

FootSteps

The newsletter for members of The Erythromelalgia Association
FootSteps online: www.erythromelalgia.org or www.burningfeet.org

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TEA ends dues, widens website access

TEA has moved from an organization with annual membership dues to one with a one-time membership donation to join. Also, TEA's website's Articles Library, Newsletter Archives and listing of Member-recommended Doctors will now be available to the general public, as TEA meets the needs of the EM community and realizes that we are navigating a world where free information abounds.

To protect member privacy, TEA will continue to restrict to members only the sharing of selected contact information through the online Member Directory. As incentives for becoming a TEA member, those who make a one-time modest donation to join will receive a new-member packet to include a copy of the new *A Patient's Guide to EM*, EM awareness bracelets and a TEA bookmark.

Among the benefits of membership are receiving publications like *FootSteps* and timely emails announcing newly published articles, treatments and research. Because of these changes, TEA will not be calling for membership renewals this year. However, we hope members, previous donors and friends will still donate to TEA at this time at www.erythromelalgia.org/Donate.aspx or mail a check to 200 Old Castle Lane, Wallingford, PA 19086.

Aids for cooling needed even more

Staying cool may be just a little harder through early fall in the U.S. Warmer-than-normal temperatures are forecast for the entire U.S.—even Alaska—by the National Oceanic and Atmospheric Administration's Climate Prediction Center. For help beating the heat anywhere in the world, TEA suggests some devices available on the Internet or through catalogs. Some are recommended by members.

- **Cooling Cap, Visor**—use evaporation to keep your head up to 20 degrees cooler than outside air, made by a supplier of cooling apparel for athletes and the military. Soak in cold water for at least two minutes and wring out excess. Lasts for hours. Offered at hammacher.com.

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The Erythromelalgia
Association

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As warm weather hangs on, some cooling devices may help

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Raise funds for EM using links.

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The intent and purpose of this publication is to inform those with EM or their friends and families — not, in any way, to provide medical advice.

Cooling aids

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- **Cooling Towel**—Mission towel has proprietary Enduracool fabric you can soak in cold water, wring out and drape around your neck and shoulders. The fabric cools to 30 degrees F below normal body temperature, instantly cooling you. Lasts for hours. Headbands, wristbands and more also available from Missionathletecare.com. Similar towels offered at Amazon.com.



- **Bed Fan**—circulates cool air between the sheets, has a wireless remote control and adjustable height for different mattress thicknesses. One member keeps hers at the foot of the bed and uses it in addition to central air and a portable air conditioner. Offered by Brookstone.com, Amazon.com.



- **Aircast Cyro/Cuff for foot, ankle with gravity-fed cooler**—cuffs wrap completely around the foot or ankle and fill with ice-cold water from the gravity-fed cooler. Wheelchair-bound member reports when combined with elevation, the cuffs provide relief from burning pain and swelling as they compress the foot. Cyro/Cuffs also available for any affected body part. Find at Amazon.com, EBay.com.



Remember to shop online at smile.amazon.com and goodshop.com to help raise funds for TEA!

New link on website

TEA recently became a sponsor of "Putting Rare Diseases Patients First" (PRDPF.org). This organization's goal is to serve the global rare diseases patient community by providing empowering information to patients and the parents of children with rare diseases about the clinical trial and drug development process. The group periodically offers free "webinars," online seminars about the latest diagnostic techniques for rare diseases.

More information is available at PRDPF.org and on TEA's website. Hover over *What is EM* and click *Links*. Scroll down to *General Support Group Sites*.



Your stories: everyone has one

Everyone can empathize with those who have experienced difficulties just getting an EM diagnosis and then living with EM's continuing challenges. TEA encourages you to write your story. Then, e-mail your story along with a "head shot," to GaylaKanaster@aol.com or 2532 N. Fremont St., Tacoma WA, USA 98406. Because our space is limited, please limit stories to 350 words or less.



*Danni Wortmann
Hartington, Nebraska, USA*

Prior to developing erythromelalgia I enjoyed a busy life raising our children and helping my husband on our farm. We did a little traveling and I liked walking several miles a day. I have a master's degree in Nutrition from University of Nebraska at Lincoln and have worked part-time as a dietitian. I used to do calligraphy as well. I still enjoy swimming and am able to do this a few times each week in an indoor pool as I am unable to go outside in the heat for too long. Having the terrible burning pain, not only in my hands and feet but in my whole body, has changed who I am and what I do. Making plans too far into the future is hard as I never know how I will feel. I used to love spending time outside in the summer. During the winter I loved to ice skate but am no longer able to do either.

My husband Ron and I have been married 34 years and have a farm in northeast Nebraska. We raise cattle, hogs, corn, soybeans and alfalfa. I'm grateful my husband is a very hard working, loving and considerate person. He has helped me tremendously in dealing with EM. We are so blessed to have grown children who are happy and successful. Our son Nathan is a firefighter/paramedic in Norfolk, Nebraska. Our daughter Katie is married and lives in Omaha, Nebraska, where she works as director of marketing and public relations for Opera Omaha. With this EM, I now focus on things I can do, such as visiting and calling friends and reaching out to others in need.

Editor's note: Danni is an active TEA volunteer.



*Patricia Brown
Caseyville, IL, USA*

I'm 45 years old and my battle with primary inherited EM started at age nine. I was hospitalized because of my symptoms yet the doctors told my mother it was all in my head. I spent a lot of time as a child and young adult dealing with the severe burning pain with no explanation of why. After suffering a stroke in 2012, my symptoms became worse with pain that is unthinkable to the average person. I ended up at the Mayo Clinic where I was diagnosed with a severe case of IEM and then shipped out the door, in no better shape than when I arrived. At least I had a name for my disease.

I see four doctors every month and have taken many different types of medication from nerve blockers to narcotics just for some relief. Not only is the pain from EM hard to bear, so is the loneliness. The thought of burning from the inside out with pain so intense you have thoughts of having parts of your body amputated is difficult for others to understand. But there is one thing this disease will not take from me and that is HOPE!! Hope that someday, someone will find a treatment and then a cure! I helped start a group called My Saving Grace Angels to tell the stories of those with EM.



The Erythromelalgia Association

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Raising Research Funds.

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Shop online, raise funds for TEA

Online shoppers can easily raise money for TEA by using any of the following links and listing erythromelalgia as your cause:



www.smile.amazon.com

Amazon donates 0.5% of the price of your eligible AmazonSmile purchases to the charitable organization of your choice.



GoodShop.com

Click the "Join" button and select our cause by typing in "erythromelalgia." Then go to GoodSearch and start shopping to benefit TEA.



GoodSearch.com

Search for participating stores and eligible products. Find coupons and help TEA earn up to 4% of what you spend. Remember to join/sign-in before making purchases.