

## An Insider's Take on RSD/CRPS

Facebook chat highlights with  
Power of Pain Foundation's Barby Ingle  
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*Barby Ingle is an author, chronic pain educator for the Power of Pain Foundation, motivational speaker and was a speaker for the American Pain Foundation's Power Over Pain Campaign from 2007-2012. She has been featured locally and nationally about her experiences with RSD. Since 2002, Barby has been a pain patient since and began mentoring other patients through The RSD Hope Organization in 2006. For more information, visit <http://www.barbyingle.com/>*

### **Barby Ingle:**

Thank you so much for having me tonight. I am looking forward to the next hour. I will answer as many questions as I can get to and will also be referring you to links and resources that I find helpful in dealing with my own RSD. I have had full body RSD for 11 years. In 2009 I underwent infusion therapy and was able to achieve remission. In 2012, I got an oral orthotic that helped me even more. I have found that a multi-disciplinary approach to treating my RSD with noninvasive treatments is what has helped me the most. I realized that every RSD'er is different and some treatment modalities may or may not work for you. It is important to be your own best advocate and researcher so that you are doing what is best for you. Only you know the answer as to what you are comfortable trying.

Tonight I will be answering questions about reflex sympathetic dystrophy. I will use the term RSD in referring to Reflex Sympathetic Dystrophy. This term is only one term used to describe this disease. Other names that mean the same thing are CRPS, Complex Regional Pain Syndrome, Causalgia, Reflex Neurovascular Disease (RND), and over 20 terms have been used since the civil war. This disease RSD is neuro-autoimmune. Researches have isolated two auto-antigens involved in the condition. The research was published in April 2011; Autoimmunity against the b2 adrenergic receptor and muscarinic-2 receptor in complex regional pain syndrome by Danielle Kohr, Pratibha Singh, Marlene Tschernatsch, Manfred Kaps, Ervice Pouokam, Martin Diener, Wolfgang Kummer, Frank Birklein, Angela Vincent, Andreas Goebel, Gerd Wallukat, and Franz Blaes. We now know for sure that neuroinflammation is involved in RSD.

## **Q: Barby what are some tips you can give to people who live with RSD?**

- Continue to research and keep a positive attitude that relief is possible.
- Follow RSD experts as they publish new findings
- Get your information organized.
- Make informed and wise decisions about your treatment plan, doctors, best hospitals for you, and taking your life back from the pain in you, you have to become educated.
- There is hope for treatments of RSD that are putting patients into remission: new research results and procedures are coming that will assist in patient care on a long-term basis.
- Journaling or keeping a log is an excellent way of identifying possible triggers, because you can go back and compare what you did prior to a current flare with other previous flares. Just take a few minutes each day to jot down your activities for the day, any new medications or other therapies started, changes to your diet, weather or temperature changes, how and when you slept – anything that could help you pinpoint changes or themes that could account for your flares. (Source: RSD in Me)

## **Q: Barby, how do you stay optimistic while living with pain?**

I became my own best Advocate... Getting an accurate diagnosis is an essential step toward getting the right treatment plan. If your symptoms affect your work, school or personal life talk with your doctor about them. RESEARCH!!!! Don't be afraid to be your own best advocate. Identify your triggers, if you have any, and avoid them when possible. Maintain a healthy lifestyle, which includes good sleep hygiene, staying hydrated and eating healthy. If you smoke, work on quitting... and if you drink do so moderately. One of my favorites is to practice relaxation and stress management techniques. The more you practice the easier it will be to lower stress levels once a really stressful event occurs. Take time for yourself. And know that if you feel that anxiety or depression most of us experience has become unmanageable, speak with your provider or a mental health care professional and work your way through it. There are many reasons to be hopeful about the future. So maintain hope! \*O/\*

## **Q: What would you say to a caregiver who has a loved one with RSD?**

Try asking them to give you a BREAK.  
Let them know, "If you want to help me, you can give me a BREAK."

