

# FootSteps

The newsletter for members of The Erythromelalgia Association  
*FootSteps* online: [www.erythromelalgia.org](http://www.erythromelalgia.org) or [www.burningfeet.org](http://www.burningfeet.org)

Winter 2015, Vol. 16, No. 1

## Board writes vision, revises mission

*"We envision a world with an end to the pain of erythromelalgia and a path to a cure."*

That's TEA's vision, developed last year, for the first time, by the Board of Directors. This vision statement describes a future when TEA's mission has been accomplished—when the work of the organization is finished. This vision statement was written under the direction of board member Becky Fisher, who led the board through the process of developing statements of both our organization's mission and vision.

"The words in the mission and vision are meant to inspire, motivate and guide the board in their actions and to provide TEA members and the EM community with hope and confidence that there exist efforts to improve their lives now and in the future," said TEA President Beth Coimbra.

It was the need to revise the former mission statement to reflect more clearly TEA's purpose that motivated the board to take on the process. By reading the mission statement, anyone should know who TEA is, why it exists, what it does, and whom it serves. So those questions—who, why, what and for whom—were discussed at length by the board during special teleconferences. *(continued on PG 7)*

## Pfizer reports EM research findings; early drug study results encouraging

While heat and exercise are frequent triggers for pain attacks in those with inherited erythromelalgia, the majority of attacks occur spontaneously with no identified trigger. Patients vary considerably in the frequency and severity of pain attacks—even those with the same genetic mutation—and some suffer significant pain between attacks while others are relatively pain-free. These are among the findings presented by Pfizer Neusentis, a UK-based research division of the global pharmaceutical company, at the International Association for the Study of Pain in Buenos Aires in October 2014.

This 2013 study followed the natural history of pain in 13 patients with inherited EM during a three-month period and represents one of the most detailed investigations in EM patients and their symptoms over time. *(continued on PG 3)*



The Erythromelalgia  
Association

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# FootSteps

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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.

## Attorney joins Board of Directors

Environmental attorney Laura Beaton has recently joined TEA's Board of Directors adding her legal expertise to this group of volunteers. A native of Arkansas, Laura graduated summa cum laude from Southern Oregon University with a bachelor's degree in Sociology. She earned her law degree from the University of Oregon School of Law, where she focused her studies on environmental law and helped plan one of the world's largest environment law conferences.



Laura is currently an attorney at Shute, Mihaly & Weinberger, LLP, a land use and environmental law firm in San Francisco, CA, U.S. She also continues her more than five years of service on the board of Cascadia Wildlands. She had previously worked at Earthjustice, an environmental law firm in Bozeman, MT, U.S., which is where she was living when her EM symptoms began. She had a difficult time getting diagnosed and found TEA on the Internet. (See Laura's story on PG 4.) She says she "is learning to live a happy and full life despite EM." She joined the TEA Board in hopes of making it easier for others to live full lives as well.

## Coming Soon: EM Patient Guide

By Elisabeth Antoine

TEA is excited to announce the upcoming publication of a new Erythromelalgia Patient Guide. Slated for release later in 2015, the guide will be distributed to TEA members and physicians likely to see EM patients.

For those newly diagnosed, the EM Patient Guide may serve as a comprehensive introduction to the disease, covering such topics as common symptoms, primary vs. secondary EM, 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, comprising oral and topical medications, surgical and other invasive procedures, supplements, and mind-body therapies. The guide concludes with information on research studies that may offer hope for the future of EM.

In addition to providing support to patients, the EM Patient Guide is also intended to expand awareness of EM in the medical field. Every patient—long-time sufferers as well as those still seeking a diagnosis—may wish to take a copy to their healthcare providers.

