IN RARE FORM



IN THIS ISSUE

RSDSA'S 2ND ANNUAL VIRTUAL CRPS AWARENESS WALK

VIRTUAL RARE DISEASE WEEK ON CAPITOL HILL JULY 14-22

YOUR KETAMINE QUESTIONS, ANSWERED

FACEBOOK LIVE WITH THE SHIRLEY RYAN ABILITYLAB PAIN MANAGEMENT CENTER

Can EMDR Therapy help with Chronic Pain and Complex Regional Pain Syndrome?

by Paul Krauss, MA LPC

This article was submitted for Mental Health Awareness Month in an effort to educate Warriors about different types of therapies.

Living with Complex Regional Pain Syndrome (CRPS) and/or chronic pain is a very difficult physical state that causes immense suffering for the person enduring it. In addition to the physical pain, the negative psychological effects of living with CRPS for any period of time can also be devastating and, according to the National Institute of Health (NIH), even discourage those suffering from seeking proper medical care or participating in rehabilitation and recovery (U.S. Dept of HHS, 2021). In fact, some people diagnosed with CRPS may develop situational anxiety, depression, and even Post Traumatic Stress Disorder-further complicating their health condition. According to the NIH, psychotherapy (aka counseling) can be helpful to those suffering from CRPS and aid in their recovery. Since psychotherapy has been recommended by the NIH for people suffering from CRPS, it is vital to discuss what types of psychotherapy may offer some relief and discuss the differences between intervention types.

It is important to note that not all forms of psychotherapy are the same and unfortunately, the training that licensed psychotherapists receive in postgraduate training is not standardized.

With new studies about the brain and the nervous system being published all the time, it is difficult to know which therapist/counselor may be effective in helping you with CRPS or chronic pain. The most common form of psychotherapy/counseling is referred to as "talk therapy." Traditional talk therapy has been proven effective in treating all types of psychological conditions, such as depression, anxiety, substance abuse, adjustment disorders and much more-In fact, the treatment effect of talk-therapy is .79 (Or according to a meta-analysis of over 10,000 studies on psychotherapy; those who receive psychotherapy will be better off than 79% of those who do not receive psychotherapy) (Wampold, 2001). Yet, traditional talk therapy may not be as effective for those with CRPS and/or chronic pain as a type of psychotherapy intervention named "Eye Movement Desensitization and Reprocessing Therapy" (EMDR Therapy). EMDR Therapy is generally thought to be more effective than traditional talk therapy for those suffering from chronic pain, and thus it is important for those suffering from CRPS and chronic pain to know this information. Secondly, it takes a good deal of postgraduate study to be certified as an EMDR Therapist-which is good news for those looking for a highly-trained psychotherapist. Note: A good EMDR therapist should also use traditional talk therapy methods along with their advanced techniques in their treatments—so you don't have to totally give up one treatment for the other, the focus is just altered.

There is a great deal of information describing EMDR therapy, what it consists of and how it works, but that is not the purpose of this article. Instead, it is vital to explain why EMDR therapy may be helpful for those suffering from CRPS and chronic pain, and why, in fact, it may be more effective than traditional talk-therapy for CRPS. EMDR therapy has been proven effective for treatment of trauma (and PTSD) in numerous studies and part of this effect is thought to come from the "desensitization effect" of the intervention. In the case of trauma, it is the emotional distress surrounding a traumatic incident that is desensitized, whereas in the case of chronic pain, EMDR Therapy has been shown to be effective in reducing chronic pain as it targets the affective response to the pain itself (Tesarz, Jonas, Leisner, et al., 2014). In addition, the "emotional focus of EMDR [therapy] appears to be consistent with what we now believe to be the neurophysiological mechanisms of pain, particularly in terms of the involvement of the amygdala, the hippocampus, and the prefrontal cortex" (Grant, Mark, & Threlfo, Catherine, 2002). The same study concluded that EMDR Therapy is helpful at working through a client's historybecause they may not even be aware of an incident or series of events that contributed to the start of their pain (Grant, Mark, & Threlfo, Catherine, 2002). If those incidents that may have "started the chronic pain condition" can be targeted as "traumatic events", the research notes that EMDR therapy will definitely have a positive treatment effect-as it is proven to work for those suffering from trauma.

