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IN RARE FORM

IN THIS ISSUE

Are There Distinct Subtypes of CRPS?

by Stephen Bruehl, Ph.D., Professor of Anesthesiology at Vanderbilt University School of Medicine, RSDSA Board Member

In 2013, the U.S. Food and Drug Administration for the first time granted CRPS the designation of an Orphan Condition, providing important financial incentives for development of CRPS-specific drugs. Despite much promise, large-scale clinical trials funded by pharmaceutical companies over the past 10 years have failed to show efficacy for several potential CRPS drugs evaluated. As a result, development of promising CRPS interventions has been halted, to the detriment of those suffering from CRPS.

All of these FDA-regulated clinical trials have studied samples of patients meeting the current international diagnostic criteria for CRPS (i.e., the Budapest criteria). CRPS is a broad diagnostic category with multiple contributing mechanisms, and in many cases, any two given patients meeting diagnostic criteria may look very different due to various mechanisms being involved to differing degrees. For example, one patient may have an exquisitely sensitive cold limb in which touch is painful, whereas another may have a hot, sweaty limb that is extremely swollen. Large clinical trials carried out to date have all tested efficacy of the drugs in samples that lump together these patients showing very different CRPS characteristics, so in essence have tested drug efficacy in a hypothetical average CRPS patient. Intriguingly, results of some trials have hinted that the drugs being tested may have worked well in certain types of CRPS patients and not in others, resulting in overall negative findings for the average patient. This situation highlights the importance of testing potential CRPS interventions working via specific mechanisms in CRPS patients likely to be experiencing those particular mechanisms. This approach, termed precision medicine, is now quite common in cancer treatment but has yet to be applied widely in pain management.

For a precision medicine approach to be applied successfully to improve treatment of CRPS, it is crucial to identify mechanistically-distinct subtypes of CRPS patients. On September 18, 2022, the RSDSA sponsored a meeting of international CRPS experts in Toronto, Canada with the goal of coming to a consensus as to the key CRPS subtypes relevant for targeting in future clinical trials and to identify the mechanistically-relevant interventions for each. Attendees included Stephen Bruehl, Norman Harden, Gary Bennett, and Peter Moskovitz (U.S.); Candy McCabe (U.K.); Frank Birklein, Ralf Baron, Heike Rittner, and Christian Maihofner (Germany); Peter Drummond (Australia); and Lone Knudsen (Denmark). All participants reviewed the research literature relevant to CRPS subtypes prior to the meeting and made recommendations based upon this literature review and their own clinical experience. One broad recommendation was to focus on subtypes of CRPS-I in precision medicine trials given potentially unique involvement of neuropathic pain mechanisms in CRPS-II. Although optimal subtype terminology remains to be determined and there may be some overlap among subtypes, the group identified several potentially distinct CRPS subtypes supported by existing research. These include:

1) Warm vs. Cold CRPS (overlaps to some extent with #2)
2) Early Acute vs. Persistent CRPS (Immune/Inflammatory vs. Non-Inflammatory)
3) Sympathetic-Mediated vs. Non-Sympathetic CRPS
4) Regional vs. Centralized + Regional CRPS
5) Sensory CRPS Subtypes (Thermal Hyperalgesia vs. Sensory Loss vs. Allodynia)
6) Painful Bone CRPS vs. CRPS Without Bone Involvement
7) CRPS With and Without Significant Psychosocial Involvement

As a proof-of-concept to demonstrate the value of targeting specific interventions towards distinct CRPS subtypes to optimize intervention responses (i.e., precision pain medicine), the group recommended initially conducting a clinical trial focused on Warm vs. Cold CRPS subtypes. The trial would use objective temperature asymmetry (≥1.5-2.0 deg C) between the affected and unaffected limb to identify patients with Warm CRPS (i.e., affected side warmer) vs. cold CRPS (affected side colder). Patients with atypical symptom patterns (Early Acute Cold CRPS and Chronic Warm CRPS) would be excluded. Based on prior research and hypothesized mechanisms, the intervention provided to both groups would be high dose oral steroids, with the expectation that steroids would be significantly more effective for pain and CRPS symptom reduction in the Warm CRPS group than in the Cold CRPS group.

RSDSA is committed to funding this type of proof-of-concept trial in order to demonstrate to the field of CRPS research the value of adopting a precision medicine approach for optimizing CRPS intervention efficacy.

Painting the World Orange from Coast to Coast!

PAINTING THE World

November 6th, 2022

Orange

2:00 PM

LOS ALAMITOS MUSEUM

REGISTRATION WEBSITE COMING SOON!

HOSTED BY:
ORANGE COUNTY CRPS SURVIVORS & CAREGIVERS SUPPORT GROUP

November is CRPS Awareness Month and this year RSDSA has **two** Painting the World events on Sunday, November 6th, the day before Color the World Orange™.

