

*Milford Daily News*

## **Red lights at Milford fire stations draw attention to rare disease**

By Alison Bosma

May 14, 2019

**Milford fire departments will be lit up in red this month to raise awareness of little-known disease erythromelalgia, which affects local youngster Sebastian Soares.**

MILFORD – The fire department will light up red for the month of May to raise awareness of a little-known disease called erythromelalgia.

“It’s considered rare, but I think more people have it than is realized,” said Milford’s Sarah Soares, whose 13-year-old son Sebastian has the disease. “I think both of us just hope that (the awareness campaign) helps more people, especially children, who have it.”

Erythromelalgia, or EM, is characterized by painful, bright red extremities, typically worsened by heat, and can be caused by more than one underlying factor. For Sebastian it was small fiber polyneuropathy. Before Soares discovered what her son had and obtained the proper medication, Sebastian was in almost constant pain.

“I could barely leave my room,” Sebastian said.

Milford’s red lights this month – at both the Birch Street and downtown Spruce Street stations – are part of a statewide campaign to raise awareness.

“I thought, ‘imagine if all the fire stations in all of Massachusetts lit up red, or participated in some way,’” organizer and Dracut resident Paula Corey said. “Maybe, just maybe, there’s that small chance that something good will come out of that. That was my vision.”

Corey, who has not yet determined the cause of her own erythromelalgia, began a public awareness campaign in 2017, desperate to find solutions. After posting an emotional video to YouTube, she said, she was flooded with messages of relief from other people suffering from erythromelalgia.

“People are going 15, 20 years, and not knowing what they have,” Corey said, adding that the frustration of being unable to understand or fix the problem takes a psychological toll. “Everybody’s just so thankful. They feel such a relief that they can put a name to it, and they can go to their doctor.”

The decision to contact fire departments, and the color of the floodlights outside, Corey said, are to reflect the nature of the disease. Sebastian and Corey both described the pain as “burning.”

“My hands and feet are on fire,” Sebastian said, describing a flare-up. “It makes my feet really red.”

Sebastian’s erythromelalgia has been reduced to a few flare-ups a month. He can now wear sneakers, play outside, and ride his bicycle.

“Now that he’s in a much better place, we can focus on (an awareness campaign),” Sarah Soares said. “When he was in that much pain, it was hard to even fathom that.”

The hope is that people who are suffering from erythromelalgia without knowing what it is will hear about and recognize the symptoms, then suggest the diagnosis to their doctors. Additionally, if the disease turns out to be more widespread than is currently thought, Corey said, it might receive more funding.

“It feels good to be able to point someone in the right direction,” Sarah Soares said. “For Sebastian, I think it puts a really positive spin on something that’s really negative. Being able to help others. He’s that kind of kid.”

Corey said she still can’t go outside in weather over 65 degrees.

“I’m still pretty isolated, but I’m able to drive,” she said, having found treatments that ease, but do not solve, the pain. “There have been huge improvements, but to someone else they sound small.”

Both the Soareses and Corey said the disease needs more attention and research.

“I always say it’s awareness, funding, research, cure, in that order,” Corey said. “I’m hopeful (a cure) will happen in my lifetime, but I’m not holding my breath.”

Only a handful of fire departments in the state agreed to put out the lights in May and post information about erythromelalgia on their websites or social media pages. Methuen and Dracut, where Corey grew up and now lives, respectively, are both involved.

“We thought it was important to participate because we have someone in the community with the disease, and it would be nice to show the support,” Milford Deputy Fire Chief Mark Nelson said. “It’s a small thing, really, for us to do. It’s not difficult.”

Corey said she hopes to try again next year, and eventually bring the movement outside the state.

“Hopefully the more people that realize that they have it, maybe it’ll get kicked out of the rare category ... and then we’ll have more help,” Corey said. “We’ll make more of a noise worldwide, and say ‘hey, we’re burning alive, and we need help.’”

Nelson said the Milford Fire Department will likely participate again.