



Support & Education

TEA publishes the newsletter *Footsteps* filled with information about current EM research findings, treatment successes, and TEA people and programs. TEA hosts a website that has a growing library of medical journal articles about EM, back issues of the newsletter, member stories and much more. TEA also helps members network and encourages them to connect with others in the organization through its online membership directory.

Research

Part of TEA's mission is to help fund research into EM's causes, treatments and, ultimately, the cure. Using Research Fund dollars, TEA supports studies into inherited EM under way at Yale University. TEA also supports EM researchers in the Netherlands, who work in concert with Yale. You, your family, friends, and employers could help TEA make a true difference in this ground-breaking research by donating to TEA's Research Fund.

Our Mission

The Erythromelalgia Association has as its mission to identify, educate, and support those suffering EM's painful symptoms; to help fund research leading to a cure for this rare disorder; to raise public awareness of EM; and to educate healthcare practitioners to recognize and diagnose EM.

About TEA

Founded in 1999, TEA originated from a handful of EM sufferers joining together to help others with this rare condition. TEA now is an international, all volunteer, nonprofit organization. Led by a volunteer Board of Directors with volunteer officers, TEA is assisted by a Medical Advisory Committee made up of doctors involved in EM research and/or experienced in working with EM patients. TEA is a member of the National Organization for Rare Disorders.

The Erythromelalgia Association (TEA) does its best to ensure that the information provided is accurate, timely and useful. However, the information contained on the TEA website or in printed communications is not to be construed as medical recommendations or as professional advice. Neither the authors, The Erythromelalgia Association nor any other party involved in the preparation or publication of the material presented is responsible for any errors or omissions in information or any results obtained from the use of such information. Readers are encouraged to confirm the information contained herein with other reliable sources and to direct any questions concerning personal health care to licensed physicians or other appropriate health care professionals.



The Erythromelalgia Association



Membership

To become a member of TEA, simply make a tax-deductible donation of \$20. This small fee brings you our newsletter, *FootSteps*, sent to your home for one year, as well as access to members' pages on our website. Please send your donation and contact information to TEA, 200 Old Castle Lane, Wallingford, PA, USA 19086. Or use your VISA or MasterCard online at www.erythromelalgia.org.

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www.erythromelalgia.org



The Erythromelalgia Association

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Raising Awareness.
Raising Research Funds.
Raising Hope.

About Erythromelalgia

Erythromelalgia (EM) is a rare and frequently devastating disorder that can severely limit people's lives. The painful, hot redness most often affects feet and legs, but also may appear in the hands, face, ears, knees, or other parts of the body.

Even mildly warm temperatures (65 degrees F or above) or moderate exercise can bring on burning sensations so intense that those with EM attempt to cool their feet any way they can. They adjust their lifestyles to avoid triggering flare-ups. Some move to cooler climates. Some become housebound.

- Along with burning pain, affected parts of the body may be very red to purple in color, perhaps swollen, and hot to the touch.
- The intensity of the symptoms varies from person to person. Some notice a continual burning pain while others are troubled with "flare-ups" or episodes lasting from minutes to days in length.
- Some with EM report that foods, chemical additives like MSG, alcoholic beverages, and some drugs can make EM symptoms worse.
- The name erythromelalgia describes the clinical features: erythros (redness), melos (extremity), and algia (pain).
- EM is more than twice as likely to strike women as men.
- The majority of people with EM are between the ages of 41 and 80, but young people can be affected as well.
- At least five percent of those with EM have inherited EM. Some of their family members also have the disorder.
- EM may also be spelled erythermalgia, which emphasizes heat (thermos).



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Medical Explanation

What goes wrong in the body during EM flares is not definitively understood. A problem with blood flow known as arteriovenous shunting has been shown to be a contributing factor as has the neurological malfunction small fiber neuropathy. EM may be associated with other diseases—the blood disorder myeloproliferative disease, for one. And EM is known to be secondary to many other underlying diseases.

Inherited EM is caused by a genetic mutation that makes pain-signaling nerve fibers overexcited and pain sensations much more intense than normal.

Treatment

Treatment begins by learning strategies that help prevent flares such as avoiding warm weather, staying in comfortably cool environments, elevating the feet and using fans. Frequent exercise like swimming or other moderate methods also can help.

A number of different therapies help different people. With the guidance of knowledgeable physicians, people with EM can systematically try various drug therapies until one is found that helps. TEA's 2008 Member Survey showed that most respondents who reported good results used one of three kinds of drug therapies—anticonvulsant medications, SNRI antidepressants or non-steroidal anti-inflammatories (NSAIDs), which are over-the-counter pain medicines. Other categories of drugs helped some others including prescription pain medications, anti-histamines, and other kinds of antidepressants. Supplemental magnesium, acupuncture, and Lidocaine patches helped still others. (Join TEA at www.erythromelalgia.org to read the full results of the 2008 Member Survey.)

A strong word of caution about the use of cold water soaking, icing, or any form of artificial cooling. Although cooling may seem to be the most obvious action and may bring immediate relief, it can create other serious problems from increased flaring to skin tissue and nerve damage, frostbite of varying degrees, or severe ulcers that can take long periods to heal.

Affected areas can be red to purple in color, perhaps swollen, and hot to the touch.

