

Woman battling rare condition helps raise awareness

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RYAN HUTTON/ Staff file photo *With ice packs on her elevated feet and her husband, Anthony, by her side, Paula Corey holds up the sign she made to help pitch the upcoming Erythromelalgia Awareness Day at the Massachusetts Statehouse, during an interview in her home last August. Corey suffers from the rare medical condition, which affects the skin of the feet or hands causing redness, intense heat and burning pain.*

BOSTON — It's been years since Paula Corey's toes started to turn bright red, since her veins began to bulge under her skin, since the pain began.

Corey, of Methuen, is living with erythromelalgia, a rare medical condition that causes visible redness, and extremely hot and painful feet or hands, according to medical professionals. The symptoms tend to come in bursts, Corey calls them “flares,” that make everyday functioning – even just leaving the house, or sleeping through the night – hard, if not sometimes impossible.

For the past few months, Corey has been working with state Rep. Diana DiZoglio, D-Methuen, on planning an erythromelalgia awareness day at the Statehouse in Boston.

Their work comes to fruition Wednesday, with a free, public event that begins at 11 a.m. in Nurses Hall. DiZoglio, who is now running for the 1st Essex District state Senate seat, will present a resolution declaring May as Erythromelalgia Awareness Month in Massachusetts. Corey will speak at the event, as will the president of the Erythromelalgia Association, among others.

“Awareness is definitely key, or the first step, in getting help for everybody,” Corey said.

Corey's battle with the rare ailment has been challenging. Medications have failed to help her. Over the winter, she suffered from constant flares day in and day out. She was unable to leave her house and had a fan trained on her to help cool her constantly – to help combat the intense heat in her body – even when it made her shiver.

With medicine proving unhelpful, Corey found a home remedy on an online forum. Seemingly counter-intuitive to combating erythromelalgia's symptoms, it recommended she soak in warm water, and gradually increase the heat. Surprisingly, she said, it worked.

“While you're in the water you're hating it, it's painful. When you come out (your appendages are) still swollen,” Corey said.

But after some time and conditioning, Corey said “you come out of the flares easier and easier and then it's not as painful as when you started.”

Corey advocates not just for herself, but for others with erythromelalgia. Beyond helping organize the awareness day, she put out a YouTube video last year detailing her battle with the condition in an attempt to help others better understand it.

“Every week I've talked to so many people around the world and they watch the video or they've read an article online and they didn't know what they had, and they're just – they're so thankful to have just come across my video and just know what they have,” Corey said.

Corey hopes Wednesday's awareness day in Boston will be just the start, and that “other states will follow.”