

rsdsa  
**community update**

VOLUME NO. 3

ISSUE NO. 1

WWW.RSDS.ORG/NEWSLETTER

Spring 2016

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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 the RSDSA Community Update include? We would love to hear from you. Please email your thoughts to [info@rdsd.org](mailto:info@rdsd.org).*

## SPECIAL THANKS

*Thank you to everyone who contributed to this newsletter, including four captivating volunteer writers and advocates for the CRPS community. We would like to acknowledge our Corporate Members whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate members include Axsome Therapeutics, Boston Scientific, Grunenthal, Medtronic, Innovative Health Solutions Neurologic Relief Center, and Florida Spine Institute. For more information about becoming an RSDSA Corporate Member, please contact Jim Broatch at [info@rdsd.org](mailto:info@rdsd.org). Thank you also HDMZ, a life science marketing agency, for helping to edit and produce the newsletter.*

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THE DIRECTOR'S LETTER

# A Spring Update

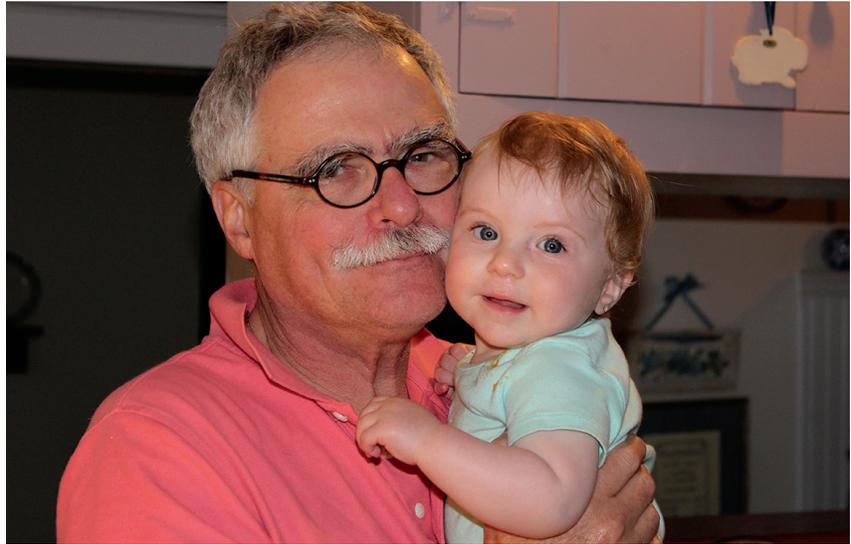
BY JIM BROATCH, RSDSA'S EXECUTIVE VICE PRESIDENT, DIRECTOR

On behalf of the RSDSA Board of Directors and staff, I want to inform you about a number of current educational initiatives we have or are initiating in 2016. In February, along with the Orange County Survivors and Caregivers Support Group, we hosted "Learning to Live Well with Chronic Pain" in Long Beach, California. It was an incredible, powerful, informative weekend. We filmed the conference and we'll post the PowerPoint presentations and videos on our website in the near future.

### Accredited Course on CRPS for MD's, Ph.D.'s, and RN's

RSDSA is sponsoring two one-hour accredited educational courses for physicians, nurses, and psychologists for three years: a "Comprehensive Overview of Complex Regional Pain Syndrome" as well an "In-Depth Look at CRPS: From Diagnosis to Treatment as Illustrated by Case Histories."

Philip Getson, DO, is the presenter for both of these programs. In order to access the two programs, you must create an account through this [website](https://education.aapainmanage.org/): <https://education.aapainmanage.org/>. It is our hope that individuals with CRPS will help promote these programs to their health care professionals.



Jim Broatch and his granddaughter Cora Marie.

### Three New Educational Brochures

Samantha Barrett, our special events coordinator is currently working on three brochures: one for people with CRPS who are interested in or are going to college, one for the colleges that may have someone with CRPS attending, and one brochure about achieving independence with CRPS. Ms. Barrett has been collaborating with Dr. Edward Kolek of Nichols College on each brochure. He is the head of the disability accommodations department at Nichols College.

Our two college brochures will focus on how to foster communication between the student and the college which ensure success. The brochure

written for students will list possible accommodations, tips on succeeding in college, important things to consider when selecting a college or other centers of higher education, and other topics suggested by students with CRPS who participated in a recent RSDSA survey.

The brochure for the colleges will emphasize how to best accommodate students with CRPS and also provides administrators with information and resources, which will allow them to better help and understand their student(s). These brochures are currently in production and will be available this summer.

Gaining Independence is another important brochure that is also in production. While writing the brochure, we are surveying the CRPS community that is or would like to be in the workforce. The brochure will focus on getting/maintaining a job, living on your own for the first time (ever or with CRPS), as well as focusing on different rights that the person with CRPS has and different resources they can access to flourish on their own.

We are still in the drafting phase of this brochure. Please send any suggestions to Samantha Barrett at [sbarrett@rsds.org](mailto:sbarrett@rsds.org) or by calling 508-942-2141.

### **The Longest Day of Golf**

The RSDSA is launching an innovative national fundraising event to support our mission of providing support, education, and hope to everyone affected by CRPS/RSD while we drive research to develop better treatment and a cure.

We need to recruit passionate golfers who will commit to playing their longest day of golf (from dawn to sunset) while raising funds for RSDSA by soliciting pledges per hole played from friends, family, colleagues, and local businesses. One time donations may also be collected. Other charities have raised tens of thousands of dollars while educating their community about their chronic illness or cause.

