

# IN RARE FORM



## Ketamine and Low Dose Naltrexone: Some useful tools in your toolbox

by Christian Stella PharmD, ABAHP

As the supervising pharmacist/owner at Precision Compounding Pharmacy, I often come into contact with patients who all commonly suffer from chronic pain disorders. What is profoundly unique about compounding pharmacies, is that we have the ability to formulate and hand tailor a prescription, all with FDA approved raw materials and ingredients. Something to consider though, are the opportunities and specific guidance provided to you when you begin to work with a compounding pharmacy. There is a level of comfortability and a grasp of personal progression upon treating with a compound. This is something not often found in a Retail Pharmacy setting. The versatile nature of compounded medications allows pharmacists to formulate and treat with a myriad of different preparations, all of which meet and reach patient expectations, as well as preferences. Experiences such as the aforementioned, allow us to carefully treat conditions like CRPS on a case by case basis. As a result of CRPS having no specific treatment regimen or medication, it has become extremely common for CRPS patients/warriors to seek out the help and care of compounding pharmacies. At Precision Compounding, we are available at your convenience for consultation and counseling services. Additionally, we have multiple nationwide shipping options.

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Extensive pain management experience and research has brought about some groundbreaking treatments of Complex Regional Pain Syndrome, or CRPS. One of them being the use of Ketamine. Ketamine is a rapid-acting, non-barbiturate dissociative anesthetic that was initially approved in 1970 in an injectable form. Ketamine works by blocking a receptor called NMDA (N-Methyl-D-Aspartate) which thereafter stops glutamate from activating excessive brain inflammation. What exactly does this mean for you? Ketamine works to stop the over excitations being caused from pain. As Ketamine is only currently approved as an injectable medication, it remains in the hands of compounding pharmacies to formulate and treat via capsules, creams, troches, suspensions, nasal sprays, etc., all of which are not commercially available through a retail pharmacy. At Precision Compounding Pharmacy, one of our most commonly used compounds is a Ketamine Transdermal formulation. For CRPS/RSD patients, our pharmacists recommend a simple formulation containing 15% Ketamine and 15% Lidocaine. We compound this in conjunction with transdermal pain cream, a highly absorbable base cream. This compound can be applied to any part/region of the body in pain. Lidocaine is a sodium channel blocker that works as a local numbing agent. Although Ketamine and Lidocaine work very differently in the body, they both help combat localized nerve pain. It is imperative for a patient with a chronic pain condition, such as CRPS, to have something in their toolbox to apply straight onto the affected area when they have breakthrough nerve pain. Transdermal pain creams including these two pharmaceutical active ingredients stay in the local area of application which limits the absorption into the bloodstream. As a result, this curbs the side effects drastically.

Ketamine is also very commonly used in a troche formulation. Troches may seem obscure and unfamiliar, but they are virtually identical to a throat lozenge that you place under your tongue or into your inner cheek. Troches are more frequently used by physicians in pain management, as they deliver the active ingredient, in this case ketamine, right into the bloodstream. Receiving a quick and efficient dosage form is important for a patient that is suffering from CRPS. Ketamine can also be dosed in a rapidly dissolving tablet, capsule, liquid suspension, and a nasal spray.

Another compound yielding profound results in the treatment of CRPS is Low Dose Naltrexone, commonly known as LDN. Naltrexone is commercially available at all retail pharmacies in a 50mg tablet dose, used to treat alcohol dependence and opiate withdrawal. In the 1980's, Dr. Bernard Bihari, MD discovered that naltrexone can be useful for patients with HIV/AIDS at a very small dose of 3mg. He coined this treatment discovery under the term low dose naltrexone. In using a notably lower dose, the naltrexone hits the opiate receptor and creates a negative feedback mechanism, therefore releasing endorphins. This process is essential and critical in treatment because endorphins are naturally produced to reduce pain. LDN also works by blocking the toll-like receptors which cause glial cell activation. This mechanism is known as the low dose

naltrexone anti-inflammatory process. What is important to note here, is the role a compound pharmacy plays in dosing LDN, in efforts of creating these various anti-inflammatory processes. Compound pharmacists and doctors collaborate in formulating naltrexone on a case by case basis, as it is not commercially available at any dose other than 3mg. Patients with CRPS can benefit from treating with low dose naltrexone in various kinds of dosage forms. Some include, but are not limited to capsules, tablets, creams, suspensions, and troches.

