

>>> NEWSLETTER <<<

FIGHTING FLAMES

The official newsletter of Fight The Flame®



FIGHT
the FLAME®

Supporting Research, Education
and Awareness of **CRPS**

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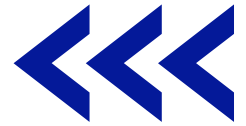
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CRPS ESSAY SCHOLARSHIP INFORMATION



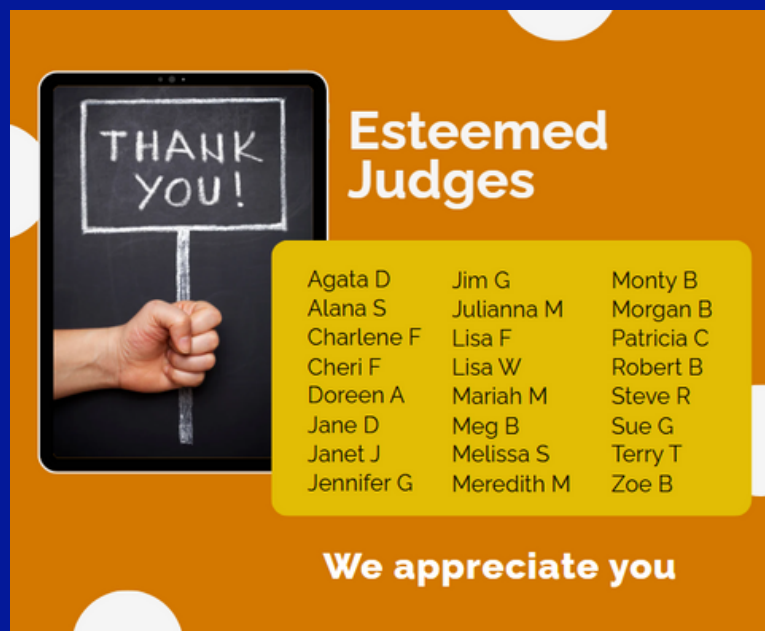
Fight the Flame awarded two CRPS Awareness Scholarships this year. The Fight the Flame CRPS Awareness Scholarship was established to support and encourage college-bound students who are passionate about raising awareness for Complex Regional Pain Syndrome (CRPS).

Applicants must:

- 1. Write a 500-word essay on how to improve CRPS awareness.**
- 2. Educate at least 10 adults about CRPS as part of an awareness challenge.**

Winners are chosen based on the quality of their essay and their outreach efforts. Fight the Flame is proud to empower young advocates who are making a real impact—one conversation at a time.

This year, we received over 200 scholarship application. Thank you to our team of amazing judges who helped choose our two winners





Complex Regional Pain Syndrome (CRPS) is considered the most painful disease known to modern medicine, yet it remains relatively unknown to the general public. Many CRPS patients do not appear visibly ill and are often overlooked by the medical community. It is important to note that anyone can develop CRPS at any point in their life.

How can awareness about an invisible disease like CRPS be raised to help patients, families, and communities access resources for support and treatment?

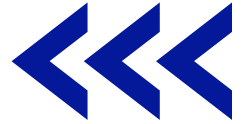
When my mom was diagnosed with CRPS twelve years ago, I was too young to understand. The words glial cells and myelin sheath were thrown around, but sounded gibberish. Hospital visits signaled that my family was different, but I didn't grasp why.

That is, until I understood science. Eighth grade introduced mitochondria, and tenth grade, neuronal signaling. CRPS became clearer, and science, my calling- the mechanism behind my family's differences. I crave to be the scientist finding the cure for CRPS. I yearn to be the physician treating patients compassionately- the expert who, through effective dialogue and listening, recognizes the Budapest Criteria before

patients see multiple doctors, as my mom did.

Time is of the essence before the CRPS monster spreads. And yet, most physicians are uninformed, except those who previously treated CRPS. Experience is key, but medical schools don't prepare physicians, and that lack of preparation often comes with a lack of empathy, as physicians fail to listen to patients, even denying their pain. This is especially true for female warriors, who are often grilled like criminals. Their pain is believed to be exaggerated or fabricated.

The solution? Incorporating Chronic Pain 101 into medical and nursing school curricula, introducing future medical professionals to common signs to ensure timely diagnoses. As a year-round intern for RSDSA for four years, CRPS education is my motto. I've created RSDSA's primary educational tools, highlighting diagnostics, treatment options, and compassionate medicine. I've spread awareness in my community and globally. I've supported warriors, learning about daily struggles and physician neglect. I've connected with experts and contributed to RSDSA's newsletters, website. and events, combining scientific advancement, human



connection, and seeds of hope. I've presented to high schools, inspiring the next generation of medical professionals to obtain a scientific and humanistic understanding of warriors' struggles. And, I've raised more than \$39,000 for research. Change cannot happen solely in medical and

nursing schools, or in labs and hospitals: medicine is only one piece of the puzzle. Battles with insurance companies over "investigative" treatments, prolonged approval processes, a lack of incentives for companies to develop chronic pain medications, and insufficient research funding have transformed CRPS into a legislative issue.

