

IN RARE FORM



How YOUR Voice Can Make a Difference

by RSDSA's Advocacy Committee

Thank you to those attending the advocacy webinar on January 27th. If you missed it, you can watch our presentation on the RSDSA YouTube channel [here](#).

February 28th is Rare Disease Day and a great time to reach out to your elected representatives who represent all of us. For first-time advocates, this is a great opportunity to introduce yourself and to start your conversation with your members of Congress and both your Senators. For those of you with newly elected representatives, now is a good time to introduce yourselves. To make it easier, we are partnering with the Rare Disease Community to promote the day.

Our first “ask” of your representative or senator is quite simple: join the Rare Disease Caucus. The Rare Disease Congressional Caucus helps bring public and Congressional awareness to the unique needs of the rare disease community (including patients, physicians, scientists, and industry). It creates opportunities to address roadblocks to the development of, and access to, crucial treatments. The Caucus is a powerful force in support of legislation that will improve the lives of people with rare diseases.

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Why do we keep asking you to speak up, write emails and letters, and make appointments to meet your elected officials?

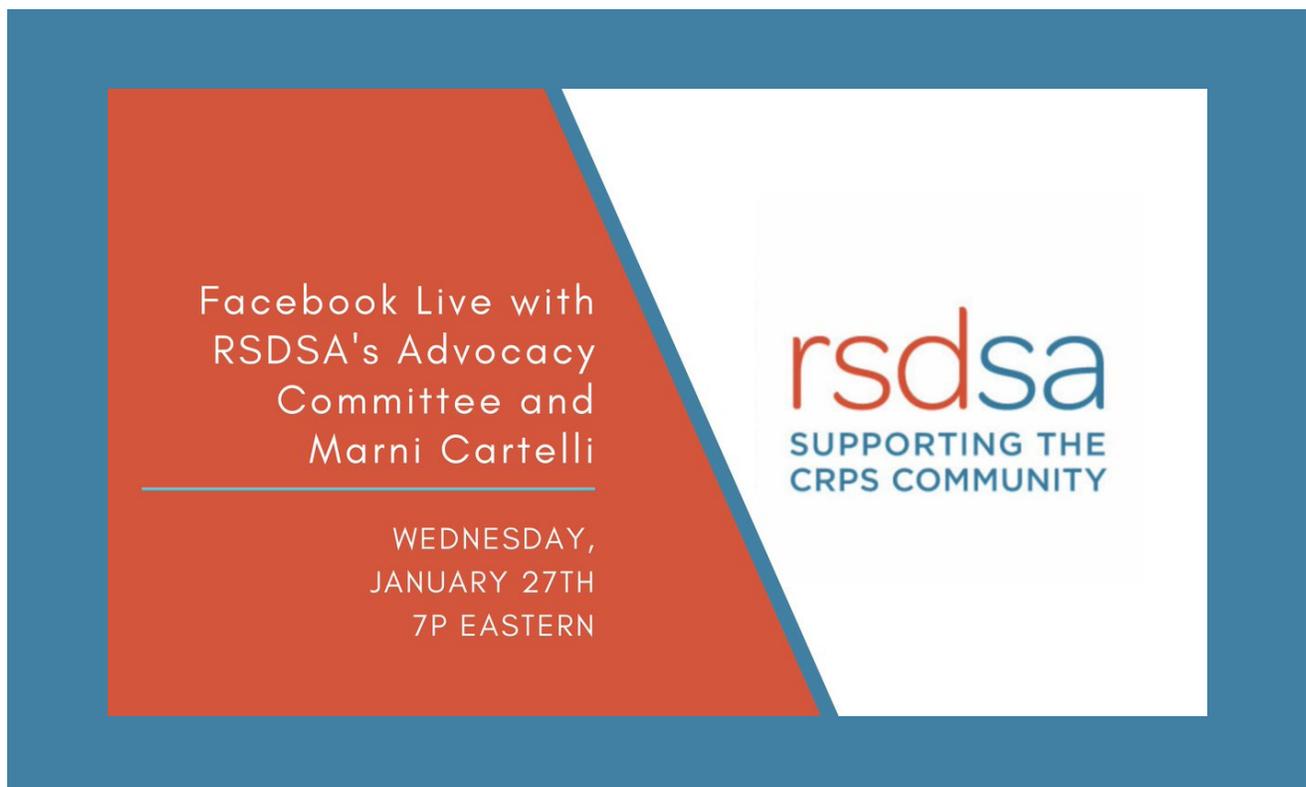
It is only through making your voices heard that you can raise awareness of CRPS/RSD, an officially recognized rare disease. It is your voice added to your peers that can turn that recognition into action, leading to new medical standards, better reimbursement, and treatment. Silence is not golden with stakes this high. We deserve equal rights, support and care and it is time you told your story to someone empowered to create the changes for you, your family, and for us all.

