

rsdsa  
community update

VOLUME NO. 2

ISSUE NO. 4

WWW.RSDS.ORG/NEWSLETTER

Winter 2015

# The Center for Courageous Kids

COVER STORY p.4



FEATURE STORY p.6

When CRPS Severs the Nerves of Our Work Lives:  
How to Transcend the Heartache

# INSIDE THIS ISSUE

## THE DIRECTOR'S LETTER

**A Winter Update** 3

## EVENTS

**We Feel So Good: Our Experience at the Center for Courageous Kids** 4

**Events Calendar** *Back Page*

## CRPS COMMUNITY & CULTURE

**When CRPS Severs the Nerves of Our Work Lives: How to Transcend the Heartache** 6

A therapist comes to terms with her heartache from her inability to work after CRPS

**Back to School: Educating Teachers about CRPS** 11

A guide to being your child's best advocate

## HEALTH & FITNESS

**The Need for an Active Sex Life** 13

Must CRPS and sex be exclusive?

**Fall Harvest Quinoa Salad** 15

A vegetarian treat

**Find Us Online**

**Blog**

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

**Twitter**

[@rdsda](https://twitter.com/rdsda)

**Facebook**

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

**YouTube**

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

[RSDSAofAmerica](https://www.youtube.com/user/RSDSAofAmerica)

**Instagram**

[@rdsda\\_official](https://www.instagram.com/rdsda_official)

## CALL FOR AUTHORS AND IDEAS

*Do you have a personal story, art, or knowledge to share with the CRPS community? 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, Lilly, Medtronic, and Purdue Pharma. For more information about becoming an RSDSA Corporate Member, please contact Jim Broatch at [info@rdsd.org](mailto:info@rdsd.org).*

THE DIRECTOR'S LETTER

# A Winter Update

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

On September 19, RSDSA sponsored Dr. Philip Getson as a presenter at the American Academy of Pain Management Annual Conference. His two lectures on Complex Regional Pain Syndrome (CRPS) were attended by more than 400 medical professionals. His presentations on the diagnosis, treatment, and management of CRPS (CRPS 101 and Complications associated with CRPS) will serve as an accredited CME/CEU program for physicians, nurses, and eight other medical specialties. The program will become available in January.

## RSDSA Opposes Ketamine Rescheduling

RSDSA's Professional Medical Affairs committee wrote to the FDA to oppose a revision by the World Health Organization (WHO) to the international scheduling of ketamine. China requested ketamine's reclassification to be a Schedule 1 medication because of rampant illegal use of ketamine in Hong Kong and mainland China.

## RSDSA Issues Call for Proposals for Development of Guidelines for Ketamine Infusion in the Treatment of Complex Regional Pain Syndrome

RSDSA has invited applications for a clinical survey award for the



JIM BROATCH AND HIS GRANDDAUGHTER CORA MARIE.

purpose of developing ketamine infusion treatment protocols that will obtain consensus among CRPS practitioners. This will form the basis for controlled clinical trials of ketamine in the treatment of the neuropathic pain of CRPS.

Since the precise mechanism of CRPS disease is elusive, treatment has been directed to symptom relief and control of secondary physiological effects. NMDA dependent transmission in spinal pathways has been implicated in the hyperalgesia and allodynia of CRPS. Dramatic remission of severe pain has been observed for variable intervals following ketamine infusion. Ketamine, previously used exclusively for dissociative, general anesthesia and recently as a recreational drug, is increasingly employed for outpatient infusion treatment to induce remission of symptoms and signs of CRPS. But its use in CRPS is "off label". Protocols vary widely and no guidelines for the

use of ketamine in CRPS exist.

The research will identify the variety of routes, dosage, duration, and schedule of ketamine infusion for CRPS. If you are interested in applying, individuals may contact Jim Broatch at [info@rsds.org](mailto:info@rsds.org) or by calling 877-662-7737.

## Medical Marijuana for CRPS Is Approved in Connecticut

The RSDSA was instrumental in securing the addition of Complex Regional Pain Syndrome to the list of approved conditions under Connecticut's medical marijuana law. Medical experts say marijuana has the potential not only to ease the pain suffered by CRPS/RSD patients, but also to lessen the side effects of other medications used to treat the condition, which include depression, nausea, and headaches. Special kudos to Drs. Pradeep Chopra and Karen Devassy who helped make this addition possible.