- B – Believe it is real and help keep my stress low
- R – Realize that I look healthy but have limitations
- E – Ease your mind by asking questions or visits [www.powerofpain.org](http://www.powerofpain.org)
- A – Ask before you touch me
- K – Keep sharp and sudden noises to a minimum

## **Jodi, Thanks for your question: Barby, can you tell me more about IV- Ketamine, and Oral Orthotics, and how they have helped you with your pain?**

Ketamine is what got me into remission. Infusion Therapy: Ketamine, a dissociative anesthetic, is being used in the treatment of RSD more and more. During the infusion the patient is monitored constantly, and it should be administered only by a qualified physician such as an anesthesiologist. The theory of ketamine use in RSD/CRPS is primarily advanced by neurologist Dr. Robert J. Schwartzman of Drexel University College of Medicine in Philadelphia, and researchers at the University of Tübingen in Germany, but was first introduced in the United States by Doctor Ronald Harbut of Little Rock, Arkansas. Ketamine blocks NMDA receptors that might reboot aberrant brain activity and binds to the same glia receptors that opioids do, except they calm instead of excite the glia receptors.

There are two treatment modalities; the first consists of a low-dose subanesthesia Ketamine infusion of between 10–90 mg per hour over several treatment days, this can be delivered on an outpatient basis. This is called the awake or subanesthesia technique. One study demonstrated that 83% of the patients that participated had complete relief and many others had some relief of the symptoms. Another evaluation of a 10-day infusion of intravenous ketamine (awake technique) in the RSD patient concluded that “A four-hour ketamine infusion escalated from 40–80 mg over a 10-day period can result in a significant reduction of pain with increased mobility and a tendency to decreased autonomic dysregulation”. source: [www.powerofpain.org](http://www.powerofpain.org)

## **Q: What do you think are the best pain advocacy organizations?**

Great RSD & Pain Resources can be found at: [www.painpathways.org/pain-resources/](http://www.painpathways.org/pain-resources/), [www.powerofpain.org](http://www.powerofpain.org), [www.rsds.org](http://www.rsds.org), and [www.rsdhope.org](http://www.rsdhope.org)

## **Good Reads**

- 1) Is Reflex Sympathetic Dystrophy/Complex Regional Pain Syndrome Type I A Small-Fiber Neuropathy? By Oaklander AL, Fields HL. Published by Ann Neurol 2009
- 2) Injuries of Nerves and Their Consequences. By Mitchell SW. . Published by J.B. Lippincott & Co.; 1872
- 3) Dystonia in Complex Regional Pain Syndrome Type I. by Lang AE, Chen R. . Published by Ann Neurol 2010
- 4) Neurological findings in complex regional pain syndromes – analysis of 145 cases. By Birklein F, Riedl B, Siewke N, Weber M, Neundörfer B. . Published by Acta Neurol Scand 2000
- 5) Abnormal movements in complex regional pain syndrome: assessment of their nature. Muscle Nerve by Verdugo RJ, Published by Ochoa JL. 2000
- 6) Cortical and spinal abnormalities in psychogenic dystonia. By Espay AJ, Morgante F, Purzner J, Gunraj CA, Lang AE, Chen R. . Published by Ann Neurol 2006

7) Visualizing microglial activation in vivo. Glia by Banati RB. 2002

## **Q: Barby, what other treatments would you suggest for RSD?**

There is ALWAYS hope. There are so many new and emerging treatments, both medication, non-medication, procedures, complementary and alternative therapies, bio-behavioral therapies, and combination treatments in any of these categories. There are many RSD specialists nationwide who are devoted to seeing patients who feel that there are no other options. A great list can be found at <http://powerofpain.org/rsd-crps/> and [www.rsd.org](http://www.rsd.org)

The general strategy in CRPS treatment is often multi-disciplinary, with the use of different types of medications combined with distinct physical therapies. The treatment principles in children and teenagers are similar.