It's easy to participate. Individuals organize locally and approach their local golf course (most

private golf courses are closed on Mondays) to see if they can play the course from dawn to dusk for charity. Teams can compete against other teams from their area or against teams across the country for the best game, the most funds raised, and even the most festive golf attire. Start practicing your golf swing now! If you are interested, please contact Samantha Barrett.

### **Recent RSDSA Research Grant Awarded**

In December, the RSDSA Board of Directors awarded a \$92,621 grant to study Sympathetically Maintained Pain in Complex Regional Pain Syndrome (CRPS). Dr. Peter Drummond of Murdoch University in Perth Australia is the principal investigator.

His team hypothesizes that one possible contributor to CRPS is an abnormal connection between the pain processing system in the brain and the sympathetic nervous system, which regulates emotional responses and automatic processes such as sweating and changes in skin temperature. Dr. Drummond's team has already found strong evidence of this link in animals after an experimental nerve injury, and in a small number of individuals with CRPS. In particular, they have found that a receptor molecule targeted by the sympathetic nervous system is over-expressed on pain-signaling nerves. Consequently, activation of the sympathetic nervous system (e.g., during emotional arousal) might inadvertently

activate pain-signaling nerves and increase pain.

To further explore this possibility, over the past few years, his team has collected skin samples from nearly 100 individuals with CRPS and, for comparison, from 45 pain-free volunteers and 30 individuals with another form of chronic pain. They plan to examine these samples to determine whether the molecular target is associated with particular pain characteristics (e.g., pain triggered by a nerve injury, heightened pain sensitivity to chemicals that stimulate the sympathetic nervous system, or pain that increases when the sympathetic nervous system is active).

In addition to the molecular target, biological markers of inflammation will be investigated on nerves, blood vessels and other cells in the skin samples. Doing this is important because it will help to clarify the relationship between the molecular/receptor target and chronic inflammation and pain in CRPS. Although running the tests is technically demanding and time-consuming, Dr. Drummond believes this is a unique opportunity to identify what could be a crucial generator of pain in CRPS. If so, this may open up new avenues for more effective management of pain in CRPS.

Best of health,



# Hope on the Horizon: A Slice of Recent Research into CRPS Treatments

BY KAREN E BINKLEY, MD, FRCPC

If you have CRPS, you may already realize that existing treatments do not work as well as we would like. The best hope for improved treatments will come from a better understanding of what is going wrong in CRPS, so that we are better able to fix it.

In this column, new developments in our understanding about CRPS, and implications for treatment are reviewed.

## Predicting Ketamine Response

Ketamine infusions can greatly benefit some patients with CRPS, but unfortunately, not all CRPS patients respond. While the infusions can be well worth it for some people, they are also expensive, time consuming, and unpleasant. Enduring weeks of infusions is frustrating if they don't provide any benefits.

Researchers in Philadelphia may have come up with a way to predict in advance which CRPS patients will respond to ketamine infusions. They studied microRNAs before and 5 days after ketamine infusions found in seven ketamine responders and six non-responders. (MicroRNAs are small molecules found in cells that influence the extent to which genes are expressed.) The researchers found that 33

*The best hope for improved treatments will come from a better understanding of what is going wrong in CRPS.*

microRNAs differed between responders and non-responders before therapy, so they could easily tell the two groups apart.

This was a very small study, but if the results can be replicated in larger trials, analyzing these microRNAs may be a way of predicting which patients will respond to ketamine, saving a number of CRPS patients from undergoing ketamine infusions that will not help them.

Further studies into why these differences in micro RNAs exist, and how that contributes to CRPS symptoms, may lead to better treatments as well.

## Genetic Alterations in Chronic Pain

Pain can affect your genes? Apparently so.

Studies indicate that chronic pain can result in permanent or

semi-permanent changes that alter how genes are expressed.

Researchers in Montreal and Palo Alto have shown that chronic pain can affect gene expression in the parts of the brain called the prefrontal cortex and amygdala. This occurs by adding or removing chemical tags, including some called methyl groups, to the DNA that makes up the genes.

The important part of this work is that it may be possible to more clearly define exactly what changes are contributing to the persistence of chronic pain, so that they can be reversed. Indeed, there are medicines that can change the way methyl groups are added to or are removed from DNA. So it may be possible to reverse the changes in gene expression that contribute to the maintenance of chronic pain.

Such treatments are a long way off from being available in the clinic, but it is reassuring to think of the potential avenues that may yield new treatments.

## ABOUT THE AUTHOR

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

EVENTS

# Getting the Word Out

BY JENNY PICCIOTTO

On November 1st, 2015, it was raining in Charlotte, North Carolina. Groups of healthy young athletes mingled with CRPS patients sporting canes and wheelchairs in the drizzle. Friends and families gathered in Race Village. The Governor and Mayor had declared the day CRPS Awareness Day, the Wells Fargo Duke Energy Building was lit up in orange, and 250 bright orange bags filled with sponsor gifts and CRPS information packets were ready to go. 175 runners and walkers, and 50 volunteers gathered for the 3rd annual Fight the Flame® 5K race, decked out in their Fight the Flame T-shirts. The course was prepped for both athletic participants and CRPS runners/walkers, with encouraging signs posted along the route, benches positioned to offer a spot to rest, and golf carts ready for anyone who couldn't make it to the finish line.

None of this would have happened without the love and dedication of the Stillitano family.

Beth Stillitano is the consummate CRPS warrior. She has had CRPS since 1996, when she tripped on construction debris in the hallway of the school where she was teaching. Only twenty-four and just married, she underwent four knee surgeries.



*Beth Stillitano is the consummate CRPS warrior.*



Beth Stillitano is the lead organizer of the Fight the Flame 5K.