Best of health,

EVENTS

# We Feel So Good: Our Experience at the Center for Courageous Kids

BY SAMANTHA BARRETT

There are countless children who suffer from chronic pain. A majority of these children do not get to do things that their able-bodied friends are able to do, including summer camp. The Center for Courageous Kids helped us change this for our friends with pediatric pain. This was made possible by a collaboration between The Coalition Against Pediatric Pain, RSDSA, U.S. Pain Foundation, Rock Out to Knock Out RSD, and of course The Center for Courageous Kids. Acting as a united front, we were all able to help these kids have the time of their lives.

The children, aged 7 to 17, and their families were able to partake in a few days of pure fun in Scottsville, Kentucky. Each family was assigned a counselor or two to help them through their time at camp. Most of the counselors are going to school for various medical degrees. They are truly the future of medicine. The children and their families were able to participate in activities such as horseback riding, fishing, boating, cooking, and bowling, as well as woodshop, arts and crafts, swimming, and countless other activities. There was also a carnival, a movie night, talent show, and the Messy Games. The Messy Games seemed

to be a highlight for everyone. It doesn't get more fun than a competition to see which lodge can get the messiest!

CCK was very attentive to the different dietary restrictions and the need to inconspicuously watch for symptoms of flare-ups and overheating in the children. Camp-goer Emily Schellhammer said, "Camp is amazing and there, you aren't an illness or injury or anything. You are a name and a kid. You're equal to the person(s) next to you. Here, no matter what, you fit in. You aren't

judged. Here you're free and happy and know you are not alone."

Some of these families haven't been able to bond like this in quite some time. Having people from all over the country created a network for the kids and their parents. A mother of two of the campers, Marianne St. Clair, said, "The camp experience provided our family a place to connect, exchange information, and develop lasting positive memories with other RSD/CRPS families. Smiles and



Kids at the camp enjoyed the outdoors, many trying fishing, horsebackriding, and boating for the first time.

laughter are the best medicine and although the journey was difficult to get there and home, the trip was so worth it for the children and mom."

No one would have ever imagined that a summer camp could be so life changing. It was truly amazing to get to know the kids, parents, counselors, and other staff members at CCK. We would like to thank all who came out to participate and all who came

#### ABOUT THE AUTHOR

*Samantha Barrett is the special events coordinator at the RSDSA. She has had CRPS for 9 years. When she isn't working, Sammie can be found cheering on the Boston Bruins or playing with her puppy, Phantom. Sammie cannot resist a good book, a record, or some yarn. You can reach her at sbarrett@rds.org.*

out to help. This camp was a dream come true for everyone, particularly Sue Pinkham, who was the driving force behind the pediatric pain camp.

RSDSA is extremely proud to have been a part of this pilot year for the pediatric pain camp. We have high hopes for another camp experience in years to come. We know there are more kids out there who would greatly benefit from and enjoy this camp. These experiences are incredibly important and life-changing. If you would like to learn more about this camp, or if you would like to contribute to help us give children this chance again, please contact Sue Pinkham at [suepinkham@comcast.net](mailto:suepinkham@comcast.net) or (781) 771-2095.

## ORDER A PENNY PIG TO HELP CRPS KIDS!

Help send a kid with chronic pain to camp this coming summer!

Welcome Penny Pig into your home and fill her up. We ask that you send back the contents as a donation to help fund our camp efforts. You can keep the pig even after you donate!

Get yours today! If you would like to add Penny Pig to your home, email your mailing address to [info@rds.org](mailto:info@rds.org).



The camp brought together over 75 children, family members, and clinicians for an unforgettable experience that transcended pain.

# When CRPS Severs the Nerves of Our Work Lives: How to Transcend the Heartache

BY ELISA FRIEDLANDER

I sat next to my four-year-old client, Sophie, (name changed for confidentiality) as I did every week in my psychotherapy office. We were in front of the sand tray and I had one hand in her favorite puppet. Sophie only chatted with Monkey after he shared his own woes and ideas for managing life as a preschooler with a disability.



The monkey, whose insides allowed for multiple movements including blinking, stopped communicating for all of three seconds when Sophie said, “Make the monkey talk! Make the monkey talk!”

I was in pain and needed a brief rest, but from my periphery I saw Sophie’s absorbing eyes pleading for her friend to stay connected to her. My client had a routine of engaging deeply with Monkey and she demanded I avert eye contact with her. Of course I would; Sophie’s sacred relationship was with Monkey, not me.