Painting the World Orange
Los Alamitos Museum (11062 Los Alamitos Blvd Los Alamitos, California 90720) or Zoom
2p Pacific

Join RSDSA's Reflex Sympathetic Dystrophy California-Support Community (RSDCA) and the Orange County CRPS Survivors and Caregivers Support Group for an in-person, or via Zoom, fun afternoon of painting and camaraderie. There will be a silent auction, raffles, hors d'oeuvres and beverages.
Register here

Painting the Journey to the Garden
Paramount Brethren in Christ Church (19106 Longmeadow Rd Hagerstown, Maryland 21742) or Zoom
2p Eastern

Join instructor Katy Thomas, as we make our garden grow with hope and friendships. Growing up, Katy had a love of art which continued into adulthood. With a parent having a chronic condition and having one herself, Katy finds great joy using painting to unite us for a time of fun while also benefiting RSDSA.
Register here

We also support Color the World Orange™ to raise awareness of CRPS during our annual Awareness month by contacting local and state governments to ask for proclamations declaring November as CRPS Awareness month and for public buildings to be lit orange on Monday, November 7th.

It is never too late to contact your local representative to ask for a proclamation. We have a letter/email template for "how to ask" on the next page. You can edit the template to fit your words. If you need help finding your representative, visit house.gov and enter your zip code.

[CITY OR STATE OF ____]
c/o [MAYOR OR GOVERNOR]
[STREET ADDRESS]
[CITY, STATE, ZIP CODE]

[DATE]

Greetings (**Name of Official**),

I am writing to you today, because I am a constituent who suffers from Complex Regional Pain Syndrome (CRPS), formerly known as Reflex Sympathetic Dystrophy Syndrome (RSD), a debilitating rare disease.

The month of **November is CRPS Awareness Month**. Others and I afflicted with this rare disease will wear orange all month to raise awareness. Orange was the color chosen by the CRPS/RSD community as the awareness color because it represents the burning pain we feel each day.

I respectfully request that you help me raise awareness which may lead to a cure for this pervasive and progressive disorder. Please, consider issuing a proclamation declaring **November CRPS Awareness Month** and officially recognizing it in (**Name of Municipality**) this year.

CRPS is an extremely painful nerve condition, one of the most painful conditions known to humans. CRPS affects the sympathetic nervous system which controls digestion, heart rate, respiration, and more. With COVID people got a small taste of what it is like to live with a rare chronic illness such as living with the unknown, more questions than answers, no cure, the isolation, and the fear. These are just a few of the things that people with chronic illness live with every day.

Here are four CRPS facts:
- CRPS is considered the single worst source of pain, and the pain level ranks higher than childbirth, cancer, and even amputation according to the McGill Pain Index Chart. CRPS can spread beyond the initial injury site, eventually affecting the whole body.
- Less than 1% of all dollars spent on health research is used for pain research! This is so sad considering today's epidemic of prescription drug abuse and the opioid crisis. We need to find better and safer alternatives for pain management for chronic pain conditions
- CRPS is known as Suicide Disease because patients become desperate with pain and suffering. In addition to the high pain levels, patients experience sleep deprivation, and social isolation,

- There is CURRENTLY NO CURE for CRPS. The best the doctors can do is treat the symptoms and put “band aids” on any new symptoms.

I wanted to share the above information with you, so you have a clear understanding of life with CRPS before sharing the proclamation (please see below) because it is imperative that we bring attention to this horrific, debilitating syndrome. Increased awareness is very crucial because the earlier the diagnosis of someone the more likely they are to find pain relief. We need to better educate the public but more importantly medical staff, so they are well versed in how to manage and treat CRPS.

Thank you for your time and consideration.

Sincerely,
Name & Your Contact Info.
Visit rsds.org for more information on our syndrome.

2022 Treating the Whole Person: Optimizing Wellness Virtual Conference Videos

Thank you to everyone who joined last month's virtual conference!

All sessions were recorded and will be uploaded to the RSDSA YouTube Channel by the end of the month. Be sure to subscribe to our channel while you're there!

Thanks for supporting RSDSA’s Longest Day of Golf!

One of our major annual fundraising events, the Longest Day of Golf, took place on Monday, September 19, 2022! Our golfer, Tony Consiglio, completed 132 holes from 7AM to 7PM and is ready to participate in 2023!

Donors still have the opportunity to contribute per hole completed, give a one-time gift, or a recurring monthly gift here.

