

rsdsa community update

VOLUME NO. 4

ISSUE NO. 3

WWW.RSDS.ORG/NEWSLETTER

Fall 2017

**This issue was sponsored by McLarty/Pope National CRPS/RSD Lawyers
www.mclartypope.com/rsd/crps**

RSDSA Is Helping Youth See A Brighter Future with CRPS BY SAMANTHA ANDERSON

Over the past few years, RSDSA has continued to add new initiatives to our goals and missions. However, there was a demographic we had not been reaching to the fullest extent that we wanted to help more- children. Children have been diagnosed with Complex Regional Pain Syndrome as frequently, if not more, than adults in recent years. We know that approaches for treatment and coping can be different for children, so we decided that we needed to ensure the children's voices were heard. When The Coalition Against Pediatric Pain (TCAPP) started planning a camp for children living with chronic pain syndromes, we found our first project.

This year, we experienced our third Pediatric Pain Week at The Center for Courageous Kids in Scottsville, Kentucky. The first year we attended, the camp had 19 children. This year, we had almost 70 children and their families. The camp was completely filled by children with chronic pain syndromes and the families who support them. Imagine being diagnosed at six years old and being told you have to live with this pain for the rest of your life. We wanted to help fill these children with hope. Prior to attending camp, many of these children had never met a person living with chronic pain syndromes. This camp becomes a life-changing experience, as these kids get to be kids for the first time in a while. They are surrounded by people who understand them and will not judge them for needing to go nap or using their wheelchairs during one part of the day, even if they had not been using it earlier. These amazing children connect with one another to form lifelong bonds, maintaining friendships outside of camp. At camp, there is not much discussion about the medical conditions these children live with, but there is certainly an emphasis on fun.

Continued on page 10



PLEASE SUPPORT OUR ANNUAL APPEAL (page 3)
Please help us shine a light on hope.

INSIDE THIS ISSUE

	Page
Please help us shine a light on hope.....	3
Hope on the Horizon.....	5
CRPS Word Search	6
Do Epigenetic Differences Contribute to CRPS Risk.....	7
Hi I am Mickey and this is my RSD Story	9
RSDSA is helping you see a brighter future with CRPS (Continue).....	10
Three Fall events help sustain RSDSA's Mission.....	11
Injuries Surgery and CRPS Reduce the Risk of Spread.....	12
My RSD Story <i>Marcia Nolting</i>	14
Through Sickness and in Health	15

Find Us Online

Blog

www.rds.org/blog/

Twitter

@rds

Facebook

www.facebook.com/rds

YouTube

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

Instagram

@rds_official

Editor

Lauren Bentley
laurenbentley93@gmail.com

CALL FOR AUTHORS & IDEAS

Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? Is there a special topic you would like to see included in the RSDSA Community Update? We would love to hear from you. Please email your thoughts to info@rds.org.

SPECIAL THANKS

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Aetna, Axsome Therapeutics, Grunenthal, Ketamine Treatment Centers Partnership, McLarty/Pope, Medtronic, Neurologic Relief Center, NoPainHanna.com, Purdue and Relax Release Relief. For more information about becoming an RSDSA Partner, please contact Jim Broatch at info@rds.org.

Please help us shine a light on hope

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

Dear Friends,

In this time of great uncertainty in the world, RSDSA continues to be steadfast in its commitment to help all those affected by Complex Regional Pain Syndrome (CRPS). Thanks to your generosity, we're forging ahead with new initiatives, while continuing our meaningful educational programs, health conferences, community support, and funding of CRPS-related research. Thanks to your generosity, we are making a profound and lasting difference in the lives of people with CRPS and their loved ones.

SHINING A LIGHT OF HOPE

Together, we continue to strengthen the CRPS communities around the country and foster education, support, and hope to so many who are isolated and unsure of where to turn. Our mission is constant and unwavering. For over 33 years, we have been the leading CRPS not-for-profit organization committed to reaching those who feel hopeless. We are determined to be here for all who need us no matter what stage of the CRPS journey they are on. We reach out in every way we can: social media networks, quarterly newsletters, conferences, video presentations, educational webinars, and awareness-generating events around the country.



"When I found out I had CRPS my world shattered, until I reached out to RSDSA. The warm response and help assured me, I was no longer alone."

RSDSA community member

When people with CRPS meet us at conferences, educational seminars, or local fundraising events, they greet us with warmth and gentle hugs, as though we are family. We represent a safe haven, a home away from home where they feel secure. We do whatever we can to find the resources that are needed. We understand the magnitude of this

debilitating and excruciatingly painful neuroinflammatory disorder, knowing that it does not discriminate, attacking children, teenagers, and adults. While there is no cure, there is hope and possibilities for the future.

"Thanks to RSDSA, I have found the strength to keep going and overcome so many obstacles. They gave me the support and resources, I had no idea they even existed."

*A Brad Jenkins Patient
Assistance Recipient*

A NEW INITIATIVE FOR YOUNG ADULTS WITH CRPS- TOGETHER WE MADE IT HAPPEN

This year, we had many exciting achievements and sponsored new initiatives. We are proud to be a sponsor of the Pediatric Pain Week at the Center for Courageous Kids, with more children and families becoming involved each year. We have finalized our Resource Compendium, which will be invaluable to people in pain, medical professionals, and all those interested in the most up-to-date information. Our conferences attracted exceptionally large and enthusiastic groups of people with CRPS. People from 14 states attended our Arkansas conference.

