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Massachusetts Residents Awareness Day about erythromelalgia

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Erythromelalgia (aka erythermalgia) is an old name for a mix of symptoms that most often affect the feet and hands. Less often symptoms start in other places, particularly on the face, or spread there. **The classic symptoms are unexplained redness, pain, and swelling, worsened by warmth.** Many patients cool their skin for relief. The first full medical description was by Mitchell, a Civil War surgeon. He gave the name “erythromelalgia”, which means red swollen limbs in Greek.¹ Some patients notice white or blue skin at times.

More than half of patients with erythromelalgia have objective evidence that it is caused by small-fiber polyneuropathy (SFPN). The body’s nerves become damaged and activate to send signals to the brain when they shouldn’t. This triggers pain and changes in blood flow in the skin. These same “small fibers” also control other sensations such as itching, and many inner organs. Some patients notice dizziness, gastrointestinal distress, headaches, and occasional difficulty thinking. Often these are due to the same circulation difficulties that cause the skin redness. I suggest that erythromelalgia patients ask their doctors if they might have SFPN. Recommended tests include a tiny skin biopsy from the leg, or autonomic functions testing (AFT) including sweating.² Skin punches can be taken in most doctors’ offices and shipped to labs such as Mass. General’s for analysis. AFT are only available at a few university hospital labs including MGH.

New England is a center for research on erythromelalgia and SFPN. Dr. Waxman’s team at Yale focuses on rare but important genetic cause of erythromelalgia and SFPN.³ MGH treats and studies genetic, autoimmune and other causes. Erythromelalgia that starts suddenly in otherwise healthy adults and children with no relatives who have it is sometimes autoimmune, particularly when it starts after infections or possibly vaccinations.⁴

Best medical treatment depends on knowing the specific cause in each person. If erythromelalgia symptoms are bothersome, pain killers or over the counter remedies may not help, and they don’t help nerves heal. Genetic and autoimmune neuropathies require different treatment and both can improve dramatically with smart medical care.⁵ Since many doctors don’t know about erythromelalgia and SFPN, we encourage patients to learn themselves and educate their team. Spread the word that erythromelalgia can be figured out and cured. Here are some sources of more information. Good luck and best wishes.

NeuropathyCommons website has non-commercial information about how to get care for polyneuropathy:

<https://neuropathycommons.org/>. This handout will be posted there.

Link to February 5 2018 talk at Radcliffe to the public about small-fiber polyneuropathy

<https://www.youtube.com/watch?v=s66LvWQ5Qso> or search the internet for Oaklander and Radcliffe

Link to August 18 2017 Boston25News story on erythromelalgia

<https://www.fox25boston.com/news/woman-still-searching-for-a-cure-after-3-years-with-unexplained-burning-pain-1/594505020>

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