its blood vessels, smooth muscle cells that make your hair stand up and sweat glands. These nerves also contain a lot of sensory neurons that report to the central nervous system everything that is happening at and within this remarkable interface between you and the world. When you let a practitioner touch you, a

lot of neurons will be activated. Most of them will remark, "I was touched." And that's it. They stop firing. There are some however, that will continue to fire as long as someone continues to touch you, especially if they are stretching your skin a little bit. These are the ones I suspect help the brain change itself. They say, "I am being continuously touched... still being touched... still being touched..." and they keep going, keep firing and transmitting data until the person takes away their hands.

Here is a hot tip: you **can** do this by yourself. It takes a bit of time to figure out how, but the way I do it for occasional crabby back pain, for example, is to line up a piece of dycem (although any sticky material that comes in a sheet you can cut to size will work. A piece of yoga mat is a good example) four or five inches square between my sore bit, and a wall or door jam. Then I move a bit this way or that way until I find the right direction to hold in. Meanwhile my skin organ is being tugged appropriately and some crabby cutaneous nerve in my back is getting what it needs to stop complaining.

If you are a practitioner, it behooves you to be gentle. If you do mild skin stretch on skin surface that is not allodynic (sore to touch), you do not need to worry because the nervous system is going to register your input everywhere anyway. So, begin your touch somewhere that isn't sore, nearby, or in the same place on the other side of the body. And then sit back and let the person's nervous system do all its own heavy lifting and changing.

Furthermore, you will somewhat be moving cutaneous nerves. If you know where they are likely to come out into the skin organ through their little aponeurotic rings, you can even target them by pulling the skin organ itself (into which they firmly embed) and thereby pulling the cutaneous nerve a bit further through its ring. You can find the rings by carefully palpating for spots that may feel somewhat, or a lot, tender. So be careful— don't prod. Be kind. Then pull the skin organ in a way that relieves tenderness.

### Conclusion

In the end, if you are the person who has pain, know that movement is good. You may have avoided moving for a long time because of pain but think about the health of that 45-mile neural tree inside your body and how much it depends on movement to get healthy and then stay healthy. "Motion is lotion," as we say. Consider how you inhabit your body. Notice, then change up what I like to call default resting positions: always crossing the same leg, never the other. Always leaning on the same elbow, never the other. Always falling asleep on one side, never the other. Nothing we do in our body is "wrong," but we are built with two sides, and both sides should receive about the same amount of exposure to resting behaviours, or something might start to hurt one day out of the blue. Find a therapist you like and trust. Stay in charge of your own wellbeing, even as you take on their suggestions and oversight. Work together with them and don't give up, ever.



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# It Takes a Village

BY JENNY PICCIOTTO

Complex pain requires a multidisciplinary approach, according to S. Shar Hashemi, M.D., F.A.C.S., a board certified surgeon who has completed fellowships in orthopedic hand surgery and peripheral nerve surgery. We met on a video call to discuss the extraordinary surgery his team recently performed for a patient who had undergone amputation of his leg below the knee and was unable to use his prosthetic due to severe CRPS Type II nerve pain.

The team includes specialists with expertise in physical medicine and rehabilitation, hand and nerve surgery, neurology, specialized peripheral nerve imaging, orthopedics, and cell based therapy. Their website describes the scope of their practice:

At Nerve, Bone and Joint Institute, we utilize our multidisciplinary training complemented by state-of-the-art medical devices to diagnose and treat neuro-musculoskeletal conditions. We evaluate patient conditions on a case-by-case basis and provide a personalized management plan for each individual patient condition. In creating the patient management plan, NBJI physicians consider a full-spectrum of treatment modalities encompassing restorative, regenerative, and reconstructive options.

Dr Hashemi explained that “Our goal is to solve complex neuro-musculoskeletal problems. I look

at the problem-set as a team approach. It takes a village to evaluate a CRPS patient. From the biological, psychological, and social aspects, we engage a team of experts to analyze the patient’s concerns, perform a detailed physical exam, create a plan of care and execute the plan.”

The first step is to establish a specific diagnosis by analyzing data and test results, and getting first hand data from the patient. “We use a few different ocular lenses when we look at these problem-sets; orthopedic, neurosurgical and reconstructive,” Dr. Hashemi says. “We start with a detailed history, then complete a detailed physical exam including a peripheral nerve exam, and correlate our findings with the diagnostic tests performed.”

The essential task, he explains, is to “get to the root cause” of the problem. Additional testing may be needed to determine whether the problem is soft tissue, muscular, tendon, joint, neurologic, or vascular. This specific and detailed diagnosis then drives their analysis to determine the best course of treatment.

Approximately sixty percent of the patients at NBJI have a nerve injury. Of those about twenty-five percent have a diagnosis of CRPS II, which differs from CRPS I in that there is a known peripheral nerve injury. CRPS

patients, he notes, are often dismissed or not thoroughly worked up by a multidisciplinary team. “Etiologies of pain can be multifactorial; biomechanical and peripheral nerve sources need to be evaluated. I have seen some patients with spinal cord stimulators who achieve great relief and others who remain symptomatic. It is these symptomatic, challenging cases that our NBJI team enjoys seeing.”