- Blocks/Injection of a local anesthetic such as lidocaine is often the first step in treatment. Injections are repeated as needed. The results of local anesthetic injections are short lasting and the procedure is risky.
- Cortical Integrative Therapy (CIT®)—a scientific, research-based treatment designed to address brain and neurological dysfunction in both children and adults. By adopting a multidisciplinary approach, we are changing the way in which brain-related disorders and traumatic brain injury (TBI) are treated.
- EEG Biofeedback, various forms of psychotherapy, relaxation techniques and hypnosis are adjunctive treatments that assist coping.
- Graded Motor Imagery and Mirror Therapy
- Infusion Therapy: Ketamine, Lidocaine, Stem-cell, IVIg
- Medications: Physicians use a variety of drugs to treat RSD, including antidepressants, anti-inflammatories, and the entire pharmacy of opioids.
- Psychotherapy aims to increase the individual's sense of his/her own well-being.
- RSD Physical and occupational therapy
- Scrambler therapy (aka: Calmare)
- Surgical, chemical, or radiofrequency sympathectomy
- Topical lidocaine patches /lotions Compound lotions

## **Q: Are there opportunities in clinical trials for RSD and what's the best way for someone to get involved in research?**

Current Studies: Information provided by WHO International Clinical Trials Registry and RSDSA ClinicalTrials.gov: Current Clinical Trials Regarding RSD/CRPS:  
[www.clinicaltrials.gov/ct/search?term=%22Complex%20Regional%20Pain%22%5bCONDITION%5dpain%5bALL-FIELDS%5d](http://www.clinicaltrials.gov/ct/search?term=%22Complex%20Regional%20Pain%22%5bCONDITION%5dpain%5bALL-FIELDS%5d)

Botox and Chronic Pain: A New Research Study  
[www.rsds.org/3/research/Stanford\\_BotoxStudy.html](http://www.rsds.org/3/research/Stanford_BotoxStudy.html)

Effects of Vaporized Marijuana on Neuropathic Pain -  
<http://clinicaltrials.gov/ct2/show/NCT01037088>

Chronic Pain Clinical Trial: Currently Recruiting -  
[www.rsds.org/3/research/Omneuron\\_ClinicalTrial.html](http://www.rsds.org/3/research/Omneuron_ClinicalTrial.html)

Cerebrospinal Fluid (CSF) Repository - Drexel University is currently recruiting for a CSF repository that would allow the use of CSF in biochemical studies of various neurologic diseases.  
[www.rsds.org/3/research/DrexelCSFStudy\\_07152008\\_114.html](http://www.rsds.org/3/research/DrexelCSFStudy_07152008_114.html)

Dystonia and CRPS Study - The NIH/NINDS is sponsoring an outpatient research study assessing patients with Focal Dystonia (FD).  
[www.rsds.org/3/research/DystoniaCRPS\\_07072008\\_111.html](http://www.rsds.org/3/research/DystoniaCRPS_07072008_111.html)

Brain fMRI for Children and Adolescents with Complex Regional Pain Syndrome - Children and adolescents (ages 9 to 20) may be eligible to participate in a clinical research study conducted by the Children's Hospital Boston and McLean Hospital in Belmont, Massachusetts.  
[www.rsds.org/3/research/brain\\_fmri\\_for\\_children\\_.html](http://www.rsds.org/3/research/brain_fmri_for_children_.html)

Treatment of Chronic Pain using Real Time fMRI -  
[www.rsds.org/3/research/real\\_time\\_functional\\_fmri.html](http://www.rsds.org/3/research/real_time_functional_fmri.html)

Neurotropin to treat pain associated with complex regional pain syndromes I and II (RSD and Causalgia) - [http://www.rsds.org/3/research/neurotropin\\_research.html](http://www.rsds.org/3/research/neurotropin_research.html)

