

June 2023 | Volume 13

FIGHTING FLAMES

Official Newsletter of Fight the Flame

SUCCESS!

Fight the Flame
CRPS CONFERENCE
"LEARNING TO THRIVE WITH CRPS"
APRIL 22, 2023 - CHARLOTTE, NC

On a cold, rainy Saturday, 70 people from various parts of the country gathered for a day of support, learning, and friendship.

There were seven presentations in total with guest speakers, all experts in their own field.



Dr. Robert Schwartz educated us about Thermography and how it helps with diagnosing CRPS.

Dr. James Deering discussed Neuro-modulation treatments.

Marie Theriault - demonstrated and we participated in the art of Qigong.

Information about fusion Therapy was shared by Dr. Neal Taub.
The therapists from BK counseling enlightened us with tools on how to practice self-care.

CRPS and dentistry were presented by Dr. Glenn Gittelson.

Our last speaker, Dr. Traci Patterson a CRPS Fighter herself, spoke of effective ways to treat and conquer CRPS"

(continued on page 2)

NEWSLETTER HIGHLIGHTS

Conference Highlights

pages 1 & 2

Q&A with John Ayers, Esq

page 3

Scholarship

page 4

Scholarship (con't)

page 5

Announcements

page 6

(continued from page 2)

This was a great opportunity for people to network with other people affected by CRPS and connect with other caregivers.

We were joined by 30+ people via live stream and many others ordered and watched the recorded sessions.



Are you interested in purchasing a copy of the conference, please go to:
<https://www.ticketsignup.io/TicketEvent/CRPSConference/Register>



FTF Mission

The mission of Fight the Flame is to raise awareness and educate medical personnel and the public about Complex Regional Pain Syndrome (CRPS); while providing resources to support the CRPS community.

Q & A with John Ayers, Esquire Ayers, Whitlow, & Dressler

For our May FTF Support Group Meeting, we had Mr. John Ayers, of Ayers, Whitlow, & Dressler speak to us about CRPS and Social Security and Workers' Compensation. He discussed the laws and procedures for navigating these systems. After his presentation, fighters were able to ask questions.

"I've been out of work since late Sept of '22. After 3 months of short-term disability then began long-term disability in Dec '22. The insurance provider told me that if I was still on long-term disability after 6 months, they would have one of three law firms contact me to aid me in filing for Social Security Disability benefits. Do I have to use the lawyers they suggest?"

-No, you can always choose a lawyer of your own choice.

"If I am approved for Social Security Disability, am I automatically eligible for Medicare and/or Medicaid?"

-Yes, but there will be a lag.

"I've been on Social Security Disability since my early 40s. Will I need to file anything to change my benefits when I reach my retirement or will it change automatically/Will my retirement SS amount be different/Will my Medicare plan remain the same?"

-No, you do not need to do anything, everything changes over automatically.

"Should I appeal if I have been denied Workers' Compensation and Social Security?"

-YES!

"Can I fire a lawyer? And if so, am I liable for legal fees?"

-Yes & No. You can fire your attorney, and no you are not responsible for legal fees. Lawyers get paid from your settlement. Both lawyers may be eligible for fees.

"My medical records indicate several times that I have CRPS – I have met the criteria set by the Budapest criteria. Will this be taken into consideration?"

-Yes. Medical records are key. SS treats medical documents as facts

"I am a stay at home mom trying to get back into the workforce and then got injured and I had my injury. Have not been able to work or drive for two years. Can I apply for SS at all?"

- Yes – sooner than later

"Is thermography submissible now?"

-Thermography helps to show an excellent visual to help prove disability

HAVE YOU MISSED A SUPPORT GROUP MEETING?

We record most meetings, just ask for the link.

FTF SCHOLARSHIPS

Did you know that Fight the Flame offers college Scholarships?

Last month we awarded another two FTF/CRPS Awareness Scholarships.

To be eligible for the award, High School Seniors, have to write a 500-word essay answering the question "How would you spread awareness about an invisible disease such as CRPS so that patients, families, and communities are able to find resources for support and treatment of CRPS" In addition to the essay, applicants must educate at least 10 people (over the age of 18) about CRPS and complete a communication log

Thank you to our judges (Zoe, Michelle, Steve, and Stephen) for deciding our winner. This year we had 28 applicants from 22 states. The most common themes to promote awareness were: using social media, hosting educational seminars & public speaking events and encouraging patients to speak openly about their CRPS stories.