Now, let us put the pharmaceutical jargon aside. Your journey(s) with CRPS is something I am a part of. Not as your pharmacist, but as yet another system of support. I have made it a promise and goal of mine in my professional career to help combat the symptoms and struggles of this disease. Each and every warrior story I have come into contact with has left a lasting impact on me and gives me all the more reason to help your community to the best of my abilities.

Learn more about Precision Compounding Pharmacy at [precisionpharmacy.net](https://precisionpharmacy.net).



## What do you want to see on the new RSDSA website?

We are in the process of updating our website's look and feel in order to give Warriors like you a better experience.

The Communications Committee would love to hear from you. What would you like to see on our website that is not already there? Send your suggestions to [alexisdavis@rsds.org](mailto:alexisdavis@rsds.org).

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

We are hosting a one hour Facebook Live during our virtual walk on Saturday, June 26, 2021 at 1pm Eastern/10am Pacific!

Join us at [facebook.com/rsdsa](https://facebook.com/rsdsa) as Jim Broatch, Executive Vice President and Director of RSDSA, Kelly Considine, CRPS Warrior and 2nd Annual Virtual CRPS Walk Chair, and our top teams lead us through a fun hour of awareness and connections. Wear your walk shirts or anything orange!

## 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's 2nd Annual Virtual CRPS Awareness Walk is in Less than Three Weeks!

RSDSA's 2nd Annual Virtual CRPS Walk is on Saturday, June 26th! It's not too late to join by registering, donating, and/or buying a walk shirt. We are 85% to our goal of \$50,000 and we can get there in the next three weeks!

It can be difficult to ask for money, but we are here to help. Below is an email that you can send to your family, friends, and coworkers when including your appeal for donations.

Dear Friends,

Today I am asking you to support me in raising funds for RSDSA, the national association for RSD/CRPS. As my friend, you know that Complex Regional Pain Syndrome (CRPS) is an extremely rare, very painful, and generally chronic neuro-inflammatory condition. Most people with CRPS are in great pain and many are disabled.

Why are funds needed?

- For assistance with treatments
  - CRPS is classified as a “rare disorder” by the FDA because fewer than 200,000 Americans have it. With such a small cohort there is no profit to be made, so little research is done. Since there are no approved treatments, most patients must pay out of their own pockets - without insurance help.
- For information distribution
  - Sadly, very few doctors even know that CRPS exists. With over 7,000 rare diseases, doctors can't be expected to have expertise on all of them. Consequently, it takes the average patient seven doctors and several years to get accurately diagnosed. Even then, there is scant information about what to do.
- For support
  - Being diagnosed with a rare condition is extremely lonely. Despite having wonderful friends and family, no one understands the severity or grief as someone who shares your diagnosis. Finding that support is essential and extremely challenging.

How will your contribution help?

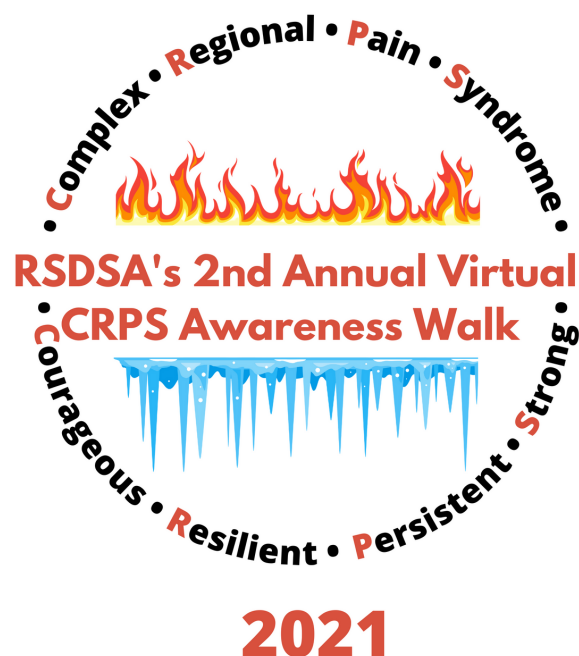
RSDSA does amazing work on a shoestring budget and has been a lifeline for me personally thanks to:

- Treatments - RSDSA guides organizations and researchers on what is needed. They are a bellwether to new therapies and medications.
- Information - Dr. Google gives a lot of conflicting advice on CRPS, but RSDSA provides reliable information I can trust. In addition to an extensive website, they host conferences and live presentations by experts in the field on all issues for which we need guidance.
- Support - RSDSA hosts virtual support groups, networking events and has an informative CRPS blog.