## **Q: Any help from the fatigue?**

Dysautonomia/Postural orthostatic tachycardia syndrome (POTS) - A disorder characterized by orthostatic intolerance. Orthostatic intolerance (OI) is the development of symptoms when standing upright which are relieved when sitting back down again. There are many types of orthostatic intolerance. OI can be a subcategory of dysautonomia, a disorder of the autonomic nervous system occurring when an individual stands up. It affects more women than men (female-to-male ratio is at least 4:1), usually under the age of 35. Up to 97% of those who have chronic fatigue syndrome (CFIDS) have shown in studies to have some form of OI. Some symptoms are altered vision (blurred vision, "white outs," black outs), anxiety, exercise intolerance, fatigue, headache, heart palpitations, as the heart races to compensate for the falling blood pressure, hyperpnea or sensation of difficulty breathing or swallowing, lightheadedness, nausea, neurocognitive deficits, such as attention problems, sensitivity to heat, sleep problems,

sweating, tremulousness, weakness. A good resource for more information on this is [http://www.dinet.org/pots\\_an\\_overview.htm](http://www.dinet.org/pots_an_overview.htm).

**Q: I was diagnosed three years ago with fibromyalgia. I broke four bones in my right ankle last February. I've been sent recently to an ankle specialist. He wants me to see a pain management clinic for CRPS. Is it possible to have both fibro and CRPS? Are they two different diseases?**

There are studies that have come out that show that fibro is a subset of RSD. As blood testing is developed more information will be available on it. A good source now is this video of Dr. Getson speaking about it at PAINWeek 2012; <http://www.youtube.com/watch?v=EpQxQa7zIUU>.

**Q: Have you read the Spoon Theory and do you think it applies to RSD?**

I have. It is very similar to the energy penny bank article posted below. It helps caregivers and family/friends understand what people with pain who have a harder time explaining, are going through on a daily basis.

**Q: What are some causes and common triggers of pain flares?**

Although it's not possible to prevent all flares, identifying what causes most of your flares and taking steps to try to prevent those triggers can help reduce the number and intensity of flares significantly. In my experience, some of the most common triggers for RSD flares are: illness, injury, over-working your body, stress, temperature changes, weather changes and traveling.

Illness or injury - Just as an illness or injury often triggers the onset of RSD, another illness or injury can trigger a flare. Even something as simple as a blood draw or catching the common cold can result in a flare. And, if you are like me, the falls I get from vertigo, double vision, and balance issues can cause an injury/trauma. Avoid injury, don't eat after other people, don't eat out of the same candy bowl or chip bowl as others and wash you face and hands to help avoid illness.

Over-working your body - Any time we push ourselves too far physically whether it is during physical therapy or spending a day with our kids or in my case nephews, we are in danger of triggering a flare. On those rare days when we feel a little better than normal, it's so hard not to try to catch up with all of the chores and activities we've been unable to do for the past month or two. We should be very careful to not over do it, even when you feel good. Over exerting yourself can come back and bite you in the form of a pain flare. For some good examples on how to save your energy pennies check out the article by Ken Taylor -

<http://www.painpathways.org/2013/05/02/caregiver-toolbox-saving-energy/>

Stress – We often hear of how prolonged stress negatively affects our health and can lead to heart attacks and strokes. What we don't always realize is that stress can have a significant impact on RSD symptoms as well. Stress can come up on us really quick (finances, family member gets sick/injured, increase in responsibilities). As stress increases so do our flares, so finding ways to keep life low stress will help us better manage when a crisis does arise quickly that we are not prepared for.

Temperature changes - Many people with RSD are extremely sensitive to cold or heat or both. Being exposed to those uncomfortable temperatures, even for relatively short periods of time, can sometimes trigger a flare. I keep a blanket and pillow in the car to help keep me warm while my husband uses the air conditioner, that way we can both be comfortable and the pillow helps take some of the bumps out of my ride.

Traveling – A trip is not easy for someone with RSD and even the best trip may be followed by a flare. The cabin pressure changes, weather changes, temperature changes, disruption of sleep, getting bumped all can play a factor. Here is a great article on traveling tips for pain patients and their caregiver by Ken Taylor: <http://www.painpathways.org/2013/07/08/caregiver-toolbox-travel/>

Weather changes - Possibly the most common cause of short-term RSD flares can be attributed to changes in the weather. Even in remission I experience RSD flares with barometric pressure changes. Whenever the barometric pressure change passes through, many people with RSD experience an increase in their symptoms – particularly in their pain level.