The CRPS community must capture Congress's attention through relentless lobbying, advocacy, and storytelling. As an

RSDSA Advocacy Committee Appointee and a Rare Disease Legislative Advocate with the EveryLife Foundation for Rare Diseases, I've presented to Congress to advance the equitable development of and access to treatments through science-driven legislation. With others, I've successfully advocated for the creation of an FDA Rare Disease Innovation Hub, meant to centralize and expedite the approval of therapeutics. I've also advocated successfully to expand telehealth access, motivated by my mom's long trips for Massachusetts General Hospital's specialists.

In spreading CRPS awareness, there's power in numbers. Our voices and stories are amplified when weaved into a single display of CRPS strength and grit. With these endeavors, patients, families, and communities can access the compassionate medical care and life-saving



Congratulations!
Samantha R.!



Complex Regional Pain Syndrome (CRPS) is a disease most people have never heard of and that's exactly the problem. Often called "the most painful disease you've never heard of," CRPS is a chronic, debilitating condition that disrupts the nervous system, typically after an injury or trauma. Its symptoms include intense burning pain, swelling, skin discoloration, and extreme sensitivity to touch. But because CRPS is rare and invisible, patients often face delayed diagnoses, isolation, and misunderstanding. Raising awareness isn't just about education, it's about giving patients hope and a voice.

To change that, we first have to make CRPS visible. People can't talk about what they don't know so we need to shine a light through stories, education, and creative outreach. For example, awareness campaigns using art and animation can make the experience of CRPS more relatable. As a future animator, I hope to use storytelling to help others visualize what's often hidden. Through animated videos, character designs, or infographics based on real patients' experiences, we can reach wider audiences, especially young people, and build empathy in ways traditional facts alone can't.

We can also start awareness earlier, by

integrating CRPS into school health curriculum or a student-led discussions. Teachers, nurses, and peer leaders could benefit from basic knowledge about symptoms and how to support students with unexplained pain.

Social media, too, is a powerful tool. Short reels, TikToks, or YouTube videos with simple facts and personal stories could help CRPS reach beyond just the medical community and into the hearts of everyday people.

Access to trusted resources also matters. Flyers in clinics or QR codes linking to organizations like Fight the Flame can connect patients and families to help more quickly. Community events can host speakers living with CRPS or booths with interactive education. Empathy grows through connection, and when people hear real stories, stigma begins to fade.

Ultimately, awareness is the gateway to action. It leads to earlier diagnoses, better treatment, stronger support systems, and most importantly patients feeling seen. Those living with CRPS deserve more than silence. They deserve understanding, compassion, and visibility. My goal is to use the skills I'm building in storytelling, design, and advocacy to help amplify

CRPS ESSAY SCHOLARSHIP WINNER - GREYSON R.



those voices.

Awareness isn't just a campaign, it's a commitment. A promise to stand beside those who live every day in pain, and help carry a truth that's too often hidden.

I may not have CRPS, but I know what it means to feel invisible, to carry something heavy no one else can see. That's why this matters to me. And that's why I'm committed to helping fight the flame.

Congratulations!
Greyson R.!

BETTER CALL I.T.

A heartfelt thank you to Ross Feldman of Better Call IT for generously volunteering his time and expertise as Fight the Flame's IT Director. Ross has made our tech headaches disappear and helped make our work smoother and more efficient.

We're incredibly grateful for his support and commitment to our mission.

Need IT help? We highly recommend Ross!



Look Familiar?

Don't Worry. We Understand.

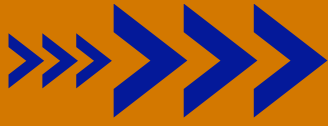


**BETTER
CALL I.T.**

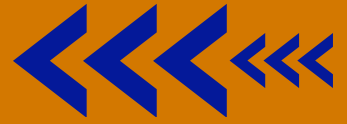
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BIG NEWS ALERT!



UPCOMING DATES

Be sure to mark your calendars!

Saturday, 7/12/25 - Support Group Meeting
Saturday, 8/9/25 - Support Group Meeting
Saturday, 9/13/25 - Support Group Meeting



Sunday, 9/28/25 - FTF 5k/1k
Saturday 3/21/26 - FTF CRPS Conference

@www.FightTheFlame5k



FIGHT THE FLAME 5K/1K
9/28/25 • CHARLOTTE, NC

ENDING SOON

EARLY BIRD SPECIAL

JULY 9, 2025 -
REGISTRATION PRICING
GOES UP

Sign up today:

[HTTPS://WWW.FIGHTTHEFLAME5K.ORG/](https://www.fighttheflame5k.org/)



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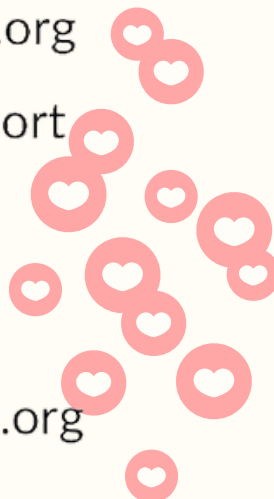
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FIGHT THE FLAME
Supporting Research, Education
and Awareness of CRPS

Save the Date

CONFERENCE CRPS

MARCH 21, 2026
COURTYARD - WAVERLY
CHARLOTTE, NC

more details to come...