

IN RARE FORM



RSDSA's New Population Health Advisory Board

The RSDSA Board of Directors has approved the formation of a new advisory board, the Population Health Advisory Board, with three important missions. This new advisory board will work with public and private health plans, hospitals, hospital systems and accountable care organizations to:

1. Uncover related conditions that can help to identify new CRPS patients, alert their doctors and, through their electronic medical record systems, provide the tools to properly diagnose, treat and care for new and existing CRPS patients;
2. Develop information that can identify effective new treatments and support FDA approval for existing ones; and,
3. Provide the data and information needed to equip and fund clinical, pharmaceutical and academic researchers toward even more treatments to slow, stop or even reverse the progression of CRPS.

The advisory board's overall mission is to expand the knowledge base on a national scale to provide the tools, information and capabilities to overcome the difficulties CRPS and all rare diseases have – lack of size, resources and interest challenging virtually all rare disease communities.

Why now and not earlier? We are taking advantage of new legislation which when enacted into law, will provide a Center of Excellence for Rare Diseases within

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the FDA whose responsibility is to speed, support and enable the approval or clearance of new treatments, understanding and management of rare diseases. Further, the challenges of trying to create awareness among hundreds of thousands of doctors and nurse practitioners is overwhelming. Providing new tools that will work in the background and activate when appropriate is both doable and a growing reality for mainstream conditions. RSDSA is the first to adapt these new tools for a rare disease.

We have assembled an accomplished team of professionals; physicians, academic researchers, population health management experts and related specialists who are volunteering their time, skills and expertise to the benefit of the CRPS community.

Nonetheless, this is a large task. It will take time to accumulate the resources, collaborators and data sources to achieve our collective goals. We on this new advisory board are committed to our mission and will provide reports on progress to you regularly.

Sincerely and on behalf of the Advisory Board Members,

James Doulgeris, retired CEO, Osler Health, and CRPS patient

Consider Taking "The Big POTS Survey" If You Have CRPS and Postural Tachycardia Syndrome

Dysautonomia International has partnered with Vanderbilt University and University of Calgary to create the largest POTS study in history, which patients refer to as "The Big POTS Survey." The second paper resulting from this study was focused on employment and economic impacts of POTS. Researchers found that POTS contributed to significant economic and employment impacts for patients and their caregivers.

You can check out the research paper [here](#).

If you have been diagnosed with POTS by a doctor, take a moment to participate in the Big POTS Survey [here](#).



RSDSA'S LONGEST DAY OF GOLF FUNDRAISER

SEPTEMBER 27, 2020



RSDSA's Longest Day of Golf is Monday, September 27, 2021

RSDSA's Longest Day of Golf is a one-day event to raise funds and bring awareness to CRPS.

This year we have a new golfer named Tony Consiglio. Consiglio is excited to represent RSDSA in the Longest Day of Golf. He has supported many organizations through golf events, including serving on the board of the Heroes Hope Healing Golf Classic in support of the pediatric cancer center at Eastern Maine Medical Center.

You can make pledges for LDOG (i.e. \$1, \$3, \$10, etc) for every hole Consiglio golfs for 12 hours on Monday, September 27th.

RSDSA also encourages safe participation at a golf course in your community. Each year we have teams across the country comprised of friends, family members, and colleagues who are able to make a one-time donation or a contribution for each hole played.

It is through your help and generosity that we are able to continue our work in the RSDSA community. Your caring support truly makes a difference!