But that didn't stop her. Over the course of 19 years, she has progressed from being confined to bed, to using a wheelchair, to walking with a cane. She has tried everything from opioid therapy to Trigger Point injections, nerve blocks and Calmare. Recently she has begun ketamine infusions. Through it all she has valued the love and support of family and friends. She is still happily married. Together, she and her husband have raised two children. She is active in the CRPS community, sharing her story, raising awareness, and raising money for research.

Fight the Flame 5K was born in 2013 when Landon Stillitano needed to complete a community service project. He was 12 years old, and loved to run. He knew about the RSDSA's annual Achilles 5K because Beth's sister had participated in the event for many years. He decided to organize a local 5K in support of his mom.

It was a big success, with 175 registered participants. Of these, there were 20 people with CRPS who met one another for the first time. They created a support network that keeps in touch online. When enthusiastic racers said they would be back the next year and people

who had never heard of CRPS before were moved to make contributions, they decided to make it an annual event.

Since then, Beth has become the lead organizer. The annual Fight the Flame 5K is held in November to coincide with CRPS Awareness Month. Since 2013, the group has raised over \$50,000 in donations contributed generously to the RSDSA for research.

Organizing is a team effort, and getting the word out about CRPS is a top priority. Morgan, who has CRPS, was a student at University of North Carolina at Charlotte when she participated in the 2014 run. She interned for Fight the Flame during her senior year and has stayed on as an event organizer. Beth's daughter Alana, a senior in high school, organizes 40 to 50 volunteers from her school. She helps the students learn about CRPS while they help with posters, stuffing race bags, and volunteering on race day.

The sponsor drive is focused on awareness too. Each sponsor is contacted in person, and given an information packet about CRPS. Community outreach includes a website, Facebook page, social media, public service announcements and a billboard. The group also helps set up sister events in other cities.

"We have to just keep getting information out there," Beth says. "No one is going to pay for research studies if no one knows about CRPS."

This year's Fight the Flame 5K will be held on Sunday, November 6th. All money raised will be donated to further educate the public, raise awareness and help fund both the RSDSA sponsored LDN research at Stanford University and its Brad Jenkin's Patient Support Fund.

The RSDSA applauds the work of Beth and the Fight the Flame team for their tireless efforts to promote awareness and their generous contributions to the CRPS community. You can learn more about Fight the Flame at [fighttheflame5k.org](http://fighttheflame5k.org) and [facebook.com/FightTheFlame5k](https://facebook.com/FightTheFlame5k).

*"No one is going to pay for research studies if no one knows about CRPS."*



#### **ABOUT THE AUTHOR**

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

## EVENTS

# Color the World Orange™ 2015 Unites CRPS Community to Bring Global Awareness

BY THE COLOR THE WORLD ORANGE TEAM

The second-annual Color The World Orange, held Nov. 2, 2015, was a huge success, bringing global awareness to complex regional pain syndrome (CRPS), also known as reflex sympathetic dystrophy (RSD).

More than 30 buildings and landmarks around the world turned orange on Nov. 2 for Color The World Orange, and 75 proclamations were granted by politicians across the U.S. recognizing the event and CRPS/RSD.

Held annually the first Monday of November, Color The World Orange was started in 2014 to unite those affected by CRPS/RSD. The event is a day where all CRPS patients, along with friends, family and medical professionals, can join together and bring global attention to a disorder that too few people understand.

“The second-annual Color The World Orange was a huge success and proved that working together can make a difference,” the Color The World Orange organizers said. “By continuing to support each other, we will bring even more awareness to CRPS/RSD and show the world that while we are in pain, we are strong.”

Supporters from around the world took the Color The World Orange message to heart by working to have building and landmarks turn orange for Color The World Orange on Nov. 2.

In the U.S., the Con Edison Clock Tower in New York; the dome of the Nassau County, NY Theodore Roosevelt Executive and Legislative Building; the Terminal Tower in Cleveland; Houston’s City Hall; the soda bottle at “Pops”; the Crystal Bridge at the Myriad Botanical Gardens in Oklahoma City, Oklahoma; the Light Blades in Wharf District Park in Boston; and the Crazy Horse Memorial in South Dakota were all lit orange on Nov. 2 for Color The World Orange, as were buildings in Chicago.

In Pennsylvania, the dome of the Westmoreland County courthouse, the Gulf Tower and the tower fixture in the lobby of the PNC Tower in Pittsburgh, the South Street Bridge in Saegertown, and the PPL Tower in Allentown, were all lit orange. In Florida, the Amway Center and the fountain at the Lake Eola Park in Orlando, and the 110 Tower in Ft. Lauderdale, were also lit orange, as were the VUE building and the Duke

Energy Center in Charlotte.

In Australia, the water fountain in the Burdekin Shire Council, the SkyPoint Observation Deck, the State Library of Queensland, the Queensland Performing Arts Centre, the Brisbane Convention & Exhibition Centre, the Melbourne Observation Wheel and the Brisbane Treasury Casino and Hotel were all orange on Nov. 2. In the UK, the Brighton Wheel was also lit orange.

*Mark your calendar.  
Join the third-annual  
Color The World  
Orange on Nov. 7.*

Four supporters ran the NYC Marathon in honor of Color The World Orange and CRPS/RSD awareness and additional supporters in the UK completed a 12-hour bikeathon. There were also skateboarders and skydivers, all bringing awareness to CRPS/RSD.

There were 75 proclamations granted in the U.S., including 34

from state governors. That is an increase from 45 proclamations and citations granted in 2014.