Because of your help, this year RSDSA created a new program for young adults (age 18-30) with CRPS. Our first RSDSA Young Adult Weekend Retreat was a wonderful success. This event created a new opportunity for young people with CRPS to meet and support one another, while being able to share information on how they transition from child to adult. The weekend consisted of workshops on a variety of topics specific to young adults, as well as outdoor activities and the chance to branch out independently. This group continues to meet and plan further initiatives for RSDSA's young adults.

Shining a Light on RSDSA Initiatives & Achievements 2017

This past year, we:

- Hosted the first Young Adult Retreat Weekend (ages 18- 30)
- Published the fourth edition of *In Pain and Agonizing over the Bills, Resources for People with CRPS*
- Began delivering *The RSDSA Community Update* to both your electronic mailbox and to your home, featuring latest scientific breakthroughs and stories, to share with health professionals and friends
- Sponsored *Treating the Whole Person: Optimizing Wellness* conferences in Tennessee and Arkansas, featuring complimentary approaches to healing
- Co-sponsored Pediatric Pain Week at the Center for Courageous Kids for the third consecutive year

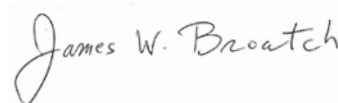
In addition, we are now:

- Collaborating with research experts internationally
- Facilitating support groups around the country. We now host a monthly conference call with group leaders to learn from each other
- Fostering self-advocacy through mentoring and peer-to-peer groups
- Heightening awareness about alternative treatments for CRPS via conferences, website, videos on YouTube, and the *RSDSA Community Update* newsletter
- Promoting awareness through national and regional events across the country
- Partnering with medical device manufacturers and pharmaceutical companies in their clinical trials

We cannot reach these milestones and fulfill these initiatives without your help. Together, we will shine a light on hope. Imagine the possibilities if we all come together.

To your health,

James W. Broatch, MSW
Executive Vice President,
Director



Hope on the Horizon

BY KAREN E. BINKLEY, MD, FRCPC - BINKLEYK@SMH.CA

If you have CRPS, you may already realize that existing treatments do not always work well. 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.

REPURPOSING: NEW USES FOR EXISTING DRUGS

Basic scientific research into the cause and mechanism of a condition is important so that appropriate treatments can be devised. Thanks to such research, it is now known that CRPS is caused by inflammation in the nervous system, resulting in increased transmission of pain signals. This knowledge has led to the use of various anti-inflammatory treatments for CRPS including corticosteroids, high dose intravenous immunoglobulin, plasma exchange and immunosuppressants such as mycophenolate.

Recently, a research group from Brazil examined the effect of simvastatin, a medication used to lower cholesterol. Simvastatin and related medications are known not only to reduce the risk of heart attacks by lowering cholesterol, but also to reduce inflammation. They can also reduce pain. In an animal model of CRPS, called chronic post-

“Thanks to such research, it is now known that CRPS is caused by inflammation in the nervous system, resulting in increased transmission of pain signals”

ischemic pain, the investigators showed that simvastatin reduced pain behavior in the treated animals. However, it did not reduce markers of inflammation, as researchers had hoped. Nonetheless, this indicates that statins could perhaps be explored for similar anti-pain actions in patients with CRPS. It is too early to recommend treatment with statins for pain at this time. In some patients, statins can cause muscle pain and, in very rare cases, muscle damage. It is good to know, however, that there may be other options to control pain in the future.

WATSON THE COMPUTER: REPURPOSING ON A GRAND SCALE

You may have heard about Watson, the computer that played on the TV game show Jeopardy. Watson can sort through vast amounts of data and make relevant connections. It has been used to find potential new



treatments for end-stage cancers by looking through databanks of existing medications and linking how they work with what is known about how a normal cell transforms into a cancerous cell. Watson has found treatments that were potentially useful in a number of cases. More recently, it has been reported that Watson has been used by researchers and clinicians at Toronto Western Hospital at the University of Toronto, to find existing medications that may be helpful in the treatment of Parkinson's disease, a neurological disorder that affects movement.

Could Watson be used to scan databanks of existing medications that might be helpful in treating CRPS? The answer is yes, but with a caveat. Feeding the necessary information into the computer is time intensive and expensive. Estimates suggest that it would cost approximately \$250,000 and identify only potential medications. Then,

it would be necessary to set up clinical trials to see if the medications actually worked as predicted. As of yet, no one has been able to come up with funding for this project, but it may be something that could be accomplished in the future. If anyone has ideas for fundraising, please get in touch with me.

AND NOW FOR SOMETHING COMPLETELY DIFFERENT

In this column, the focus has been on treatments that alleviate the underlying abnormalities that cause CRPS. But sometimes

there are treatments that can be of use without changing the underlying problem. One potential item is the Keeogo, a Canadian invention that allows patients with weakened or painful conditions to better walk and move. The device is strapped on and takes pressure off the affected limb or limbs. It supports the movements of the user and is not used for persons with total paralysis. You can find more information at www.keeogo.com. This may not be suitable for everyone, as it is possible that the points of contact may be too

painful for some CRPS patients. However, if the pain can be controlled, this may be a way for some patients to regain mobility.

References:

Effects of Simvastatin Beyond Dyslipidemia: Exploring Its Antinociceptive Action in an Animal Model of Complex Regional Pain Syndrome-Type I. Vieira G1, Cavalli J1,2, Gonçalves ECD1,3, Gonçalves TR1, Laurindo LR1, Cola M1, Dutra RC. Front Pharmacol. 2017 Sep 4;8:584.