Dr. Hashemi told me about his patient and the delicate surgery they performed. While working alongside a highway, the man’s foot was run over by a vehicle, resulting in extensive damage to his bones and soft tissue. His surgical team in Ohio attempted reconstruction to preserve the foot, but insufficient blood flow led to infection, and he ultimately underwent a series of amputations resulting in the loss of the leg below the knee. He suffered intense pain at the stump and was unable to wear the liner for his prosthesis, much less put it on to walk. This once active man in his prime was no longer able to enjoy his relationship with his wife, work, or take part in community activities he once enjoyed.

“He was basically bed-bound,” Dr. Hashemi said, “a motivated gentleman, a previously active member of society.” He noted that “In America there are about a million amputees and twenty percent of them have chronic

pain. The pain could be from CRPS II, Phantom Limb Syndrome, or painful neuromas.”

Despite a regime of medications and a spinal cord stimulator, the man continued to experience severe pain. After twelve years and multiple dozens of doctors, he eventually met one who was familiar with Dr. Hashemi’s work at NBJI and suggested it would be worth the trip to Washington D. C. for an evaluation. After a tug of war with insurance approvals, denials, and reversals, the patient decided to make arrangements to pay for his own treatment. Dr. Hashemi explained that “NBJI worked closely with him to make his dream come true by offering a dual risk agreement where our team would provide expertise care at an efficient cost. We believe in service excellence.”

A thorough diagnostic workup was completed before proceeding to surgery. “We completed an orthopedic and peripheral nerve exam and learned there were several nerves adhered to the amputation site that precluded him from wearing the liner or the prosthetic. We performed selected image guided diagnostic blocks and demonstrated that he had significant relief in the region of pain. We know that he was on morphine for twelve years. This may not be able to get you off morphine, we told him, but our goal is to transfer the nerves that are damaged and supercharge the nerves that are working to maintain your ability to flex your knee but remove the pain at the stump site.”

In the procedure, called Targeted Muscle Reinnervation, “The goal is to preserve motor function while removing sensory pain that

was overwhelming the system. We relocated the critical sciatic nerve and its branches. The tibial and peroneal branches were transferred to those motor branches needed to preserve his ability to flex his knee.”

Dr. Hashemi described the microsurgery in deeper detail:

“We proceeded to surgery after cardiac clearance, preoperative labs and lumbar spine imaging, and electro-diagnostic testing to a four hour surgery under anesthesia where we exposed the sciatic nerve, high up on the thigh - not where the amputation is. With our intra-operative nerve monitoring team and the use of a microscope and microsurgical technique, we identified which branches (of the sciatic nerve) are going to the area of pain, (and) which branches are innervating the muscle that needs to be preserved. We excised the branches that were going downstream but at a higher level (than the painful stump), and connected them as nerve transfers to the motor branches of the biceps femoris and the semitendinosus. So what that did was allowed us to move nerves that were previously causing him severe pain, not allowing him to wear the liner, and prosthetic, to the point that our goal would be for him to immediately be able to wear the liner, and then within a month to start wearing the prosthetic.”

In the post operative period, the patient was amazed that he was able to touch the area without pain, but Dr. Hashemi was and remains cautious. It would take time to assess the outcome of the surgery, he told the patient. “Initially the indwelling catheter masks the pain, then the nociceptive medications

mask the pain; then we can examine the outcome of the surgery.” As a surgeon, he wants to see great results, but working with the team back home and gathering objective data is necessary.

“We don’t jump to a conclusion,” he says, “Allodynia, color changes, and lack of use have all improved. Manually putting pressure on the stump site has improved even though there was no incision there. At this stage he did not have a flare up. Narcotic and all other medication requirements have gone down, and his satisfaction and hope for life continued to go up. He has been able to wear his liner every day and is preparing to try wearing the prosthetic. After weaning off the morphine he took for twelve years, he even cancelled his appointment with pain management because the time can be utilized to work with physical therapy.”

I asked Dr. Hashemi whether or not they took any precautions to prevent a spread of CRPS for this patient, given the precautions we often hear that surgery for a patient with active CRPS is contraindicated.

“Yes,” he said, “there are a couple things we need to do. First we need to make sure this is CRPS II with a peripheral nerve injury. The patient must meet the Budapest Criteria. Literature states that surgery is an aggressive move in CRPS patients. We feel that the literature is misspeaking and misrepresenting the entire spectrum. We understand that applies to CRPS I, but don’t think it applies to CRPS II.”

In addition, precautions are taken during the procedure. “In the

operating room, these patients already have a neuropathic agent, a nociceptive agent, a muscle spasm agent on board, and they are given IV ketamine through the surgery to calm down the NMDA receptors. The surgery itself is delicate tissue handling and an infusion pain catheter is in place to make sure that this stays localized and the patient doesn't have an overwhelming response."

(This case) "is an example of an active treatment of a nerve condition where there is nerve injury and we create a function for the peripheral nerve. We create a function for it so it doesn't sit there in a mechanosensitive area and constantly send substance P and neuro-hormones to the spine through the dorsal root ganglion and communicating through the brain."

Dr. Hashemi told me that the patient is recovering not only from the surgery, but has recovered hope that his quality of life is improving, allowing him to engage more meaningfully with his family and community.