**Q: What is the best advice you received from someone else with RSD, and how has that affected your life?**

My stepsister, who got RSD in 1994, taught me to be my own best advocate knowing that some providers are not always up to date with current information and treatment options. It helped me keep fighting even after seeing so many providers that really didn't understand; now I know if I am with a provider who doesn't know about RSD, I offer to bring them studies and info. If they are not receptive, I switch to a provider who is.

**Q: Are there known causes of RSD?**

This disease RSD is neuro-autoimmune. Researches have isolated two auto-antigens involved in the condition. The research was published in April 2011; Autoimmunity against the b2 adrenergic receptor and muscarinic-2 receptor in complex regional pain syndrome by Danielle Kohr, Pratibha Singh, Marlene Tschernatsch, Manfred Kaps, Ervice Pouokam, Martin Diener, Wolfgang Kummer, Frank Birklein, Angela Vincent, Andreas Goebel, Gerd Wallukat, and Franz Blaes. We now know for sure that neuroinflammation is involved in RSD. See pdf of study:

<http://powerofpain.org/wp-content/uploads/2013/09/CRPSautoimmunity.pdf>

*Back to the question oral orthotics:*

Here is a link to a video with more info. But I do use the oral orthotic since Dec. 2012, and it has been amazing for me to help with neuro-inflammation, balance and coordination issues with my RSD. <http://www.youtube.com/watch?v=TwF1J9TeGE8>

**Comment: Thank you Barby, for making time to share some information about RSD with us. You have continued to keep me inspired. I also love reading your four books on RSD.**

It is my pleasure. I am so happy to be able to share the information I have and to be able to help you all. Thank you for participating and thank you for reading my books!

**Q: I know that stress is very important. What about if you are sensitive to the smell of smoke?**

Sensitivity to smells like smoke is common for RSD patients. Below is a list of other common symptoms.

What are expected symptoms of RSD? There are four main symptoms for an RSD diagnosis. Chronic burning pain- includes allodynia; extreme sensitivity to touch, sound, vibration, wind, and temperature. Inflammation - this can affect the appearance of the skin; bruising, mottling, shiny appearance, blotchy or pale appearance, and tiny red dots are some examples. Spasms - in blood vessels and muscles of the extremities, called vasoconstriction, insomnia/emotional disturbance - (including limbic system changes such as short-term memory problems, concentration difficulties, and irritability). As noted on [www.rsdhope.org](http://www.rsdhope.org), not all four symptoms are required for a diagnosis but most patients do have at least three out of the four at any one time. There are a great many additional symptoms that can occur but not all patients will have all symptoms. Some of the symptoms may even be transient depending on the stage the patient is in; the time of day, weather, noise level, current medications, whether or not the patient was treated with ice or hot/cold contrast therapy, etc. What makes this disease even more difficult for doctors to diagnose and treat is that patients can present with different symptoms at different times, even from one appointment to the next.

Other symptoms can include: extreme sensitivity to touch - bone changes - chronic fatigue / body fatigue – emotional disturbances- hearing/vision - low-grade fever - limbic system dysfunction – movement disorders / dystonia – nails/hair changes- vascular constriction of blood vessels, arteries, veins. Thoracic outlet syndrome symptoms, sensitivity to smells/smoke, ischemia (intestines, heart..), headaches, migraines, optical migraines, coldness in the affected extremity. More on RSD symptoms can be found at <http://powerofpain.org/rsd-crps/>.

**Amy North:** Hi, Everyone. On behalf of our editor-in-chief Dr. Richard Rauck, we'd like to thank Barby and all those who participated in tonight's chat LIVE from PAINWeek. We are excited to offer this forum for information and inspiration.



**Barby Ingle:** Thank you all for participating tonight. It was very exciting to be apart of this chat live from PAINWeek. Thank you to PainPathways Magazine for giving me this great opportunity.

You can reach Barby Ingle at: [barby@powerofpain.org](mailto:barby@powerofpain.org) or on Facebook at [www.facebook.com/barbyingleauthor](https://www.facebook.com/barbyingleauthor).

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