Supporters raised more than \$4,650 for the RSDSA to be used for research through a kickoff

## GET INVOLVED

### Facebook

facebook.com/  
ColorTheWorldOrange

### Website

colortheworldorange.com

event, a FirstGiving fundraiser, as well as Zazzle and Bravelets sales.

There were also multiple news articles and TV news reports about the second-annual Color The World Orange.

The defining memory of Nov. 2, though, was all of that orange. Social media turned orange, too, as supporters posted pictures with the hashtag: #CRPSORANGEDAY.

There was orange food, orange shirts, orange pins, orange balloons, orange wigs, orange

shirts, and lots of orange ribbons. There were doctors, nurses, babies, grandparents, mothers, fathers, friends, classmates and colleagues, all wearing orange.

“The second-annual Color The World Orange was a huge success due to the hard work of all of the wonderful Color The World Orange supporters,” the event’s organizers said. “Our supporters’ amazing effort is what allows the event to continue to grow and bring more awareness each year. Please mark your calendar and join us for the third-annual Color The World Orange on Nov. 7.”

# We Are Going Back to Camp!!!

The Center for Courageous Kids is hosting Pediatric Pain Week from July 25-29.

To apply, please visit [www.courageouskids.org](http://www.courageouskids.org).

If you know a child living with chronic pain syndromes, this is the place for them! From archery to horseback riding, there is something for every child at CCK.

You must apply prior to May 30. See you there, campers!



# 120 Days of Healing

BY MARCY RIZZO

I heard the snaps before I felt the wiry nap of the office carpet against my skin. I considered getting up and pretending that I didn't just round the bend and crash. I was a newcomer to this job with the MIT Technology Review. I still had to prove I was competent, reliable, and a person who didn't cry, whine... or fall.

It quickly became clear to me that this fall on October 13, 2013 was not ordinary. As it turned out, that fall would profoundly alter the next few years of my life, and of those close to me.

Prior to the fall, I knew for a couple of months that something was going to happen to me. Pushing myself too hard at work, I was anxious and wildly driven to complete a difficult project that involved writing a big report and producing an event for the Russian Federation. There was a hard deadline to achieve, and Russian partners were formidable in their expectations. I barely slept and hardly ate. The moment my eyes popped open after a couple hours of fitful sleep, my only thoughts were of the next line of copy. I felt as though I was suffocating from the pressure on my chest: I just could not catch my breath.

It was just a job right? I asked myself. Of course. But for those of us that teeter on the OCD line, there will always be one more



thing to do before we permit ourselves the next reward. After a long year, this research project would culminate in just two weeks at an event in Moscow. This was the home stretch. If I could just hold out and finish the last pieces, it would be behind me. There was no point in holding back now.

When I fell, nearly everyone in the office was out at an annual

event on campus. I was plowing furiously forward like a steroidal gerbil, begrudgingly leaving the computer (my ball and chain) to dash off to the printer. En route, I hit a slippery spot on the rug and my legs slid out from under me. I fell hard, hip on wrist, as I came around the corner.

Someone pulled up a chair for me. My wrist and hand were in a

*To heal,  
I had  
to move  
through  
the layers  
of pain.*

very strange position. The last thing I recall is my head folding forward. I passed out, gurgling for about 10 minutes, I'm told. When I came to, two handsome EMTs were arriving. They were so lovely and sweet that on the way to the hospital, I tried to fix one of them up with my daughter. I felt oddly safe and protected for those 13 minutes until they dropped me off in the emergency room hallway. A funny thing about pain is that the pain itself is hard to recall exactly, but the thoughts, smells, colors, sounds and sense of place that surround it are clear.

My wrist snapped in two places and chipped in a third. I went through two rounds of traction and manipulation/ closed reduction, then surgery, and then several casts while the bones healed.

Five days after surgery, I was due to fly to Russia for a week-long trip to present my hard-won work. Arranged long before my injury, I went on the trip despite my pain. I wore a cast that was split to enable my opening it if the pressure from the plane affected the swelling. When I arrived back home and removed

the cast, my forearm looked like it was from a scene in a horror movie. There was not even an inkling of familiarity to make me sense that this was my hand.

I expected to have my old hand back in a short time, as promised. Instead, strange things began to occur. While it is my wrist that broke, it is my hand that is possessed. My hand would swell like a balloon so that my fingers seemed all stuck together. It would turn shades of purple with hot pink spots. It became shiny, like a sweaty bald head under a hot sun. Pain buzzed through my hand like it was submerged in a pool of electric current. Sometimes my hand would feel lit from within; other times, it felt cold and encrusted in ice.

Reflex sympathetic dystrophy, affectionately still called by some as RSD, was mentioned very carefully by my doctor and hand therapist. I didn't pay much attention at first. I thought they were telling me worst case scenarios, not relaying a diagnosis. They were circumspect on the topic, to say the least. But as time marched on, I kept failing to meet the usual milestones of recovery of hand function. Worse, the tiniest movement caused intense, unbearable pain.

I started learning more about RSD, renamed to complex regional pain syndrome (CRPS) in the 1990's. Experts believe that RSD/CRPS occurs as a result of dysfunction in the central or peripheral nervous systems.

What a strange thing. I read that the pain typically grows worse rather than better over time. If RSD/CRPS occurs after an injury, it is often out of proportion to the severity of the injury. I stop reading and start to understand the reticence of my medical team to assign the condition. It is not exactly hopeful. There is no cure for CRPS.

Apparently, however, there was a path to overcome RSD. Movement. My surgeon said, "You are making me look bad, kid. If you don't move those fingers, we'll have to go in surgically to pull out the scar tissue."

As I understood, it was a race against time for the hand to heal before the scar tissue consolidated and usurped those happy tissues whose job it was to enable a fist or a wave; to hold a fork or clasp a bra.