Karen Binkley MD FRCPC

CRPS Word Search

Q J G L P I T T A S N H V H J E E R R W Y P B Z X
U K B K A O P H L R S N S O C S F E N C F D M J J
A Y S G I U N E N O Y E C D I R G A Y N B A Y N C
W V W C N U J T S T Q N N A E I A P P L J K E D M
T K V D U Q K U A L X C R E O W R E G I N Y X C I
H S J V F Z R E P A O D H N R G J M S X A O Q W H
Q U E G K Z Q S A S N O A K K A V F C E K J N T J
R E F L E X A D D U P L J F L A W L O Y R P Y B J
R T M Q G J D A F E W W S C W C T A M Q W Z C R S
X S E E H G M Y Q X K Z G Z H Y N P M I V I Z B I
B N D P T W U B S V Y U U R U M K V U H J S Z Y H
H O P S M Q A U P T H Y O D T A T A N E Q J A U E
B L O B A S M R N Z R N V V Q P P A I A Y G H Q U
T V Y J T X X N I O I O M G Z R F C T Q K H P L Q
X X F F U S S C B C L E P C G F T V Y U U V S J T
V V L V L B K Z P D X V X H A L A A H G Z Y C R J
G P C Q T K W A Y C T Z D E Y X P I H Z Z F O N L
G P Z N W E I Y S Q O H L Y C J I N I E R P Z W H
H O D Q E N L E V Z Z X W A Y U N Y A D P Z U W W
A N T K H H T X R W G E R L D O Q D K U D K X J H
F W M D G I R B D Z E L L P C M W O S P N K W K T
Q P J Q D A K T H F F P Q W V L W L N C H N H W E
C I T E H T A P M Y S M X Q T T K L N A I X V D D
Z X A K E D U C A T I O N W P G B A E H T E F H O
L L P Y Z E O Q G N H C N E M O R D N Y S L M W L

ALLODYNIA
AWARENESS
CHRONIC PAIN
COMMUNITY
COMPLEX
DYSTROPHY
EDUCATION
FUNDRAISE
HOPE
PAIN
REFLEX
REGIONAL
RESEARCH
RSDSA
SUPPORT
SYMPATHETIC
SYNDROME
THETUESDAYBURN

Solution on pag. 14

Do Epigenetic Differences Contribute to CRPS Risk?

**STEPHEN BRUEHL, PH.D., PROFESSOR OF ANESTHESIOLOGY
VANDERBILT UNIVERSITY MEDICAL CENTER, NASHVILLE, TN**

One of the mysteries of CRPS is why one person develops the condition whereas another does not despite both experiencing similar injuries. While risk factors for developing CRPS are only poorly understood at present, knowledge of such risk factors might permit earlier intervention or even prevention of CRPS after injury in high risk individuals. Studies in both CRPS patients and in experimental animal models of CRPS have increased in highlighting a role for immune alterations and inflammatory processes in CRPS¹. We might therefore expect that differences between individuals in the immune and inflammatory systems could contribute to CRPS risk following injury.

One likely source of immune and inflammatory differences would be genetic, deriving from differences from person to person coded in the individual's DNA. Genetic factors are known to contribute to risk for a variety of diseases, such as cancer and Alzheimer's disease. To date, evidence for genetic risk factors in CRPS comes from a handful of studies and is limited in part by lack of replication from one study to the next (i.e., finding the same genetic risk factors across studies). One genetic finding that has been replicated suggests a role for differences in the human leucocyte antigen (HLA) system in determining risk for CRPS^{2,4}. The HLA system produces proteins that are responsible

for regulation of the human immune system, and a role for this system in CRPS fits with other recent evidence for immune mechanisms in CRPS.

It is often believed that DNA "hardwires" a person for risk, meaning a person with a genetic risk factor will develop the condition whereas a person without the risk factor will not develop it. The emerging field of epigenetics indicates that this view is incorrect. Just as important as the genetic code in a person's DNA is whether specific genes are "turned on." Epigenetics addresses this key issue of whether genetic risk factors are turned on and whether protective genetic factors may be turned off. In genetic language, such epigenetic differences are referred to as gene expression differences. To those not familiar with the area, it may come as a surprise that gene expression can be influenced by environmental factors and that these gene expression changes can be passed down to offspring, just as the actual DNA code is inherited by offspring. A key way in which gene expression is altered is by the process of DNA methylation, a chemical change referred to as CpG sites (places in the DNA code where the amino acids Cytosine and Guanine occur in sequence linked by a phosphate).

My colleagues and I at Vanderbilt have recently completed the

first study of differences in DNA methylation in CRPS patients compared to non-CRPS pain patients, a study funded in part by a generous research grant from the RSDSA. Taking advantage of DNA methylation data collected as part of a larger Department of Defense funded study, we compared nine patients meeting the Budapest criteria for CRPS with 38 patients experiencing persistent pain who did not meet CRPS criteria. Although this particular CRPS sample was somewhat unusual in that all patients (in both groups) had persistent limb pain following a post-traumatic amputation resulting from military service in Iraq, the study did allow us to compare DNA methylation between individuals with pain plus typical CRPS features and individuals experiencing pain without CRPS features. We hypothesized that differential patterns of DNA methylation might account for why some of the individuals studied developed features diagnostic of CRPS and others did not, despite the fact that all underwent a similar type of injury.