Manipulating Monkey and even using simple toys in sessions became increasingly hard for me. I had been in pain since early adulthood from a genetic

spine-related disease, and it worsened over the years. Although my pain was “invisible,” it felt like somebody was slicing me with burning razor blades from my neck down my arms; it was searing and horrific.

I got through that session by breathing, silently praying, and fantasizing about throwing that eight-inch, troublemaking, pain-inducing pest of a monkey out the window. I wanted to cry. I wanted to stop. I wanted Monkey to help me the way he helped my client. More than anything though, I wanted to do the work I loved without pain. None of these were options at the time.

Meditation, using my foam roller, stretching, walks between sessions and countless other tools that got me through work

for many years no longer alleviated my pain. Any medication strong enough to help would have made me loopy; not a good quality in a therapist.

I began to wonder how I would handle each session when my next client was a child. I felt some relief before adult sessions. I knew I could shift positions and change back supports when needed, versus using my body the way I did in play therapy. Still, I felt like I was failing; what kind of therapist was I becoming if I didn’t want to be there? If I couldn’t be there? I realized I was no longer able to give my clients what they needed. I was literally praying for the session to end... what kind of therapist does that? I cried every day after work about it. I didn’t know what to do. I needed to step away, at least temporarily, from the work that was so important to me.

The instant I felt the pain surging and saw Sophie’s face was a defining moment for me. It marked the beginning of the weeks that led to my decision to take “a couple months” off from my busy private practice for my first cervical spine

---

surgery and healing. That was three years ago and I have not been able to return to work.

The surgery, which I had hoped would provide at least some relief, caused Complex Regional Pain Syndrome (CRPS). Following the surgery I had both the pre-existing pain, which prompted the surgery, and new pain that exceeded anything I ever experienced in my life. It felt like burning hot jagged edges of glass scraping my spine.

This led me back to the surgeon time and again pleading for help. He responded that other patients did great and I should be fine, saying he did a particularly “aggressive” surgery in my case, so I needed more time to heal than most. At one appointment he pointed out chocolates of gratitude on his desk from another patient, and at another appointment voiced to his intern how atypical my complaints were.

He gave me narcotics and ordered an ice machine. The narcotics did nothing for the pain, and I lived for the twenty-minute increments when I could wear the mini-freezing aid on my spine. Of course like most, I had never heard about CRPS, so I was oblivious about the additional, irreversible damage that likely resulted from months of ice use. Meanwhile, as the pain kept increasing, all I wanted to do was recover and return to my practice as planned.

I consulted another neurosurgeon who took my

concerns seriously and ordered images. He discovered the hardware had shifted and that was the most likely cause of my worsening pain. He then performed a revision multi-level fusion surgery and found that the screws from my first surgery had come completely out, leaving the titanium plate detached. A dislodged screw destroyed half of a healthy vertebrae above the location of the original attempted fusion. In addition, one of the grafts had broken and the other never fused. The bone spurs, which were meant to be removed, were still there. An orthopedic specialist said my spine looked like that of an 80 year-old. I was in my mid-40’s.

While in the hospital recovering from my revision surgery, I began to feel like I had thousands of burning splinters in my hands. It was unbearable and nobody could tell me when or if the pain would go away. Everybody, including my surgeon, said it was probably nerves firing from the surgery. Yes, and that excruciating nerve pain has spread to multiple limbs over time. I developed increasingly severe joint pain, hyperacusis, and other symptoms.

Although the doctors had all suspected CRPS, they wanted to wait six months from the onset of the hand pain prior to formally making the diagnosis. They could see, in retrospect, that it began in my spine from the first surgery, then spread to my hands from the second surgery. I was officially diagnosed by my

neurosurgeon, neurologist and primary care physician, all highly regarded in their field. When I changed insurance companies over to Kaiser, however, they insisted I start the diagnostic process from the beginning, despite having the diagnosis in my records. Several specialists eventually re-confirmed the CRPS diagnosis, but beyond unnecessary, it was unnerving, so to speak, having my treatment delayed by this process.

Moving forward, I tried various treatment modalities based on current research, medical consultations and intimate knowledge of my body. The disease continues to spread and is complicated by other medical conditions, but those of us in this world know, there is virtually no chronic pain like CRPS. The life of self-care for somebody with CRPS is like having a full time job. The last time I actually worked was three years ago. Last May marked an anniversary date for me. The anniversary of the day I sat in my doctor’s office sobbing from pain and discussing a plan for my first surgery. More significantly, it was the day I stopped working in my private practice.

