Support & Education
Although TEA has members around the world, the organization strives to stay in touch through various modes of communication. TEA publishes a quarterly newsletter filled with information about the most current research findings, treatment successes, and TEA programs. For those with Internet access, TEA hosts a Web site that has a growing library of journal articles about EM, back issues of the newsletter, and links to other sites of interest. Since TEA’s founding in 1999, it has led the way in obtaining and organizing information about EM from around the world. Much more needs to be done and TEA is helping to do it.

Research
One of TEA’s primary goals is to fund research projects into the causes and treatments of EM. In 2005, TEA made its first substantial contribution to EM research by helping to fund studies under way at Yale University in the U.S. Also in 2005, TEA awarded a “seed-money” grant to researchers in the Netherlands through the Clinical Research Grant Program of the National Organization for Rare Disorders. You, your family, friends, and employers could help TEA make a true difference in this groundbreaking research by making a donation to TEA’s Research Fund.

Membership
To become a member of TEA, simply make a tax-deductible donation of $20.* This small fee brings you our quarterly newsletter, FootSteps, sent to your home for one year, and access to the Members’ Pages on our Web site. Please send your donation to TEA, 200 Old Castle Lane, Wallingford, PA 19086, U.S.A. You may use your VISA, MasterCard, Discover or Paypal account online at www.erythromelalgia.org. *Though the regular membership fee is $20, TEA will accept any size donation.

Our Mission
Founded in 1999, The Erythromelalgia Association (TEA) is a nonprofit organization dedicated to supporting people with EM by maximizing their health outcomes and improving their quality of life; funding research into the causes and treatments of EM; and increasing awareness of EM among health care practitioners, patients, family members and the general public.

About TEA
TEA has members of all ages who reside in approximately 20 countries. TEA originated from a handful of EM sufferers joining together to try to help others with this rare condition. Everyone involved is a volunteer, including our officers and the members of the Board of Directors. TEA also is assisted by a Medical Advisory Committee made up of several doctors experienced in working with EM patients. TEA is a member of the National Organization for Rare Disorders.

The Erythromelalgia Association (TEA) tries to ensure that the information provided is accurate, timely and useful. However, the information contained on the TEA Web site 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. Updated 12/2005
About Erythromelalgia

- EM is a rare disorder that can occur at any age and affects both genders.
- Most cases of EM are idiopathic (cause unknown). Sometimes EM is secondary to other medical conditions including autoimmune, neurologic or blood disorders. Lupus, polycythemia vera and multiple sclerosis are examples.
- EM also can mimic other illnesses such as Complex Regional Pain Syndrome.
- Infrequently EM may develop following an injury or surgical procedure.
- Some people have the inherited or primary form of EM and usually have other family members with the disease. Recently an EM gene was identified as were several mutations to this gene. Apparently each affected family carries a different mutation.
- Both the blood vessels and the nervous system are usually involved in EM.
- The name erythromelalgia describes the clinical features: erythros (redness), melos (extremity), and algia (pain). There are other ways to spell EM including erythermalgia, which emphasizes heat (thermos).
- Remissions are possible, but infrequent.

With the help of the members of The Erythromelalgia Association (TEA), their doctors, and future research, control of EM symptoms is entirely feasible.

Classic Symptoms

If you have been diagnosed with EM, symptoms may include hands or feet that are very red to purple in color, are perhaps swollen, hot to the touch, and have burning pain. For some, EM symptoms may appear in the face, ears, knees or other parts of the body. 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. Warm temperatures seem to be the most frequent trigger for EM episodes. Flare-ups are provoked by heat and exercise, and symptoms are relieved by cooling and elevating the affected extremities. Some TEA members have found that foods, spices like MSG, beverages (particularly alcohol) and some drugs can make EM symptoms worse.

Medical Explanation

The following medical description should help you and your physician better understand this condition. Jay Cohen, MD, Chairman of TEA’s Medical Advisory Committee, defines Erythromelalgia in the following way: "EM results from a maldistribution of blood flow with some areas not getting enough blood and calling for more. The extra blood gets through other open vessels, including arteriovenous anastomosis, that is, the connection between the arterial and venous systems. This vicious cycle continues to worsen until the overall appearance of the skin is of too much blood flow."

Dr. Cohen further says: “even mild erythromelalgia can greatly affect normal functioning and quality of life. Patients avoid warm weather and limit their activities to cool or air-conditioned locations. Some move to cooler climates...many patients cannot wear socks or closed shoes even in winter.” When patients are severely affected, they can be house bound because of the continually painful symptoms. Elevation of the affected limbs becomes necessary and normal life is disrupted.

Treatments

There appear to be several subtypes of EM and different subtypes respond to different therapies. Treatment consists of trying various approaches until the best therapy is found. In his article, “The Treatment of Erythromelalgia,” Dr. Cohen discusses a wide variety of possible therapies: “In my experience, there are two types of medications that have demonstrated the most reliable effectiveness in treating EM.” They are calcium antagonists (prescription drugs and magnesium) and one type of antidepressant medication. There also are many other medications and medical interventions that are helpful for some people.

In addition to medical treatments, there are actions that individuals can take to help maintain a more comfortable daily life:

- Elevation of the feet either above the heart or level with the hips
- Staying in a comfortable environment, for instance, an air-conditioned house.
- Frequent moderate exercise. Many people report that without frequent exercise, their EM symptoms are generally worse.

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 creates other serious problems. It has been demonstrated that icing or other cooling actually result in increased flaring, thus making the symptoms worse. Other problems may include skin tissue and nerve damage, infections, even severe ulcers that can take months to heal. Contrary to outdated medical information, this method of treatment is not advisable.