Our results, not yet published in a peer-reviewed scientific journal, are intriguing. We examined over 450,000 CpG sites, and identified all sites for which DNA methylation differed between CRPS and non-CRPS patients. We employed methods that adjusted both for the small number of patients studied and

for the large number of CpG sites examined. We found that 250 CpG sites were differentially methylated between the two patient groups, with five of those sites highly significant in the statistical sense. One of the five sites showing the largest group difference was in the HLA-DRB6 gene (a gene in the immune regulatory HLA system described above). Interestingly, this is exactly the same gene identified as a top hit in the only other available gene expression study in CRPS3, which used alternative methods that did not examine the DNA methylation targeted in our study. The similarity of these two findings using different methods represents an important replication, highlighting the likely importance of epigenetic differences in the immune system in determining CRPS risk. This conclusion is supported by the fact that five of the 250 CpG sites differing between groups in terms of DNA methylation were in genes known to be involved in the HLA immune pathway. Also of interest was the finding that five of the CpG sites differing between CRPS and non-CRPS pain patients were in genes known to be involved in the system regulating inflammation. These findings which indicate gene expression differences (via DNA methylation) in multiple immune- and inflammation-related genes is entirely consistent with animal work and other human studies supporting a role for immune and inflammatory mechanisms in CRPS. Other notable findings revealed DNA methylation differences between CRPS and non-CRPS pain patients in genes impacting on oxidative stress responses, the renin-angiotensin

system, blood vessel formation, skin resiliency and bone turnover. Each of these findings fit with theoretically plausible roles of these diverse systems in CRPS (e.g., bisphosphonate drugs target bone turnover mechanisms and have shown some efficacy for treating CRPS).

Our DNA methylation data were examined not only in terms of individual CpG sites, but also in terms of known gene networks reflecting common underlying biological functions. These analyses indicated that CRPS patients displayed significantly different patterns of DNA methylation (compared to non-CRPS pain patients) in five functional categories reflecting immune system function, three hormone-related categories, and two categories related to differences in cation and ion transport (i.e., ability to move molecules across cell membranes in the body). These latter findings hint that novel CRPS risk factors related to differences in hormone regulation and transport across cell membranes may deserve further investigation.

In summary, our results for the first time suggest that risk for CRPS following injury may derive in part from differences in whether or not genes are expressed (i.e., turned on or off) through the process of DNA methylation. Consistent with known CRPS mechanisms and limited available genetic studies, the strongest finding was for an association between CRPS risk and expression of immune-related genes, with results also highlighting the likely importance of inflammatory-related genes.

We have partially replicated our results in terms of the genetically-determined component of gene expression, finding differences in five of the same genes identified in the study detailed above between a broad “limb pain” group (1,564 patients) and a “no limb pain” group (3,070 patients). Nonetheless, determining the ultimate clinical value of these findings must await true replication. If future studies find similar results, these findings may help guide research into novel mechanisms contributing to CRPS (e.g., hormone-related) and would highlight the need to further develop interventions that target immune and inflammatory-related mechanisms contributing to CRPS.

References

1. Bruehl S. Complex regional pain syndrome. *BMJ* 2015; 351:h2730.
2. de Rooij AM, Florencia Gosso M, Haasnoot GW, Marinus J, Verduijn W, Claas FH, van den Maagdenberg AM, van Hilten JJ. HLA-B62 and HLA-DQ8 are associated with Complex Regional Pain Syndrome with fixed dystonia. *Pain* 2009; 145: 82-85.
3. Jin EH, Zhang E, Ko Y, Sim WS, Moon DE, Yoon KJ, Hong JH, Lee WH. Genome-wide expression profiling of complex regional pain syndrome. *PLoS One* 2013; 8(11):e79435.
4. van Rooijen DE, Roelen DL, Verduijn W, Haasnoot GW, Huygen FJ, Perez RS, Claas FH, Marinus J, van Hilten JJ, van den Maagdenberg AM. Genetic HLA associations in complex regional pain syndrome with and without dystonia. *J Pain* 2012; 13: 784-789.

Hi I am Mickey, and this is my RSD story

BY MICKEY NOONAN (SUBMITTED BY HIS SON ANTHONY)

I developed RSD a little over 18 years ago when I broke my left wrist. The break healed fine but the swelling and pain was still unbearable. By the time I was diagnosed with RSD, I no longer had any use of my left hand/forearm. I wasn't responding well to pain medications, so my doctors sent me to Johns Hopkins Hospital. They felt the RSD was extremely aggressive and recommended a sympathectomy immediately to contain the RSD in my left arm. The sympathectomy surgery consisted of deflating my lung and cutting the sympathetic nerves in an effort to stop the spread of the disease. It did not work. The RSD still spread to my right arm and side in a matter of a month. The surgery was repeated on my right side.

While I was still in the hospital with a chest tube from the surgery, my legs started swelling and turning colors. When I asked the doctors about it, they said the RSD had already gone into my legs. Within a few weeks I was bedridden and wheelchair bound.

It has been a hard struggle over the years to just survive with the pain. I have been fortunate in having very good, caring doctors who do all they can, but nothing takes RSD pain away. It just helps enough so I don't put my head through the wall.

Besides numerous oral medications, I also have a pump implanted in my stomach and wired

to my spine dispensing morphine and clonidine 24/7. When flare-ups get really bad, I also get nerve blocks in my neck and back. However, these have not been working lately and my doctor is worried. Because my limbs are so swollen, I get infections a lot and wind up in the hospital for two weeks on IV antibiotics about twice a year. The arm specialist keeps trying to talk me and my other doctors into amputating my left arm because of high amount of infections.

I did manage to fight and get out of the wheelchair and now walk with a cane or walker. It was a very hard and painful struggle, but worth every minute of it. This enabled me to be able to do things with my kids and drive again. Sadly though, I seem to have taken a turn for the worst this past year. It is getting unbearably painful to walk. I am almost to the point where I cannot climb stairs without my knees buckling. I know at my age if I go back in a wheelchair I won't get out again. I have to fight but it is really starting to scare me.

