



FIGHTING FLAMES

The Official Newsletter of Fight the Flame®

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A Letter to my Enemy

Dear CRPS,

I hate you. I absolutely detest you. You destroyed my dreams, goals in life and how I was to live in this world. One accident should not have ruined my life.



The pain you cause me is overwhelming. Sometimes it is so bad, I pass out, throw up and cannot even hear my own thoughts. You lay in my nerves but burn deep into my bones, muscles, skin. It feels as if you have a pickaxe and you keep tearing my body up. Many times, I feel as if my blood was replaced with ignited kerosene.

Just when I feel I can manage the alarming, cutting pain, you bring up other symptoms that weigh me down. My body shakes, jerks, and sometimes freezes up. Migraines set in and I start to become dizzy. I am astounded at how you sneak your way into all parts of my body. You have taken away so much from me, my career, being the mom and wife I wanted to be, and being able to be choose freely what I can or cannot do.

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LOOK INSIDE
and find lots of new information.

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A letter to enemy

My passion for reading is still there but it is no longer enjoyable because now my eyes do not track well and my vision is blurry. I was never able to teach my daughter how to play hopscotch, or my son how to ride a bike. Even the idea of something as simple walk with my husband has now been abandoned. We always have to wonder if an outing or a vacation will be disability-friendly; will I be able to use the wheelchair.

I can never predict when you will shoot me into a distressing pain flare. What sets off those flares is a mystery. There are days when I can walk around, with no flare up, and days when I am almost sedentary and you will cause violent pain. Scheduling and keeping plans with others is extremely difficult.

We met in my leg 20+ years ago and then you had the nerve to spread. I guess you did not want to make the rest of my body jealous, so you spread up and down. Leg, feet, arm, hand, shoulder, face, head, hell even my jaw hurts. You have extended yourself through to my fingers making writing anything a chore. Somehow you have gotten hold of my circulatory system causing temperature changes and numbness. So much of my body is now under your control. I never thought you would creep into my digestive, cardiac

and endocrine system causing adrenal issues. My skin is mottled and changes color and temperature. I have hideous sores all over body. My nails keep splitting and my hair is completely damaged.

The diseases you have brought by damaging these systems is relentless.

Dystonia, Dysautonomia, Barre Lieou Syndrome, Trigeminal Neuralgia, and plenty of others. I have tried so many treatments it is insane: medications epidurals, reflexology, Injections, physical therapy, aqua therapy, cranial-sacral therapy, Calmare therapy, DBT, CBT, counseling, diet, reflexology, meditation, ketamine infusions, hypnotherapy and others. If someone told me to stand on my head and I would be rid of I would look at the world upside down forever.

Since you came along, I have to be so selective on where I go. Will it be too crowded or noisy? Vibrations run through me like nails on a chalkboard. I love music. If I was not to become a teacher, I would have wanted to be a singer. As you progressed you have made it impossible to go to or enjoy live music. I miss



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A letter to enemy

They say knowing you have a problem is the first step to finding a solution.

Well, we already know our problem: CRPS is unknown in the real world.

What is the solution?

Awareness When one says that they have Complex Regional Pain Syndrome, we cannot have people give us a blank stare. No one is going to want to help those with CRPS if they have never even hear of the disease. This means we have a big job to do. We need to use our brains, willpower, and actions. How do we spread awareness about CRPS? How do we educate those who do not understand?

The first step is to simply talk CRPS. CRPS and its symptoms are not a taboo subject. When others ask you how are you doing, don't just respond with "I'm fine". Nobody battling CRPS is just fine; you are fighting your own war.

Gently explain to people that you are working to manage your painful disease.

Step two: Question; question everyone in the medical community that you come across if they know about CRPS.

Unfortunately, the majority of those you speak with will not have even heard of the disease.

Use this as an opportunity to educate. Explain what Complex Regional Pain Syndrome is, give them a brochure about CRPS. Hopefully, once they understand, they will help others to be aware of CRPS.

The third step is to learn. Educate yourself. Read about new research or new treatments that are being discovered. Go to support group meetings, ask questions. Be an informed patient, know what procedures you are having, having them, and what are the outcomes. You MUST be your own advocate.

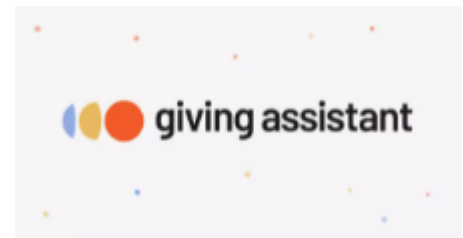


The fourth step is action. Do not just tell yourself that you will do something, do it. You can make a difference. Help fundraise, so we can better fund important educational and research projects. Host your own birthday fundraiser for CRPS, help gain sponsors for on advocate. Do you have an extra few dollars, that you can donate to Fight the Flame? Every dollar donated helps Fight the Flame complete their mission. We know our problem, CRPS needs more attention. Now it is up to you to help resolve this problem.

Like to Shop?

Did you know you can raise money for Fight the Flame just by doing your regular online shopping?