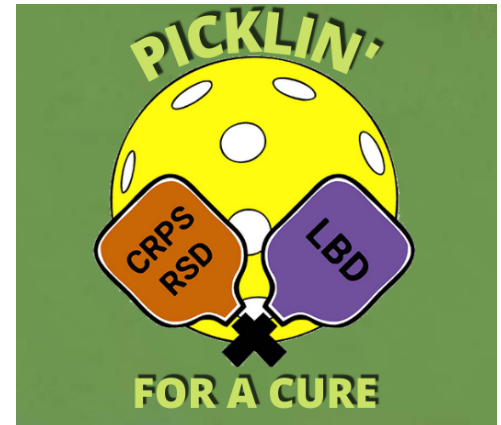
[Learn more on the Longest Day of Golf page on Qgiv.](#)

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 is now open and closes on September 30th. The tournament begins on October 15th and ends on October 17th.

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



Is Your 'Go Bag' Ready for Emergencies?

If there is one thing we are all learning these days, it is to expect the unexpected. One thing we can do to help make ourselves ready is to create a Go Bag. A Go Bag has all the essentials you need in an emergency so that when you need to leave your home you don't waste time running and gathering whatever you can think of.

This is not the doomsday survivalist guide of supplies to keep in case of a zombie apocalypse. This is a bag of essentials for trips to the emergency room or evacuation due to extreme weather conditions and other natural disasters. It can include:

- Phone and/or tablet
- Headphones (if you can tolerate the touch) to block out noise and help to create a bubble of calm
- Phone charger – The #1 most requested item in Emergency Rooms
- Your medical information preferably kept in a sheet protector or plastic bag. You could also put this information on a USB drive or store copies in the Cloud for convenience.
 - Info should include your name and date of birth, health insurance information, diagnosis and medical history (synthesized for quick review), prescriptions, name, dosage, and frequency
- Toiletries – a few small items such as a toothbrush, hand sanitizer, a packet of wipes, deodorant, hair scrunchies, etc.
- Essential medications and a [RSDSA medical card](#) for trips to the emergency room
- Water and easy-to-pack non-perishable snacks like energy bars, trail mix or crackers. Consider bringing a sports drink if you like to help keep up your energy
- Create a written contact list in case your phone loses power with numbers for an emergency contact person (family or friend), your doctor, and your pharmacy
- If you use a non-battery powered assistive device such as a cane, walker, wrist guard or sling, include a back-up or two. It could be a long day that turns into a long night and any assistance could be welcome
- Comfy socks and a hoodie for warmth and for comfort. If you have an easily portable warm blanket, make sure to bring it with you. It's not uncommon in an emergency to spend a night in less-than-ideal conditions, and a blanket can go a long way in helping both to keep warm and give comfort.

Thank You for Supporting the 3rd Annual Flame Out Walk to Extinguish RSD/CRPS

Thank you to the walkers, donors, and sponsors of the 3rd Annual Flame Out Walk to Extinguish the RSD/CRPS. This beautiful walk took place on Sunday, September 12th at Joe Palaia Park in Oakhurst, New Jersey. We thank you everyone for coming out for a great day with blue skies, beautiful weather, and a high level of energy and enthusiasm.

The Hopkins Family gives special thanks to the uncles at Vietnam Veterans of America Chapter 12, who have been there for every walk. Thank you to all the volunteers who have given their time and to the donors who have generously supported the 3rd Annual Flame Out – Extinguish the Pain Walk.

A very special thank you to our sponsors:

Vietnam Veterans of America, Chapter 12
Asbury Park/Wall Elks Lodge 128
VFW Post 2226 - Oakhurst
VFW Post 2179
O'Dowd Associates
Pamela & Daniel Moore
Assistive Choices

and our In-Kind Sponsors:

Dean's Natural Food Market
Igloo Italian Ice
Wawa - Neptune City, Rte. 66



without whom the event would not be possible.

We are happy to report that donations are still coming in and we hope to reach our goal of \$14,000!

So, what's next? We encourage you to share your experience and any photos you took with your donors and follow up with those who may not have contributed to your fundraising efforts just yet as they can still donate [here](#).

