



rsdsa

community update

IN THIS ISSUE

CRPS Benefits from the Recent FDA Designation as a Rare Disorder

Donors Bring Integrated Solutions to CRPS to Dallas & Offer An All New Pediatric Track

I'm Erin Klempp and this is my story...

RSD/CRPS Can Change Your Life... Sometimes for the Better

Fight the Flame 5K Race & Walk

12th Annual Achilles Walk for Hope & Possibility Grossed More Than \$107,000!

**All New
Pediatric
Track!**

rsdsa

Fall 2014

Breaking News...

CRPS Benefits from the Recent Food and Drug Administration (FDA) Designation as a Rare Disorder



Complex Regional Pain Syndrome (CRPS) was recently designated as a rare disorder by the Food and Drug Administration. A disease is considered rare if fewer than 200,000 people in the United States have it.

This designation has already generated much greater interest than ever before in CRPS and is enticing pharmaceutical corporations to consider developing medicines to treat CRPS. During the last sixteen years, only two pharmaceutical companies have sponsored a clinical trial for the treatment of CRPS in the United States.

During the last year,

RSDSA has been approached by four pharmaceutical companies which are exploring the possibility of sponsoring a CRPS clinical trial for people in the United States. One corporation has scheduled an international clinical trial for the treatment of CRPS to begin this November.

The Orphan Drug Act approved in 1983 grants added incentives to spur the development of drugs or biologics for rarer diseases. The unique incentives are a seven-year period of marketing exclusively after an orphan drug reaches the American market, tax credits for the costs of clinical research, opportunities to

apply for grant funding for certain clinical testing expenses, and assistance in clinical research study design, and a waiver of Prescription Drug User Fee Act filing fees. More than three hundred products have been developed for rare diseases since the Act's passage (only 10 were approved before the act passed).

Surgeon General C. Everett Koop once remarked that "the treatments of today cannot be those of tomorrow." Hopefully, the FDA designation of CRPS as a rare disorder will lead to new effective and safe treatments for this syndrome.

Donors Bring Integrated Solutions to CRPS to Dallas!

Register Now!

On September 7, 2014, RSDSA, with your help, will bring the Integrated Solutions to CRPS Conference to Dallas. For the first time ever... We will offer a Pediatric Track at the conference for children and adolescents. The pediatric portion of the conference will be interactive and fun while also informative! Please tell others about our new pediatric focus and register now. We hope you will join us! You can help RSDSA change lives in Texas!

SPONSORSHIP OPPORTUNITIES

**HELP US BRING
INTEGRATED SOLUTIONS
TO CRPS TO...DALLAS!**

WHEN: FALL 2014

WHERE: DALLAS, TEXAS

SPONSORSHIP: \$500

FOR MORE INFO: CHRISTINE HOMA, DIRECTOR OF DEVELOPMENT

CONTACT: 860.987.8994 OR CHOMA@RSDS.ORG



RSDSA 30th Anniversary Gala & Bounty of Hope Auction

Please consider supporting our event by donating gift certificates, airline miles, timeshare vacations, unique items such as sporting event tickets, shows, or services.

**Thank YOU
for
giving
CRPS/RSD
survivors
HOPE
for a
brighter
tomorrow!**

*Stay strong
everyone and
know that
we are
all in this
together!*

~~ Erin Klemp

We Are All In This Together

By: Erin Klemp

On November 26, 2010, I was involved in a motor vehicle accident. I did not realize at the time that the bruise I had on the inside of my right knee could turn into my worst possible nightmare. Two days after the accident I wasn't able to put weight on my right leg and foot. My foot swelled up and I was unable to even put a shoe on. Throughout the first year after my accident, many doctors saw me, but no one seemed to understand the sudden swelling, change of color in my leg and foot, the sensitivity and the burning pain I was suffering. I started physical therapy the first year to try and maintain range of motion as that was deteriorating quickly. After four months, I was referred to Wascana Rehabilitation Center to go through an in depth tertiary program aimed at assisting in my road to recovery. I attended this program for 16 weeks, every day. I went through intense physical therapy, exercise therapy and pain management classes. However, we were not seeing improvement so I was discharged from the program. Finally after numerous times pleading with the doctors and pain specialists, I was referred to a neurosurgeon in Regina SK Canada. He took one look at my lower limbs since it had spread to both limbs and instantly diagnosed me with RSD. I was relieved to finally get answers, but very scared knowing my life was changing drastically. I was in a wheelchair all the time as I was unable to stand or walk any longer.

A month after my visit, I was scheduled for a trial stimulator implant to try and reduce some of my pain. The trial was a success and after two days, I had the permanent stimulator put in place. I had about 60 percent pain relief almost instantly; it was the best feeling. I spent two months in the hospital recovering, but in April 2012, I noticed I was getting a burning feeling going up both of my arms. Instantly I broke down in tears knowing exactly what was happening. I made a quick phone call to my neurosurgeon advising him of the situation and I had surgery two weeks later. He placed a stimulator for my upper limbs to try and gain control of what was spreading. This devastated me! Thoughts were running through my mind... how I was going to do things with my two young children who were six and four at the time? There were many adjustments that I would have to make, but I was determined not to let this bring me down. I always try to keep very positive and always look for the good in all of this. During this most recent hospital stay, my doctor and pain specialists used numerous types of medications, but they were not getting the desired outcome. They discussed with me the possibility of trying Ketamine over a 4-hour period. They tried it twice and had positive results. They got permission to try it over a 24-hour period while I was in the hospital. I agreed to have it done, and once again I had relief during it, however as soon as it was over, the pain started returning. My neurosurgeon tried to arrange a trip to the U.S. to have the ketamine treatments done there as they could possibly do a bit more. However, we were unable to get the approval to have me transported to the U.S.

