

# IN RARE FORM



## IN THIS ISSUE

**THANK YOU FOR  
SUPPORTING RSDSA'S  
2ND ANNUAL VIRTUAL  
CRPS AWARENESS  
WALK**

**RSDSA FUNDS TWO  
INNOVATIVE RESEARCH  
GRANTS**

**NEW HAMPSHIRE AND  
OKLAHOMA LEAD THE  
WAY IN GUARANTEEING  
ACCESS TO OPIOID  
THERAPY**

**UPCOMING EVENTS**

## Virtual Meeting of the Board of Scientific Counselors of the National Center for Injury Prevention and Control

The CDC's Board of Scientific Counselors of the National Center for Injury Prevention and Control (BSC/NCIPC) will hold a virtual meeting on **Friday, July 16**.

The meeting will provide an overview of the process/progress for updating the CDC Guideline for Prescribing Opioids, discuss the BSC Opioid Workgroup's report on the draft Guideline and provide a public comment opportunity.

Societies, patients and other stakeholders are encouraged to register to provide comments about the CDC's guidelines including pain management best practices.

Pre-registration is required by accessing the link [here](#).

This is a virtual meeting and open to the public, limited by the capacity of the conference webinar, which is 2000 participants.

Individuals **can submit written comments on or before July 23rd** by submitting comments to [ncipcbsc@cdc.gov](mailto:ncipcbsc@cdc.gov). All written comments will be included in the meeting minutes.

# Thank You for Supporting RSDSA's 2nd Annual Virtual CRPS Awareness Walk



Jim Broatch, RSDSA's Executive Vice President and Director, and Kelly Considine, 2nd Annual Virtual CRPS Awareness Walk Chair during our 2021 Walk

RSDSA would like to thank each and every one of you for supporting our 2nd Annual Virtual CRPS Walk. Our sponsors, donors, teams, and registered participants made this event a success!

During the Virtual Walk, our team was joined by CRPS Warriors across the country who discussed why the Walk and RSD/CRPS awareness is important to them. Click [here](#) to watch the full livestream on Facebook and [here](#) to watch it on YouTube.

Livestream participants included:

- Kelly Considine of Kelly's Crusaders - Torrington, CT
- Sheryl Freed of Team Sheryl's Shoulders to Lean On - Stony Brook, NY
- Diana Jordan - Arlington, VA
- Janet Huff of Team Huff - Eastpointe, MI
- Christine Evanson - Folsom, CA
- Cassie Christensen of Team Just Keep Swimming - Sacramento, CA
- Anthony Appleton, PhD - Fort Collins, CO

## Thank You to our Walk Teams

Amo Maz  
BBAwareness  
Bernhardt  
Betsy's CRPS Team  
Blue Ridge Mountain Team  
Boni's Believers  
Calloway Crew  
Campbell  
CRPS Philly Area  
CRPS Winners  
Heather's a CPRS with CRPS  
Inspired  
Just Keep Swimming  
JZ's Fire Fighters  
Kelly's Crusaders  
Ladybugs Unite  
Leo's Awareness & Goodies

## Marion's Warriors

Melissa's Movers  
Mighty Warriors  
Phoenix Rising  
Proctor  
PTs  
RSD Fire Flies  
RSD Zoom Support Group  
Ryan Doyle  
Seickel's Warriors  
Sheryl's Shoulders to Lean On  
Survivors & Supporters  
Tales of the CRPS  
Tara's Terrific CRPS Warriors  
Team Glietkie  
Team Huff  
Team Mango  
Team Robertson

## Team Rubio

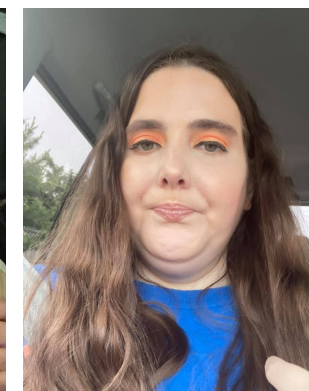
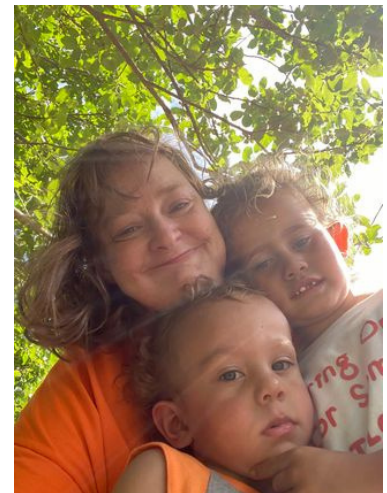
The Pirates Cassandra & Phelan  
Thunder Sisters  
Warriors Within

## Top Fundraising Individuals

Mary Ann Ludwig  
Christine Evanson  
Sheryl Freed  
James Considine  
Diana Jordan  
Janet Beyersdorf-Hufnagel  
Anthony Appleton  
Rachel Hymel  
Kristine Campbell



# Check Out These Photos From the Walk





# New Hampshire and Oklahoma Lead the Way in Guaranteeing Access to Opioid Therapy

New Hampshire and Oklahoma lead the way in guaranteeing Access to Opioid Therapy. Kudos to advocates in NH & OK who worked with their legislatures to increase access to opioid therapy. Sadly, since the issuance of the CDC Guidelines in 2016, many individuals on stable long-term opioid therapy have been forcibly tapered or cut off from their opioids entirely—often without a viable alternative.