September/October 2022 Event Recaps

The 4th Annual Flame Out - A Walk to Extinguish RSD/CRPS took place on September 18, 2022 at Joe Palaia Park in Oakhurst, New Jersey! (Photo Credit: Calmare Therapy NJ USA's Facebook Page)

The Show of Force, a unique fashion show experience, combined with gala art exhibits, auctions, catered dining and more, benefitting RSDSA, took place on October 8, 2022 in Thunderbolt, Georgia. (Photo Credit: Reneé LaSalle's Facebook Page)

The 2nd Annual “Picklin’ for a Cure” event supporting RSDSA, Lewy Body Dementia Association, and The ALS Association took place October 14-16, 2022 at Udall Park in Tucson, Arizona! (Photo Credit: “Picklin’ for a Cure” Charity Pickleball Tournament Facebook Group)

MILLER KERR

Captain of the Kilgore College Rangerettes

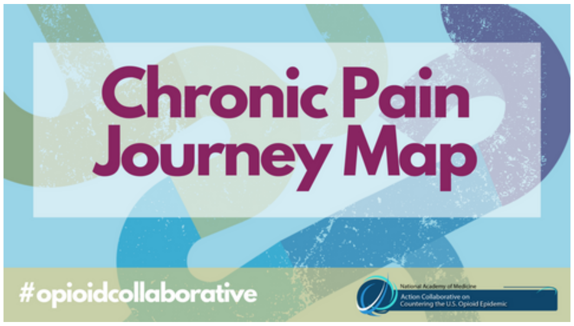
> “I will never forget the feeling of being handed the Captain's baton and finding out I would be the next Captain of the Kilgore Rangerettes! I am honored to lead this team through the next year, and eager to accomplish all of our goals.. I am grateful for all of the support I have received from my teammates and directors, and I am so excited for an amazing year!”

DREAMS DO COME TRUE...

Miller Kerr, from Dallas Texas, was selected as the 82nd Captain of the Kilgore College Rangerettes. Miller is in her sophomore year and before attending Kilgore, she attended Ursuline Academy of Dallas where she was the Captain of the Jesuit Rangerette Drill Team. Miller is excited to be opening The State Fair of Texas and going back to the Macy's Thanksgiving Day Parade with her teammates where they will be performing in uniform this year.

Miller is overjoyed to realize her dreams, as she was diagnosed with Reflex Sympathetic Dystrophy / Complex Regional Pain Syndrome after a playground accident in 5th grade leaving her unable to walk. She spent six weeks at the Cleveland Clinic, where she underwent various types of intense therapies. Upon return, she enrolled in a dance class in the 6th grade as a way to "keep moving", and the rest, as they say, is history! Miller has become an advocate for those dealing with RSD/CRPS, and had her first event in support of the RSDSA raising over $10,000 and creating awareness about this medical syndrome.

Explore the Chronic Pain Journey Map



A new resource from the National Academy of Medicine's Opioid Collaborative highlights gaps in chronic pain care and actions that can be taken to improve the pain management process. This tool, known as the Chronic Pain Journey Map, was informed by individuals with chronic pain and clinicians in pain management to understand the patient-clinician experience when navigating treatment.

If taken up, the actionable strategies outlined in the map can accelerate a range of pain treatments by outlining approaches to effective communication that lead to strong clinical relationships and strategies to prioritize the quality of life for people with pain.

Explore the Journey Map to learn more: https://bit.ly/3NKJvFc

Cartober is almost over!

Much like Giving Tuesday, Cartober is an online giving campaign held throughout the month of October to highlight the impact vehicle donations can make. Cartober also encourages people to drive change by donating their unwanted car, truck, RV, motorcycle, or boat to their favorite nonprofit or public media station.

CARS 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 here.

rsdsa
SUPPORTING THE
CRPS COMMUNITY

A Special Shoutout to Amanda Pitre

Since 2018, Amanda Pitre has donated more than $3,300 to support RSDSA's Pediatric Camp for children in pain and our Young Adult Retreats. What is so remarkable is how she raised these funds, by redeeming cans and bottles. Amanda splits the proceeds between RSDSA and a personal fund for her to buy an accessible house.

This year, Amanda helped RSDSA along with Zoe's Heroes sponsor a virtual camp for children in pain as it was recommended that our campers with complex medical conditions should not attend the Center for Courageous Kids in person.

Support RSDSA by Shopping at Big Y in Connecticut

RSDSA is benefiting from the Big Y's Community Bag Program through November 31, 2022.

For every community shopping bag sold at the Big Y at 150 Boston Post Road in Milford, Connecticut, RSDSA, will receive $1. Help us spread the word to those in the 06460 area!

We want your feedback!

Please send any suggestions or upcoming events of interest to our community to info@rsds.org and please consider donating at rsds.org/donate.

Thank you to our Title Sponsors

Our title sponsors make RSDSA events and awareness activities possible. Please join us in thanking and supporting them!

Abbott | The Baker Family Charitable Fund | Diana and Peter Smith in memory of Stephanie Theresa Smith | Dr. & Mrs. Lawrence and Judy Zager, in loving memory of Hunter Lia Zager | Lynn & Michael Coatney | The Cochran Firm, National CRPS/RSD Lawyers | Takeda