As the founder of NBJI, Dr. Hashemi places great value on a genuine connection with his patients. His practice, which started with a single patient nine years ago, has grown organically. Since then he and his team have helped 4,000 people. He is interested in building bridges with patients and insurance carriers so he can deliver treatments to patients earlier. He knows that research and data collection are necessary to show insurers that this type of treatment can be successful and cost effective.

"Ongoing research in peripheral

nerve is required to continue to provide patients with the advanced treatment options and design more accurate diagnostics. We work with human problems, using expert analysis, one case at a time. Our success starts with one patient and builds from there. We need more patient education and big data collection to advance our field in peripheral nerve surgery. I believe artificial intelligence and machine learning can facilitate this process dramatically."

His mission for the future is to offer nerve surgery Fellowships to groom future doctors to help patients around the world with these problems.

"I believe," he says, "that in life everyone is here for a reason and my reason for being here is to solve complex problems. I feel we have the skill set to at least attempt to solve these problems."

<sup>1</sup><https://nerveboneandjoint.squarespace.com/about>

<sup>2</sup>[nerveboneandjoint.squarespace.com](https://nerveboneandjoint.squarespace.com)



#### 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.*

#### EASY WAYS TO GIVE

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- **Set up a collection canister in your local grocery store.**
- **Plan an event with the help of RSDSA by emailing us at [jkrassner@rsds.org](mailto:jkrassner@rsds.org)**



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# Neuro-acupuncture: Hope for CRPS?

BY JENNY PICCIOTTO

At the end of April in the midst of COVID-19 stay at home orders, I had the pleasure of talking with Jason Hao, a Doctor of Oriental Medicine, who practices and teaches a special type of acupuncture to treat central nervous system disorders including Complex Regional Pain Syndrome (CRPS). Despite the lockdown, we were able to connect face to face on Zoom. Cheerful and accessible, he showed me models of the human skull, explained how neuro-acupuncture differs from traditional acupuncture, and described the remarkable way this treatment has transformed lives. Derived from traditional Chinese Scalp Acupuncture, neuro-acupuncture incorporates Western medical models such as neuro-anatomy, the mapping of areas of brain function. (Note: Quotations have been lightly edited for clarity and flow)

“My treatment, neuro-acupuncture, is a contemporary acupuncture technique, integrating Traditional needling methods with Western medical knowledge of neuro-anatomy, neurology, and neuroscience. It is a new type of acupuncture. It is a very effective technique to treat neurological disorders of the central and peripheral nervous system such as stroke, Multiple Sclerosis, Parkinson’s, Traumatic Brain Injury, PTSD, Phantom pain and CRPS, as well as Cerebral Palsy and Autism. My new technique often produces remarkable results with just a few needles, much faster than other acupuncture traditional methods.”



He explained that the brain controls all of the body’s activities including sight, smell, taste, speech, balance and the experience of pain. By accessing projections of the sensory and functional areas of the brain at the level of the scalp, neuro-acupuncture stimulates the brain, blood vessels, nerves, and dopamine system deep inside. According to the article “Review of Clinical Applications of Scalp Acupuncture,” co-authored with his wife Dr. Linda L. Hao, DOM, Ph D:

“Unlike traditional acupuncture, where one needle is inserted into a single point, in scalp acupuncture needles are subcutaneously inserted into whole sections of various zones. These zones are the specific areas through which the functions of the central nervous system, endocrine system, and channels are transported to and from the surface of the scalp. From a Western perspective, these zones correspond to the cortical areas of the cerebrum and cerebellum responsible for central nervous system functions such as motor activity, sensory input, vision, speech, hearing, and balance.”<sup>1</sup>

Dr. Hao studied Traditional Chinese Medicine at Heilongjiang University in Harbin, China before immigrating to the United States in 1989 to teach at Texas College of Traditional Chinese Medicine. He was the first Chinese teacher in the Southwest Acupuncture College. He and his wife Linda Hao, DOM, PhD, who graduated from the same University, co-authored the book Chinese Scalp Acupuncture. They founded the Neuro-acupuncture Institute (NAI) in Santa Fe in 2015 and have since graduated over 150 students from the program. They travel across the globe teaching and lecturing about this hybrid technique. “We only have two hands,” he says, “so want to share this life changing therapy with as many people as possible.”

The Mayor of Santa Fe honored the Haos for their service to the community in 2018 by declaring February 16th, 2018, (Chinese New Year) “Drs. Jason & Linda Hao Day”. The Proclamation recognized their contributions to the community, their professional excellence, and the spirit of compassion and dedication they devote to helping people suffering from neurological disorders.<sup>2</sup>

We discussed many conditions Dr. Hao treats with this technique, but honed in on CRPS. “Traditional acupuncture to the limbs,” he said, “doesn’t work with CRPS because the body is over stimulated and very sensitive. Instead of stimulating the area of pain, the diagnosis for treatment is based

on which part of brain function is awry.”

“For CRPS we focus on the sensory and motor areas. Stimulating those areas improves nerve and brain functions, makes circulation better, nerve synapses connect better. When they communicate and balance, the pain will go away. We have treated many patients who were paralyzed or in a wheelchair who were able to get up and walk after treatment. Working with CRPS kids who have painful swelling and color change, after putting the needle in pre-motor areas, the color change and swelling goes down immediately.”

He has treated between seventy to eighty CRPS patients. The results, he says, are mostly positive, although three to ten percent of patients do not respond.