I went to hand therapy three times a week, often walking the 10 miles round trip to distract myself from the pain. Since my right hand is dominant, everything I tried to do with my left at first ended in something breaking or dropping. My car: a stick shift. I did nothing but walk and go to therapy. Friends brought me food, sometimes coffee. My son shoveled me out through the winter. I kept walking then, using a woolen sock to keep my hand warm, as I could not get it into a mitten or glove. I took a leave from my job. I only had the energy to heal. And I wasn't sure it would ever happen.

### Wading through the pain

With RSD, I learned the nervous system misfires, sending pain signals to the brain when there is no physical reason for the pain or constraint of movement. Although the break and surgery was to the wrist, RSD affected the entire hand, and at times the whole arm. I could barely move my fingers and wrist.

To heal, I had to move through the layers of pain. . I don't mean achy, throbbing kind of hurt, but a sharp, screeching siren that demanded I stop. I would move my fingers a tiny bit and breathe. When the pain abated, I would move my fingers a little more. My therapist gave me a glove with hooks and rubber bands to mechanically bend the fingers slowly, one notch at

a time. Pain signals the body to stop, yet I had to ignore those signals and keep moving. Oddly enough, my best friend is a hand surgeon. If he wasn't present during these early sessions, I would have stopped. It seemed incongruous to move in this way.

As a way to work through the debilitating pain and regain hand movement before I lost the battle to encroaching scar tissue, I not only did every manipulation known to 13th century torturers, I also used art. I was moving from Medieval to Renaissance! I would draw or paint everyday. I would also sing, dance, and eventually cook, activities that lifted my spirits and aided my recovery. These activities also provided a way for me to measure improvement in a

sensory framework, beyond the incremental clinical measures.

These 120 days of healing, as I've come to call this period, represent the four months after the removal of my cast. The body of work I curated from these painting sessions is a tribute to recovery. It is also a demonstration for others, so they can understand not only the dance of pain, but the potential contribution of art and movement in the healing process. Painting was part of my four-element healing program of art, song, dance and food.

### The healing process

Art – A storyboard of 15 framed drawings I created during my healing. They are grouped into healing segments of 4 to 6

These three excerpts from Marcy Rizzo's artwork during her 120 days of healing each represent a stage in movement gained.



paintings each. Each segment represents a stage in movement gained, and the healing is measured by the use of a more refined drawing instrument.

Song – I sang two songs – “Wayfaring Stranger” and “Warm Love” –up to 20 times a day, sometimes at the top of my lungs, other times quietly. It became my form of prayer.

Dance – I danced sometimes in my house alone, sometimes even in my favorite graveyard, where I knew those watching wouldn’t tell. I also danced to my favorite local musicians around the city, wearing a safety glove so others knew to be careful of my hand. To avoid self-consciousness, I moved my attention to someone in the room who needed love. I would dance for them. As it turns out, just about everyone needed that love.

Food – I love to cook, but initially I could not even peel an orange, much less chop an onion. Cooking became a slow advance toward recovery. I would invite someone to dinner so that it required sustained efforts at chopping and cutting for nearly every ingredient – a great feat for a woman with a non-functional right hand. Believe me when I tell you that this started out badly.

It has been a couple of years since the fall. Visible symptoms of RSD have abated. Yet, I still can’t make a fist, I drop things randomly, and often deal with pain in my hand and wrist as well as stiffness in the fingers.

Sometimes the entire arm aches so badly, I need to just lay it down. But as I’m told, my progress has been exceptional comparatively. When in doubt – move.

Mark Twain said that the definition of insanity is doing the same thing twice and expecting a different result. It is not quite so simple. The body is a miracle of interpretation. The life I live is the life I attract, largely due to what I know and believe at the time. My point is that we can help ourselves with the simple tools we have close, even if it is just a pencil. Pain, like death, can be

an advisor or the enemy. Were I a praying woman, I would ask for grace and one more chance. And I ask the same for you.

#### ABOUT THE AUTHOR

*Marcy Rizzo writes about her fall into CRPS and how art and perseverance help to pick her up. Based in West Newton, MA, she is senior content producer at the MIT Technology Review, where she researches and creates educational content to help enable innovation in emerging countries. Marcy is the mother of two beautiful children, Talia, 27 years old, and Joe, who turned 18 this year. She calls herself an artist when she is creating. Anyone who makes an effort to create, she says, is an artist. You can contact her at [Mbrrr17@gmail.com](mailto:Mbrrr17@gmail.com). You can read the report she developed when she fell at [http://forinnovations.org/upload/MIT\\_Technology\\_Review.pdf](http://forinnovations.org/upload/MIT_Technology_Review.pdf).*



# A CEO with CRPS Reclaims His Life

BY ELISA FRIEDLANDER

Mark Bertolini, chairman and CEO of the Fortune 100 company Aetna, shares his life following a near-fatal accident that resulted in CRPS. His subsequent practice of yoga and meditation was so positive that it led Mr. Bertolini to implement classes for employees at the worksite.

Our conversation took place over speakerphone and, in the spirit of full disclosure, I informed Mr. Bertolini that my dog was listening in. He revealed a soft spot in his heart for dogs as well. As part of his philanthropic work, Mr. Bertolini is a board member for a guide dog organization where he lives in Connecticut. His latest contribution includes raising and training a seeing-eye dog.

**Mark Bertolini:** I'm doing the first year socializing. She's nine weeks going through all the puppy stages so it's real fun.