Join us for RSDSA's 2nd Annual Virtual CRPS Awareness Walk

Learn more about our 2nd Annual CRPS Awareness Walk from CRPS Warrior Kelly Considine, the Chair of this year's event by watching Kelly's video <u>here</u>.

We've also included details about our Walk Incentive Program below. Register for the walk today at <u>rsds.org/walk</u>.





RSDSA'S 2ND ANNUAL CRPS VIRTUAL AWARENESS WALK

When you participate in RSDSA's 2nd Annual Virtual CRPS Awareness Walk, the funds you raise fuel our mission and provide, support, education, and hope while driving research for better treatments and a cure.

RSDSA realizes fundraising is a lot of work. That is why we are thanking our participants for their efforts by offering incentive prizes for different fundraising levels.

~YOU MUST BE A REGISTERED FUNDRAISING PARTICIPANT TO EARN INCENTIVE GIFTS~



Prizes are not cumulative and subject to change

RSDSA's Advocacy Committee is Hard at Work

Your RSDSA Advocacy Committee are fellow CRPS Warriors. We have spent the past few months working with the EveryLife Foundation lobbying Congress to pass the STAT Act (Speeding Therapy Access Today Act of 2021). The STAT Act creates a Center of Excellence for rare diseases in the FDA aimed at streamlining the approval or clearance of new and existing pharma and medical devices. On the RSDSA website at <u>rsds.org/advocacy</u>, you can access a sample CRPS advocacy letter asking your State and Federal Representatives to support the STAT Act.

Rare Disease Week on Capitol Hill 2021 is coming up on July 14th – July 22nd. This weeklong event will be virtual this year. This event is an invaluable opportunity to meet with Senators, Congressmen, and other rare disease advocates via Zoom appointments. Be heard – you can register to participate in the week <u>here</u>.

Why is this important?

We need you to be a part of the process in any way possible. Our representatives need to know that even though CRPS Warriors are rare, we are their constituents. Rare disease is a silent crisis in the US and will remain so until we take action and tell our stories.

We are not only CRPS Warriors, but we have loved ones who are also affected by CRPS. The RSDSA's Advocacy Committee needs our lawmakers to hear your voices so that CRPS Warriors and their loved ones may impact the kind of change we need to not only survive but thrive.

We all, as patients and families and caregivers know how miserable and debilitating CRPS is. We all live it. We know how CRPS burns and affects the body. We know the flairs, exhaustion, fog, and pain. We also know that hope can sometimes get lost. It's easy to lose hope when you become aware that the first time CRPS was identified after the Civil War and then to see that there is still no cure nor an FDA-approved pain treatment. We understand the frustration.



There is hope!

One of our biggest hurdles is getting a proper CRPS diagnosis. Some of us had it over a decade before getting an accurate CRPS diagnosis. To address the issue of early diagnosis, we are looking at leveraging new technology as a solution. Thus, one of our projects is a proposal using artificial intelligence to aid early CRPS diagnosis for future patients. We will update you more when more information becomes available, but please know that this innovation can help future CRPS patients in physician awareness and diagnosis.

What is essential now is that you should know your Advocacy Committee is thinking big, but to enact the kind of change CRPS warriors and their families need comes from working together. We are hoping you could make your voices heard, and you can do this from the comfort of your own home. If we get loud enough together, we can make an impact for the better.

Jeri, Jim, Megan and Nancy
You can contact us at <u>advocacy@rsds.org</u>.

Save the Date for these Upcoming RSDSA Fundraising Events

We're excited for CRPS Warrior Christina Whearley's <u>Saving Those Overwhelmed by Pain</u> (<u>S.T.O.P.) Spring Stroll</u> event on Saturday, May 29th in Old Town, Manassas, Virginia and for CRPS Warrior Nicole's <u>fundraising event for her climb to the top of Mt. Kilimanjaro</u> this June.