“If the CRPS is long established there are likely to be more complications. Instead of local focused pain, other parts of the body have pain. It affects emotion, like anxiety, or depression. They may have other complications like neuralgia, or fibromyalgia. Patients are in shock, tense, and after many medications, injections, they have tried so many things, there is a loss of hope. The whole system is affected. The limbs may be rigid, or have muscular atrophy, with one leg stronger than others. Any movement hurts. For those kinds of patients we may need to treat more areas of the brain, so they would probably need more than four treatments.”

He told me about some of the CRPS patients he has worked with. The editor of Chinese Scalp Acupuncture was his patient twenty years ago. His method cured her

of CRPS, he says, and they have remained good friends ever since. Another case involved a young gymnast who fractured the growth plate in her leg and developed CRPS.

“Zoe was a gymnast who had injured her leg, had full body pain, and was disabled. During treatment the color change on her feet went away, swelling went down and she was able to get up and run. She was cured after one treatment.”

The idea that a single treatment of anything could alleviate long standing severe CRPS is astonishing, but Dr. Hao says his success with pediatric patients continued. “Her mother knew many others through a support group and sent other nine to twelve year olds - twenty-eight children with CRPS – and after between one to four treatments with only four needles on the head Zoe’s mother reported we had 100% recovery rate.”

He put me in contact with Sue Rempel, one of his patients, who developed CRPS in her left knee following surgery. After seven years, numerous medications and interventions, the CRPS had spread and Sue was confined to bed and a wheelchair. Wiped out by the medications, she held on to the little hope she had left, when her doctor at the Cleveland Clinic told her she would soon need a morphine pump. When her friend, a physical therapist whose patient had been cured of paralysis by Dr. Hao, suggested he might be able to help her, she knew she had to try.

“By the fourth or fifth treatment I could stand and bear weight,” she says, “but I was flying back and forth for end-of-life care for my mother.” She tells me that the trauma of the

CRPS was re-triggered by activities she associated with the pain. Although the excruciating disabling pain never returned after those initial treatments, it took about twenty treatments over the course of a year to completely recover. “My pain level is now zero. He gave me my life back.”

Neurologists have told her it is impossible, but she is off all pain medications and fully functional. She is back at work as a volunteer hospice nurse, sits on three company boards, and volunteers at the Neuro-acupuncture Institute. “In my experience as a patient many people have complex health issues that can require more treatments. For younger patients who have not had CRPS long, four visits can work. But many of us have had it for a long time; our body has a strong memory of the pain and can hold onto it longer.”

Last fall she went to Ecuador on a medical mission and hiked a 6,000 foot volcano, then went on to realize her dream of climbing Machu Picchu. As an RN with a Masters in Nursing, she says that it is easy to dismiss the effectiveness of Oriental medicine because we don’t understand it, but there are many treatments in Western medicine that we also don’t understand.

There are no clinical studies of Dr. Hao’s technique, which has been developed and refined over decades of clinical experience. He is working on securing funding for research with Autism, Cerebral Palsy, CRPS, and Muscular Sclerosis. In his experience between 5-10 % of patients don’t respond to treatment. “We need to figure out what kind of patient it works for, at

*Continued on page 17*

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# Spotlight on Support Groups: Treating CRPS & Chronic Pain with Functional Medicine and Calmare Therapy

BY MELISSA WARDLAW

Hello, fellow CRPS Warriors! I would like to introduce you to the CRPS/RSD, Chronic Illness & Pain Support/Empowerment Group of Metro Atlanta, Georgia. I started this local, in-person group about six years ago and we later added a corresponding private Facebook Group that has approximately 65 members and counting. Our members consist of patients and their spouses/caregivers, both men and women, with multiple different ethnicities and ages ranging from teens to the 70s! This is more proof that CRPS, chronic illnesses & pain do not discriminate.

Because our meetings and group activities take place in person, we have had to adapt and find new ways of connecting and offering support to members, as most groups have had to do during the COVID-19 lockdown. In April 2020, we held a virtual ZOOM meeting which was successful, having a little over twelve members in attendance. Despite the ZOOM app cutting us off after 40 minutes and having to start over a few times, it was helpful to check in and share our concerns about COVID-19 as well as the stress that comes along with it. The quarantine has had a devastating effect on many of our members, resulting in additional flares of pain & symptoms.

We also just recently had our first Facebook Live with a very special guest, Rabia Vaughns (PA-C), titled "Treating CRPS & Chronic Pain with

Functional Medicine and Calmare Therapy." We also touched on strategies to more effectively prepare for the COVID-19 crisis. Rabia owns and operates a Functional Medicine practice and has recently opened the first clinic in Georgia that offers Calmare "Scrambler" Therapy. Rabia is unique in that her husband has suffered with CRPS for four years, which is one of the many reasons that motivated her to bring Calmare Therapy to Georgia!

Despite having some technical difficulties in the Facebook Live (mainly on my end), we modified so members were able to hear Rabia loud and clear! Below are the highlights of Rabia's presentation.