Below is Maria B. from Florida our national winner essay:

I know you don't feel seen.
I know you are in pain.
I know your suffering goes unnoticed because you look "normal."

When I was a child and saw you peeling vegetables on the bed, I couldn't understand. Now I realize you were doing the things you set out to do, even if that meant making adjustments to manage your pain.

I am so proud of you for fighting CRPS every day and being strong in the face of this condition. It takes a lot of courage to keep pushing forward in the face of chronic pain, and I admire your bravery.

Grandma, you've taught me so much about perseverance and the importance of taking care of oneself, and I will always be grateful for that.

CRPS is a chronic condition that causes severe

and often debilitating pain. Despite being one of the most painful diseases known to modern medicine, it remains relatively unknown. This lack of awareness can be particularly challenging for patients who do not look visibly ill and are overlooked by the medical community. In this essay, I will discuss how we can raise awareness about CRPS so that patients, families, and communities can find resources for support and treatment.

One of the most effective ways to raise awareness about CRPS is through education. This involves providing accurate information about the condition to healthcare professionals, patients, and the public. Educating patients about the disease's signs can help them seek medical attention earlier, improving their chances of receiving appropriate treatment. My grandma's CRPS was not taken seriously in India where doctors in rural areas often dat

(continued on page 6)

Thank you to our volunteer judges:
Zoe B, Michele W, Steven R. & Stephen S.

(continued from page 5)

dismiss patients because the doctor-to-patient ratio is far too large.

Another way to raise awareness is to use online platforms. Social media can be a powerful tool to reach a wide audience and share information about CRPS. Sharing personal stories can help raise awareness about CRPS and its impact on patients' lives. Social media platforms can also be used to connect patients and their families with support groups. Advocacy organizations can also help coordinate events such as awareness walks, and fundraising campaigns, and educational seminars.

Finally, we can raise awareness about CRPS by encouraging patients and families to speak openly about their experiences with the disease. This can help reduce the stigma associated with chronic pain and promote a greater understanding of the challenges faced by patients with CRPS. These challenges are not something to be ashamed of but rather communicate because they will help the greater community.

In conclusion, raising awareness about CRPS is crucial to ensure patients and their families can access the resources and support they need. An invisible disease is still a real disease. My grandma is secretive about her pain and works hard to hide it, like many CRPS patients. But it is time for us to recognize the impact on their lives, their fortitude and determination, and the ways we can work together to raise awareness to help the long-term outlook of these patients

S P O N S O R S H I P

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2023 FTF 5k/1k Sponsors

• (as of 6/25/23)

We are in need for additional sponsorships and prizes for the FTF5k/1k. Can you help? Email Beth@FighttheFlame.org

Announcements



Upcoming 2023 FTF Support Group Meetings

Meetings are from 1-3 pm EST

June 10	Taking Care of Yourself
July 8	How to Ask for Help Guest Speaker: Deborah Barrett, PhD, LCSW
August 12	Polyvagal Theory Guest Speaker: M. Jill Jones, LISW-CP
September 9	TBA

All meetings will be via Zoom.
Questions, email: Beth@FightTheFlame.org

DO YOU HAVE AN HOUR OR TWO A MONTH TO ASSIST FIGHT THE FLAME?

Fight the Flame is a nonprofit with no paid employees. As someone with CRPS, you know that no one person can do it all. Many hands make light work... We are desperate for help.

- Graphic design
- Research
- Photography
- Write an article for newsletter
- Be a task coordinator for the race
- Contact potential sponsors/donors

contact: Beth@FightTheFlame.org



SUPPORTING RESEARCH, EDUCATION & AWARENESS OF PSD/CRPS

SAVE THE DATE:

10th annual Fight the Flame 5k and 1k Family Stroll & Roll

September 24, 2023
McAlpine Creek Park
Charlotte, NC

for more info contact: Beth@FightTheFlame.org

Special
Thanks to
Angel, Dena,
& Jennie for
their tireless
work and
dedication

Wishing you a low pain day!

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