

June 2024 Vol. 18



FIGHTING FLAMES

The Official Newsletter of Fight the Flame

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Announcements



We are looking for business sponsorship and in-kind donations for this year's Do you own or know of businesses that can help?



Would you like to have an article, poem, piece of artwork highlighted in the next issue of Fighting Flames? Just let us know, we would be happy to include it.

Just email: Beth@FightTheFlame.org



You asked, we answered...

Question for the next issue:

What coping tip has worked best for you?

Please submit your tips to Beth@FightTheFlame.org

Announcements Continued...



Special Shout-Outs to our Scholarship Essay Judges
Karen S., Michelle W., Steve R., Steve S., and Zoe B.



An extra-special thank you to:
Angel, Dena T., Jennie R.
They have been helping FTF obtain sponsors and prizes for the
upcoming annual Fight The Flame 5k and 1k



Don't forget to follow us on social media:
Facebook: <https://www.facebook.com/groups/FighttheFlameSupport>
X (formally Twitter): @FightTheFlame5k
Instagram: FightTheFlame5k
TikTok: @fighttheflame.crps
LinkedIn: <https://www.linkedin.com/company/fight-the-flame1>
Pinterest: <https://www.pinterest.com/FightTheFlame/>

Fight the Flame CRPS Awareness Scholarship

The Fight the Flame® CRPS Awareness Scholarship was created to motivate students to raise awareness about Complex Regional Pain Syndrome.

To apply, students must:

- Be a high school senior with a grade point average of 3.0 or higher and have been accepted to accepted to pursue a four-year undergraduate degree from an accredited institution
- Answer one essay question (500 words): How would you raise awareness about an invisible disease like CRPS so that patients, families, and communities can access resources for CRPS support and treatment
- Provide a completed communication log showing that you have educated 10 people about CRPS.

This year we had
25 applicants
from all over the
country; SC, TX,
HI, AZ, IL, CA, MI,
MN and NJ. t

WINNERS

Victoria G., from CA
Shan P., from MI

Spreading Awareness of CRPS by Victoria Galeana

Cheerleading. Extraordinary and breathtaking to watch. Although this sport is made of strong, beautiful women with great talent and skill, it is known as one of the most dangerous sports in the world. Girls tossed twenty feet in the air to only come shooting down, trusting that your bases catch you. However, what happens when they don't? This happened to cheerleader Paulina Abdul who severely damaged her neck in a stunt gone wrong. She suffered for years with this invisible pain, bouncing between surgeries and prescriptions for painkillers. Finally, she was diagnosed with CRPS.

My name is Victoria Galeana and as a competitive cheerleader, I have seen my fair share of injuries on the mat, and have even taken a few falls myself. We tend to think this will never happen to us but when it does, what do we do?

Instead of waiting to personally experience this disease and others, we can take action now to spread awareness. We can start by explaining what it is. Complex Regional Pain Syndrome or CRPS, is a disabling condition that often goes unnoticed due to its invisible nature. It affects individuals physically, mentally, and emotionally, yet many people remain unaware of its existence, leading to challenges in finding support and treatment. Important strategies to spread awareness about CRPS can be focusing on the importance of sharing personal stories, collaborating with medical communities, and implementing educational initiatives like a "Disease of the Month" program in schools.

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Spreading Awareness of CRPS by Victoria Galeana

One of the most effective ways to raise awareness about CRPS is through personal stories. By sharing the experiences of individuals who have been affected by CRPS, we can humanize the condition and help others understand its impact. Through interviews, videos, and written stories, we can provide a platform for patients, families, and caregivers to share their journeys, challenges, and accomplishments. These stories not only educate the public but also offer support and validation to those currently battling CRPS, fostering a sense of community and empowerment.

Schools play a pivotal role in raising awareness about invisible diseases. Implementing educational initiatives such as a "Disease of the Month" program can serve as a platform to educate students, teachers, and parents about lesser-known conditions, similar to CRPS. By partnering with medical clubs, student organizations, and local healthcare providers, schools can host informational sessions, distribute educational materials, and initiate important discussions about CRPS and its impact on individuals and communities.

Spreading awareness about complex regional pain syndrome requires an approach that involves sharing personal stories, collaborating with medical communities, and implementing educational initiatives in schools. By amplifying the voices of those affected by CRPS, fostering partnerships with healthcare professionals, and engaging students and communities in dialogue and education, we can break the silence surrounding this invisible disease and ensure that patients, families, and communities receive the support and treatment they deserve. Together, we can shine a light on CRPS and empower individuals to seek help, find hope, and reclaim their lives.

Fighter Spotlight

MEET

Jeanne Connor Dessert

I would like to share a bit about my experiences with the Fight the Flame organization. Like so many patients with complex regional pain syndrome (CRPS), it took quite a while for me to get properly diagnosed. Once I did, I was anxious to get as much information as I could and I was thrilled to find Fight the Flame, which provides invaluable, accurate information and incredible support. There are even outreach opportunities directed at caregivers and this has benefited my spouse as well. It's truly amazing.