# Pfizer reports EM research findings; results encouraging

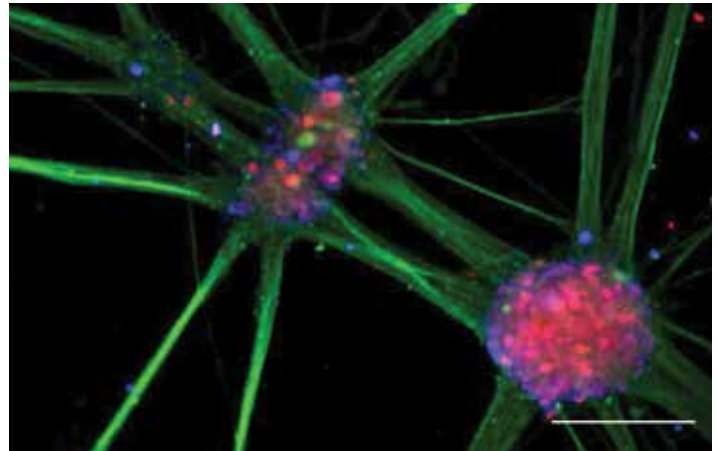
(continued from PG 1)

Performed at the Pfizer clinical research unit in New Haven, CT, U.S., the study was made possible by the collaboration between Pfizer and the Yale research group led by Stephen Waxman, M.D., Ph.D., according to Ruth McKernan, M.D., Chief Scientific Officer at Neusentis.

A second study of five people with inherited EM found most responded well to an experimental drug and experienced less heat-induced pain on days when they received the drug compared to when they received a placebo. Still at an early stage in its development, the experimental drug is designed to block the Nav1.7 sodium channel proven by Dr. Waxman's group to be involved in the transmission of EM pain. While these results are encouraging, Dr. McKernan stresses additional investigations need to be conducted to better understand whether this drug has the potential to provide long-term relief. Interestingly, the same drug is also being tested in patients suffering from diabetic neuropathy, she says.

Known as a double-blind cross-over study, patients were given the drug on one occasion and a placebo on the other, and neither patients nor doctors knew which time the patients received the drug. Each day pain attacks were triggered three times by warming the skin using heated blankets.

An optional part of this study asked participants to donate blood. Using state-of-the-art technology, the Pfizer research team generated stem cells from the blood cells and then made them into sensory neurons. (The stem cells have the same genetic forms of Nav1.7 channel as do the donor blood cells.) Scientists at Neusentis found sensory neurons made from EM patients' blood were more active than those obtained from healthy donors. They also became even more active when warmed up, reproducing just what happens in patients. When the drug was added to the sensory neurons, it blocked the activity and returned them to a more normal state.



*Made from the blood of a patient with EM, these pain-sensing sensory nerve cells—colored green to make them more visible—behave just like the nerves that stretch from the spine all the way to the hands or feet. These fibers show abnormal sensitivity to heat just as some patients with EM do. Pink spots are cell nuclei. (Photo courtesy of Pfizer)*

Additionally, the effect of the drug was greater in neurons from patients than from unaffected donors. These findings have given the researchers clues to the potential effectiveness of the drug, not just in people with inherited EM, but with other pain conditions, too.

Dr. McKernan adds, "As always, we are indebted to the patients and their relatives who participated in these clinical trials. Without their dedication we would not be able to conduct our research. Having cell systems in which we can test new drugs, and even drug combinations, in the lab before giving them to patients, is a big step forward."

In response to a request from TEA for comment, Dr. Waxman writes, "We are pleased to be collaborating with Pfizer on this study. In my view this work moves the field in the right direction. While we still have a lot of work to do, I am optimistic and I believe that, in the end, we will win the battle against EM."

## EM research studies underway in Norway and California, U.S.

**Oslo, Norway:** EM studies are currently underway at Norway's Oslo University Hospital, being undertaken by a team led by Mari Skylstad Kvernebo, M.D. Her mentors, Knut Kvernebo, M.D., from the University of Oslo, and Cato Mørk, M.D., from the Norwegian University of Science and Technology in Trondheim, have previously contributed much knowledge regarding EM's blood flow abnormalities.

Earlier this year, the group aired a brief television spot aimed at increasing awareness of EM, after which they were inundated with emails from viewers with undiagnosed EM symptoms. The team is now trying to examine all of these patients clinically and has so far diagnosed twenty with EM—a significant (continued on PG 6)



# Your stories:

*Everyone can empathize with those who have experienced difficulties getting an EM diagnosis and then living with EM's continuing challenges. TEA encourages you to write your story. Then, send it, along with a "head shot," to Gayla Kanaster, [GaylaKanaster@aol.com](mailto:GaylaKanaster@aol.com) or 2532 N. Fremont St., Tacoma, WA, USA 98406. Because our space is limited, we request that stories be no more than 350 words in length.*



*Laura Beaton  
San Francisco, CA, USA*

Having erythromelalgia is hard enough, but when you develop it as an adult in a small town where most of the

doctors have never heard of it—let alone having seen a case—you are likely to be faced with particularly difficult challenges. This is what happened to me in my early 30's.