Best Wishes,

Linda & Bob Hopkins and RSDSA



TREATING THE WHOLE PERSON: OPTIMIZING WELLNESS

VIRTUAL CONFERENCE

OCTOBER 25-28

rsdsa
SUPPORTING THE
CRPS COMMUNITY

Join us for Treating the Whole Person: Optimizing Wellness Virtual Conference October 25-28

RSDSA invites you to register for part one and part two of our free Treating the Whole Person: Optimizing Wellness virtual conference from Monday, October 25th, through Thursday, October 28th, 2021.

Our live conference sessions begin at 7:00p Eastern each night, but you'll want to join us 30 minutes earlier at 6:30p Eastern for virtual networking chats and our exhibit hall!

We'll also have the networking sessions and the exhibit hall open for 30 minutes after our sessions end.

A few of our sessions topics include:

- Comorbid Conditions Associated with CRPS
- Advocacy
- CRPS and Litigation
- Obtaining a Support Animal
- With more to come!

Caretakers and medical professionals are also welcome to attend. Just like last year, once you register, you will receive two tickets: One for our Monday & Tuesday sessions and one for our Wednesday & Thursday sessions. Look out for details as they are coming soon!

Host an Event with RSDSA

You can make a difference in the lives of CRPS Warriors and those who love them by helping to raise awareness, funds, and by building a community when you host a special event. Help spread the word about CRPS by inviting your friends, family, coworkers and everyone you know to get involved in our mission, events and activities.

You can organize in-person, virtual, or hybrid events. Special events can be opportunities for fun, engagement, and education. Every dollar raised supports RSDSA's mission and makes our work possible. Your donations are gratefully received, impactfully used, and profoundly appreciated.

Need ideas of what to do?

- Be creative. Do it your way; run a beard growing contest, bake cookies, host a pool party with tickets, whatever works for you and your community.
- Fundraise on Facebook: Create a Facebook Fundraiser to celebrate a birthday, milestone or holiday and invite friends and family to donate to your fundraising page.
- Do you have access to a community or outdoor space? Throw a senior prom, game night or pancake breakfast.
- The yard sale is one of our favorites. It raises money and gets rid of stuff at the same time!

We are here to help you plan your own special event. When you're ready, please contact Jeri Krassner, RSDSA's Special Events Coordinator, at jkrassner@rsds.org or 917-597-7256.

Mark Your Calendar for CRPS Awareness Month Events

November is CRPS Awareness Month and this year it is flanked by two dates that are important to us. Monday, November 1st is Color the World Orange™, and Tuesday, November 30th is Giving Tuesday, the day devoted to global charitable giving.

RSDSA is currently planning for our month. We will work with Color the World Orange™ to raise awareness with local and state government proclamations declaring November CRPS Awareness Month and the lighting orange of public buildings.

You can find out “how to ask” for a proclamation on the Color the World Orange™ Facebook Page [here](#).

Please stay tuned for announcements of upcoming events for CRPS Awareness Month!

Facebook Live with Francesca Beaudoin, MD, MS, PhD

RSDSA is hosting a Facebook Live with Francesca Beaudoin, MD, PhD to discuss emergency department care for patients with chronic pain on Monday, September 27th at 7p Eastern.

Francesca L. Beaudoin MD, MS, PhD is an Associate Professor and Interim Chair of the Department of Epidemiology and an Associate Professor of Emergency Medicine and Health Services, Policy and



Practice. She has written and implemented practice management policies for health care systems on pain management and opioid prescribing, and has served as a member of the Food and Drug Administration Anesthetic and Analgesic Drug Products Advisory Committee.

She will discuss her experience with chronic pain and CRPS patients in the emergency room and provide tips on getting what you need out of an emergency room visit.

Join us at facebook.com/rsdsa on Monday, September 27th at 7p Eastern to chat with Dr. Beaudoin. If you have questions, please send them to us at info@rsds.org or bring them to the live discussion.

Don't forget: If you miss one of our Facebook Live sessions, you can always watch the recording on the RSDSA YouTube Channel.

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.