We recently teamed up with Giving Assistant, so you can shop online AND support our cause—all in one place. Simply sign up at GivingAssistant.org, and start earning more cash back on your purchases at over 3,000+ popular online retailers. Then, donate some of your earnings to our organization. It's simple, free, and makes giving back a breeze.



Fundraising Through Shopping | Great Deals. Good Deeds.

Giving Assistant shoppers earn cash back so they can donate to your nonprofit. Learn more!



Who's Ready to Play?

BINGO!

Time to have some fun - see your friends - and win some prizes!!!

\$5.00/card

Everyone is invited!

To purchase your Bingo cards:

Sunday, July, 18 2021
4:30pm via Zoom

https://paypal.me/FighttheFlame?locale.x=en_US

**You Asked.
We
Answered.**

**What is one thing you wish people
would understand about CRPS?**

I have good days and bad days, just because I can do something one day doesn't mean I can do it the next day. And I usually need down time after doing things to rest and recuperate. - S.M.

The fatigue is real. But that it is different than being tired and able to sleep. Painsomnia. - M.T..

Good days do not mean I'm not sick - D.Z.

Nothing,,,, I've given up worrying what others think. - I.M.

**Ask before
you touch me
- M.B.**

Even though I may look like I am fine, I have learned to mask my pain over the 20 years better than I have learned to express my pain. - A.K.

We aren't looking for your sympathy and we're not attention seeking... We are just trying to live and function with the hand we were dealt A.H

The pain is real - R.H

It really does exist!! - H.D

...the pain never stops ... ever - L.M.

Question for Next Issue:

What specialty is primarily responsible for your pain management?

- Please send your thoughts to Beth@FightTheFlame.org



FIGHT THE FLAME[®]
SUPPORTING RESEARCH, EDUCATION & AWARENESS OF RSD/CRPS

Fight the Flame 5k and 1k Stroll & Roll

Sunday, September 26, 2016
McAlpine Creek Park, Charlotte, NC

Registration is now open!

Register yourself, start a team, forward this
link to others.

go to:

<https://runsignup.com/Race/NC/Charlotte/FightTheFlame>

Do you know a business/store/restaurant/spa/hotel that
would want to sponsor our 5k or donate a gift certificate for
our amazing raffle?

if so, please email Beth@FightTheFlame.org to get sponsorship information



A letter to my enemy

working, it is why I went to school and received my bachelors' and Master's degree. You robbed me of teaching for the rest of my life.

People look at me and say that "I look good" or "You cannot possibly be that sick, you are out and doing things" So many times, I have wanted to turn around and scream. What would they have me do, stay in bed and cry all day.

Nobody understands you; people have never heard about you and doctors do not know enough about you. How is it that one day I can walk into the post office and yet the very next day that same task be impossible. You make no sense. Why would you pick me? I have done nothing that audacious in life to deserve you. No one has. Your pain is so torturous that several of my friends who tried to overpower you are no longer here.

Even family members do not fully understand that going out in the heat, even for a few minutes, will overwhelm me and I will sweat profusely. When it is cold it is almost impossible to leave my home. The cold wind on my body is sheer torture.

Sleeping is an amazing luxury for me now. If there is ever a night that I sleep four hours in a row, I celebrate. My memory has left me and trying to think of the correct words for items I

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clearly know is difficult (like my children's names), embarrassing and extremely frustrating. I am always tired and fatigued because of your hold over me.

I am sick of you keeping me a prisoner. You think you have won. You keep throwing me curveballs and I am still here. I once read that when a person who has CRPS was asked what they do for a living? She replied "Surviving." I have never said that out loud, but it is exactly how I feel. After a horrid pain flare, when at that moment I feel as if I cannot go on, I remind myself that I am a fighter and that I have been through days like this before and have woken up the next morning.

I am stronger than I thought possible. I do fight every day. I get dressed, put on makeup and smile religiously. I am strong, I will not let you defeat me. I will keep going and be the best wife, mother, sister, cousin, aunt, and friend I can possibly be. I am strong and I will survive.

Your arch nemesis,

Beth

Previous issues of
Fighting Flames are
located on our website:

www.FightTheFlame.org

Important Dates:



Saturday, July 10 - FTF CRPS Support Group Meeting

Sunday, July 18 - FTF Bingo

Saturday, August 14 - FTF CRPS Support Group

Saturday, September 11 - FTF CRPS Support Group

Sunday, September 26 - **Fight the Flame 5k and 1k Family Stroll & Roll**

Saturday, October 9 - NO MEETING this month

Saturday, November 13 - FTF CRPS Support Group

Saturday, December 11 - FTF CRPS Support Group

FTF is Looking For:

Newsletter contributors

Would you like to write an article?
Share your story?

Email Beth@FightTheFlame.org

Learn about our support group:

**2nd Saturday
of each month
1- 3pm EST**

Come meet, talk to,
support other people
who understand
what you are going
through

Upcoming topics are listed on our website:
www.FightTheFlame.org

**If you would like to join our email list, send
an email to: Beth@FightTheFlame.org**

Wishing you a low pain day!

Connect with us:



Fight The Flame Support



@FightTheFlame



www.FightTheFlame.org



@FightTheFlame