For a couple of years before I developed EM, I had been dealing with some relatively mild but mysterious symptoms that my doctors guessed were some sort of autoimmune disease. Then, one day I noticed one of my hands was red and hot and burned. I did not think much of it until it became a regular occurrence in both of my hands and feet. But then it was my knees, too. And then my face and ears started turning red and burning.

I went to see my local doctor (I was in Montana at the time), and I went through a gamut of tests, mostly focused on my facial flushing. No one could figure it out. Finally, I resorted to the Internet, searching for anything I could about "red hot hands and feet and face." That is when I found TEA's website.

I devoured the information on TEA's website, scrolling through pages thinking, "That happens to me! And that, too!" I printed a number of pages and returned to my doctor to suggest to him that I might have EM. Happily, he was open to hearing what I was saying, and he tentatively agreed that it looked like I had EM but that he wanted to send me to an academic medical center to confirm. Off I went to University of Washington in Seattle, and the diagnosis was confirmed.

Having a rare and painful condition is hard. It's hard to live with, hard to get diagnosed, hard to find treatment, and hard to explain to people. So, I felt like I needed to do something to help others with EM. I began volunteering for TEA, answering emails, and eventually I was asked to join the Board of Directors, an offer I enthusiastically accepted.

I have spent the past few years learning to live with EM. I am lucky that in my case—though my EM is widespread and flares frequently—a combination of medications and pain management techniques has reduced the pain to a manageable level, so I can still work full time and enjoy some recreational activities. To be blunt, EM sucks. But it is my new normal, and I am moving forward trying to deal with it the best that I can.



*Mary Ann Coplin  
Augusta, GA, USA*

I am 62 years old, married, with two adorable mini schnauzers. My battle with EM began in my late 30s

when I started to experience intermittent symptoms of burning pain and swelling in my hands. Little did I know just how much my normal life was about to change. My symptoms gradually became more chronic with a constant burning pain in my feet. My hands started to exhibit Raynaud's-like symptoms and my face started flushing. I now know I have autonomic dysfunction, which causes me to have an extreme reaction to pain in general, and a very low tolerance to cool and warm temperatures.

I finally received my diagnosis of EM and small fiber/peripheral neuropathy from Dr. Mark Davis at the

# everyone has one

Mayo Clinic. I attended a three-week chronic pain program there, which was somewhat beneficial, but also overwhelming. In 2013, I was genetically tested, which indicated that I have mutations to the EM gene. I have tried every treatment offered to me, from oral and compounded medications, to infusions, nerve blocks, and even a spinal cord stimulator implant. Unfortunately, they have all been unsuccessful because I either could not tolerate the side effects or they were ineffective. I have found that the best therapies for me in calming my mind and body are Viniyoga, deep breathing, meditation, an online support group, and striving to accomplish something positive every day. My husband is my rock, and my ultimate goal is to be able to hold hands with him again.

I would encourage every member to consider becoming a volunteer for TEA. The need is great, and I, personally, have found it to be a very rewarding experience. We are a unique group of people who have the ability to reach out and touch each other by lending a helping hand in any way that we can. What better way to add value and purpose to your life than to make a positive difference by contributing to the cause of TEA and your fellow members.

