

FootSteps

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

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Cooling shoe, other projects under way

Micro-cooling technologies now exist that are small enough to fit inside a shoe. But, designing a cooling insole is a very complex engineering project. It needs a micro-cooling system with a wireless personal control (as from a cell phone). It needs to be able to take the pressure of walking, flex with the foot, withstand sidewalk temperatures, be lightweight and safe.

When TEA member Darlene Kordich Hall read about micro-cooling technologies, her first thought was of a cooling shoe. Housebound because of EM, Darlene began exploring the idea online. Her doctoral work in social psychology and master's degree in nursing made her familiar with doing research. A resident of Toronto, in 2013, she wrote a proposal for a project to develop a cooling insole for footwear using micro-cooling. She presented it to the mechanical engineering department at the University of Waterloo in Waterloo, Ontario, Canada. This school is a Center of Innovation with a large mechanical engineering department that requires students to complete real-world projects to graduate. A group of fourth year engineering students took on the project in 2014. After discovering that an insole would not be possible, they designed a prototype for a cooling sandal that still needed work. Another student group picked up the project in 2015 and has created a design that will be tested starting in January 2016.

Darlene then learned about a group in Switzerland that was trying to develop a cooling boot. Their research is funded by a Swiss initiative aimed at development of nano- and micro-technological advances in health and the environment. While the vision for this project is very promising and they did develop a prototype, according to the group's mentor, things are currently on hold.

Coming soon: EM patient guide

By Elisabeth Antoine

TEA is excited to announce the upcoming publication of a new Erythromelalgia Patient Guide. Now in the design phase, the guide will be printed in early 2016. The guide will be distributed to TEA members and physicians likely to see EM patients. It will serve as a comprehensive introduction to the disease, covering such topics as common symptoms, finding a doctor, reaching a diagnosis, symptom relief, lifestyle modifications, and coping strategies. Perhaps most importantly, the guide includes a detailed list of available treatments.



The Erythromelalgia
Association

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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.

From the President



At the World Orphan Drug Conference I attended recently in Washington, DC, leaders of rare disease support groups recommended mission statements be one short, simple sentence that states why the organization exists. Changes to mission statements are needed because the way the world communicates has changed drastically—it seems everyone is competing to get our attention with messages as brief as one or two words or a phrase.

So TEA Board members pondered the question: "What did the founders of TEA wish to accomplish with this organization?" We know they wanted to find and connect with other people affected by EM to exchange treatment and coping experiences to help reduce their pain and make all of their lives better. **The founders knew that armed with information people with EM could educate health care professionals to be better partners in the search for treatments. TEA's board concluded that 16 years later the reasons for TEA's existence remain the same. They crafted the following phrase that sums up the reason TEA exists:** *"To empower those affected by EM to improve their quality of life."* We use the word "empower" because TEA strives to provide accurate, up-to-date information to help those with EM determine their own best daily regimens. We use the words "improve their quality of life" because any new treatments or behaviors learned through TEA allow those with EM to have better days going forward.

This new mission phrase is meant to be easily remembered and repeatable, so that we as supporters and beneficiaries of the organization can easily tell others about TEA. About ten years ago, we added the web address www.burningfeet.org because it is easier to remember and spell. Back then we were working to improve communication and awareness just as we are now with the mission statement.

Through the years *FootSteps* has been one of TEA's most trusted vehicles for communicating accurate, up-to-date information about EM and TEA. Producing each edition involves our volunteer editor along with other board members collecting and researching timely information, then writing and editing articles. TEA is fortunate to have a retired public relations executive with years of publication production experience serving as the editor to ensure professional standards are met. This includes working with graphic designers and printers for the final product. It has become increasingly harder to find the healthy hours needed to produce this document and in the past two years, we have decreased the number of newsletters published. You'll notice that this issue is four pages, rather than the usual eight. We're hoping in future you'll appreciate receiving shorter, more frequent editions of *FootSteps*.