Later in the year we will be joining the Rare Disease community for a legislative week in Washington, DC. Now is the time to make a relationship with your representatives so when the week comes around, we can join all our voices together in a chorus to be heard. We will help you to reach out and amplify your voice as a community.

For more information or questions, please contact us at advocacy@rds.org.

Your fellow Warriors and volunteers in our common cause,

Jeri, Jim, Marni, and Nancy

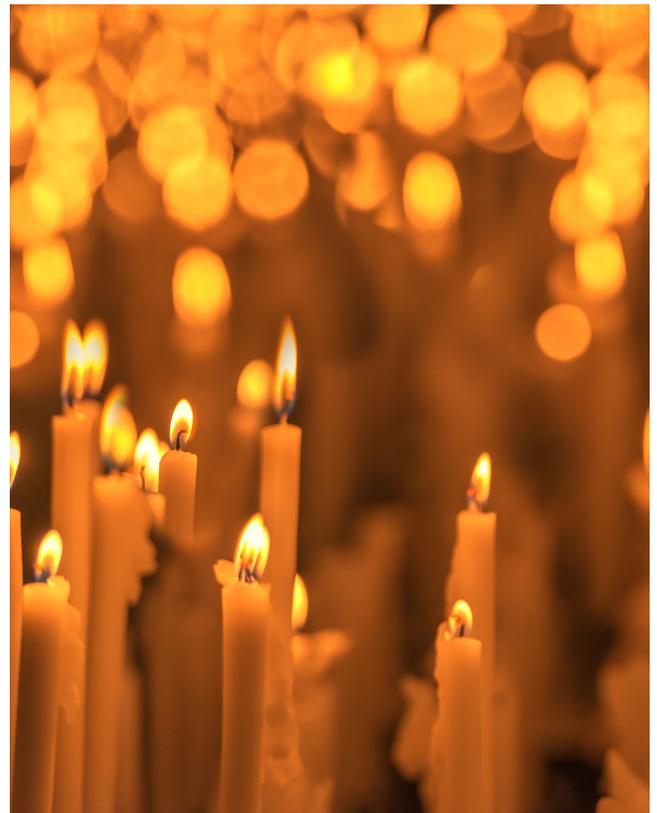


Click the image above to watch the replay of our Facebook Live focused on advocacy.

Peace By Piece

Submitted by Nancy Gardner whose son passed from complications of CRPS in 2015 at the age of 45. He wrote more than 200 poems about his journey living with CRPS/RSD.

>> Combining	>> Piece By
>> The Moments	>> Piece
>> That Add Up	>> We See A
>> To Our Lives	>> Pattern It
>> Is Like Doing	>> Becomes
>> A Complex	>> Clearer
>> Jig Saw	>> With That Help
>> Puzzle	>> Plus
>> Without the	>> Patience and
>> Picture	>> Perseverance
>> It's A Challenge	>> Everything
>> At First	>> Eventually
>> Nothing	>> Comes Together
>> Seems To	>> Knowledge
>> Work Out	>> And Awareness
>> It's Taking	>> That It Only Takes
>> All The	>> One Missing
>> Pieces	>> Piece For It
>> And Then	>> To Never
>> Seeing	>> Be Complete
>> Slowly And	>> We
>> Often By Feel	>> Search Harder
>> How They	>> For Those
>> Interlock	>> Last "Missing"
>> And Fit	>> Pieces
>> When We	>> Finding They
>> Can't Seem	>> Have Usually
>> To Find	>> Been Right Before
>> A Way	>> Our Eyes the
>> When We	>> Whole Time
>> Feel Like Quitting	>> When We
>> We Remember	>> Finally Have
>> It's Always	>> Them All In
>> Better With	>> Place
>> Someone	>> There Is A
>> Helping Us	>> Blessed Relief
>> To Solve It	>> And That's the Real
>> And Together	>> Last Peace
	>> ~KPG



Help RSDSA Find An ASL Interpreter

RSDSA would like to have an ASL interpreter for upcoming Facebook Lives in order to better serve the community.

Please send us an email at info@rsds.org if you have a recommendation!