*Editor's Note: Mary Ann updated the contact information of the US doctors and posted the names to the new website directory. Angela Demerle assisted her with the updates. Maddalena Lavarini posted the international names.*



*Renate Heinrich  
Oldenburg, Germany*

I am a 67-year-old retired pediatrician with non-inherited EM and Raynaud's. Fortunately I could be barefoot and use a fan or cooling elements in my office. After suffering from EM for 18 years, I am now retired and able to change my condition of living and behavior to more activity and

movement. I've also made changes in my diet. By the process of elimination, I have learned to avoid any food that triggered EM symptoms, plus no caffeine, alcohol or nicotine. I am a vegetarian and include a lot of vegetables, protein, omegas 3 and 6 (especially oil and nuts) in my low carb diet. I try to avoid situations that either warm my feet or make them too cold. Creaming my feet after my shower with SebaMed foot cream with 10 percent Urea provides some relief. In the beginning I tried all possibilities of traditional and alternative medicine without any effect on the EM attacks or pain, so I continued for years trying to manage with cooling. I even carried cooling elements in a mobile freezer when I traveled.

A few years ago I started walking as much as possible. Even at home, I move around a lot. I elevate my feet when I have to sit and lie down in the evenings, since sitting too long brings on EM attacks and swollen feet. I wear leather sandals and boots with leather soles and socks made of bamboo material. I wear wide pants of light fabric to cool my legs and warm upper garments to avoid freezing. My EM has improved amazingly since I have increased my walking to long distances several times a week (around 20km). I even joined a walking group. I spend the winter in the moderate climate of southern Spain for four months and walk in the mountains there. I still get symptoms that I counteract by going barefoot, or spending the evening lying down. But it's so much better that I feel almost healed! I wanted to share this and maybe encourage others to include exercise by walking, which I think is the cause of most of my improvement.

(Renate would welcome emails from other TEA members at: [renaheinrich@gmx.de](mailto:renaheinrich@gmx.de))



## Donations up 52% in 2013

Donations made in 2013 totaled \$30,874, up 52 percent over 2012. Membership renewals and donations made when new members joined increased an impressive 97 percent over the prior year. Included in the total is \$3,512 that was given specifically to the Research Fund.

Because we are a nonprofit agency, your donations are the lifeblood of the organization. For example, these gifts will be used to fund special projects such as preparation and printing of the EM Patient Guide or upgrading or completely replacing the website. In previous years, we listed in this space the names of people who made donations throughout the year. But the 771 donors who gave in 2013 when joining or renewing memberships, or without being prompted, are too many to be listed in this issue. Here's how the \$30,874 breaks down.

- Donations under \$50—571 donors—\$10,965
- Supporter \$50 to \$99—72 donors—\$3,700
- Sponsor \$100 to \$249—117 donors—\$7,345
- Benefactor \$250 to \$499—4 donors—\$1,307
- Patron \$500 or more—7 donors—\$7,530

At the end of 2013, TEA had a successful Annual Appeal for an additional \$22,996. Those who gave in response to the 2013 Annual Appeal were recognized in a previous issue. All those who gave in 2014 will be recognized in the future.

TEA salutes everyone's generosity!

## Facebook builds EM awareness

With more than 1,107 "likes," TEA's Facebook page has attracted a following since its launch in 2013. TEA President Beth Coimbra made it a priority in recent months to post EM-related items that come to the attention of the TEA Board of Directors. Using one of the world's most popular social networking platforms, TEA is sharing timely information with people with EM. And it is also raising awareness about EM among the general public.

Those Facebook users who "like" TEA's page (now 1,107+) automatically receive new posts. If any of these 1,107+ people who "follow" the TEA page decide to "share" a post with their friends, the number of people reached multiplies. For instance, 36 of TEA's "followers" recently shared a link to the National Library of Medicine's explanation of EM, ultimately reaching 3,686 people. And a post that explained TEA's new cover photo saying it was a submission from our Paint your Pain Contest reached 2,855 people.

To find TEA's page on the Internet, enter [www.facebook.com/erythromelalgia](http://www.facebook.com/erythromelalgia). And while you're there, "like" it.

## New research *(continued from PG 3) By Elisabeth Antoine*

number considering the country's small population. The primary focus of their work is on skin microcirculation. Using capillary video microscopy, a technician analyzes films taken before and during EM flares, looking for any commonalities that may lead to new insight into the disease.

**Stanford University:** In early 2014, Stanford University, located in Palo Alto, CA, U.S., launched GenePool, a whole-genome sequencing project that aims to give researchers access to a vast pool of genetic data. Donors' DNA samples will be stored in the GenePool biobank, to be used either in a specific genetic research study at this time or saved for

future undetermined research on a range of diseases. Donors must be patients of Stanford Hospital and Clinics.