**Elisa Friedlander:** Have you done that before?

**MB:** No, but every year I make a donation to provide for the development of a dog for somebody who needs assistance for sight. They socialize these dogs very differently than you would a normal puppy; the manual's like an inch and a half thick.

**EF:** Are you doing that on your own or do you take him to classes?

**MB:** We go to classes once a week for the twelve weeks.

**EF:** I helped train a hearing dog. I was teaching parenting classes at the time; there were a lot of similarities!

**MB:** There are a lot of similarities. Puppies, like babies, discover everything through their mouth. But babies have gums and puppies have very sharp teeth, so my hand looks like a pincushion.

**EF:** Ouch. But that's sweet.

**MB:** It's fun.

## We shift from pooch-talk to Mark's injuries...

**EF:** I read online about your ski accident. Tell me about that, and your subsequent CRPS diagnosis.

**MB:** I was skiing with my daughter. She yelped and I took a quick look over my right shoulder. I caught the left edge of my ski and hit a tree with my head turned back. I broke C2, C3, C5, C6 and T1. Unconscious, I rolled around behind the tree and then slid head first 60 feet down into a river. The cold water ran over my neck for two hours while they tried to rescue me. They had to create a pulley system to get

*It was the cold water that prevented my spinal cord from swelling and rupturing and killing me.*

me out of there on a backboard. Actually, it was the cold water that prevented my spinal cord from swelling and rupturing and killing me. I had a right upper subdural hematoma. I hit the tree so hard that I fractured my left scapula down the middle. I macerated my brachial plexus and was mostly paralyzed on the left side for the first two months after the accident.

**EF:** How frightening...

**MB:** Yeah, I was in a coma for about a week. They had given me last rights...and when I woke up they said "My G-d, he's alive." Then they said, "What do you

*It worked for about a month, but then the pain came back in a more horrific way.*

need to know?" The last thing I remember was looking back at my daughter and she gave me the thumbs up that she was ok. Then, the next thing I remember is the nurse giving me a sponge bath. So I asked the nurse, "How do I get out of here?"...She said, "Well you need to be able to walk with a walker up and down the stairs. So five days later I did that, then signed out against medical advice.

**EF:** Really?! Were you in pain?

**MB:** You know, interestingly enough, I didn't have a lot of pain at all, until about a month and a half later. One night I woke up with this searing pain in my left hand, like somebody had chopped it off. [The neuropathy] is from the tip of my left ear all the way down to my left fingertips. It just burns all the time, like I hit my funny bone really hard. In the beginning [the doctors] said it will resolve as I get more use back in my arm and when the nerve heals, but that never happened.

**EF:** When did you return to work?

**MB:** I had the accident on February 18th and did our investor meeting on May 15th. I walked down the aisle with a neck brace and a tripod cane and gave the presentation for the company.

**EF:** So from the time you were in

the hospital to the actual CRPS diagnosis, how long was that?

**MB:** It actually took them a long time to figure that out. At first they thought they could do some nerve blocks and suggested other options. I was probably diagnosed within the first twelve months.

**EF:** You know about the benefit of earlier diagnosis and treatment options. Had anybody mentioned RSD prior to that twelve month mark?

**MB:** No.

**EF:** So with all of the complications, nobody suspected.

**MB:** Well they always thought it was going to get better.

**EF:** Of course.

**MB:** If you don't get better it's your fault, not theirs.

### **Treating the pain**

**MB:** I met with anybody who had any idea about how to deal with this, I saw dozens of neurologists, a handful of neurosurgeons and met with a psychiatrist for awhile to see if it was all in my head. I went to different whack-job practitioners doing pounding on the back of my chest, hanging me upside down and having me recite things backwards and all this other crazy stuff. I got off the opiates when I got into the cranial sacral therapy, yoga and acupuncture. I still carry my own needles



Mark sits on his modified motorcycle beside his son.

*I needed to do all these things to get control of my life because, if I didn't invest in it, nobody else will.*

with me and administer my own acupuncture.

**EF:** I have never heard of anybody doing that. Does it help you?

**MB:** When my physician pulled [the needles] out and left the room, I put little pen marks so I could see where they were.

**EF:** You were really taking control of your treatment.

**MB:** Well, as you know, suffering from this issue, people think you're a little crazy anyway.

**EF:** Yes, unfortunately. Has your pain changed over time?

**MB:** My pain has changed. I saw Pradeep Chopra; he has me on low dose naltrexone (LDN)

and beta blockers at night to sleep better. That's actually provided some relief to my pain. I have some return of function in my hand and proprioception in my arm now. (*Editor's note: Proprioception is the ability to sense body placement and stimuli.*)

**EF:** I know that you can't go on the LDN if you have been recently taking opiates. Were you taking them at the time, and did you have trouble transitioning?

**MB:** After my first year on the opiates, I was totally stoned. It was like the Peanuts movie when his mother used to talk.

**EF:** Right, "Wah. Wah. Wah!"

**MB:** It wasn't working for me so I just stopped them...When I went on the LDN I wasn't taking anything for pain. In the middle of that I even tried high dose ketamine therapy. I went in the hospital and they locked me up in an ICU for seven days and administered 50 milligrams of ketamine an hour for seven days. It was quite the stoner dose. It worked for about a month, but then the pain came back in a more horrific way.

**EF:** Did they tell you that sometimes the pain comes back worse after treatment?

**MB:** They suggested I go on booster infusions, which I tried for awhile. So one day, I'm in the infusion therapy center and I'm getting legally high on Special K. I'm the president of a company listening to Rachel

Ray make a flaming ragù listening to "Burning Down the House." It was hysterical, I couldn't make this up. I said this isn't going to work, I'm not doing it.