## **Functional Medicine**

Functional medicine is a framework that looks at the whole person as an individual instead of just the patient's diagnosis or symptoms. It asks the question of "why" the illness appears. What factors drive illness and what factors drive health? The goal is to reduce things that make people sick and increase things that make people well. It is less about treating symptoms and more about getting to the root of problems. The overall goal with CRPS and chronic pain is to calm down an already inflamed nervous system! Functional medical practitioners partner with patients as individuals who are part of a comprehensive medical team. They also spend A LOT of time with each patient. Rabia believes every CRPS patient

is an expert and, in turn, has to become their own advocate.

In terms of where she starts with a new Functional Medicine patient, Rabia said that because each patient is different, there is no "one size fits all" process. However, she will usually start with a comprehensive history and medical history. This includes gathering information on genetics, testing, childhood trauma, symptoms, stress, personality type, hormones, triggering events (injuries, accidents, stressful happenings), etc. Testing will vary depending on the individual patient's symptoms and needs. Some of the types of testing that are available include measuring hormones, cortisol, thyroid, antibodies, TSH, digestive function, allergies, food sensitivities and many more.

She then determines mediating factors such as lifestyle, diet and exercise, hormones, endocrine system, nervous system, etc. and works from there to determine an individual plan for using the mind and body's own healing powers to obtain further wellness.

For additional information, please visit Rabia's website at [www.newlifewellness.net](http://www.newlifewellness.net).

## **Calmare Therapy**

Calmare Therapy, otherwise known as "Scrambler Therapy," helps by interfering with the constant pain signal, "scrambling" the brain's constant pain message

and correcting it to the normal “no pain here” message. This can help relieve pain and restore function. It goes straight to the root cause of CRPS, as opposed to just treating or masking symptoms of pain.

It works by placing small electrodes on the skin around (not on) the affected extremity or areas of pain. With CRPS, our brains get constant messages of pain. Calmare Therapy works to override that signal and instead delivers synthetic “no pain” information to the brain which, in essence, tells the brain that we don’t have pain.

According to Rabia, if it will work, one should notice a difference within the initial session to a few sessions. Usually it takes approximately 10 sessions, typically having five sessions per week.

Calmare is non-invasive and has no side effects. Contrary to popular belief, it CAN be done in conjunction with taking opioids and Ketamine, but NOT with anticonvulsants or other medications, such as Lyrica or Gabapentin. CBD/THC can also interfere with its effectiveness. Ideally, patients will be off as many medications as possible to have the best chance of success. Rabia prefers to work with the patient’s pain management physician to wean off any medications prior to treatment.

In Rabia’s opinion, Calmare Therapy is a great treatment to try FIRST, before any medications or invasive treatments and before CRPS has had a chance to spread. Booster treatments are common from a few months to a few years.

Calmare Therapy works well in conjunction with Functional Medicine. This way, patients are retraining their brain AND body at the same time - hence, the “mind/body” approach.

### **Member Q & A**

*What is the difference between a TENS unit and Calmare Therapy?*  
A TENS unit treats symptoms - when the TENS unit is not in use the symptoms and pain will still be present. Calmare delivers NEW information to the brain of “no pain” which then sends this message to the body ultimately breaking that feedback loop. In short, Calmare treats the source; TENS treats the symptoms.

*Is Calmare Therapy effective for Full-Body/Systemic CRPS?*

For full-body CRPS (or fibromyalgia for example), Calmare can definitely work but it will likely take longer than the 10 standard treatment sessions. With Calmare, you can treat five different sections of the body at a time.

Rabia believes it makes so much sense to try Calmare in the beginning of a CRPS diagnosis; however, it also makes sense to try it no matter how long you have had CRPS or where you have it since it’s non-invasive and there are no side effects.

*Can Calmare Therapy be used with a Spinal Cord Stimulator (SCS)?*

Using Calmare with a SCS or DRG is a contraindication. However, some doctors are doing it, but the device just needs to be turned off. Also, similar to a TENS unit, a SCS doesn’t send “no pain” signals like Calmare does.

*What is the cost of Calmare*

*Therapy? Does insurance cover it?*

Calmare Therapy is usually less than Ketamine infusions as well as many other therapies. It is also covered by some insurances. Please check with your provider. Rabia also provides a superbill which makes filing easier.

Rabia has had very good success to date using Calmare Therapy. She is in amazement and doesn’t want to call it a miracle treatment, but she has been very impressed with the results thus far. For more information, please visit her website at [www.georgiacalmaretherapy.com](http://www.georgiacalmaretherapy.com).

### **COVID-19 Strategies**

Rabia says that many of the strategies we can use to boost our immune systems and reduce inflammation to aid with COVID-19, we can use in general for CRPS and Chronic Pain. Rabia’s top three tips to reduce inflammation are the following:

- 1) Focus on nutrition - eat nutrient dense foods
- 2) Focus on healing the gut
- 3) Work on calming the nervous system to bring down stimulation and stress (this is a challenge when we are always dealing with chronic pain and our nervous systems are always on high alert)

#### Nutrition - “Food as Medicine”

- Start with one meal at a time!
- Try boosting color (think of the rainbow)
- Eat foods with high doses of Vitamins C and A (colors include oranges and reds)
- Eat lots of vegetables (non-starchy, like leafy greens) and fruit
- Eat stuff that grows from the earth
- Eat organic as much as possible

