

FootSteps

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

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Summer Appeal adds income



This stack of donation acknowledgements is ready to be sent to Summer Appeal givers.

Thank you to the more than 100 generous donors who answered TEA's first ever Summer Appeal with gifts totaling almost \$7,500. The Summer Appeal is an effort to raise financial support for TEA's programs. It follows the successful 2016 Annual Appeal, when 328 donors gave a total of \$24,282. These annual gifts allow TEA to cover the cost of programs and accumulate funds for future gifts to researchers despite recently eliminating annual membership dues.

New TEA Website Takes Shape

TEA's redesigned website is taking shape following several months of work with King Design, a Pennsylvania website design firm hired by TEA's Board of Directors, reports Beth Coimbra. At least three proposals from design firms were considered before the job was awarded. The new site has a modern and engaging design with large images to draw in visitors. It features more intuitive navigation so the audience can move effortlessly from one section to another. The site is optimized for viewing on phones, tablets or desktops so it will be easy to use no matter what the device.

Before building the new site King team members asked many questions, such as about TEA's stakeholders (i.e., people with symptoms looking for answers, TEA members/frequent visitors, health care providers, etc.) With this background, King first designed a map for the website's layout. After TEA's board approved this general layout, King then suggested a simple, professional look for the overall design. Behind the scenes, King's developers were building the system for managing the varied content on the site—donor pages, articles library and the many other features that TEA website visitors have been enjoying for years. This system also allows TEA administrators to easily add new information and securely maintain donor data. As of Sept. 1, work continues on the final design of the website. Board members need to update some content and wording, photos for the site need to be chosen and website functions need to be tested. There is much more hard work to be done, but the new site should be up by the end of 2017.



The Erythromelalgia Association

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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.

TEA 2016 financials strong

By Beth Coimbra, CPA, TEA President and Treasurer



TEA manages its funds very carefully. As a 501(c)(3) corporation—a nonprofit—TEA's income comes almost entirely from donations. As an organization, TEA seeks to be transparent and fully inform members of its status.

Here's a summary of TEA's financials for calendar year 2016:

TEA's Statement of Financial Position (balance sheet) on December 31, 2016, showed its Operating Fund balance at \$146,503, an increase of \$26,567 over 2015. TEA's Research Fund was \$39,178 at the end of 2016, an increase of \$6,835 over the prior year. TEA's Patient Guide Fund maintained a balance of \$3,464 as of December 31, 2016. TEA's sources of income during 2016 included donations from the 2015 Annual Appeal, contributions made by new and continuing members as well as donations made throughout the year in honor or in memoriam of TEA members or others. The sale of EM bracelets brought in other income. TEA also took advantage of cost-free online fundraisers like AmazonSmile and NetworkForGood. TEA's cash outlays in 2016 were for items including printing, postage, website design/maintenance, office supplies, etc. The largest portion of TEA's expenses went to the printing and mailing of the newsletter, a highly coveted member benefit. Finally, our Statement of Activity (Financial Statement) shows that income exceeded expenses during the year by \$33,266. These excess funds are safeguarded by TEA's board for future projects such as updating our website, which is the main portal of information for educating the public and increasing awareness of EM.

Your stories: everyone has one



Carine Prévot
Nantes, France

In January 2015 my right foot suddenly turned red and became very hot. I could not sleep without a fan on my feet. My life changed until I finally found something that worked for me. I started putting my feet on a hot water bottle, then taking them off when it became too painful and then doing the same on and off in a few minutes. I did this three times a day for 30 minutes for a week, then 2 and 3 weeks.... I quickly found that I no longer panicked when my feet started to flare because my nerves had become less sensitive to pain. I now continue to heat my feet every day, when I am eating in the evening. After this "rehabilitation" of nerves, I felt I must also temper the excessive vasodilation that occurs when there is a heat stimulus. Inspired by a scientific article that indicated vasodilation itself could be desensitized, I decided to heat my feet for half an hour before going for a walk. In this study a heat stimulus was applied on the skin of volunteers for half an hour. The scientists noted the level of induced vasodilation and then repeated the stimulus after two hours. The vasodilation was then lower! Now, I don't do this anymore before walking, except if the temperature is very hot outside. I just heat my feet 30 minutes per day at the evening meal. I don't need to cool my feet any more, even after a stay on the hot water bottle at 50 °C (122 °F). I just feel a strong sensation of heat rather than burning. I'm still amazed at my results since I had tried many things before without success.

