## September 2022 | Vol. 8



# FIGHTING FLAMES

The Official Newsletter of Fight the Flame

# **REGISTER NOW!**



**Meet Other CRPS Fighters** 

Run, Walk, Cheer

**Win Fabulous Prizes!** 

# NEWSLETTER HIGHLIGHTS

The Most Remarkable Thing pg. 2

We Asked - You

Answered

pg. 3

DIY - Weighted Pillow pg. 4

**Contests** 

pg. 5

Fight the Flame 5k and 1k Family Roll & Stroll pg. 6

> Support Group Information

pg. 7

## **The Most Remarkable Thing**

The most remarkable thing happened to me today. I was pitching Fight the Flame and our upcoming 5k this morning at a different running event. I must have walked up to at least 50 different groups and started to promote Fight the Flame and speak about CRPS.

"What, CRPS, what's that?" was the most common response. I spoke with almost 500 people and not one among them had even heard of this disease.

After an exhausted hour and half, I distributed all but one race rack card and was looking forward to just giving it out, getting back to my car, drive home and go to sleep.

Well, my nap was going to have to be put off for a little while.

I approached a group to a group of 10 young men and women who had all successfully finished the race. I began to ask if anyone was interested in participating in a 5k at McAlpine Creek Park that raises awareness and money for a medical charity. Responding to which charity, I began to explain CRPS. I had only got out out the words, Complex Regional Pain... I was cut off by the leader, who was the youngest of the group and she finished my sentence, "Syndrome?" I was taken aback She had actually heard of the disease. Not only had she heard of it, she knew its symptoms, causes and even possible treatment plans. While discussing more, I grew to discover that this entire group worked at Atrium Health in Pineville. Nine

out of the ten group members were familiar with Complex Regional Pain Syndrome and had worked with at least one person who struggled with CRPS. These nine people were physical therapists, an occupational therapist and others in the medical field. In my 25 years with CRPS, this has never happened to me. I did not feel like a stranger or a crazy person explaining this never heard of disease. It was the first group of people who understood the disease and the challenges me and others face. I could have kissed all of them (but of course didn't) just for being knowledgeable.

This is my vision for our future. To have anyone you walk up to know about CRPS. Everyone has heard of cancer, fibromyalgia, ALS, muscular dystrophy. Hasn't CRPS earned the right to be first in peoples' mind when thinking about pain disorders? Those of us that suffer with CRPS believe so. The goal of Fight the Flame is to see that happen. All medical personnel and the public are aware of Complex Regional Pain Syndrome and important resources are made available to us. Yes, of course I would like my future to include a cure for this disease. However, right now I would settle for public acknowledgement and medical advances through awareness and education.

### 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.

# We Asked, You Answered What is Your Best Pain Management Tip?

Soak in a Epson salt bath to relieve swelling and pain. Just sit and relax the best you can. - S.A.

Find something that you like to do. It can be watching your favorite movies, hobbies, listening to music or meditate. I do all these, plus I paint on canvas. Wishing everyone many blessings! #NeverGiveUp II - C.F.

Music and going to my happy place.J.B.

I use books and jigsaw puzzles to distract and escape my pain. Distraction therapy. And then other times, when I'm not as strong, I cry. - S.B

Reminding myself that this too shall pass - B.S.

Take time to relax, get a massage if you can, soak in a tub with some soothing music, meditate, learn to take relaxing breaths. Being in constant pain is exhausting and stressful so doing little things for self care are REALLY important. - C.L.R

Moist heat therapy -L.D

I try and go to sleep. It doesn't always work, but I put on something funny and relaxing and just try and keep my eyes closed so I hopefully go to sleep. - M.N.

Do things to feel human again. With chronic pain it can just feel like you are just going through the motions of life, not your life. A lot of times depression is also involved so certain things can help both. Routines.

Showering every day (if you can). Treating yourself. - R

Remember that there is no shame to use medication demonized by the world around us. Somethings work for one but not the other and vise versa. If it gives you relief than good for you don't worry about others worry about yourself and a trustworthy doctor.- M.P. Kee

Whilst I know in some countries it's illegal the best pain medication I have found is whole plant cannabis. - A.W.

There is nothing you can do anything about this shit.
Accept and embrace your pain. The reason of some people's creating is experience nothing but anguish. That's all that is. - S.T.

Keep breathing, slow, deep, and with your lower belly. Visualize each part of your body relaxing, softening, easing, working your way slowly all the way from the scalp to the neck, shoulders, arms, fingers, chest, back, abdominals, obliques, hips, legs, feet, and toes- E.M..

Sleep siesta every day. Avoid what cause you more pain - C.M.

Breathe -K.A.R

Bad moments/hours/days/weeks eventually end, hang in there. - S.G.

Question for the next issue:

Have you taken up any new hobbies or interests since being diagnosed with CRPS?

# **DIY No-Sew Weighted Pillow**

### Materials Needed:

- · Birdseed or lentils
- · Pillow Stuffing (ex. Poly-fil)
- · Sandwich Ziploc bags
- · Duct Tape
- Throw Pillow Case w/Zipper





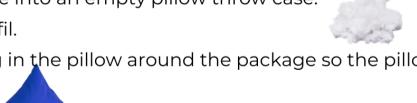
#### Directions:

- · Pour birdseed into (4) sandwich Ziploc bags.
- · Remove all air from bags and seal tightly
- · Lay out filled bags 2x2
- · Using duct tape, connect all the bags together, making one big package.
- · Flip the bags to the other side and seal with Duct tape.
- · Place the now I big package into an empty pillow throw case.
- · Fill up the pillow with Poly-fil.

· Be sure to pack the stuffing in the pillow around the package so the pillow is



- · Zip up pillow.
- · You did it!



Post a picture of your completed DIY Weighted Pillow on our social media pages







# HAVE YOU HEARD?









**SCAN ME** 

Sign up to walk or run the 5k or 1k



### We cannot wait to see you on September 25th!

COME OUT TO SUPPORT.
SEE OLD FRIENDS.
MEET OTHERS WITH CRPS.
RUN, WALK, OR CHEER.
VISIT THE RACE VILLAGE.
WIN SOME PRIZES.



# 2022 FTF 5k/lk Sponsors

<u>Signature Sponsor</u>



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Piedmont Physical Medicine & Rehabilitation · Stanley Specialty Pharmacy ·

### **Save The Dates**



FIGHT THE FLAME.

SUPPORTING RESEARCH, EDUCATION & AWARRENESS OF REAL/CIPS

Upcoming 2022 FTF

Support Group Meetings

Meetings are from 1-3 pm

September 10 CRPS and Eye Complications

Dr. Kurt Heitman, M.D

October 8 How to Ask for Help

November 12 Myofascial release, CRPS, and potential at home strategies.

David Phillips, MS kinesiology, LMBT.

All meetings will be via Zoom.

If interested in attending a meeting, please email

ппи.

Do you have a topic you would like us to discuss? Questions we can help answer?
Email:
Beth@FightTheFlame.org



Wishing you a low pain day!

# **CONNECT WITH US:**



**Fight The Flame Support** 





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