Here are just a few specific examples of some of the things that FTF provided me within just the first few months: online support in their large Facebook group of people from around the world, monthly Zoom support group meetings, a professional conference featuring medical professionals as presenters - which was held both virtually and in person (I chose to participate virtually since I was housebound at the time due to the illness. From the comfort of my home, I was able to listen to speakers ranging from MDs to a Qi Gong practitioner).

Fight the Flame holds an annual 5k and so much more.

Fight the Flame works tirelessly to raise awareness about CRPS and educate the public about this condition. I am grateful for everything they do!

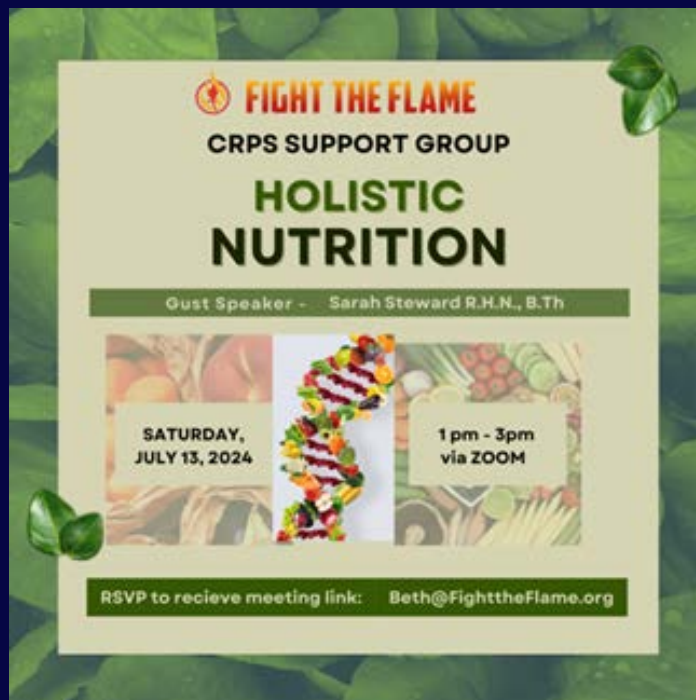
Upcoming Support Group Meetings & Events

July

13

HOLISTIC HEALTH PLANS

Guest Speaker: Sarah Steward, RHN Nutrition Steward



Sept.

29

Fight the Flame 5k & 1k Family Roll and Stroll

Email Beth@FighttheFlame.org for Zoom link

Past Support Group Meetings

In 2020, when COVID-19 hit, the FTF CRPS Meetings switched from in-person meetings to Zoom. In the first year, we were not able to afford our account, but thanks to a special donor, we purchased the Zoom platform in 2021 and we were able to record our meetings. Unfortunately, we don't have every meeting since then recorded, but there are still a lot. We keep this channel private. If you would like to watch one of the recorded meetings, just let me know and I will send you a link.

Check out the past topics:

- Disability & Accessibility - guest speaker Chris Sparrow
- Ketamine - guest speaker Dr. Jonathan Leake
- Brain Fog
- Cooking - guest speaker Chef Jared Mond
- Aromatherapy
- Getting through the Holiday Season
- Emotional Freedom Techniques/Tapping - guest speaker Molly Purvines
- Polyvagal Theory - guest speaker Jill Jones
- How to Ask for Help - guest speaker Debbie Barrett
- Taking Care of You
- CRPS & The Law - Mr. John Ayes, Ayers, Whitlow, & Dressler
- Migraines - guest speaker Yohannes Woldenamanuel
- Caregiving
- CRPS & the Weather
- CRPS & Eyes - guest speaker Dr. Kurt Heitman

- Creating a wellness plan – guest speaker Gwen Herman
- CRPS & Teeth – guest speaker Dr. Gittleston
- Coping & self-care – guest speakers Caylee King/Shannon Berger BK Counseling Services
- Chiropractic Care – guest speaker Dr. Jordan Lukens
- Pain Devices – OSKA and HiDow representatives
- Patient Advocacy guest speaker – Lori Clemmons
- Coping w/ CRPS
- Handling the Holidays
- Reflexology guest speaker Melania Giangreco
- Symptoms of CRPS
- Discussion w/ Mindy Bledsoe - star of “The In-Between” about a woman who has CRPS (the actress does as well)
- Dr. Deering and Dr. Cooney (Calmare therapy)

2024 Fight the Flame 5k and 1k Family Roll & Stroll Details



FIGHT THE FLAME

- **Location:** McAlpine Creek Park; Charlotte, NC
- **Date:** September 29, 2024
- **Registration is now open:**
<https://www.fighttheflame5k.org/>
- **Ways to get involved:**
 - Sign up to run, walk.
 - Start a donation page – send to all your family and friends.
 - *The more we raise, the more Fight the Flame can make a difference.*
 - **Would you like to participate for free. After you register, you will receive a referral code. Have 5 or more people register using your code and you will receive a refund on your registration! For more details, email Beth at Beth@FighttheFlame.org.**

Can you give
FTF a few hours
a month?

We could use
your help!



2024 Fight the Flame 5k and 1k Family Roll & Stroll Sponsor Leaderboard

Signature Sponsor



Platinum Sponsors





Do you have any special skills such as marketing, social media postings, fast typist, etc? Then, Fight the Flame needs your help!