If you're interested in creating a fundraiser for RSDSA, email Jeri Krassner, RSDSA's Special Events Coordinator, at <u>jkrassner@rsds.org</u>.

Milford, Connecticut Residents: Purchase a Reusable Bag at Big Y to Benefit RSDSA

RSDSA has been selected to be a part of the Big Y Foods Community Bag Program this month. The Big Y location at <u>150 Boston Post Road, in Milford, Connecticut</u> will donate \$1 for every \$2.50 community bag they sell for the entire month! The bags are available at various registers and at the reusable bag rack. If you are having trouble finding the bag, ask a Big Y team member!

Continued from Page 2

Further positive effects of EMDR Therapy were witnessed in various studies, with one stating that "altering the emotional dimension of pain might thus involve changes in the way pain is 'remembered' and reproduced within the nervous system" (Grant, Mark, & Threlfo, Catherine, 2002). If we think of some aspects of chronic pain are the way the nervous system remembers a "pattern" [of pain], then by utilizing EMDR therapy, we can, in effect reduce or desensitize that pattern. We know that EMDR Therapy is targeting the brain areas involved in storing pain patterns and we know that EMDR Therapy is effective at treating traumatic events (and such incidents sometimes lead to chronic pain), and therefore, the chances are that EMDR Therapy can be helpful for those suffering from CRPS and chronic pain because the therapy directly addresses the symptoms; the symptoms aren't merely "discussed", they are directly targeted by the intervention.

There are many in-depth studies noting that EMDR Therapy can be effective for those suffering from chronic pain for a variety of reasons: One such study discussed a theory based on its results: "EMDR treatment could help decrease or eliminate pain sensations by enhancing interhemispheric communication and cortical integration of traumatic memories. As a result, there could be a decrease in the negative emotional arousal with a concomitant reduction in hypervigilance that may also lead to a decrease in pain perception" Mazzola, Alexandra, Calcagno, et al., 2009). Be advised, despite the positive results in each study reviewed on EMDR Therapy's effects on chronic pain, EMDR therapy is not a cure-all. Researchers noted that "even though all of the results pointed in the same direction [reduction of pain], the pretreatment/posttreatment effect size calculations of these studies revealed that the effect sizes varied considerably depending on the underlying pain condition and the length of treatment" (Tesarz, Jonas, Leisner, et al., 2014).

Since psychotherapy is recommended by the NIH for people with CRPS, then those with CRPS would be advised to work with a counselor/psychotherapist that is certified in EMDR Therapy, because EMDR therapy has been researched to target the emotions tied to the pain sensations, the pain sensations themselves, and possible incidents or events that contributed to the origination of the chronic pain. All of the studies cited noted that EMDR Therapy can reduce chronic pain in people, however, it is important to understand that a good deal of participation may be needed from the sufferer as the amount of positive reduction varied upon the sufferers' condition and the amount of therapy received. At the very least, EMDR Therapy can help those with CRPS move through the difficult psychological symptoms related to the pain, and may help them with further participation in rehabilitation treatments and recovery.

To find a Certified EMDR Therapist visit: https://www.emdria.org/find-a-therapist

To learn more about EMDR Therapy visit: <u>https://www.emdr.com</u>

<u>Paul Krauss MA LPC</u> is the Clinical Director of Health for Life Grand Rapids, home of The TraumaInformed Counseling Center of Grand Rapids. Paul is also a Private Practice Psychotherapist, EMDRIA Consultant in Training (CIT), host of the Intentional Clinician podcast, Behavioral Health Consultant, Clinical Trainer, and Counseling Supervisor. Paul is now offering consulting for a few individuals and organizations. Paul is the creator of the National Violence Prevention Hotline (in progress) as well as the Intentional Clinician Training Program for Counselors.

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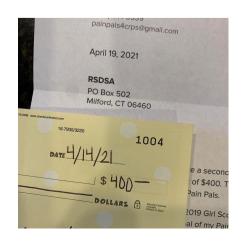
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Special thanks to Pain Pals For CRPS Warriors for making another donation to RSDSA for CRPS awareness, research, and support! Pain Pals are stuffed elephants made with many textures for desensitization therapy.