- Increase protein intake that has zinc and amino acids which are important for building new things in the body (i.e., meat, nuts, seeds, eggs, shitaki mushrooms, etc.); minimum 60 grams/day for women; men 70+
  - Increase “good” fats that reduce inflammation and have omega 3 and 6 such as fish, salmon, halibut, cod, nuts, seeds, avocados, etc.; stay away from “bad” fats such as dairy and red meat that increase inflammation
  - Omega 3 supplement - “just because you don’t eat it doesn’t mean you don’t need it” good for brain and heart health; need it for every cell in the body
  - Stay away from processed foods, especially sugar (ideally only 20-30 grams/day)
  - Swaps are good, such as coconut, berries, paleo brownies (google for substitutes)
  - Give your body more of what it needs and less of what it doesn’t to help prevent viruses
  - Do your best; some is better than none
- \*\*Email Rabia for “Phytonutrient Spectrum Food” and “Detox Food Plan” documents

#### Healing the Gut

- Your brain is tied to your gut; what happens in your gut impacts your brain
- 90% of serotonin is made in your gut which impacts stress, anxiety and depression
- Inflammation in the gut impacts inflammation in the rest of the body
- You have bacteria in your gut; by adding more plant based and fermented foods (Kimchi, sauerkraut, yogurt, etc.) that have live bacteria you will reduce inflammation
- Greater than 50% of our immune system is located in the gut. Processed foods (sugar, and

other foods that shouldn’t be there) can override good foods (fiber, etc.) and you will have “bad growth.” You will then start having digestive symptoms and GI issues.

- Eat more prebiotic foods such as bananas, apples and artichokes
  - Stress also affects the gut
- \*\*Email Rabia for “The 5R Framework for Gut Restoration” document

#### Calming the Nervous System

- Manage physical and emotional stress
  - Hydration is very important for pain but also for staying well in general
    - Focus on what you CAN control, not on what you can’t. For example: Did I social distance? Did I wear a mask?
  - Take a walk outside; turn off the news; call loved ones; try yoga classes on YouTube; meditate and do breath work; get enough rest
  - Now is the time to try new things
    - Supplements/Vitamins: High potency multivitamin, Omega 3, prebiotic and probiotic (multivitamin of the gut)
  - Ask yourself three things everyday:
    - 1) What real food did I eat today?
    - 2) How did I care for my gut today?
    - 3) How did I manage my stress today?
- \*\*Email Rabia for a probiotic supplement recommendation link

Rabia also provided our group with the following link of additional tips for boosting immunity during the COVID-19 outbreak.

<https://www.ifm.org/news-insights/boosting-immunity-functional-medicine-tips-prevention-immunity-boosting-covid-19-coronavirus-outbreak/>

**To find out more information about Rabia Vaughns (PAC), Functional Medicine and Calmare Therapy in Georgia, or to email her for the additional resources mentioned in this article, her business contact information is below:**

New Life Wellness: [www.newlifewellness.net](http://www.newlifewellness.net) Georgia  
 Calmare Therapy: [www.georgiacalmaretherapy.com](http://www.georgiacalmaretherapy.com)  
 Phone: 706-688-9355



#### **Bio:**

Melissa Wardlaw was diagnosed with CRPS/RSD as a result of a spinal cord injury (non-paralyzing) suffered during a routine medical procedure. She also suffers from fibromyalgia, lumbar and cervical degenerative disc disease, migraines and additional chronic medical issues. Formerly a Business Executive/Consultant with an MBA in Entrepreneurship, she is also a Certified Career Coach and Certified Professional Resume Writer, and now spends her time career coaching and offering peer counseling/advocacy (pro bono) to those dealing with similar medical struggles. As a fierce advocate, she also runs both in-person and online support/empowerment groups for CRPS/RSD and chronic illnesses/pain in the Metro Atlanta area. A “fur mom” to two cats, Melissa is an avid volunteer and supports multiple organizations committed to rescuing animals and helping those with chronic illnesses/pain. She can be reached at [crpsatl@gmail.com](mailto:crpsatl@gmail.com).



# What is the Relationship of a Differential in the COL11A1 Gene to CRPS?

BY STEVEN BRUEHL, PH.D. • PROFESSOR OF ANESTHESIOLOGY • VANDERBILT UNIVERSITY OF MEDICINE

## In our DNA methylation study that was supported by RSDSA

(Bruehl S et al. DNA methylation profiles are associated with complex regional pain syndrome after traumatic injury. *Pain*. 2019; 160: 2328-2337), we found that differential methylation in the COL11A1 gene was the ONLY gene location (out of 450,000 sites examined across the genome) that showed true genome-wide significance for a link to CRPS development after traumatic injury. DNA methylation (in which gene activity is turned off or on by environmental or genetic factors) is not exactly the same as showing links between genetic mutations and CRPS, but our findings are certainly suggestive of possible links between genetically-determined collagen-formation variants and CRPS.

Here is a relevant section of the article discussion regarding COL11A1 for what it's worth:

"The largest differential methylation effect in the current work was for the COL11A1 gene. COL11A1 is involved in collagen formation, and notably, the only prior gene expression work in CRPS found that one of the top differentially expressed genes was also a collagen-related gene, MMP9.<sup>37</sup> There is no prior evidence of a specific role for collagen-related factors in CRPS, although we might speculate that given the role of collagen in skin formation,<sup>54</sup> altered expression of genes such as COL11A1 and MMP9 might contribute to altered skin growth often characteristic of CRPS.<sup>7,8</sup> In addition, it may be relevant that both the COL11A1 gene and the KRT16 gene

are part of the TFAP2A gene regulatory network.<sup>77</sup> The protein expressed by the KRT16 gene has been shown to be a target for autoantibody responses in a preclinical CRPS model.<sup>61</sup>

Here are the other relevant references cited above:

37 = Jin EH, Zhang E, Ko Y, Sim WS, Moon DE, Yoon KJ, Hong JH, Lee WH. Genome-wide expression profiling of complex regional pain syndrome. *PLoS One* 2013;8:e79435.