According to [Pat Anson, Pain News Network](#), New Hampshire's bill HB 1639, "amends state law to add key provisions that protect the rights of both pain patients and their doctors."

Under the law, physicians and pharmacists are required to consider the "individualized needs of pain patients, treat them with dignity, and ensure that they are "not unduly denied the medications needed to treat their conditions." Furthermore, under the New Hampshire law, "all decisions" regarding treatment are to be made by the treating practitioner, who is required to treat chronic pain "without fear of reprimand or discipline."

Another provision of the law requires that a diagnosis of chronic pain made by a physician anywhere in the U.S. that is supported by written documentation should be considered adequate proof that a patient has chronic pain. That part of the law is intended to make it easier for out-of-state pain patients to get treatment in New Hampshire.

The law is the result of two years of lobbying by a small group of patient advocates known as the New Hampshire Pain Collaborative, which worked closely with state Sens. John Reagan and Tom Sherman in drafting the legislation. Key provisions eventually became part of the healthcare omnibus bill that won bipartisan support in the New Hampshire Senate and House of Representatives and was signed into law by Governor Sununu.

Bill Murphy, a member of the Pain Collaborative, made [this](#) video to help other patients and advocates create similar legislation in their states.

In Oklahoma, Governor Kevin Stitt signed SB57, passed unanimously by the Oklahoma House and Senate. According to an article in the Pain News Network, "one key amendment emphasizes that 'individualized treatment' be provided to patients without tapering or mandatory dose limits." To read the story, [click here](#).

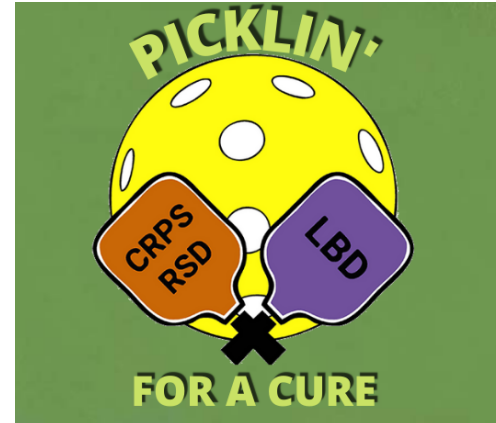


## Register for Picklin' for a Cure in Tucson, Arizona

Please join us for 2021 Picklin' for a Cure: an awareness and fundraising pickleball tournament for RSDSA and Lewy Body Dementia Association.

Registration opens on June 8th and closes on September 30th. The tournament begins on October 15th and ends on October 17th.

Learn more about registering for the event [here](#).



## Register for the 3rd Annual Flame Out Walk to Extinguish RSD/CRPS in Oakhurst, New Jersey

Join the Hopkins Family in supporting RSDSA at the 3rd Annual Flame Out Walk to Extinguish RSD/CRPS in Oakhurst, New Jersey on September 12th. This event is sponsored by the Vietnam Veterans of America, Oakhurst, Chapter 12.

The Hopkins' daughter, Judy, has RSD, and they are hosting this 3rd annual event to support her, RSD/CRPS Warriors, and RSDSA. Please join them as attendees step off to remember those who, daily, battle the syndrome.



## Host an Event with RSDSA

Are you looking for a way to raise awareness of CRPS in your area?

With our neighborhoods opening up as we return to going to in-person events (or hybrid activities), now is a good time to plan a fundraising CRPS community awareness event.

Fundraising events are a fun, meaningful way to raise awareness and support for the RSDSA Warrior community. Many fundraising events are in a loved one's honor and some are even centered around a favorite pastime, such as golf, pickleball or gaming.

Here are just a few event ideas:

- Plan a golf tournament
- Host a BBQ or pancake breakfast
- Set up a yard sale
- Plan a local walk
- Gather for a poker night
- Organize a wine tasting

We are here to help you plan your own event. If interested, please contact Jeri Krassner, Special Events Coordinator, at [jkrassner@rds.org](mailto:jkrassner@rds.org) or 917-597-7256.

## RSDSA on Precision Compounding Pharmacy Live

Jim Broatch and Nurse Beth Seickel joined Christian Stella (Pharm D, ABAHP) of Precision Compounding Pharmacy on the Pharmacy's livestream to discuss compound medicine for CRPS, having a "CRPS toolbox," what RSDSA is up to and more.

Watch the full episode [here](#) on YouTube.