In the past three and a half years since my accident I've been through numerous surgeries, nerve blocks, countless medications, etc. But here I am today, April 22, 2014 living with two spinal stimulators, in a wheelchair but living most days with reduced pain. My message to everyone living with RSD is "Do Not Lose Hope!" This disease is determined to change our lives; it is how we live with it that decides how we carry on. Every day I wake up hoping things have improved, I have better days where I go do things with my kids, and other days when I do not leave my house. People look at RSD sufferers and judge, not knowing what we are suffering from on the inside, and it's not always visible on the outside to others. I am hoping the knowledge that I was able to share from my experience will help someone! Stay strong and know we are all in this together! Thank you for taking the time to read my story

~~Erin Klemp





**Let's STOMP out
CRPS!**

**"YOU can Help
RSDSA change
lives in Texas!"**

Dallas, TX

9-7-2014

**For opportunities
to donate, support,
and volunteer, or
to get up-to-date
information, visit
www.rsds.org**

*"Living with any
chronic illness
changes the way
you live.. It is up to
you to decide if it
will be a change for
the better. "*

~~ Linda Lang

RSD/CRPS Can Change Your Life... Sometimes for the Better

By: Linda Lang



A while back I saw an interview on CBS News about a 28 year-old man who had a severe stroke that left both his legs paralyzed. He spent the winter months lying on the couch with no interest in anything. The Spring brought with it warmer weather and sunshine and his wife opened up the windows. He began to hear a vaguely familiar sound every afternoon. It piqued his curiosity, and so he finally hoisted himself into his wheelchair and ventured outdoors for the first time since he was released from the hospital.

He came upon a high school team at baseball practice and realized that the sound he'd been hearing was that very special sound that a ball makes when it makes contact with the sweet spot of the bat. To the teams' consternation, he began to come everyday. He carefully watched each player and gave pointers which helped improve their game. The coach invited him to be his assistant and the teens began to trust him and shared with him all their problems both on and off the diamond.

Something had changed inside this man and he found the strength and desire to go to college. He worked hard to lose the wheelchair and use crutches to propel his useless legs. After graduating, he landed a job as an athletic director at a school for children with special needs.

They did not notice his disability and he did not see theirs. A short video clip showed how much the kids adored him and how much he adored them. Next, the interviewer asked if he felt bitter about having had a stroke at such a young age.

His response was very unexpected. He said that before the stroke he was a bartender going nowhere fast. Now he has a job which gives his life a sense of meaning. If it hadn't been for the stroke, he would still be unhappy and unfulfilled and his life would count for very little.

After watching the CBS interview with the amazing coach, it gave me pause and I thought back over the past year and all the amazing people I have met. I've had the honor of speaking to close to 100 people with RSD/CRPS. Many of them have volunteered for the RSDSA Peer-To-Peer program. An overwhelming majority of these volunteers said that living with this illness has changed their lives for the better! While they would not go so far as to say they were glad to have RSD, they did report that they learned to reinvent themselves, to concentrate on what they "could" do rather than dwell on the abilities they had lost. Most agreed with the man in the news report... that the life they are now living is far more meaningful than the one they lived when healthy. Each said they recognized they had a choice... to spend the rest of their lives being miserable because of the pain and disability of RSD, or to find things they could do that brought them a sense of fulfillment and



Fight the Flame 5K Race/Walk 11-2-2014



even joy.

If a person with RSD had shared these insights with me during the first years of my journey with RSD, I would have either thought them crazy or that they really didn't understand this disease and they must not actually have RSD.

Then, as now, I need a walker and even with it, I'm unable to go very far. I used to look out my apartment window, filled with anger towards anyone on the sidewalk who was able to walk. It took a long time, a lot of hard work and the example of others to help me realize that I could either make the pain and disability the central fact of my life or I could concentrate on the abilities that I still had, the things that brought me pleasure and a sense of self-worth. And it was no contest!



Now what I have been able to do is nothing compared to what others with RSD have been able to accomplish. A veteran who once defined his life by his impressive physical abilities now designs and makes jewelry. A woman from Newfoundland, Canada didn't know what to do with herself, but for some reason, picked up a paintbrush, something she had never done before and now she's a true artist. Her paintings are filled with riotous color and joy (a few are shown here). The teens I spoke to were also unbelievable! Almost everyone of them volunteered at something: working at an equestrian ranch to help autistic children with muscle control, running and monitoring a Facebook page for teens and young adults with RSD, tutoring, peer counseling and the list goes on. All the while these same teens were also going to school, getting good grades and living with RSD.