I ended up sending three successions of letters to my clients saying there were complications with my surgery; I needed more healing time and would return at a later date. Finally I got that I was not coming back, and I referred my clients to other therapists. I needed to clear out my office but I could

barely lift an envelope; my family did it all for me. Reminders of my practice still sit in our garage: office supplies, toys, framed pictures and credentials, books, furniture. The sand tray. Monkey.

When I first stopped working I was devastated. Like any experience of grief and loss, with work the process became much easier for me, but it has not been linear. Feelings come up during anniversaries, other significant dates and certain

*We need to remember it is not the work we did, but the various personal qualities we brought to our work that continue to make us valuable.*

life events. I felt the grief when I was initially denied disability (like most are) and again when I “won” my disability hearing (a mixed blessing). I felt it when I sold my car, a symbol of independence that offered me space to reflect upon my work.

To this day, I feel grief when the CRPS spreads to another limb, making my fantasy “work comeback” seem less realistic. Sometimes I feel a twinge when I am helpful in somebody’s life, or when I connect with children. On occasion I feel it when I overhear people talking in my professional lingo. Early on I began crying at

a restaurant when I overheard a group of teachers discussing challenges about their students’ behaviors. I wanted to go to their table and offer my consultation services. It felt like hunger, as if I hadn’t eaten in days. Instead, I formulated guidance for the teachers in my mind as I fiddled with the straw that kept me from having to use my hands to pick up my water glass.

Throughout my years specializing in pain and disabilities, certain themes have come up. The most relevant is that my clients would do or give anything to return to the world of work. The same is true for people in my personal life. My CRPS community also had some things to say and generously offered input about how they have been impacted by the loss of their work, or how they cope with it:

Melanie, 60, was an RN until her injury and subsequent CRPS diagnosis. When it was evident she could no longer perform her nursing duties, she lost her job. “The isolation and uselessness I feel are overpowering at times. I am in so much grief over the loss of the life I once had, let alone the extreme pain I face daily,” she says.

Jesika, a 40 year-old pharmacy technician describes herself as being a casualty of the disease. She says, “I lost my job after I got surgery to try to recover and be able to work. Ironically that effort took all my chances away, my dreams, my identity, my life.”

Kristie, 38, was an RN like Melanie. She recalls feeling all alone, isolated and afraid for her financial future when she stopped working. It was hard for her to go from being a caretaker to needing others to take care of her. “I decided that I couldn’t dwell in the negativity of losing my career, and that I needed to focus on the positives,” she said. Kristie began assisting with the administrative duties of some online support groups and started an in-person support group.

Sarah is 36 years old and was a senior accountant working her way up the corporate ladder; she had also recently been accepted into an MBA program when CRPS interfered with her plans. She describes her job loss as horrifying, confusing and isolating. “Several years of not working left me feeling extremely depressed, alone and longing for the enjoyment and satisfaction I got from my work,” Sarah says.

Each of these individuals has grappled with losing the privilege of going to work each day. So many of us can relate to the commonalities of their stories: dedication to our work, isolation, loss and the subtext that leaving our jobs was not actually a choice. Not with our off-the-charts pain levels. Personally, I also relate to the hardship of being in a caretaker role throughout my life, to depending on others for simple daily tasks.

CRPS-related job loss appears to be a source of emotional

distress for the overwhelming majority of people I hear from or talk with, regardless of the length of time they have been unable to work. Although I continue to struggle every day in various ways, there are numerous things that keep me going and staying hopeful around the issue of work. With the understanding that we are all unique in our circumstances and needs, I offer some coping strategies that are extremely helpful to me:

### 1) Name the grief.

Allow yourself to move fully into the emotional pain. Acknowledge the monumental losses you experienced because you had to stop working. This frees your mind and body from carrying the burden and from creating more problems over time. I cried a lot, talked, sought comfort in nature and relationships and prayed. I wrote about the meaning of the work I loved, feelings about leaving my clients, the private practice I built and more. Remember, it is normal and inevitable for feelings of grief and sadness to pop up from time to time. If it feels too overwhelming, or you feel depressed or “stuck,” there is strength in seeking support, and a licensed therapist can be very helpful (bias noted)!

### 2) Create structure.

Plan activities within the perimeter of your abilities and limits. I gave up trying to write at the same time each day. Instead, I scan myself after each morning (or more realistically, noon-time) ritual and then set up small chunks of time to write

(breaks included) for the day. I also schedule time for tasks like researching information, making appointments and requesting transportation. I meet a friend for weekly swim therapy and started a monthly CRPS support group. Creating structure can help you regain the sense of purpose, accomplishment or routine you may be missing from your workdays.