There are many people out there suffering from RSD whose stories are similar to mine. Some may not be quite as bad and some may be much worse than me. In my own family, my cousin, who is about the same age as me, has been suffering with RSD in her leg for a very long time. My nephew has recently developed it in his leg and it has now spread throughout his entire body.

What everyone with RSD does have in common is the pain. RSD pain is like replacing your blood with gas, setting it on fire and then getting hit by a truck. It's no wonder that RSD is listed as the most painful chronic disease on the McGill Pain Index. Many of us with RSD will develop other health problems as a result of this disease. RSD not only effects the nerves, bones, skin, muscle, hair and nails, but it can also affect the major organs, as well as causing mental problems such as insomnia and severe depression. Some treatments help while others may not help.

It is unknown why certain people have RSD. There is no cure so please donate to help fund research for everyone suffering from RSD/CRPS.

Thank you for reading my story.



ABOUT THE AUTHOR

Mickey is pictured with his son Anthony on the Intrepid in New York Harbor. Sadly, Mickey passed away in May 2017, of natural causes, after struggling with CRPS for almost two decades.

RSDSA Is Helping Youth See A Brighter Future with CRPS *Continued from front cover*

Not only is camp important for the youth, but also for their caregivers. These caregivers get to see other children who live like their child, showing that they are not alone. They also get to connect with other caregivers and form a support network. They become each other's strongest advocates, resources and great friends. These camps are of the utmost importance for the future of CRPS. The children get to learn how to be themselves, how to cope, and how to know their limits while the caregivers learn and receive more resources to fight for their children.

After doing Pediatric Pain Week, we realized that there is an in-between group that needed our help as well- young adults. Camp caps off at age seventeen. Many of the young adults in our community were diagnosed as children and are now trying to transition into adulthood with CRPS. We also have several young adults who were recently diagnosed. It can be difficult to navigate the beginnings of adulthood with CRPS, as it is even difficult for those without CRPS. Stepping out on your own into universities, your own housing, and even the workforce can be challenging with a disability. Then there are the additional challenges that the world presents such as relationships, knowing your limits, becoming your own advocate and understanding the healthcare system. This is a huge change, especially when caregivers have acted on behalf of these young adults for so long. We wanted to help these young adults gain independence and find ways to take control of their lives. We held our very first Young Adult Retreat in June to start helping our young adults with these issues.

Our pilot program for the Young Adult Retreat was a great success. We had young adults, age 18-29, from all different backgrounds attend this retreat. We allowed an open discussion style forum, discussing issues from self-defense to self-advocacy. The discussions went on through the night, even outside of the conference room. More bonds were formed and these young adults formed their own support network. The feeling of being understood is crucial to finding the confidence to develop the skills needed in today's world as a disabled adult. Our young adults hiked, kayaked, and participated in other activities throughout this weekend, showing how they knew their own limits. These additional activities furthered the bonds and led to our young adults planning to meet up outside of the retreat. One of our young adults, Melissa, wrote: "We shared stories of bad flares and doctors who didn't believe us, like I had with others I had met, but we also talked about college experiences, traveling, working full-time, being on our feet all day, doctors still treating us like children, and so many other things that didn't really apply with others I had met with RSD/CRPS." Another Young Adult Retreat attendee, Jess, wrote: "The instant connection and pure understanding amazed me. I had no idea how powerful it would be to venture into a community where others don't just get RSD, they have RSD." These young adults broke out of the bubble of isolation that so many children and young adults with CRPS put up to avoid pain or anxiety. They are actively taking part in bettering their futures, as well as the futures of others with CRPS.

It is important for our children and young adults to feel supported. They have so much life ahead of them and we want to make sure that they have the resources, support, and hope that they need to be successful adults. They are the future of CRPS. They will be our advocates, support group leaders and, potentially, our doctors one day. The more we are able to help them, the better our community can be. Helping even just one child or young adult can help the entire community. We look forward to future Pediatric Pain Weeks and Young Adult Retreats. If you would like to learn more about these events, or to learn more about how you can help with these events, please email info@rsds.org.



ABOUT THE AUTHOR

Sammie Anderson, RSDSA's Special Events Coordinator, is a 10-year CRPS warrior. When she's not planning events, you can find her playing with her dog, Phantom, spending time with her family, visiting her local Starbucks, or doing something Disney related.

Three Fall events help sustain RSDSA's Mission

BY JIM BROATCH

THE LONGEST DAY OF GOLF

On October 2, Josh Rosen of Hoboken, NJ golfed 111 holes at the Innis Arden Golf Course in Old Greenwich, Connecticut. Eight other individuals also played on behalf of local charities. Mr. Rosen's heroic efforts resulted in raising close to \$15,000 to underwrite RSDSA programs and initiatives. Individuals contributed by pledging a per hole played amount or by making a one-time gift. The Longest Day of Golf (LDOG) is a unique fundraiser. It costs RSDSA no expense. This year's event occurred on a Monday when the private course was closed; enabling Josh to play from dawn until dusk. He even eagled his 72nd hole played. Josh played tirelessly. When someone was ahead on a hole, he raced to another tee to continue his golf marathon as fast as humanly possible. Josh has pledged to return next year to play on behalf of the RSDSA community. A special thank-you to Hank Ludington, our Board President who helped organize the LDOG. For more information about conducting a LDOG in your

community, please contact us at info@rds.org or by calling 877-662-7737.