### **Living with CRPS**

**MB:** It cost me my marriage, quite frankly. My then-wife blamed me for the accident and said, "I told you not to be nuts on the ski lift like that." I was in pain all the time then, and she would say, "Get over it, the accident happened a long time ago."

**EF:** That's awful. How has CRPS impacted other areas of your personal life?

**MB:** It takes awhile to get ready in the morning, get out of bed. I like to do my yoga every morning to begin my day so that I'm in a good place mentally.

**EF:** Did you go through periods of depression and/or anxiety? That's secondary to this for so many people.

**MB:** I guess I did have depression, but when my then-wife told me she needed to get out of this relationship, I had this sort of epiphany, I'm in this by myself, if I don't deal with it it's going to get only worse. I used to run four miles every morning. I was very muscular, 180 pounds and only eight percent body fat when I hit the tree. I went up to 240 pounds after that accident. I'll never forget her saying to me, "Look at you, you're a fat slob." She said, "You're always in pain." So I decided to get back in the gym and do as

much as I could, lose my weight and find another way to exercise. I needed to do all these things to get control of my life because, if I didn't invest in it, nobody else will. At that time I had been married for twenty-seven years.

**EF:** You lost so much. Did you get any mental health counseling to deal with the grief?

**MB:** I went to somebody who didn't really understand my condition well enough. She actually said to me, "You're a masochist, trying to live a life you can't live anymore, and you're only hurting yourself and the relationship." I got up in the middle of that and said, "You know what, you don't know anything about what I'm going through," and I left and never went back.

**EF:** So did you find another therapist?

**MB:** I found somebody else and spent about three months with him, every other week.

**EF:** Do you have a CRPS community or know other people who have CRPS?

**MB:** No, I don't actually.

**EF:** Is that something you feel you would like to do, to connect with other people?

**MB:** It's nice to know there are more people out there that have it. I think it would be helpful at some point.

**EF:** Do you use any assistive devices and are there frustrations around the barriers you face?

**MB:** We actually have a huge program here devoted to helping disabled people work, so my whole office was set up for me when I came back.

**EF:** That's rare, fantastic. How did they know what you needed?

**MB:** They're experts at it. I call them the 'ergonomic police,' it was really helpful... But one of the things I found absolutely frustrating was that whenever you go somewhere and say, "I need handicapped assistance," they assume you're in a wheelchair. There is a view of a handicapped person in a chair; I find that frustrating.

**EF:** Right, all the blue symbols of a person with a disability in a wheelchair. What else have you learned about yourself through this process so far?

**MB:** One of the hardest parts of this type of injury is the impact on body image.

**EF:** Oh, yes, I know that one.

**MB:** Right? That was probably one of the steps along the journey for me, that I was never going to be able to bench-press 350 pounds. But that didn't matter anymore, you have to sort of get over that. The whole idea that you can still be important, attractive to others, in a relationship and not be what you were before is really hard for people to figure out.

**EF:** That is so true. I don't think it's a start-and-end process, I think it's something that's ongoing.

**MB:** One of the things I found is that my world was tied up in all the relationships I had, and I had never spent enough time being comfortable with who I was by myself. You find yourself isolated from others as a result of dealing with it. Unless you are comfortable being with yourself, it's really hard.

*The whole idea that you can still be important, attractive to others, in a relationship and not be what you were before is really hard for people to figure out.*

**EF:** Well said, and I think connecting to other people who have CRPS helps with the isolation. As you know, nobody knows what you're going through.

**MB:** You can't possibly describe it to anybody, and you never believe you can handle it. When the doctors told me "You have RSD and it's going to be a lifetime thing," it was like a death sentence. I thought, Well this is it, I'm done.

**EF:** And it also makes quite an impact based on how they tell you that.

**MB:** Yep.

### **Mark reclaims his life**

**MB:** I'm in a relationship now that's been fairly strong. She's actually a cranial sacral therapist and a yogi, so she has a sense of understanding. She also has Ehlers-Danlos. She's seen Pradeep Chopra so we're both on the same medication protocol.

**EF:** That's convenient!

**MB:** Within two years of my accident, actually the second anniversary of it, I got back on my skis and skied the same run.

**EF:** Tell me about that voice inside you that said I have to do this on my second anniversary.

**MB:** I had to reclaim my life. This injury's not me; I can work around this.

**EF:** What else did you do?

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**MB:** I hired an adaptive ski instructor and got back on my skis. I got my motorcycles modified so I could ride them, and I took adaptive golf and learned how to golf with one hand. I also got back to driving with one hand. I learned how to tie my tie by watching the movie "Bullitt" where Steve McQueen ties his with one hand while driving. I learned to do all sorts of things and then I got into yoga and mindfulness as a way of trying to control the pain. [The accident was]

February 18th, 2004 at 1:05 PM.

**EF:** You really know the specifics.

**MB:** I know the tree. I actually went and put a brass plaque on it that said: "Mark was here."

### **The worlds of medicine and insurance**

**EF:** Other than implementing these wonderful meditation and yoga classes, has CRPS changed the way that you run your company?

**MB:** We invest a lot to make sure the people who work here have the best work environment for their own specific needs. I think the other part is empathy, which starts at the top.

**EF:** Absolutely. How can RSDSA, and the CRPS community in general, work together with you to increase awareness for earlier diagnosis, and make access to treatments better?

**MB:** It would be worthwhile to get an understanding about how to diagnose CRPS, and then what cocktail of things to offer people out of the box that can help them find the right path.

**EF:** The CRPS community would like to see some protocols. There is so much disparity in how doctors think about CRPS. How can the medical world come together on this?