Sincerely,

Beth Coimbra

Mayo Clinic study: topical midodrine may improve EM

By Elisabeth Antoine

JAMA Dermatology recently published a research letter written by Mark Davis, MD, and colleagues, reporting that topically applied midodrine may be a viable treatment for EM. Midodrine is an alpha-1 agonist, a class of medication that causes vasoconstriction. It is thought that this tightening of blood vessels and reduction in blood volume may reduce EM symptoms in some patients. Oral midodrine has previously been reported in one case to reduce skin temperature, redness, and pain associated with EM, so it was logical to suppose that a topical preparation might provide similar benefits without the systemic side effects. In a two-year study that concluded in 2013, 12 EM patients from the Department of Dermatology at Mayo Clinic in Rochester, MN, were given a midodrine hydrochloride 0.2% cream and instructed to apply it to the affected area three times daily. Of the 12 patients, 9 were female, and 11 were Caucasian. Their ages ranged from 26 to 79, with a mean age of 57. Prior to the study, ten reported having severe EM symptoms, while one reported only moderate symptoms. (Pain level was not documented for the 12th participant.) Most had previously been prescribed treatments for their EM—drugs noted were gabapentin, trazodone, and combination gel amitriptyline 2%/ketamine 0.5%—but had received no substantial relief.



All but one patient reported improvement from the topical midodrine. Four of these claimed “substantial” improvement, while 7 saw only “some” improvement. No one had her symptoms worsen during the study. In most cases, it appeared that the drug had an immediate effect: 10 patients said that they responded to the treatment within minutes of application, although the exact timing was not documented. Adverse effects of the midodrine were minimal. One patient reported nonspecific gastrointestinal tract discomfort and another saw an increase in blood pressure. Despite the small scale and admitted limitations of the study, its authors believe the results suggest that topical midodrine is well tolerated and may improve the symptoms of EM.

The study was conducted by M. Davis, C. Morr, R. Warndahl, and P. Sandroni at the Department of Dermatology, Mayo Clinic, Rochester, MN. The full article Topically Applied Midodrine, 0.2%, an α_1 -Agonist, for the Treatment of Erythromelalgia is in TEA's online archive.

Your stories: everyone has one



Dottie Deline
Portland, Oregon, USA

About fifteen years ago, at age 60, I noticed my feet were getting red, swollen, and warm, especially after exercising. I walked every

day, rain or shine—I loved getting outdoors in the invigorating fresh air. Rather abruptly, that came to an end. Not knowing what was going on, I finally found a rheumatologist who diagnosed erythromelalgia. That began a long period of research, trial and error medications, and some fear on my part as to how I was going to manage this challenging situation.

Today, I look back on that early period of EM and am glad it's behind me. I feel I am stronger and more capable of doing things I didn't think possible and I've gradually found medications I can tolerate. One of the best suggestions I got from my internist was wearing compression stockings. They have been a lifesaver. She recently prescribed a diuretic as the swelling in my legs and feet was becoming problematic. It has turned out to be a great help. Swimming allows me to exercise and be buoyed physically and mentally by the water. I also go to a chair exercise class and belong to a writing group called “Honoring Our Memories.” Visiting with my four grandchildren and their families keeps me busy, as does healthy cooking and baking whole grain breads. This year I am enjoying working on TEA's fundraiser and awareness campaign selling TEA's bracelets. It's great seeing orders come from all over the world. I track them and send out the bracelets. I am honored to help TEA in this important mission.



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TEA bracelets, bookmarks raise funds

Sales of TEA's ongoing fundraisers—the EM awareness bracelets and bookmarks—as of Oct. 1, 2015, have earned \$670.00. Members unable to check the website may not even realize they can purchase 10 bookmarks for a \$10 donation and 10 awareness bracelets for \$20 (including postage and handling).

Just created in 2013, TEA bookmarks display the work of TEA "Paint Your Pain" contest winner Andrea Davenport. Her drawing shows a figure with hands, feet and face on fire. With "burningfeet.org" imprinted on them, TEA bracelets have been sold since 2007. Those who prefer not to order online may send a check payable to The Erythromelalgia Association and a note specifying the number of bracelets or bookmarks to: TEA, 200 Old Castle Lane, Wallingford, PA, 19086, USA. TEA volunteers handling the mailings are Dottie Deline, bracelets; (see Dottie's story on PG3) and Danni Wortmann, bookmarks. Danni's story and photo are on TEA's website. Maddalena Lavaranni, UK Networking Chair and TEA board member, handles distribution in the UK.