61 = Tajerian M, Hung V, Khan H, Lahey LJ, Sun Y, Birklein F, Krämer HH, Robinson WH, Kingery WS, Clark JD. Identification of KRT16 as a target of an autoantibody response in complex regional pain syndrome. *Exp Neurol* 2017;287:14–20.

77 = Zhang M. Transcriptional regulatory element database. Available at: <http://rulai.csh.edu/cgi-bin/TRED/tred.cgi?process=home>. Accessed March 5, 2019.

Continued from page 13

what stage, and type of CRPS."

Barriers to research include funding and having a large patient population for testing. Dr. Hao says he would like to collaborate with neuro-medical professionals and use Functional MRI studies to understand exactly how this treatment affects the brain. The documentary film "A Return to Life," which follows his patients before, during, and after treatment is in post production and the trailer can be viewed at the NAI website. During my hour-long talk with Dr.

Hao I was struck by his enthusiasm and relaxed, genuine attitude. He described many patients and conditions he has treated, including several at Walter Reed Medical Center who had Phantom Limb pain and CRPS. Interviews and testimonials on the Institute's web site and articles about him in the media offer tributes to unexpectedly swift and amazing cures.

With a smile he tells me, "Now our son is grown up, I have more free time. I'd like to give something

back to society, help more people change their life, and return to a new life."

<sup>1</sup><https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3833481/>

<sup>2</sup>[https://www.youtube.com/watch?time\\_continue=141&v=ZoSMrKuly70&feature=emb\\_logo](https://www.youtube.com/watch?time_continue=141&v=ZoSMrKuly70&feature=emb_logo)

<sup>3</sup><https://www.youtube.com/watch?v=nAGEdcHbvNA>

<sup>4</sup><https://www.neuroacupunctureinstitute.org/films-photos/film-gallery/a-return-to-life.html>

<sup>5</sup><https://www.acupuncturetoday.com/mpacms/at/article.php?id=30431>

<sup>6</sup>[https://www.santafenewmexican.com/news/health\\_and\\_science/doctors-honored-for-neuro-acupuncture-miracles/article\\_cb62cc39-58f2-5ebe-bd6c-1b73d3fac3ac.html](https://www.santafenewmexican.com/news/health_and_science/doctors-honored-for-neuro-acupuncture-miracles/article_cb62cc39-58f2-5ebe-bd6c-1b73d3fac3ac.html)

**I showed up to the athletic training room at Princeton on September 1 in a large boot and on crutches, unable to bear any weight on my ankle. Luckily, I recovered quickly and was back to running in three weeks. By mid-October I was back to fully training for indoor track. Little did I know, I had just awakened a beast in my shin that did not fully unveil itself until January 18, 2011.**

I began experiencing pain in the middle of my tibia at the end of October and stopped running right before Thanksgiving 2010. Several scans and inconclusive test results later, I began treatment for a mid-tibia stress fracture. Shortly before Christmas I was put on crutches. For the next three weeks, I was completely non-weightbearing, so when I returned to campus on January 4th (my birthday), off crutches, I felt great...for a total of 10 minutes. That's when I knew something wasn't right. The burning sensation worsened under sheets and while wearing pants, to the point where I was back home studying for finals crawling three feet from my room to the bathroom.

It was not until a Saturday night in the middle of January, when I called Dr. Lisa Callahan complaining of a constant and horrific burning sensation on my shin, that we realized what we were dealing with. On Monday morning, I was in the office of Dr. Dan Richman, a renowned pain management doctor whose specializes in RSD/CRPS. By Tuesday I received my first of eight Lumbar Sympathetic Nerve blocks.

From January to March, I was a full-time student who was barely

at school. Each Monday afternoon, I would travel over an hour to the Hospital for Special Surgery in New York City (HSS) to receive the blocks. Afterwards, I would be very loopy from the Ativan given before the procedure so I would stay home, and my mom would drive me to school at 6:30am on Tuesday, a 70-minute drive, making it just in time for 9 am Psychology lab. Both of my parents were (and still are) absolute saints throughout this time.

Although it was suggested by the Dean of my residential college, my parents, and my doctors that I take a year off, I refused. Being on campus with my friends and teammates, going to class and to the training room was the normalcy I needed to get me through this mentally and physically painful time. Even though my concentration and memory temporarily declined due to the Lyrica, a medicine used to normalize overactive pathways, and my grades suffered, I still do not regret my decision to stay. My doctor began to immediately wean me off the Lyrica but kept me on the Ketamine cream to continue to reduce the amount of pain and inflammation in my shin. Of all the treatments, the topical Ketamine, physical therapy exercises, and therapy sessions were the most beneficial in defeating this disease. Aside from my family, staying at Princeton was the only thing keeping me going. If it wasn't for such a strong support system, I would have felt like there wasn't much point in being alive.