I don't want you to feel uncomfortable with this request. Your friendship is my most important support. But there are others with CRPS who are not so lucky and your support can also assist them greatly.

To contribute, please use this link [rds.org/walk](https://rds.org/walk). You can choose to give anonymously, or you can choose to give openly with an amount that is anonymous. Any contribution is gratefully accepted. The RSDSA is a relatively small organization, and they take their financial stewardship seriously.

Thank you for your consideration.





## Facebook Live with Dr. Wayne Jonas

RSDSA is hosting a Facebook Live with [Dr. Wayne Jonas](#) on **Wednesday, June 9th at 7p Eastern** to discuss Healing in the Time of COVID with an emphasis on chronic pain and pain management.

Dr. Jonas is a practicing family physician, an expert in integrative health and health care delivery, and a widely published scientific investigator. He is the Executive Director of Integrative Health Programs for the Samueli Foundation, an organization supported by Henry and Susan Samueli to increase awareness and access to integrative health.



Additionally, Dr. Jonas is a retired Lieutenant Colonel in the Medical Corps of the United States Army. From 2001–2016, he was President and Chief Executive Officer of the Samueli Institute, a non-profit medical research organization supporting the scientific investigation of healing processes in the areas of stress, pain and resilience. His work at the Samueli Institute set the bar for evidence-based research in the areas of pain, stress and human performance.

Dr. Jonas was the Director of the Office of Alternative Medicine at the National Institutes of Health (NIH) from 1995–1999, and prior to that served as the Director of the Medical Research Fellowship at the Walter Reed Army Institute of Research. He has led and participated in hundreds of research studies beginning with his time as Director of the National Institutes of Health Office of Alternative Medicine. His research has appeared in peer-reviewed journals such as the Journal of the American Medical Association, Nature Medicine, the Journal of Family Practice, the Annals of Internal Medicine, and The Lancet. Join us at [facebook.com/rsdsa](https://facebook.com/rsdsa) on Wednesday, June 9th at 7p Eastern to chat with Dr. Wayne Jonas.

Don't forget: If you miss one of our Facebook Live sessions, you can always watch the replay on the [RSDSA YouTube Channel](#) as we do record each one.

## A CRPS Warrior Climbs Mt. Kilimanjaro

We're excited for CRPS Warrior Nicole's [fundraising event for her climb to the top of Mt. Kilimanjaro](#) this month! Learn more on her fundraising page now.



## Interested in writing for the RSDSA blog?

Our team is always looking for Warriors to share their story on the RSDSA blog in order for other Warriors to learn more about their journey and ways to relate.

Interested in telling your story? Send us an email at [alexissdavis@rsds.org](mailto:alexissdavis@rsds.org) so we can send you our blog template.

## 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](#).

RARE  
ARTIST



## "The In-Between" Movie Comes To Streaming Platforms

You can now watch "The In-Between" whenever and wherever!

"The In-Between" stars Mads and Junior, best friends who set out on a road trip to Portland from L.A. Mads is struggling with diabetes and Junior is a CRPS Warrior.

CRPS Warrior Mindy Bledsoe plays Junior in the movie and is also the director.

"The In-Between" is now available to view on digital platforms (like [iTunes](#), [Amazon](#), etc.) and on Blu-Ray & DVD across North America.



## Find CRPS Clinical Trials on ClinWiki

ClinWiki is a free search tool that enables researchers and patient advocates from specific disease communities to curate relevant trials. It also helps patients, caregivers, and care teams make informed treatment decisions.

When you search for CRPS, or click [here](#), information about upcoming trials becomes available. Keep this site bookmarked!



## 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.

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

[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](#).



## 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).