

TEA in Print

In 2016, TEA released *A Patient's Guide to Erythromelalgia*, a comprehensive resource covering all aspects of the disease, from symptoms and diagnosis to treatment and daily coping tips. The guide may be ordered or downloaded on TEA's website.

TEA also publishes the newsletter *FootSteps*, which is filled with information about current EM research, as well as EM-related news and announcements. Back issues of *FootSteps* may be found on TEA's website.

Research

Helping fund research that will lead to new treatments—and eventually a cure—is a central goal of TEA. Using Research Fund dollars, TEA has succeeded in helping fund encouraging research being done by scientists at highly regarded universities such as Yale. When making donations to TEA, you may choose to allocate your gift to the Research Fund.

Membership

TEA's current membership base extends into 17 countries worldwide. To become a member simply click the Join button at erythromelalgia.org. Making a donation of \$20 or more is encouraged. Donating may be done on the website or by sending a check to TEA, 200 Old Castle Lane, Wallingford, PA, 19086, USA. This small contribution allows you exclusive access to TEA's online Member Directory of members who have opted to be included.

Funding

To help underwrite our programs and services, we rely on contributions from members, grateful patients, their families, concerned individuals, small businesses, and foundations. There are many ways to donate, including a direct tax-deductible donation of any dollar amount, shopping with AmazonSmile (choose Erythromelalgia (Erythromelalgia) Association as your charitable organization), or by participating in the TEA Bracelet or Bookmark Fundraiser. See erythromelalgia.org for details.

Our Mission

TEA's mission is to empower those affected by EM to improve their quality of life. TEA provides education, awareness, and community through our website, member services program, newsletter, social media presence, and networking programs. TEA promotes research through relationships with academic researchers, clinicians, and pharmaceutical companies with an interest in EM. TEA also raises funds to support EM research.

About TEA

The Erythromelalgia Association (TEA) is an international, all volunteer, nonprofit organization that provides educational and networking services online and offline that no other agency in the world is providing. TEA works to raise awareness of erythromelalgia and helps fund research into this rare disorder. Founded in 1999, TEA is funded almost entirely by donations. Most functions of the organization are carried out by the volunteer Board of Directors, assisted by some other dedicated volunteers. A member of the National Organization for Rare Disorders (NORD), TEA has a Medical Advisory Board, a requirement for members of NORD. TEA is proud to have gathered a group of prestigious and dedicated physician researchers to serve as advisors to the organization.

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**The Erythromelalgia
Association**

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www.burningfeet.org

**Raising Awareness.
Raising Research Funds.
Raising Hope.**

What Is Erythromelalgia?

Erythromelalgia (EM) is a rare neurovascular condition that most commonly affects the feet, but may also occur in the hands, face, or other parts of the body. The term “neurovascular” indicates that both nerves and blood vessels are involved. The three hallmark symptoms of EM are:

1. **Redness**, caused by excessive blood flow to the area
2. **Heat**, meaning that the skin will feel warm or hot to the touch
3. **Pain**, which may range from mild tingling to severe burning

Additional symptoms may include swelling or changes in perspiration, and the skin may be cold and/or bluish purple when not actively flaring.

EM flares may be intermittent or continuous and are most commonly triggered by warmth, physical activity, or stress. Flares are generally relieved by cooling the affected area; however, extreme measures such as soaking in cold water or use of ice packs are not recommended as they can damage the skin and worsen the condition.

- The term “erythromelalgia” derives from the Greek words *erythros* (redness), *melos* (limb or extremity), and *algia* (pain). An alternate name is “erythermalgia,” which incorporates the Greek word *thermos* (heat).



EM patient's feet during a flare.

- EM is considered a rare disease, with estimates of affected people ranging from 1.3 to 15 per 100,000.
- Studies have found EM to be more prevalent in women than men.
- An estimated 5 to 15% of EM cases are hereditary, caused by mutations of the SCN9A gene.
- Primary EM describes cases not caused by another disease. Most cases of EM have no identifiable cause.
- Common causes of Secondary EM include blood disorders, peripheral neuropathy, autoimmune diseases, and nerve damage.

There is currently no cure for EM, nor a single treatment that works for everyone. Many treatment options are available, and a trial-and-error approach is often recommended.

TEA Online

TEA's newly designed website, erythromelalgia.org, contains a wealth of resources aimed to educate and support those affected by EM. A key component is its growing library of almost 100 Medical Articles, where you can sort by category—General, Treatment, Research, and EM/Raynaud's. Each article is concisely summarized for easy browsing. “In the News” articles, FootSteps newsletters, and the Research Timeline, a chronological list of major scientific findings, will help keep you up to date on all the latest EM news.

Aided by members around the world, TEA has compiled a Physician Directory, an international list of doctors who treat EM, searchable by location. On the Member Stories page, members have shared accounts of their individual EM journeys. The website also features a Q&A with two leading EM researchers, results from the 2008 Member Survey, and details about TEA's 2012 Art Contest “Paint Your Pain.” The winning entry “EM” is on the cover of this brochure, courtesy of artist Andrea Davenport.

Members of TEA and those who join TEA while online may access the Member Directory. TEA provides this directory of members, who have agreed to be listed, as a service for members who would like to meet others with EM. In addition, TEA hosts a Facebook page, which provides the latest EM news as well as an opportunity to connect with others through social media.