The road to my first race began in the Fall of 2012 but to say it was smooth sailing would be an enormous lie. I had taken the better part of two years off but

was finally able to run five days a week that fall and begin workouts by the end of October. However, I began to let my mind get the best of me by convincing myself that I needed to lose weight. I felt great in workouts until my body could no longer handle being under-fueled. I celebrated my 21st birthday over the toilet with the Norovirus, losing even more weight. When I returned to campus a few days later, my roommate was horrified by how skinny I looked. My teammates and coach voiced their concerns as well, but I was able to hide behind having had the Norovirus. It wasn't until I was in the hospital with a Kidney Infection (from a UTI) looking at my back in the mirror, bones sticking out more than usual, that I realized I was too skinny. That realization allowed me to see that it wouldn't be the CRPS stopping me from competing but instead, the games I was playing in my head.

Three weeks after I got out of the hospital, I finally had a breakthrough in practice. It was time to ask my coach if I could race. On February 16, 2013, I stepped onto the start line in the 800 meters for the first time in almost three years. The best part about that day wasn't the race but the people who were there to cheer me on. My support system helped me to believe I would run competitively again, even when it felt unlikely.

Even though I did not accomplish anywhere close to what I had hoped to during my time in the NCAA, I can say this experience taught me the importance of resiliency. It is the reason, along with my doctors, parents, family, friends and physical therapist, that I haven't had a serious CRPS-related setback in over nine years. For that, I couldn't be more grateful.

# Stuffed Sweet Potato with Curried Chickpea: A Recipe from Chuck Hood

## Ingredients:

4 medium sweet potatoes  
1 teaspoon extra virgin olive oil  
15 ounce Unsalted chickpeas, rinsed  
1/2 teaspoon salt  
1/2 teaspoon black pepper  
1/2 teaspoon curry powder  
2 cups baby kale Leaves  
1/4 cup cilantro

## Yogurt Sauce;

1/2 cup plain yogurt  
1 teaspoon olive oil  
1 teaspoon lemon juice  
1/4 teaspoon garlic powder  
1/4 teaspoon turmeric or curry powder  
1/4 teaspoon salt

## Instructions:

1. Pierce sweet potato several times with a fork. Microwave on high for 10 minutes or until tender.
2. In a medium sauté pan or skillet, add in olive and chickpeas over medium heat. Add in salt/pepper and curry powder, cooking 5-7 minutes. Add chopped kale to pan and cook for 3 minutes.
3. In small bowl, combine the sauce ingredients together.
4. Cut open sweet potato length-wise, stuff with chickpea and kale mixture. Top with yogurt sauce. Garnish with cilantro leaf and lemon zest.

## Poetry Corner

# A Poem for RSDSA Helpers

By George Brugliera

*Morning came early today;  
Now showered and clean,  
Felt my icy cold steering wheel,  
The traffic scene.*

*The sun arrived right around lunch,  
But my job took it back,  
Left my nerves in a bunch.*

*The studying I do,  
For work and my job,  
Leaves welts on my eyelids,  
And stress that pulls hard.*

*Driving from work  
The song soothes my soul,  
Or silent meditation  
From all that life pulls.*

*Believe or not,  
I'm sitting at home,  
Just wondering how you're doing  
As I make up this poem.*

*Sometimes I can't see the sun,  
Even though the sky is clear.  
But I feel the warmth,  
From all of you,  
The ones that care.*



## RSDSA BOOK QUIZ GIVEAWAY [WWW.RSDSA.ORG](http://WWW.RSDSA.ORG)

The first ten respondents who answer all of the following questions correctly will receive a free copy of the *The Dyodyne Experiment* by CRPS Warrior James Doulgeris and V. Michael Santoro.

In **The Dyodyne Experiment** the novel's heroine, Sarah Randall, contracts CRPS because of injuries. Imagine the first DNA tracking device delivered using a Genetically Engineered Virus. Available on [Amazon](http://Amazon) in paperback and via Kindle.

***The action is fast and furious, and many readers will stay up late, desperate to read just one more chapter...*** - Sandra Iler Kirkland, Vine Voice



1. In what year was RSDSA incorporated as a 501(c)3 non-profit?

- a. 1984
- b. 1960
- c. 1977
- d. 2000

2. How many branded items does RSDSA sell in its store?

- a. 5
- b. 10
- c. 12
- d. 9

3. How many research projects is RSDSA currently funding?

- a. 7
- b. 5
- c. 3
- d. 1

4. True or False

Since 1992, RSDSA has funded more than 2.2 million dollars in CRPS-related research.

5. True or False

There are 184 videos on the RSDSA YouTube channel.

6. How many states & territories have RSDSA Support groups?

- a. 50 plus Puerto Rico & Washington DC
- b. 45 plus Puerto Rico & Washington DC
- c. 47 plus Puerto Rico & Washington DC
- d. 38 plus Puerto Rico

7. To date, how many Facebook Live presentations has RSDSA hosted?

- a. 6
- b. 5
- c. 3
- d. 4

Please email Jeri Krassner, RSDSA Special Events Coordinator with your answers. I will reply to all contestants. Thank you, Jeri, [jkkrassner@rsds.org](mailto:jkkrassner@rsds.org)