TWO SEPTEMBER WALKS

RSDSA was the grateful beneficiary of two September awareness and fundraising walks. The second Annual Eisenhower Park walk on Long Island was an incredible, enjoyable day. Last year's walk raised \$25,000. The walk committee greatly exceeded this year's goal and raised over \$56,000 this year. The walk also featured a cook-out, a crafts table for children, and several educational booths. Our exhibitors and sponsors handed out pamphlets and answered questions throughout the event. Kudos to our walk committee of Debbie Hunter, Beth Seickel, Stacy Udell, and Samantha Anderson.

On the following weekend, Dawn Hesser organized an annual fundraising and awareness walk at the Cooper River park near Cherry Hill, NJ. More than 150

individuals with CRPS and their family and friends participated and the event raised more than \$20,000. If you're interested in organizing an event in your community, please contact us at info@rds.org or by calling 877-662-7737.



CORPORATE SPONSORSHIP OF THE RSDSA COMMUNITY UPDATE

This issue is being sponsored by McLarty and Pope (National CRPS/RSD Lawyers). Bryan Pope has presented at a number of RSDSA conferences. Here is a link to Mr. Pope's presentation at a recent RSDSA conference, <https://youtu.be/nBh6P8gYDWc>. If you or your Corporation is interested in sponsoring a future issue, please contact us directly at info@rds.org.

END OF THE YEAR APPEAL

Please consider making a donation to RSDSA, as we strive to help all those affected by CRPS by continuing our meaningful educational programs, health conferences, community support, and funding of CRPS-related research. Please consider making an end-of-the year gift by mailing the enclosed envelope or by visiting, <https://rds.org/donate>. You can also choose to make a monthly donation if that is easier. Every donated dollar will make a huge difference.



Injuries, Surgery and CRPS: Reducing the Risk of Spread

BY JENNY PICCIOTTO

When I read a study about the spread of CRPS, I was reminded about something I really don't like to think about. I wanted to push it out of my mind, but with a colonoscopy screening coming up it was a good reminder. It was motivation to find out how to reduce my risk.

The study reported some alarming statistical results. It was published in the Scandinavian Journal of Pain in January, and was titled "The risk of pain syndrome affecting a previously non-painful limb following trauma or surgery in patients with a history of CRPS." ¹ The authors reviewed the history of 93 CRPS patients at their clinic over a 20 month period. Overall, 19 of them (20%) experienced a spread in another limb. Out of those 19 patients, 15 had a documented "inciting event" such as an injury or surgery in a previously pain-free area, and 4 did not. There were a total of 20 individuals in their study with a documented "inciting event". 15 of these 20 people (75%) developed secondary CRPS. While the authors recognize that this 75% statistical finding cannot be generalized, they did conclude that their results "strongly suggests that patients with a history of CRPS may be at considerable risk of developing secondary CRPS."

They recommend that:

"Patients presenting with new extremity injuries or requiring surgery on another extremity may benefit from preventative therapy or early intervention if signs of secondary CRPS develop. When deciding

whether to proceed with any elective extremity surgery, knowledge of and proper counselling about the possible increased risk of secondary CRPS would be beneficial."

So what are "inciting events" and can we avoid them? Injuries, broken bones and surgical procedures are known triggers for CRPS, so it makes sense to do everything possible to avoid them. Elective surgery is usually discouraged, although it may be considered to correct an underlying problem if it is driving symptoms. Surgery could be necessary in the event of an illness, accident, or emergency. And while we can say no to elective surgery it's not so easy to prevent injuries. Then there are common medical events like a tooth extraction, root canal, blood draw, or other routine procedures that could trigger a spread. What follows is a summary of what I learned, including some practical tips about things we can do on our own, and a discussion of medical interventions you could discuss with your doctor.

Knowledge is power, and unfortunately much of the medical community is sadly in the dark about CRPS. Arming yourself with facts and educating your care providers may be your best protection. Keeping a one page summary of your condition and treatment plan to give to any medical professionals you interact with is a good start. You should include the name of your pain management physician, who can consult with your other providers. Put one in your wallet in

case of emergency. You can also keep a file of important research and treatment options you can refer to when discussing your treatment plan with your doctors. Simply knowing what could put you at risk puts you in a better position to make choices about your activities and your medical care.

The RSDSA can help. There are resources like informational brochures that you can download or order on their website. They have an extensive library you can search for information to bolster your own, and your doctor's knowledge. They also sponsor two accredited continuing education courses for medical professionals, "A Comprehensive Overview of Complex Regional Pain Syndrome" and "An In-depth Look at CRPS: From Diagnosis to Treatment." These courses are available through the American Academy of Pain Management. The more our doctors know about CRPS, the better they will be able to help us navigate our health care.

There are also practical things you can do in everyday life to keep your body healthy and reduce environmental risk. While it is never easy to exercise with pain, doing what you can to remain fit and strong can reduce the risk of an accident. You may be able to find new strategies to manage tasks that have become challenging and might put you at risk. Consider using a wheel chair through the airport or installing special equipment to help you in and out of the bath. Ask your phlebotomist to use the smallest

needle possible when you have blood drawn. Take whatever precautions you can to keep yourself safe.

Vitamin C is a simple and affordable preventative measure. It has been shown to reduce the risk of developing CRPS, and might even decrease pain in established CRPS.² According to a recent report, "Vitamin C is currently established as the most efficacious preventative therapy for the development of CRPS."³ Another survey of studies using Vitamin C following surgery determined that "Vitamin C appears effective in preventing post-operative CRPS I," and recommends taking 500 mg for 50 days after surgery.⁴

The article "Perioperative management for patients with Complex Regional Pain Syndrome" ⁵ was published in Pain Management Research in 2012. The authors complete a review of preventative measures and offer some recommendations. These include taking time to evaluate the risk of a surgery against its potential benefit, postponing surgery until symptoms are well managed, and taking vitamin C after surgery. They discuss the value of regional anesthesia, and recommend it be started before and continued after the operation when possible. They stress the possibility of a flare after surgery, and recommend several medications such as clonidine, ketamine, gabapentin and methadone to manage increased pain levels. Other recommendations include physical therapy such as desensitization and pain exposure, and Cognitive Behavior Therapy which can help reduce pain by lowering stress levels.