Stanford's Wendye Robbins, M.D., has taken a special interest in EM, having treated numerous EM patients at the hospital's Pain Management Center. She is currently recruiting EM patients to participate in GenePool, so that she may soon have a sizable database in which to search for any common genetic variants. GenePool is open only to patients of Stanford Hospital and Clinics. For more information, contact the GenePool project manager, Aleksandra Pavlovic, at 650-736-1147.

## Government disability benefits offer compensation



If the onset of EM has left you unable to work, you may be eligible to receive government benefits to help compensate for your loss of income. The potential benefit depends on where you live. In the U.S., the name of the benefit program is Social Security Disability Insurance (SSDI). And there's a second need-based program called Supplemental Security Income (SSI). Both are handled by the Social Security Administration. If you're an American, first make sure you qualify. To be eligible for SSDI, if you're over 30, you must have worked and paid into Social Security for at least five out of the last 10 years before becoming disabled. (Other rules apply to those younger than 30.) SSDI pays only for total disability—no benefits are payable for partial or short-term disability. Your disability must be due to a medical condition that causes you to be unable to work and must be expected to last at least 12 consecutive months or the rest of your life.

If you think you qualify, start the application process by completing the forms online, by phone or by going to a Social Security office. The application asks you to describe your disabling condition and explain why your symptoms prevent you from working at all for at least

12 months. You also need to supply the name of your doctor and authorize release of your medical records to be used in making the disability decision. Because EM is an unusual condition, it is important to include as much information as possible. Social Security maintains a list of disabling conditions that does not include EM. The description of your EM that you and your doctor supply needs to equal in severity the conditions on that list. When you submit your application, Social Security sends it to your state Disability Determination Services Agency, which will contact your doctor and get your medical records. This agency may also contact you for more information and ask you to have a special examination. This agency has trained staff who review the information provided by your doctor and by the physician who does the special examination. Then agency staff make the decision to grant benefits or not. If your application is denied, you may appeal within 60 days.

The other program—SSI—is a need-based program that does not require work history. To qualify, you may own a home and one vehicle, but your other assets can total no more than \$2,000 for individuals and \$4000 for couples. If you're under 65 years old, you also need to be considered permanently disabled. If you're over 65 you just need to meet the asset limit requirements to qualify. There are several Social Security Administration publications that explain in detail the eligibility requirements for these programs and you can find program explanations at [www.socialsecurity.gov](http://www.socialsecurity.gov).

For links to information about disability benefits outside the U.S., go to TEA's website—[www.burningfeet.org](http://www.burningfeet.org). Then click the "What is EM?" tab in the main menu on the homepage and then click "Links" and then "Disability Compensation Program Info & Links."

## Board writes vision, revises mission (continued from PG 1)

It took a series of meetings to consider everyone's input and talk through the answers to those questions. At the end of the process, the board came to consensus about the wording for the mission statement and the new statement of vision.

The resulting mission statement is: *The Erythromelalgia Association is an all volunteer, international, nonprofit organization that works to identify, educate and support those whose lives are affected by erythromelalgia (EM). We spread awareness of EM by providing educational resources about this rare disorder to the public and to those who diagnose and treat EM, and we raise funds to further meaningful research efforts.*





## **The Erythromelalgia Association**

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**Raising Awareness.  
Raising Research Funds.  
Raising Hope.**  
[www.erythromelalgia.org](http://www.erythromelalgia.org)



**The Erythromelalgia  
Association**

# **FootSteps**

## **NLM adds link to TEA**

The National Library of Medicine (NLM) recently added a link to TEA under "Patient Support" in its informative entry for EM on the Genetics Home Reference website. It can be found by entering <http://ghr.nlm.nih.gov/condition/erythromelalgia>. Part of the National Institutes of Health, the NLM maintains this reference website of information about rare genetic disorders.

Adding links to TEA on websites with medically accurate information about EM fits in with an ongoing TEA project to increase the visibility of TEA and its services on the Internet. Special thanks to the member who alerted TEA that it was not listed on this site so we could act to get the link added.