## RSDSA Funds Two Innovative Research Grants

The RSDSA Board of Directors recently approved Jason Hale's, MD grant application. Dr. Hale, a resident physician in anesthesiology at the Cleveland Clinic, wants to see if brief periods of nitrous oxide exposure can treat CRPS pain. The goal of the study is to determine whether nitrous oxide, also known as "laughing gas," would be effective in treating pain caused by CRPS. Dr. Hale is working with Dr. Jijun Xu, MD PhD and Dr. Alparslan Turan, MD, who are staff physicians in the Anesthesiology Institute at the Cleveland Clinic.

The rationale for the research trial is based on the molecular mechanism, or how a drug works at the molecular level, of ketamine, a powerful intravenous pain medication. Brief periods of ketamine therapy are sometimes effective in treating CRPS pain, even after the effects of ketamine have worn off. Unfortunately, ketamine is wrought with side effects such as hallucinations, the therapy is costly and requires intravenous access, and toxicity can limit the amount of medication that can be used.

Ketamine's primary molecular mechanism is NMDA antagonism, meaning it blocks NMDA receptors in the brain, and this underpins its efficacy as a pain medication. NMDA receptors are believed to play an important role in the development and persistence of chronic pain, especially neuropathic pain in CRPS. Blocking NMDA receptor activity in the brain is also believed to be important in treating chronic neuropathic pain. Unfortunately, there are very few medications that act as NMDA antagonists (like ketamine), and the true utility of NMDA receptors as a therapeutic target remain unclear.

Nitrous oxide, however, is also an NMDA antagonist, and this explains why nitrous oxide, while also being sedating, directly treats pain. Nitrous oxide is cheap, safe, and easy to administer with a simple breathing mask. Based on some scientific studies in animals, the research team believes the pain-relieving effect may continue even after a patient recovers from breathing nitrous oxide. Temporarily exposing neurons in the brain to an NMDA antagonist is believed to help "reset" the maladaptive cellular mechanisms that contribute to neuropathic pain.

This small research trial will help us determine if nitrous oxide can provide effective pain relief, reduce oral opioid medication use, and improve functional status in patients with CRPS. If beneficial, nitrous oxide could become an alternative treatment option for patients with CRPS and other chronic pain conditions. Dr. Hale and his colleagues are excited to restart this clinical research trial at their institution as it was delayed by COVID.

We just began funding an international project in Switzerland. Drs. Jungel and Brunner's goal is, "We aim to understand the molecular signaling pathways underlying pain, in particular the interaction between the nociceptive system and the immune system as well as resident cells in skin. Using skin biopsies from A) patients with CRPS - affected and non-affected side, B) patients with a similar trauma but resolving and C) healthy individuals, we will get new insight into the molecular signaling pathways of skin cells to define novel biomarkers for early diagnosis, monitoring of disease and/or treatment response. In addition, we will get information about the key regulators of signaling pathways associated with pain to develop novel therapeutic strategies." Thus far, researchers have not defined any CRPS biomarkers and if successful, this study will guide future research.

Since 1992, RSDSA has funded more than \$3 million dollars in basic and clinical research. To donate to our research fund, please visit, [rsds.org/donate](https://rsds.org/donate)

## Meet Eric Moyal, RSDSA's New Board Member

Eric Moyal from Ride for Warriors is the latest member of RSDSA's board!

Eric is the brother of Anais Moyal, who is a CRPS Warrior. He currently works in fundraising for Brandeis University and also founded Ride for Warriors, a cross country bike ride that helps raise money for RSDSA.

Learn more about Eric [here](#) and the rest of the RSDSA board [here](#).





## Save the Date: Treating the Whole Person: Optimizing Wellness Virtual Conference is October 25-28, 2021

Our live conference sessions will stream live each evening from October 25-28. Stay tuned for more details on our guests, how to register, and our community auction.

## Save the Date: 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 [colortheworldorange.com](http://colortheworldorange.com) to learn more and to get involved today. It is also a great time to begin writing to your local and state governments to obtain a Proclamation for CRPS Awareness for November 1st.

RSDSA will raise awareness throughout the month with fun activities as well as a CRPS Warriors Memorial.

## Enter the 2021 Rare Artist Contest before July 16th

The 11th Rare Artist Contest is accepting entries until July 16th, 2021!

The Rare Artist Program was established in 2010 to exhibit the unique gifts of individuals affected by rare disease and to promote the expression of their stories through art. The Rare Artist Contest provides a national platform for rare artists to showcase their artwork and highlight their stories. Contest awardees are presented checks and invited to speak during Rare Disease Week on Capitol Hill in Washington, DC. Their artwork is showcased throughout the year at various patient and biopharmaceutical conferences.

Learn more about entering the EveryLife Foundation for Rare Disease's Rare Artist program. [here](#).

## Please send us feedback!

Please send any suggestions or upcoming events of interest to our community to [info@rsds.org](mailto:info@rsds.org) and please consider a donation to [rsds.org/donate](https://rsds.org/donate).