### 3) Repurpose your inspiration for work.

Take a thorough inventory of what work meant to you. What did you get out of being there? What aspects of yourself did you put into your work? Think about how you can transfer some or all of this meaning into settings beyond your work.

My instinct to do this has been instrumental in helping me cope through the heartache of losing my work. I realized I could still help others by reaching out to those with CRPS. Recently I noticed a parent looking stressed in the waiting room after his wife went in for her doctor appointment. He was trying to tend to both their small child and baby, so I read a story to the child. The father seemed to breathe easier and the child was engaged and less anxious. Small things like this count in the world and in your life. I continue to connect with children and find micro-opportunities to use my creativity, thinking and intuition.

Listen to what your body needs and continually modify your pace. Even five minutes of something

you want to offer here and there can reconnect you to the working person within you that you miss.

### 4) Express your passions.

Think of what makes you feel good. If work consumed your life, think back to your childhood passions and reignite them.

I danced like crazy as a child (and more in private as an adult)! Not being able to toss my arms up, wiggle my hips and let loose like a dork to 70’s music is hard for me, but I still have dance. I get to watch Ellen dance it up with her TV audience. I see her extending truth and caring out into the world, committing to a life with dance, and I feel like I am there. I feel hopeful. Writing about dancing helps me too, and my active fantasy life doesn’t hurt!

So don’t let “I can’t anymore” thoughts stop you; see how you may experience your particular passion in a new way.

My connection to Jewish life is an integral part of me. If you have a spiritual or religious community or place of worship, see how you might become involved.

Another idea is to try something completely new, like an art class if your body allows. Look on Meetup.com. There are groups for everything and you can come and go with no commitment. I’m in a walking group for women in chronic pain. We take gentle, slow walks with lots of sitting breaks in gorgeous nature around the San Francisco Bay area. Start your own group and be connected.

Work for many was also a social setting. Don't forget to monkey around! Adults need to play and in my opinion, play should be prescribed to everybody.

### 5) Shift your expectations.

Think of CRPS as a life-long issue you need to manage, with the ultimate goal being long-term remission (or better yet, a cure)! Instead of thinking satisfaction can only come from pain relief, and productivity from working or "doing," expect these to show up in the form of good days or good moments. Use positive self-talk to shift your expectations. Some things I say to myself:

- "I have the most painful form of chronic pain that exists, yet I'm still having this wonderful conversation."
- "I meditated and hung out with my dog today; it was enough."
- "Laughing right now feels so good."
- "I made it to most of my appointments lately."
- "I'm getting out of bed even though my burning leg pain is awful."
- "I feel so connected to people in my CRPS group, they really get it!"
- "I listened to my body today and canceled my plans; I needed rest."
- "I screamed from hand pain as I simply took a

tissue, then immediately did my guided imagery."

We work every second of the day, we're just poorly compensated! Having realistic expectations is far more helpful for our pain, and for our emotional well-being.

### 6) Challenge yourself.

Set some small, attainable goals (see above tips for some ideas to get started) and when you are ready, move onto a larger one. It can be anything; it doesn't need to be work-related.

When the impact from CRPS made me question if my brain was still functioning at pre-disease state, I needed to challenge it. I keep my state MFT (Marriage and Family Therapy) license active, but decided to take a national licensing exam. For two months I wrote on flashcards and studied them nightly in my warm bathtub. When I passed the exam, it meant that I could still set and meet goals (with significant modifications in my study process). It meant that CRPS didn't own my brain. Not passing would have been fine too, because the challenge taught me how severely CRPS impacts my functioning, and this helped me set limits in other areas of my life.

For me, challenges can range from writing a short story draft using voice recognition software, to simply getting out of bed. Consider what challenges exist in your life and give yourself the credit you deserve. When your body allows, seek other opportunities

within your capacity.

For a long time I made a living doing something that was deeply meaningful to me, and I am so grateful for that. Still, being a therapist is not my identity or what gives me value as a person. I am not my work any more than I am my CRPS; any more than my CRPS is me.

Those of us struggling with the disease are all in different stages of transition. We need to remember it is not the work we did, but the various personal qualities we brought to our work that continue to make us valuable. In solidarity, I encourage you to acknowledge and seek even small, yet significant ways you are able to use those parts of yourself. You will begin to notice moments in your life when you are joyfully on fire!