**MB:** First of all we need people to recognize that this is a real problem. [Until this happens], nobody worries about political

pathways to fix it. Then, it needs to be evidence-based.

**EF:** I know that Connecticut passed legislation for medical marijuana use. What are your thoughts about this?

**MB:** We cover medical marijuana for certain conditions. We don't cover it for depression, as an example.

**EF:** Do you cover it for CRPS?

**MB:** Yes, if it's prescribed by a physician.

**EF:** How typical is that for insurance companies?

**MB:** It's very typical as long as it's prescribed by a physician [who diagnosed] a specific condition like nausea, glaucoma or CRPS.

**EF:** Meditation and yoga seem so integral to your treatment and care-plan, and helpful for your employees. Do you think this will become a trend at other worksites?

**MB:** We actually have employers who are interested in it. We have now, I think 13,000 employees go through the program here.

### Last thoughts

**EF:** I realize you haven't talked to others with CRPS, but many who do mind-body practices and take control of their lives are still unable to work because of the horrific pain. What are your thoughts about that?

**MB:** I had to reshape this job

when I took it because I couldn't operate the way the last person did. I had more latitude because I'm an important person here and people make things happen for me when I want them a certain way...It's fascinating, the things I used to think were important before I got hurt now have no meaning to me.

**EF:** What message would you like to send to people?

**MB:** One I learned from a twelve year-old, who at age eleven told his mother that he was not a girl [as he had been raised]; he was really a boy. He was standing in front of a restaurant in San Francisco holding up a sign. Everyone lit up and smiled at it as they walked by. The sign said: "You are awesome just the way you are."

**EF:** That's a beautiful story.

**MB:** Isn't that cool? He's an amazing kid. But his mother had the courage, and he had the courage to say I'm not who you think I am. He said, "I'm not Anne, I'm Andy."

**EF:** That's perfect. Thank G-d he got the mom he did!

**MB:** Yes [laughing].

**EF:** Thank you for that wisdom. Your perspective on life, your attitude and commitment to living the best life you can is admirable. I appreciate you taking the time to talk.

**MB:** Thank you for the

conversation and I look forward to meeting in person one day.

Mark Bertolini is clearly a man who chooses to be in control of his life. This determination, along with his unique set of internal and external resources, has manifested in a meaningful existence.

As those of us with CRPS know, there is usually a price to pay for functioning beyond our limits, and I don't know what happens for Mr. Bertolini when he pushes himself (or even when he gets home from a day at work). What I do know is that he has harnessed his gifts in a way that makes CRPS and other physical problems secondary to the bigger picture of his life. I'm sure the twelve-year old boy would agree, he is awesome just the way he is.



### ABOUT THE AUTHOR

*Elisa Friedlander is a licensed marriage and family therapist living in the San Francisco Bay Area. You can read her blog at [ElisaFriedlander.com](http://ElisaFriedlander.com), find her on Twitter as [@Elisafriedlandr](https://twitter.com/Elisafriedlandr), and reach her by email at [ElisaFriedlander@gmail.com](mailto:ElisaFriedlander@gmail.com).*

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

**EVENTS CALENDAR** 

**MARCH 1**

**FUNDRAISE FOR THE COURAGEOUS KIDS CAMP!**

We collecting donations from Penny Pig to help send children living with chronic pain syndromes to a summer camp! Send in your Penny Pig donations – and feel free to keep the Penny Pig with you!

**MARCH 1 – 14**

**THIRTY-ONE BAGS FUNDRAISER**

Rachel Pinsky is back to help the RSDSA fundraiser. Before March 14, you can visit [www.mythirtyone.com/bigapplebags](http://www.mythirtyone.com/bigapplebags) to order useful home organization products or some new accessories for yourself!

**MARCH 20 – APRIL 15**

**PERFECTLY POSH FUNDRAISER**

Shop online for all-natural products for you and your home, including essential oils and more. Everything is under \$25 and 25% of sales go directly to the RSDSA. Shop at [www.perfectlyposh.com/Michellewinnposh/](http://www.perfectlyposh.com/Michellewinnposh/) and then select RSDSA Fundraiser at checkout.

**MAY 14**

**TAILS OF THE CRPS DOG WALK**, Jacksonville, FL

**JUNE 12**

**RSD AWARENESS 6K & 1 MILE WALK-RACE**, Boston, PA  
**WALK 2 MILES IN MY SHOES FOR RSD/CRPS**, Scranton, PA

**JUNE 26**

**ACHILLES INTERNATIONAL WALK FOR HOPE AND POSSIBILITY**,  
New York City, NY

**JULY 25-26**

**PEDIATRIC PAIN WEEK AT THE CENTER FOR COURAGEOUS KIDS**,  
Scottsville, KY

**SEPTEMBER 10**

**NASSAU COUNTY RSD AWARENESS WALK**, East Meadow, NY  
**WALK FOR AWARENESS AT COOPER RIVER PARK**, Pennsauken, NJ

***Don't see an event near you?***

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

**PEER-TO-PEER CONVERSATIONS** 

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

**VOLUNTEERS:**

If you wish to volunteer, please do the following.

- Please contact [LindaLang@rds.org](mailto:LindaLang@rds.org)
- Please tell Linda something about yourself and your experience with RSDS.
- Please include your email and a phone number where you may be contacted.
- We especially need teens and parents of children with CRPS to volunteer.

**THOSE IN NEED OF SUPPORT:**

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

- Please contact [LindaLang@rds.org](mailto:LindaLang@rds.org)
- Please provide your email, phone number and a little bit about yourself.

Turn hurt into help. Donate today. Call 877.662.7737 or visit [www.rds.org](http://www.rds.org)