
EVENTS

Getting the Word Out

BY JENNY PICCIOTTO

On November 1st, 2015, it was raining in Charlotte, North Carolina. Groups of healthy young athletes mingled with CRPS patients sporting canes and wheelchairs in the drizzle. Friends and families gathered in Race Village. The Governor and Mayor had declared the day CRPS Awareness Day, the Wells Fargo Duke Energy Building was lit up in orange, and 250 bright orange bags filled with sponsor gifts and CRPS information packets were ready to go. 175 runners and walkers, and 50 volunteers gathered for the 3rd annual Fight the Flame® 5K race, decked out in their Fight the Flame T-shirts. The course was prepped for both athletic participants and CRPS runners/walkers, with encouraging signs posted along the route, benches positioned to offer a spot to rest, and golf carts ready for anyone who couldn't make it to the finish line.

None of this would have happened without the love and dedication of the Stillitano family.

Beth Stillitano is the consummate CRPS warrior. She has had CRPS since 1996, when she tripped on construction debris in the hallway of the school where she was teaching. Only twenty-four and just married, she underwent four knee surgeries.



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Beth Stillitano is the lead organizer of the Fight the Flame 5K.

But that didn't stop her. Over the course of 19 years, she has progressed from being confined to bed, to using a wheelchair, to walking with a cane. She has tried everything from opioid therapy to Trigger Point injections, nerve blocks and Calmare. Recently she has begun ketamine infusions. Through it all she has valued the love and support of family and friends. She is still happily married. Together, she and her husband have raised two children. She is active in the CRPS community, sharing her story, raising awareness, and raising money for research.

Fight the Flame 5K was born in 2013 when Landon Stillitano needed to complete a community service project. He was 12 years old, and loved to run. He knew about the RSDSA's annual Achilles 5K because Beth's sister had participated in the event for many years. He decided to organize a local 5K in support of his mom.

It was a big success, with 175 registered participants. Of these, there were 20 people with CRPS who met one another for the first time. They created a support network that keeps in touch online. When enthusiastic racers said they would be back the next year and people

who had never heard of CRPS before were moved to make contributions, they decided to make it an annual event.

Since then, Beth has become the lead organizer. The annual Fight the Flame 5K is held in November to coincide with CRPS Awareness Month. Since 2013, the group has raised over \$50,000 in donations contributed generously to the RSDSA for research.

Organizing is a team effort, and getting the word out about CRPS is a top priority. Morgan, who has CRPS, was a student at University of North Carolina at Charlotte when she participated in the 2014 run. She interned for Fight the Flame during her senior year and has stayed on as an event organizer. Beth's daughter Alana, a senior in high school, organizes 40 to 50 volunteers from her school. She helps the students learn about CRPS while they help with posters, stuffing race bags, and volunteering on race day.

The sponsor drive is focused on awareness too. Each sponsor is contacted in person, and given an information packet about CRPS. Community outreach includes a website, Facebook page, social media, public service announcements and a billboard. The group also helps set up sister events in other cities.

"We have to just keep getting information out there," Beth says. "No one is going to pay for research studies if no one knows about CRPS."

This year's Fight the Flame 5K will be held on Sunday, November 6th. All money raised will be donated to further educate the public, raise awareness and help fund both the RSDSA sponsored LDN research at Stanford University and its Brad Jenkin's Patient Support Fund.

The RSDSA applauds the work of Beth and the Fight the Flame team for their tireless efforts to promote awareness and their generous contributions to the CRPS community. You can learn more about Fight the Flame at fighttheflame5k.org and facebook.com/FightTheFlame5k.



ABOUT THE AUTHOR

Jenny Picciotto is a CRPS patient, yoga instructor, massage therapist, and writer. She currently lives in Hawaii, where she leads the Oahu CRPS Support Group, and is active in the online support community.

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