#### 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, and reach her by email at [ElisaFriedlander@gmail.com](mailto:ElisaFriedlander@gmail.com).*

# Back to School: Educating Teachers about CRPS

BY MEG BOLAND

Returning to school is an anxious moment, but kids with CRPS (and their families) have reason to be nervous that go beyond the typical. In order to create a successful and supportive relationship with the new teacher and/or school, be prepared and try to “front-load” with CRPS information.

As a mom with a kiddo with CRPS and EDS, I have found that sending emails ahead of the school year that not only contain his current 504 plan, but also some basic information about CRPS, including the RSDSA Brochure “Helping Youth with CRPS Succeed in School” (linked below), help to open a conversation before the first bell. We have also found that making a video that explains CRPS in kid friendly terms, using pictures of “bad” times and “good” sometimes helps teachers and peers “see” what the disease looks like and how it might impact your student.

CRPS is difficult to know and understand. For many educators, the challenge proves overwhelming. The invisible and changeable nature of CRPS can mean fluctuating needs for students – a student who can walk one day might be in a wheelchair the next, a student who is gifted academically may need extra time or assistive technology in order to complete

work, brain fog may be worse one day than another – and this is a challenge for the school and teacher to comprehend and the system to accommodate. Being prepared and having plans in place can help you create a more positive environment for your student’s educational success.

If your child is currently without a formalized plan, keep in mind that while laws and requirements vary from state to state, there are federally mandated programs that may help your student access a free and appropriate public education, even with the complications that arise as the result of CRPS symptoms. Knowing a little about these programs and what they mean for your student is a good place to begin your journey as your child’s most important advocate. There are two types of educational plans which take informal accommodations and give them the backing of the law, meaning they aren’t “optional” or “as convenient”, these are a 504 and an IEP.

A 504 is designed to help students with disabilities, including learning and attention issues. 504 requirements are that the student has a physical or mental impairment that “substantially” limits one or more major life activities (such as caring for one’s self, working, thinking, walking,

eating, communicating, seeing, sleeping, writing, hearing, lifting, speaking, bending, breathing, or reading), has a record of the impairment (official diagnosis, letter from pain management doctor), and the impairment

## RESOURCES ONLINE

### 504 Plan Information

<https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans>

### List of Accommodations and Interventions (504 and IEP)

<http://atto.buffalo.edu/registered/ATBasics/Foundation/Laws/AccomList.pdf>

### List of Accommodations and Modifications (IEP)

<https://www.understood.org/en/learning-attention-issues/treatments-approaches/educational-strategies/common-modifications-and-accommodations>

### Educational Advocacy Information

<http://www.tcapp.org/education/>

### RSDSA’s (Awesome) School Brochure

[http://rdsd.org/wp-content/uploads/2014/12/schoolbrochure\\_final.pdf](http://rdsd.org/wp-content/uploads/2014/12/schoolbrochure_final.pdf)

or significant difficulty isn't temporary but chronic. A student with CRPS who is having significant difficulty in any of those areas should be eligible for a 504 plan. The benefits of a 504 plan are accommodations that change the way education is delivered to your student.

An IEP is another option that may be considered. In order for a student to qualify for an IEP it must be determined by the special education team (including you) that the student needs specialized instruction in order to close the gap between the child's own academic achievement and that of his/her age peers. The biggest differences between a 504 and an IEP are that an IEP is managed by a special education teacher, includes specialized instruction for your student, and can include both accommodations and modifications of the curriculum. While some students may qualify based on a learning disability, many CRPS students may qualify under the "Other Health Impaired" category.

This category is designed for students having limited strength, vitality, or alertness due to a chronic or acute health problem. Once a student qualifies, the team determines goals and discusses accommodations and modifications that are needed in order for the student to access the curriculum and a plan is written. (See the box on the previous page for a list.)

So, you've done all you can think of and things still aren't going well? You may need to seek out an educational advocate. This is a person, well versed in disabilities law, who can attend meetings with you or advise you on next steps as you continue through the journey of finding the best way to support your student at school. The previous page has links to a number of organizations that may help you find someone in your area.

If you struggle, or need to vent as school begins, or you just need to know that you aren't alone out there fighting for your kiddo, please, get in touch!



#### ABOUT THE AUTHOR

Meg Boland is a Special Education Teacher and Professional Learning Specialist (teach and mentor other teachers) living in Highlands Ranch, Colorado. She serves on the Douglas County Twice Exceptional Board (for kids who are both gifted and have disabilities that impact learning).

