April 2023 | Volume 11



FIGHTING FLAMES

The Official Newsletter of Fight the Flame

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FTF CONFERENCE

On April 22, 2023, Fight the Flame will be hosting its first CRPS Conference. The theme of this year's conference is "Learning to Thrive with CRPS." (flyer on page 4).

We have seven guest speakers, all experts in their field presenting on various subjects.

- Dr. Robert Schwartz of Piedmont Physical Medicine and Rehabilitation will be discussing Thermology and how it can assist those affected by CRPS.
- Dr. Traci Patterson, a CRPS fighter herself, will be explaining Holistic Centered Treatment and its effectiveness to treat CRPS.
- Marie Theriault will be educating us on the practice of Qigong and its benefits for pain & stress management.
- Also presenting will be representatives of BK
 Counseling Services sharing self-care and coping tools.
- Hailing from New York, Dr. Glenn Gittelson will speak with us about CRPS & Dentistry. He will be bringing a special patient with him, Jasmine, who has been under his care and has experienced life-changing benefits from his treatments.
- Dr. Neal Taub, Charlotte Ketamine Center be explaining the benefits of Infusion Therapy for people with CRPS.
- Dr. James Deering of Carolina Pain Institute will be enlightening us about CRPS and Neuromodulations.
 We are looking forward to hearing from our guests. To attend the conference, please register at: https://www.ticketsignup.io/TicketEvent/CRPSConference

HEADACHES AND CRPS



On Saturday, March 11th, the participants of the FTF Support Group had the privilege of listening to our guest speaker, Dr. Woldeamanuel. Dr. Woldeamanuel is a headache specialist

who aides those with migraines and complex pain.

Presently, there are over 300 different types of headaches. Mainly they fall into one of three categories: tension, migraine, and trigeminal autonomic cephalalgias (TAC). There is no universal trigger that can lead to migraines. However, genetics, medications, and environmental changes (altitude, barometric pressure, etc) seem to play a part. It has been found that menstruation, stress at work, sleep interruptions, and missing meals can also generate a migraine headache. Dr. Woldeamanuel advises staying as committed to a regular schedule as possible - eat regularly, no late nights, etc.

Former beliefs that foods (cheese, chocolate,) can produce a migraine have proven false.

CRPS and migraines are common conditions and share many of the same pathways (STAMP):

<u>Sensory</u> - allodynia, hypo/hyperalgesia, allodynia

<u>Trophic</u> - skin, hair, and nail changes
<u>Automatic</u> - swelling, edema, sweating
<u>Motor</u> - weakness, contractures, atrophy
Pain

As migraines and CRPS follow closely related patterns, management techniques for both are similar as well: Corticosteroids, NSAIDs, Beta/Channel Blockers, nerve blocks, ketamine, SC stimulation, and psychological therapies.

Do you, or someone you know suffer from migraines? Dr.
Woldeamanuel Is looking for participants in his ongoing study about migraines.
Please contact us for more information:
Beth@FightTheFlame.org

Dr. Yohannes Woldeamanuel is an Expert Physician and Medical Scientist, currently an Instructor at Department of Neurology and Neurological Sciences and a Senior Fellow at the Center for Innovation in Global Health, Stanford University School of Medicine.

Did you miss this meeting, email Beth@FightTheFlame.org for the secure link to view the Migraines and CRPS support group meeting

FIGHTER SPOTLIGHT

Greetings, I'm Dena Townsend. I've been married for 46 years and have 2 fantastic children, a son, and a daughter. I'm what has been referred to as "homegrown", living in Mint Hill all my life. I



love to shop, eat out and take girl trips with my two sisters who also live here.

I enjoy walking outdoors for exercise, yoga, painting, traveling, and at-home physical therapy. I consider myself optimistic and look for at least one good thing in a bad situation.

I worked in management in the commercial insurance industry for over 30 years. I loved my career as I traveled for work, met new people, training staff and third-party offices. Unfortunately, that was cut short.

In July 2018, I had surgery on my left shoulder and started PT shortly after that. That September, my shoulder locked up and I was diagnosed with Adhesive Capsulitis (Frozen shoulder). My doctor told me it would take 2-3 years to regain my mobility because I am a diabetic. Soon after, my hand froze up. My fingers were drawing in and my hand was changing colors. The doctor stated I had CRPS and sent me to specialists.

As time has gone on, some of my pre-existing illnesses have activated more, such as Interstitial Cystitis and Diabetes. I'm handling them well

and I try to stay calm, as I know being stressed only makes my pain worse - "breathe and meditate".

I still did not know anything about CRPS and I was adamant to learn. On Facebook, I joined several CRPS support groups. In 2019, I found a local support group in Charlotte called Fight the Flame (FTF). I started attending onsite and Zoom monthly meetings. It is so meaningful to get insight from others. FTF was the beginning of my CRPS education. I've learned so much from the many topics of discussion. I'm truly grateful for Beth's resources and guidance. that she works so hard to give us. One of my greatest fears was if I had to go to the hospital because of CRPS. My mind was put more at ease after this was discussed during one of the support group meetings.

I like the interaction of people and have attended the annual 5k and 1k walks every year since 2019. Also, as I was experienced in fundraising (for Crohn's disease in support of my sister), I decided



to do the same for FTF. Every year since, I have raised significant funds. Now I'm actively involved with obtaining sponsors and prizes. I do this at my own pace because you never

know how you're going to feel from moment to moment. It's a feel-good mindset for me and this is so important for chronic pain!



NEXT MEETING INFO

There will be no support group meeting this month.

We will resume again on May 13, 2023.

Our topic will be CRPS and the law (disability, social security, etc).

Our guest speaker will be Mr. John

Ayers from Ayers Whitlow and Dressler



THIS MONTH'S QUESTION:

What questions or concerns do you have about CRPS and the law?

FTF Mission/Goal

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.

FTF CONFERENCE

LEARNING TO THRIVE WITH CRPS



April 22, 2023 8 - 5 pm

Fairfield Inn & Suites 2220 W Tyvola Rd, Charlotte, NC

Cost \$15

To Register:



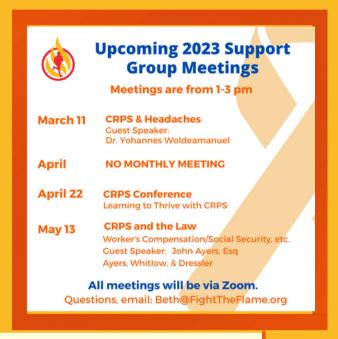
or:



https://www.ticketsignup.io/TicketEvent/ CRPSConference

Save The Dates







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
- -Help plan a support group meeting
- -Research
- -Be a task coordinator for the race
- -Photography
- -Reach out to potential sponsors/donors

-etc...

contact: Beth@FightTheFlame.org

Wishing you a low pain day!

CONNECT WITH US:



Fight The Flame Support







www.FightTheFlame.org



Important Info

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IMPORTANT - PLEASE READ

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