A case study at Drexel University in 2012 concurs that there is a significant risk for patients with CRPS who have surgery.⁶ They note that

"In general, recommendations for anesthesia in CRPS patients requiring surgery include sympathetic blockade or intravenous regional anesthesia as well as sympathetic blockade in conjunction with lidocaine." While these measures are reported to be effective for people with "localized disease, they have often been ineffective in patients with severe refractory CRPS."

In this study, "Ketamine as an Adjunctive Anesthesia in Refractory Complex Regional Pain Syndrome Patients: A Case Series," 25 patients with long standing severe CRPS were given ketamine infusions during surgery, and a series of booster infusions after. They all "returned to their preoperative pain level following surgery." The study concludes that "ketamine ... was successful in reducing pain and blocking spread in severely affected long-standing patients." The infusion protocol, which includes the use of clonidine, midazolam and an anti-nausea medication, is provided in detail.

After doing my research, I was ready to meet with my gastroenterologist. I brought my one page history and treatment plan, along with brochures I got from the RSDSA. He had never heard of CRPS before, but was interested in learning about it. I explained that I was concerned that having a colonoscopy screening might trigger a spread, and asked if his team could use ketamine during my procedure. After talking to the anesthesia department he told me they could.

On the day of the procedure, I brought my history, brochures, and a copy of the research "Ketamine as and Adjunctive Anesthesia." I spoke directly with the anesthesiologist who said it was no problem for him to accommodate my requests. The entire staff was inter-

ested in reading the literature I left with them. After the procedure, I began taking 1000 mg of Vitamin C every day.

While it can be frightening to think about the possibility of a spread, it's reassuring to know what I can do about it. I feel empowered to take an active role in my own care and make informed decisions about medical procedures.

(Endnotes)

1 Ellen S. Satteson et al, "The risk of pain syndrome affecting a previously non-painful limb following trauma or surgery in patients with a history of complex regional pain syndrome," *Scandinavian Journal of Pain*: Vol. 14 (January 2017): 84-88 [http://www.scandinavianjournal-pain.com/article/S1877-8860\(16\)30118-5/fulltext](http://www.scandinavianjournal-pain.com/article/S1877-8860(16)30118-5/fulltext)

2 Anitra C. Carr and Cate McCall, "The role of vitamin C in the treatment of pain: new insights," *Journal of Translational Medicine*, (2017 Apr 14): 15(1):77 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5391567/#__ffn_secititle

3 Goh, En Lin, Swathikan Chidambaram, and Daqing Ma. "Complex Regional Pain Syndrome: A Recent Update." *Burns & Trauma* 5:2 (Jan 2017) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5244710/>

4 Jean Luc Besse et al, "Effect of Vitamin C on prevention of complex regional pain syndrome Type 1 in foot and ankle surgery," *Foot and Ankle Surgery* Vol. 15(4), (Dec 2009): 179-182

http://rdsd.org/wp-content/uploads/2015/02/Besse_FootAnk-Surg_2009.pdf

5 Bassem Asaad and Peter Glass, "Perioperative management for Patients with Complex Regional Pain Syndrome," *Pain Management*, Vol. 2, No. 6 (November 2012): 561-567 <http://rdsd.org/wp-content/uploads/2015/02/pmt-12.pdf>

6 Schwartzman RJ et al, "Ketamine as Adjunctive Anesthesia in Refractory Complex Regional Pain Syndrome Patients: A Case Series," *J Clinical Case Reports*, 2:186 (Aug. 2012)

<http://rdsd.org/wp-content/uploads/2015/02/Ketamine-Adjunctive-Anesthesia-in-Refractory-CRPS.pdf>

My RSD Story

BY MARCIA NOLTING

My name is Marcia and I've had RSD for almost ten years and as of writing this, am post Abbott DRG stimulation surgery 4 months.

A decade ago, I tripped over a step and thought someone had cut my left ankle/foot off, it hurt so bad. The pain was instant, continuous and unrelenting. The ER thought I was insane and sent me home with what they termed a "sprain" and to rest it (translation: get over it crazy woman, we aren't giving you drugs).

Luckily, I was quickly diagnosed and found an appropriate doctor. Following that came ten doctors and every treatment available in the United States. Spinal injections, nerve suppressant drugs, pain killers, and a spinal cord simulator designed for back pain (that was all there was at the time).

Each of those things helped a little, and combined was enough to allow me to continue walking, but chronic pain was a daily reality for me and unfortunately everyone around me who had to deal with me, dealing with the pain. There were many times when I would be in bed at night, crying myself

to sleep (where no one could see me), talking myself into getting through just one more day. Many days were like that... just get through today... just get through tonight, you can do this, you are stronger than this condition, you will be able to survive.

Some nights I honestly don't know if I believed that, I just knew that I couldn't give up. I have a wonderful family, loving husband and kids I had to stay strong for. My youngest doesn't know who I am, except after RSD and essentially as a "broken" person. I just kept thinking that I had to hang in there until technology/medicine caught up to my condition and there was another option. I hoped to show my son my other self, my true self, someday.