Meg can be reached at [megboland@ferociousfighters.org](mailto:megboland@ferociousfighters.org).



Meg Boland's 11 year old son Patrick, who has CRPS and EDS, founded Ferocious Fighters, a non-profit that sends out care packages to kids with CRPS and provides safe online connections for kids who might otherwise feel isolated. So far, Ferocious Fighters has helped more than 57 kids, with a total of 103 children on its community list across the world.

Join at [www.ferociousfighters.org](http://www.ferociousfighters.org).

# The Need for an Active Sex Life

BY KIM BURKHARDT

I have been living with CRPS in my right hand since October 2008.

CRPS negatively impacts lives in wide variety of ways. There's the direct medical effect, which is complex and challenging enough. Then there's the effect on mobility, day-to-day functioning, and the reduced ability to participate in social functions. High rates of clinical depression are often a consequence of living with CRPS. And on it goes.

I have been saddened to notice that when the two topics of "chronic pain" and "sexuality" are written about together in reference to living with CRPS, it is often with a focus on "how CRPS and chronic pain negatively impact the ability to experience and enjoy an active sex life." This focus often comes from the medical community and patients alike.

It has been my experience, as someone living with CRPS, that this is precisely the wrong approach to take when talking about CRPS and sexuality. This focus does a disservice to people living with the CRPS (RSD).

While living with CRPS on a daily basis can drain one's physical, mental, and emotional capacity for engaging in many daily

*While living with CRPS on a daily basis can drain one's physical, mental, and emotional capacity for engaging in many daily activities, it's been my experience that active sexuality is an essential, integral part of reducing CRPS symptoms.*

activities, it's been my experience that active sexuality is an essential, integral part of reducing CRPS symptoms. Yes, you read that right. I noticed empirically in 2010 that sex reduces my CRPS pain. At the time, I noticed that I would get pain relief for a few minutes to several hours during and after sex. To a lesser degree, physical exercise would sometimes have the same effect.

I didn't have the medical training or vocabulary in 2010 to medically explain how sex contributed to a temporary reduction in CRPS, but it

was happening anyway.

Another woman living with CRPS has also written about sex being beneficial for people living with CRPS. (See: <http://www.thesite.org/sex-and-relationships/single-life-and-dating/sex-helps-my-pain-10184.html>)

Then, early this summer (2015), I found a book written by an MD that medically substantiates HOW and WHY sex is a proven reliever of physical pain. During sex, the brain releases a hormone called oxytocin. Oxytocin is both "the orgasm hormone" and a hormone proven to reduce physical pain. The book I found is "The Oxytocin Factor" by Dr. Uvnas Moberg. (Here's an article about the book: [http://www.dana.org/Cerebrum/2004/The\\_Hormone\\_That\\_Calms\\_and\\_Connects/](http://www.dana.org/Cerebrum/2004/The_Hormone_That_Calms_and_Connects/))

A perusal of online "chat rooms" for CRPS provides any number of posts by CRPS patients who've experienced a decline in sexual activity. Generally, the posts have statements about sexual activity being too painful and/or otherwise challenging when living with CRPS.

Unfortunately, they aren't experiencing the positive benefit of engaging in active sexuality

while living with CRPS. I am guessing that they are having trouble reaching the point during sex of having oxytocin released into their bloodstream, thereby not experiencing a reduction in physical pain. For those patients, I would seek to have the emphasis moved from “sex is problematic when living with CRPS” to “here’s how to reach the point of releasing oxytocin during sex while living with CRPS (and/or any other type of chronic pain).”

So how does a person living with CRPS shift toward thinking positively about participating in an active sex life? Here are my suggestions:

- 1** Be aware that there are people living with CRPS who are benefiting from active participation in a positive sex life.
- 2** Resolve to find times when you can “give this a try.” Stick with it. Talk with your partner; engage them in “working with you to make an active sex life.” Bring them on board to provide any needed physical and/or emotional support.
- 3** Focus on getting to the release of oxytocin (i.e., “the orgasm hormone”). Once you achieve, you’re going to stick with it.
- 4** Start with an alternative option, if needed. (Keep reading.)

## *I’m single and alone. What then?*

Sometimes an active sex life isn’t possible. You may be, for example, single or have CRPS on too many areas of the body. What then? That’s a question I’ve had to wrestle with more recently. I’m single and alone. What then? I was single and, therefore, stuck when I found the “Oxytocin Factor” book mentioned earlier. In that book, the physician provides various strategies for increasing oxytocin levels. According to Dr. Moberg, there are other ways to stimulate oxytocin. Breastfeeding, hugging a friend, and various other activities have been shown to stimulate oxytocin levels. Try reading her book: you may find ideas of your own from her book.