RSDSA's Community Auction

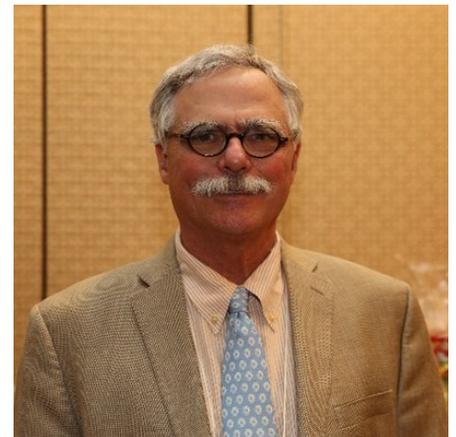
RSDSA's first online [auction is running](#) until February 14th. There are a variety of items and services for every price range including:



*Chair yoga with
Lindsey Kolb*



3 Month Rose Delivery



*Lunch with our Jim
Broatch*

Click [here](#) to bid before February 14th!

Take Note: Rare Disease Day is Sunday, February 28

Join Our Next Icebreakers Networking Event on Tuesday, February 23rd

Sign up for an evening of face-to-face networking with other CRPS Warriors!

On Tuesday, February 23rd at 7p Eastern, we'll host a networking session with CRPS Warriors who are looking to connect with one another.

The first 40 people who [join here](#) on the 23rd will get access to the session.

If all goes well, we will open this up to more than 40 people next time!



Chris

This was awesome!!!! Especially for those of us that are in rural areas and no other people around to meet with. This is the first time I've met someone with RSD and I've had it for 25 YEARS!!!!

Feedback from an Icebreakers participant in November

Donate to RSDSA

Have you thought about your legacy? Are you looking for a long-term way to make a meaningful difference in the CRPS community?

Please consider making a planned gift to RSDSA today. Planned giving options include:

- Gifts of stocks and bonds
- Including RSDSA as a beneficiary in your life insurance policy
- Including RSDSA as a beneficiary in your will.

Tax benefits apply to each of these options. Please contact your attorney, a financial attorney, or a financial advisor for more info.

Food for Thought: Benefits of an Anti-Inflammatory Diet

by Pamina Barkow, CNC

As a clinical nutritionist in a pain management clinic, I see people suffering in varying degrees of pain. Few cases have touched me on a personal level like those with advanced complex regional pain syndrome (CRPS). Perhaps that's because the more the medical field learns about CRPS the more we realize there are variables and unknowns and that often there are more questions than answers. Luckily, there are many indicators that show that changing dietary habits, specifically following an anti-inflammatory diet, can have a significant positive effect on people with CRPS.

What is inflammation?

Inflammation, from the Latin meaning "I ignite," describes the body's biological defense response to remove harmful or irritating events to our bodies and to begin the healing process. Inflammation is initially a positive and necessary response that can manifest as pain, heat, redness, swelling and loss of function. For example, if you fall and hit your knee and then it swells, inflammation is telling your body that your knee needs rest in order to heal.

Chronic inflammation has drastic effects on the body. Moreover, it becomes a self-feeding cycle that prevents the body from working optimally. Chronic inflammation has ties to cancer, diabetes, depression, heart disease, strokes, Alzheimer's, muscle loss, and many other conditions including pain, nerve damage, and CRPS.

CRPS is often described as injury to a nerve or soft tissue that does not follow the normal healing path. Many physicians agree that the complications and pain stemming from CRPS are due to exaggerated local inflammation. Basically, this means that if you have CRPS, you also suffer from chronic inflammation.

What is an anti-inflammatory diet?

An anti-inflammatory diet focuses on eating foods that heal and naturally reduce inflammation and also reduce triggers of inflammation. It means seeking out fresh greens, vegetables and fruits, giving up processed foods, watching salt and sugar intakes, eating whole grain carbohydrates, increasing intake of legumes and healthy fats, cutting out unhealthy fats, seeking out grass-fed and wild sources of proteins and increasing daily water intake.

Foods in an anti-inflammatory diet are nutrient dense; they provide a high nutrient ratio for the amount of calories. They are easy for our body to break down and extract nutrients from and in turn we get energy and healing agents from them. We call these foods anti-inflammatory foods because they literally promote calming of inflammation in our bodies. On the other end of the spectrum are foods that are difficult to break down, don't provide much nutrition, and actually increase inflammation in our system. We call these foods pro-inflammatory foods because they add fire to the inflammatory cycle.

Benefits of an anti-inflammatory diet

Following an anti-inflammatory diet provides the building blocks to:

- prevent further nerve damage
- help heal current nerve damage
- increase circulation
- improve sleep
- increase overall health
- restore optimal weight
- improve nutrient absorption
- increase energy
- decrease pain perception
- improve mood
- increase joint mobility
- prevent major and minor illnesses
- strengthen immune system

Super-foods and super-nutrients for those with CRPS

Four primary groups of foods directly fight inflammation:

Healthy fats, especially omega-3s, decrease cholesterol, hypertension, clumping of blood vessels, increase circulation, aid the cardiovascular system and are COX-2 inhibitors (decrease inflammation and pain pathways).