Learn more about Pain Pals and make a purchase today on <u>Etsy</u>.

Facebook Live with the Shirley Ryan AbilityLab Pain Management Center

RSDSA is hosting a Facebook Live with the Shirley Ryan AbilityLab Pain Management Center on **Thursday**, **May 13th at 7p Eastern** to discuss the Care of CRPS and Chronic Pain Conditions.

The event will be lead by:

- Diane Amstutz, PhD
- Benjamin Katholi, DO
- Wendy Wurtzel PT, DPT
- Maya Yuen, PT, OCS
- and SRA Lab patient Sarah H.

You can read more about the clinicians <u>here</u> and view their photos below.

Join us at <u>facebook.com/rsdsa</u> on Thursday, May 13th at 7p Eastern to chat with the <u>Shirley Ryan AbilityLab Pain Management Center</u>.

Don't forget: If you miss one of our Facebook Live sessions, you can always watch the replay on the <u>RSDSA YouTube Channel</u> as we do record each one.









Diane Amstutz, PhD Benjamin Katholi, DO Wendy Wurtzel PT, DPT Maya Yuen, PT, OCS

Your Ketamine Questions, Answered

Dr. Steven Richeimer joined us for a <u>Facebook Live in March</u> to discuss CRPS and ketamine and a few Warriors sent over follow-up questions after the discussion:

- Can ketamine help chronic migraines, fibromyalgia and organ pain from CRPS?
 - The data on the use of IV ketamine for other conditions is very limited, but we have had a few patients with fibromyalgia and refractory headaches that have partially improved with this treatment. At this point, it is too early to really know if IV ketamine is an effective treatment for these conditions.
- Does ketamine work better than nerve blocks?
 - We will usually start treatment with oral medications, blocks, physical therapy, and pain psychology. If the CRPS is not improving, then I think it is time to consider more aggressive treatment with either nerve/spinal stimulation or with IV ketamine.
- Do ketamine infusions have clot risks?
 - Ketamine itself does not cause blood clots, but for many patients that get IV ketamine, we use implanted ports or PICC lines. If a patient has an underlying tendency towards blood clots, then the port might trigger the formation of clots.
- What medications and/or interventions do you utilize to maximize the time between infusions?
 - Typically we will use oral (compounded capsules of) ketamine, or amantadine, or memantine. All of these medications are NMDA antagonists, and we have found them to be very helpful in prolonging and maximizing the response to the ketamine infusions. For the oral ketamine, we ask our patients not to use it on the days that they receive a ketamine infusion.

NORD and MedicAlert Foundation Team Up to Protect and Empower the Rare Disease Community

Washington, DC — March 2, 2021 | More than 25 million Americans living with rare diseases face many challenges, including finding information about their condition, accessing quality health care, and paying for treatments. With help from the National Organization for Rare Disorders (NORD®), the rare community is assisted with access, resources and advocacy. But what happens when someone with a rare disease has an accident or medical emergency? NORD and MedicAlert Foundation recently announced a new program to help provide protection to rare disease patients in emergency situations. <u>Read more here</u>.

Color the World Orange[™] is November 1st, 2021

It is time to partner with Color the World Orange[™] by contacting officials in your community to request that local landmarks be illuminated orange on November 1, 2021.

Visit <u>colortheworldorange.com</u> to learn more and to get involved today.

Donate your old car to Charitable Adult Rides & Services (CARS) to benefit RSDSA

<u>CARS</u> is a 501(c)3 nonprofit social enterprise owned by a nonprofit supporting only nonprofits through vehicle donations.

When you donate a vehicle to CARS, RSDSA receives 70% of the proceeds. Learn more about donating your car to benefit RSDSA <u>here</u>.



Please send us feedback!

Please send any suggestions or upcoming events of interest to our community to <u>info@rsds.org</u> and please consider a donation to <u>rsds.org/donate</u>.