In my case, it happened that I found Dr. Moberg’s book at the same time that I discovered a new musician on the radio. This musician hit the “top ten” list on the rock and roll charts, so my local radio station was playing his music several times a day. I liked his music so much on the radio that I bought his CD. I found my own way to use this

CD for something akin to “sexual meditation”. Two or three times a day. It also turns out that this musician is currently on tour and will be doing a concert soon in my city. I bought a ticket to the upcoming concert and am joking about asking my health insurance to reimburse me for the cost of my concert ticket.

And my CRPS? Reading “The Oxytocin Factor” and buying the above-mentioned music CD and concert ticket have been a great investment. In my case, yoga has also helped regulate my sympathetic nervous system. And getting another spinal sympathectomy-with-simultaneous-radio-frequency-ablation a while back helped with my various dysregulations, including hand temperature and skin variations. In the me-vs-CRPS-pain battle, me and my music CD are currently winning the battle.

The war, however, is not won. There are still bad moments. I still need pain pills sometimes, and wouldn’t leave the house without them. I had to check with my neighbors to be sure that the decibel level of my sound system isn’t bothering them, but for now I’ve made significant strides in the pain battle.

### **ABOUT THE AUTHOR**

*Kim Burkhardt holds a graduate degree in business and has worked in various aspects of business, social services and the nonprofit sector, and politics - as well as writing several books and articles (one of which was quoted in a bill that “made it to committee” in Congress). In 2008, her right hand swelled up following an “aggressive, painful handshake.” Her hand was subsequently diagnosed with Complex Regional Pain Syndrome and a bone tumor that required surgery.*

# Fall Harvest and Quinoa Salad



*Try a healthy, vegetarian fall treat that is quick, delicious, and full of color.*

## INGREDIENTS

- 1 ½ cups Quinoa
- 1 ½ cups Lentils
- 5 cups Water
- ½ cups Green onions, chopped
- ½ cups Red bell pepper, seeded, diced
- 2 tbs. Red onion, peeled and diced
- ½ cup Tri colored carrots, thinly sliced
- ½ cup Sweet potato, diced
- ½ cup Butternut squash, diced
- ½ cup Fresh corn niblets
- 6 tbs. Orange juice
- 2 tbs. Lime juice
- 1 tbs. Balsamic vinegar
- 2 tbs. Mint, julienenned
- 1 Garlic clove, peeled and minced

## INSTRUCTIONS

- 1** Add lentils to second pot of boiling water, reduce heat to medium low, and cook lentils al dente. Remove from heat, drain, and cool. Cut all of the green onions, red peppers, red onion, carrots, sweet potatoes and butternut squash into ¼ inch cubes (a small dice).
- 2** Fill a large part with water and quickly steam the butternut squash, sweet potatoes, carrots and corn until soft. Remove the steamed veggies from the pot, setting them aside to cool.
- 3** In a small bowl, combine the orange juice, lime juice, and balsamic vinegar. Combine all ingredients together in bowl, mixing the quinoa, lentils, and dressing.
- 4** Fold in remaining vegetables, garlic, and mint.
- 5** Add salt and pepper to taste.

**REFLEX SYMPATHETIC DYSTROPHY  
SYNDROME ASSOCIATION**

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



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

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

**EVENTS CALENDAR** 

**DECEMBER 17**

**JINGLE RUN** Vacaville, CA

**THROUGH DECEMBER 25**

**HOLIDAY SHOPPING WITH CINDY BURGNER ONLINE**

**JANUARY 24**

**MELANIE'S CRAZY SOCK DAY**

Since 2011, Melanie has grown Crazy Sock Day to become a successful movement aimed at raising awareness for not only RSD/CRPS, but other invisible illnesses that she and others deal with daily. Each year she asks people to wear colorful socks in an effort to spark questions that lead to opportunities for education and awareness. Visit [www.facebook.com/CrazySockDay](http://www.facebook.com/CrazySockDay) to join in.

**FEBRUARY 27**

**GRAVEY AND RICE COOK-OFF** Lafayette, LA

Benefits RSDSA. Sponsored by the Cajun Angels and Louisiana Jeepers.

**FEBRUARY 26-28**

**LEARNING TO LIVE WELL WITH CRPS CONFERENCE** Long Beach, CA

***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.