Those that went on to college were pursuing fields that helped others... psychology, therapy, PT, law, social work, etc. As adults they are raising children, working, running support groups, scout troops, etc. Those who were more disabled still found ways to help others as a way of helping themselves.

Living with any chronic illness changes the way you live. It's up to you to decide if it will be a change for the better. Making that change is not easy... it requires a lot of hard work. But the reward is priceless! This is only a small sample of what people with RSD are accomplishing. I'd love to hear about what you are doing, and if you would like to participate in the peer-to-peer program. If you are interested please send me an email at lindalang@rdsd.org

Fight the Flame RSD 5k Race/Walk

Fight The Flame RSD 5k Race/Walk began in Charlotte, North Carolina on November 3, 2013 to raise awareness of RSDS/CRPS and to contribute donated funds to research towards a cure for the disease. This year's race will be held on NOVEMBER 2, 2014 at McAlpine Greenway Park at 8:00 am.

The race originated with Landon Stillitano and three of his friends in honor Landon's mother Beth, who has suffered from the disease for over 19 years. The race began as their Bar Mitzvah project and as Landon said "Completing this project will be the first time I can help my community as a responsible adult. We created the name 'Fight The Flame' because having RSD is like having your body on fire, and we are hoping to find a cure and put out the flame."

Landon also explained, "My mom never tries to show that she is in pain, she always smiles no matter what and she is very optimistic!" The initial race was an encouraging success with close to 200 participants raising \$17,000 for RSD research and awareness.

Please come join us on November 2, 2014. If you can't make the race, please consider making a donation to our website www.fighttheflame5k.org to further raise awareness.



Contact Us

RSDSA

P.O. Box 502
Milford, CT 06460

Tel: 203.877.3790
Toll Free: 877.662.7737
Fax: 203.882.8362
E-mail: info@rdsd.org

www.rdsd.org

RSDSA 2014 Events

Craft & Vendor Fundraiser
Shady Grove, PA
September 6, 2014

**Integrated Solutions to
CRPS Conference**
Dallas, TX
September 7, 2014

**2014 CRPS/RSD Walk for
Awareness**
Penssauken, NJ
September 13, 2014

**CRPS/RSD Golf Tournament
for Samantha Harber**
Monticello, MN
September 20, 2014

RSD/CRPS Motorcycle Run
Bear Creek Village, PA
September 28, 2014

Power Through RSD Walk
Lockport, NY
October 5, 2014

**RSDSA's 30th Anniversary
Bounty of Hope Gala**
Princeton, NJ
October 25, 2014

Fight the Flame 5K
Charlotte, NC
November 2, 2014

Dinner to Benefit RSDSA
Covington, LA
November 8, 2014

**Come Out and Support
RSD/CRPS-Borrellis**
East Meadow, NY
November 22, 2014

rdsda

12th Annual Achilles Walk for Hope and Possibility

The Walk Grossed More Than \$107,000 for Research, Education and Patient Assistance



On the winding 1.5 mile course through Central Park in New York City, hundreds of you joined RSDSA on an emotional Sunday morning that brought together walkers from around the world! This amazing event was made possible by Achilles International, which held its 12th annual Hope & Possibility 5-Miler sold-out race on June 29, 2014.

"This incredible event brings together so many people from across the United States and around the world to support one another and provide hope for everyone who lives with CRPS," Christine Homa, the director of development of RSDSA said. "We have families, physicians, friends and caregivers all here to join us in supporting the CRPS community; it's a really exciting day! In addition, we have dozens of virtual walks going on around the country today, people have come together to make a difference."

"We're thankful to Achilles International for putting this on and to RSDSA for participating. Our message is so positive: "The hope and possibility of better treatments and a cure for CRPS," Casey Cashman, Walk Chairperson said. "The support of so many people from all walks of life is quite humbling. All of our walkers both onsite and virtual were incredible."

RSDSA hopes to inspire the CRPS community by instilling a sense of inclusiveness in our participants and to inspire them over and over again through the camaraderie and breath-taking support exhibited throughout the day. "I was fortunate enough to walk with hundreds of participants and experience the support and friendship first hand. When I reached the finish line alongside wheelchairs, roll-aids and children as young as 4 months old I had reached out to friends new and old," Casey added.

Thank you to everyone who participated this year and helped gross more than \$107,000 for CRPS research, education and patient support. A special thank you to our sponsors: Gruenthal USA, Inc., Crane Fund for Widows and Children, Teva Pharmaceuticals, August Enterprises Inc., Mr. & Mrs. Steve Shisler, Mr. Larry Krasin, OSM Mining LLC, Dr. Samyadev Datta, Ms. Gina Herr, and Mr. Claude Thomas. We look forward to working with all of you and Achilles International in 2015 for the 13th Annual Walk for Hope & Possibility. Watch www.rdsd.org for more information.

Top Fundraisers:

Lauren Shander \$7,343
Rob Ford \$3,913
Casey Cashman \$3,625
Kristen Haunss \$2,366
Alysia Bishop \$2,220



Thank YOU for giving CRPS/RSD survivors HOPE for a brighter tomorrow!