Then Dr. Gullo and Dr. Heros, along with the team of Abbott neuro-modulation representatives, told me about DRG stimulation and suggested I try it. I admit to feeling pretty cynical, like, "yeah, right, ok...been there done that, don't get my hopes up." The trial was good, but I had no idea what the machine was really capable of until a couple months later. About 2 months after surgery I realized, "Wow, I can work a normal person's work day and not be a total _itch and snarl at everyone!" Then I started to feel something extremely powerful, hope.

Another month went by and I noticed that compared to the other spinal cord simulator I had first, it was simply worlds apart. I have stopped using 3 meds. Also, I'm not using any prescription pain medication at all, except the machine. This is the first time in 10 years that's been a possibility.

When we went on vacation, I was able to walk through the airport without using a wheelchair for the first time. I was able to do most of the activities with my family which was exciting! I went to a Renaissance Fair with my family and walked all day on that uneven ground which previously would have been a harsh sentence of pain for days!

I've been able to do a mostly normal work day without taking anything more extensive than Aleve or Tylenol. I had given up and sold all my horses and show equipment (after a lifetime of being an equestrian) because I figured that was not something I could realistically do anymore, and I needed to face reality.

Well just last Friday, I rode with my friends for a half-day girls ride, and I WAS GOOD TO GO!!!!

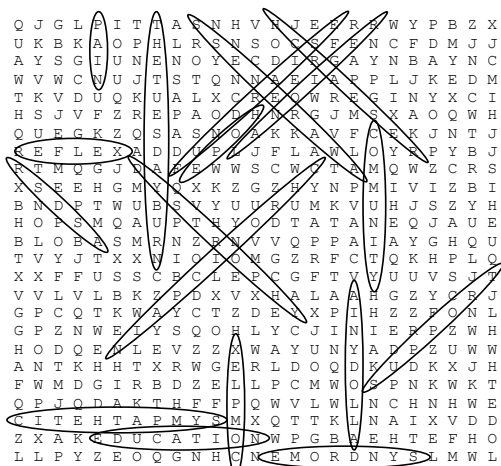
Life-changing are the only words to describe it. I'm hoping to get back to my WHOLE life! It has changed my pain level for the better. An over 90% improvement with DRG, and I'm living proof this is a successful treatment option. I'm happier, healthier, easier to live with and so much more optimistic about the future.

I think I'll travel the world....I'm done rearranging my life around RSD, I WIN!

If you would like to find a location/options near you, look up <https://www.sjm.com/en/patients/resources-and-support/clinic-locator/painspecialist>. I hope everyone with this awful condition finds help!

Marcia

CRPS Word Search Solution



ALLODYNIA
AWARENESS
CHRONIC PAIN
COMMUNITY
COMPLEX
DYSTROPHY
EDUCATION
FUNDRAISE
HOPE
PAIN
REFLEX
REGIONAL
RESEARCH
RSDSA
SUPPORT
SYMPATHETIC
SYNDROME
THETUESDAYBURN

POETRY CORNER

Through Sickness and in Health



BY GEORGY MLLSO

*If only you could explain your pain, to help me understand,
I would lay on the bed next to you and take you by the hand.
No one can imagine your pain, I've seen you cry a million tears,
And while you lay there in my arms, I can feel all your fears.*

*As I lay down beside you, I just know you hurt so much,
I want to hug you gently but you can't bear my touch.
I can hear you thinking, you're a thousand miles away,
If only I could take your pain away, I would have done it yesterday.*

*I see what this disease is doing to you, it makes me so annoyed,
The person that you used to be, this monster has destroyed.
You go through this daily agony and I know your days are long,
No one understands you, all your friends and family have gone.*

*Our love is strong, but I see your pain is so much stronger,
When I look into your once blue eyes, all I see now is anger.
I see your daily struggles and it's totally breaking my heart,
You think that I should leave you and we should live apart.*

*I understand when you're angry, that you are not mad at me,
I know it's the monster inside of you, the one that I can't see.
I lay in bed next to you, I can feel the fire burning you from within,
How the hell do you put up with it, but you never give in.*

*When I have a headache, I can take a pill and get some relief,
When you take yours, the side effects just give you added grief.
How do you put up with it, I will never know and understand,
I know how guilty you must feel, we never had this planned.*

*I don't want to see you like this, "what I see everyday,"
No one should have to suffer like this, in this day and age,
I hate your pain, I'm not angry with you, just your Monster
And all the specialists you see, and your non-believing doctor.*

*I married you, In sickness and in health, for better or for worse,
I will be with you forever, I will be your caregiver and your nurse.
We can get through this together, I will always be by your side,
Though you find everyday so hard, you will always be my bride.*



Easy Ways to Give

- **Make RSDSA your charity of choice on GoodSearch.com and use that instead of Google.**
- **Use AmazonSmile.com. and make RSDSA your charity of choice while shopping online.**
- **If you're selling things on eBay, you can give a portion of the profits straight to RSDSA.**
- **Set up a collection canister in your local grocery store.**
- **Plan an event with the help of Special Event Coordinator Sammie Anderson by emailing sanderson@rdsd.org**

**REFLEX SYMPATHETIC DYSTROPHY
SYNDROME ASSOCIATION**

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

Non-Profit
U.S. POSTAGE
PAID
Graphic Image
06460



TEL: 877.662.7737
FAX: 203.882.8362
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.

VOLUNTEERS:

If you wish to volunteer, please do the following.

- **Please contact LindaLang@rdsd.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@rdsd.org**
- **Please provide your email, phone number and a little bit about yourself.**

Don't see an event near you?

Contact Samantha Anderson
(sanderson@rdsd.org)
to discuss planning an event in your area!