Examples: fish, olive oil, flaxseed oil, canola oil, walnut oil, nuts (especially almonds), and avocados.

Foods that contain bromelain, carotenoids, flavonoids, and magnesium salicylate work to decrease inflammation in the body. Magnesium salicylate is even classified as a NSAID (non-steroidal anti-inflammatory drug) in high doses.

Examples: artichokes, spinach, sweet potatoes, apples, all berries, basil, mint, broccoli, cucumbers, parsley, onions, tomatoes, and many more.

Foods that contain amino acids glutamine and lysine. Glutamine aids in anti-inflammation, especially in the lower digestive tract, while lysine decreases inflammation by maximizing other molecules' effects of anti-inflammation.

Examples: fish, seafood, poultry, grass-fed beef, bison, soy, lentils, peas, and many more.

Anti-inflammatory herbs decrease inflammation by “altering the levels of molecules that stimulate inflammation.”

Examples: Aloe vera, echinacea, garlic, ginger, licorice, tumeric and many more. In addition, those with CRPS benefit from a daily multi-vitamin, high doses of omega 3s capsules along with vitamin E (protects the anti-inflammatory powers of fish oil), complex B vitamins, and vitamin C (to increase circulation and blood cell production).

Pro-inflammatory triggers for those with CRPS

There are a number of pro-inflammatory triggers that are particularly important to watch, including:

Unhealthy fats (over-consumption of omega 6s and saturated fats as well as hydrogenated [trans] fats; found in high-fat cuts of meat and whole-dairy products) promote increases in blood cholesterol and LDL cholesterol as well as increases the risk for atherosclerosis, increased triglycerides, increased C-reactive proteins (which lead to inflammation) and decreased HDL (good) cholesterol. They increase the risk of heart disease and type 2 diabetes and contribute to the development of cancer. Trans fats are the worst of the bunch because they provide no benefit whatsoever.

High levels of sugar and empty carbohydrates (high glycemic index foods) provide no nutritional value and are pro-inflammatory. Sugars along with alcohol block absorption of many nutrients including water-soluble B and C vitamins that are crucial for people with CRPS.

Smoking (cigarettes, pipe or marijuana), exacerbates the activity of your body's inflammatory cells... and accelerates the formation of highly toxic and mutagenic substances... fueling inflammation.

Alcohol (regular drinking) raises your body's inflammatory level by increasing oxidative stress and blocks the absorption of essential nutrients (water soluble vitamins in particular).

Lack of sleep (less than six hours of sleep per night) raises pro-inflammatory markers IL-6 and TNF-alpha and C-reactive proteins. Sleep is also the time that your body uses to heal and create new tissue.

Excess weight/overweight not only promotes inflammation but is considered a "state of low-grade systemic inflammation," which is also a state of chronic inflammation.

Gluten intolerance does not simply manifest as digestive unrest or inflammation but it can cause nerve damage. Therefore, people with any sort of neuropathy, including CRPS, are at higher risk for having this intolerance. I suggest that people with CRPS do an elimination diet (remove all triggers) or some other type of testing to measure food intolerances.

Although CRPS can be difficult to manage, making even small changes to your diet can help you feel better.

Pamina Bakos is a clinical nutritionist, works with her husband Stephen H. Barkow, MD, DABPM, at [Orange County Pain Management](#) in Newport Beach and Mission Viejo, California.

Ask the Doctor

We recently spoke with Vivianne L. Tawfik, M.D., Ph.D. at the Stanford University School of Medicine about the COVID-19 vaccine and CRPS. Here is the feedback we received from her:

“There is no specific guidance for CRPS, but the recommendation for immunocompromised patients as well as patients with autoimmune disease has been to go ahead and get vaccinated when eligible. There is no evidence for specific side effects in patients with autoimmune disease. I have extensively reviewed the literature on the relationship between vaccines and CRPS and there is no evidence to support this link either. So all that said, I have been encouraging my patients to get vaccinated when able. Expect 12-24 hours of arm soreness with the first shot and 12-24 hours of flu-like symptoms with the second (booster) shot. There is no difference between Pfizer and Moderna. I am not sure yet what will come with the newer options that may soon be approved.”

As always, RSDSA is NOT instructing/demanding anyone get the vaccine. We will simply continue to provide information that is relevant to the community if you do choose to take it. However, please consult your physician for personalized medical advice. There are also numerous CRPS Warriors who have received the vaccine so far this year who are willing to [discuss](#) their experience with you.

Please send us feedback!

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