Media feature TEA member, pain research

Longtime TEA member Pam Costa, Ph.D., is the focus of two recent, informative, widely available media stories. She appears in a BBC TV documentary featuring the “World’s Most Extraordinary People” whose very rare conditions challenge medical knowledge, leading to advances. The show will air in the U.S. sometime in 2018 and has already aired in England. In addition, a feature story about her and EM’s role in pain research appeared in *Wired* magazine in April 2017.

Despite living with the burning pain of inherited EM since childhood, Dr. Costa earned a Ph.D. in Psychology. Now 51, she lives outside Tacoma, WA, U.S., and teaches at Tacoma Community College. She and her mother—TEA board member Gayla Kanaster—are part of a large family that carries a genetic mutation found to cause the pain of EM by Yale pain researcher and professor Stephen Waxman,



Dr. Costa teaches a class at Tacoma Community College.

M.D., Ph.D. and his team. The BBC crew followed Dr. Costa for a day in 2016, filming her teaching her college class showing the fans to keep her cool, taking a yoga class in an air-conditioned studio with fans surrounding her yoga mat. They even shot her bedroom that has central air-conditioning, fans, and a separate AC unit that blows cold air under the sheets on her bed.



(Left) In the yoga studio, Dr. Costa does the extended triangle pose, with her mat surrounded by fans.

(Right) She shows her open-backed winter shoes.



Dr. Costa explains the symptoms of EM in the BBC documentary.

The BBC documentary is Episode 6 of a series “Incredible Medicine: Dr. Gabriel Weston’s Casebook.” Host surgeon Dr. Weston says medicine is full of baffling cases that are leading us to the cures of the future. She says the secrets of how the human body works often are revealed by the most rare and extraordinary conditions. For Dr. Costa, it’s peripheral nerves that react in an extreme way to heat such as temperatures of more than 65°F. Dr. Costa has inherited EM and tells the documentary audience a warm day feels to her like she’s on fire. This sensation is painful, unrelentingly painful, affecting her feet and legs and also her hands and face. Staying cool, often cold is her only relief, so she controls her environment with air conditioning and fans. Using blood samples from Pam and her family members, Dr. Waxman and his group found a mutation to a gene SCN9A implicated in pain. Further experiments led them to prove that a single mutation can cause the pain of EM. They also allowed the Yale researchers to demonstrate how the body feels pain.

In addition, *Wired* magazine told Dr. Costa’s story as part of a feature on the future of pain research that focused on people with mutations to SCN9A—the gene linked to EM and EM pain. “How a Single Gene Could Become a Volume Knob for Pain” ran in *Wired*’s April 2017 issue. It also told the story of a young man with another mutation to SCN9A who can feel no pain, the opposite effect from people who overreact to pain stimuli like heat.

The full article can be found online at wired.com/2017/04/the-cure-for-pain/.

TEA will make an announcement when the documentary will be aired in the US, and share a link when it’s available.





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TEA encourages you to share your story about how EM has affected your life. Please consider sending a "head shot" and your story (350 words or less) to GaylaKanaster@gmail.com or mail to 2532 N. Fremont St., Tacoma WA, USA 98406.



Raising Awareness.

Raising Research Funds.

Raising Hope.

www.erythromelalgia.org
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The Erythromelalgia Association

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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:



AmazonSmile

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.