

FootSteps

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

Fall 2011 Vol. 12, No. 2

Welcome to the new look for FootSteps. TEA hopes the new format and a little extra color will grab your interest and lead you inside to read about people with EM, the latest in EM research, and what's happening with TEA.

TEA is going to continue to mail this publication to its members and friends, unless you let us know you'd rather be emailed a link to it. If you want to save TEA the postage and read it on-line, just change your "Profile" on the TEA website. (See "How to edit your 'Profile,'" PG 2)

TEA encourages members to fundraise

"We were delighted to learn recently about events being planned by several enterprising TEA members to benefit TEA. We want to encourage members to fundraise on our behalf, so TEA developed guidelines for these situations," said Beth Coimbra, TEA President and Treasurer.

TEA also added a new page to the website specifically for information about fundraisers with links to fundraiser websites. (See "Cooking show benefits TEA," PG 2)

Called "TEA Fundraiser Guidelines for Organizers," these guidelines define fundraisers as any fundraising activities such as special events or campaigns that will benefit TEA, but are not directly TEA sponsored. Anyone planning a fundraiser now is asked to complete a "Fundraiser Information Form." Along with the form, organizers receive a copy of the guidelines.

"Once TEA has reviewed the form and determined the activity follows the guidelines, we can include it in the new 'Fundraiser' section of the website," Beth said.

The TEA name/logo also may then be used on any promotional materials, packaging, or advertising. TEA has to be clearly identified as a beneficiary of the fundraiser, not a sponsor.

In addition, TEA can provide educational literature like brochures and informational material, if needed.



The Erythromelalgia
Association

INSIDE

Help wanted

TEA needs you—your help,
your skill, your time.
Volunteer.

PG 2

Pain relief

Study shows XEN402 ointment
relieves shingles pain.

PG 3

Yale visit

Seeing laboratories, meeting
researchers highlight trip.

PG 6

ALSO IN THIS ISSUE

Cooking show

PG 2

Yale enrolls just two groups

PG 3

Your stories

PG 4,5,7

FootSteps

is published by



The Erythromelalgia Association

www.erythromelalgia.org

200 Old Castle Lane,
Wallingford, PA, USA 19086

Information/MemberServices
(610) 566-0797

E-mail
erythromelalgia@gmail.com

President
Beth Coimbra

Vice President
Isabelle Davis

Secretary
Deborah Mosarski

Chair, Networking Program
Gayla Kanaster

FootSteps Editor,
Principal Writer
Isabelle Davis

Contact
Isabelle.Davis@gmail.com

Any information contained in this publication is protected by copyright and may not be reproduced without express permission from the editor.

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.

Help wanted: volunteers

Remember how reassuring it was to get that welcome letter and information packet from TEA when you first joined? Or an answer to a question you emailed to MemberServices? Or finding a copy of FootSteps in your mailbox?

TEA volunteers were responsible for doing the tasks necessary to make those things happen. As you know, TEA is an all volunteer agency. Much of the work of the organization falls to the members of the Board of Directors and a small group of dedicated TEA members.

Some of the routine but very meaningful activities are going undone because TEA needs more people to volunteer.

The only qualifications you need to be a volunteer are a willingness to give a small amount of your time to TEA, ability to work with very little supervision and carry through on tasks. Because much of the work involves the website, being comfortable with computers is required for those tasks.

Here are the jobs TEA needs volunteer help with now:

1. Answer MemberServices' emails re: lost passwords, using the TEA website's member directory, paying dues, etc.
2. Printing computer-generated thank you letters to donors and mailing them out.

To volunteer, contact Gayla Kanaster, gaylakanaster@aol.com.

Cooking show benefits TEA

TEA member Sarah Ginter-Novinger of Columbia, MO, USA, held a cooking show at her home in September that is benefiting TEA. She's a Pampered Chef® consultant and her events showcase the cooking and entertainment supplies and accessories offered by the company.

Sarah is donating 15 percent of the proceeds of her sales to TEA. And her show's not over. It continues online until November 28, 2011, at www.pamperedchef.biz/sarannovinger. That link also is available on the new "fundraiser" page on TEA's website. (See *TEA encourages members to fundraise*, PG 1)

How to edit your online 'Profile'

Want to read *FootSteps* online and save TEA the postage to mail it to your home? Just edit your "Profile" on TEA's website:

1. Login to your TEA account and click on "Manage Account" in the upper right corner.
2. Click on "Edit Profile."
3. Go to the fourth question—Mail newsletters to my home—and use the pulldown menu to select "No."
4. Then scroll to the bottom of the page and click "Update."

Research Update:

XEN402 ointment relieves shingles pain

An ointment form of XEN402—the experimental drug trialed in people with inherited EM—was recently shown to provide significant pain relief in people with shingles (post herpetic neuralgia).

Xenon Pharmaceuticals, Inc. is developing XEN402 as a topical treatment for a variety of painful disorders, including EM. Like EM, shingles causes “neuropathic” pain. And like EM there are few if any effective treatments.

Xenon trialed XEN402 in pill form in a small group of people with inherited EM in 2010. While the drug showed promising pain relief, at the high doses tested, it also resulted in some side effects—side effects not observed in the ointment trial.

In the recent phase 2 clinical trial of the XEN402 ointment, 56 people with persistent pain following

shingles were treated alternately for three-week periods with XEN402 ointment or a placebo

ointment. A significantly larger number of people reported the XEN402 ointment relieved their pain as compared to placebo.

“These positive data represent an important step forward in the development of topical XEN402 for the treatment of chronic pain,” said Xenon President and CEO Simon Pimstone, M.D.

This new ointment still needs to go through more clinical trials before it is approved for use in the USA or Canada. (Xenon is a Canadian company.) Xenon expects to begin

another phase 2 trial of the ointment this year and is assessing whether such a trial can be done in people with inherited EM.

“ These positive data represent an important step forward in the development of topical XEN402 for the treatment of chronic pain ”

Simon Pimstone, M.D.
President and CEO
Xenon

Yale only enrolling two groups of EM people

In the past, many people with EM have volunteered to become part of the research being done at Yale. Currently, however, the researchers need volunteers with just two forms of EM.

Yale is enrolling into research studies people with EM who:

1. are from families in which two or more individuals have EM in more than one generation (Inherited EM).
2. have early-onset EM, i.e., individuals with EM whose symptoms developed during their first 10 to 15 years of life.

The researchers are unable to study patients with non-inherited EM and patients with adult-onset EM at this time.

Individuals with inherited EM or early-onset EM who meet the above stated criteria and are interested in volunteering in Yale’s research may contact the researchers at www.neuropathicpain@yale.edu. Please note that Yale is profiling DNA from these two groups of people with EM as part of its research program. Because it is a research program and not a clinical service, Yale is prohibited from disclosing the results of DNA profiling to patients.

The researchers want the entire EM community to know that they are highly committed to finding effective treatments for all people with EM. And they are very grateful for the willingness of TEA members in the past to volunteer to be a part of their studies.

Your Stories

Everyone can empathize with those who have experienced the long road to an EM diagnosis and live with EM's continuing challenges. TEA encourages you to write your story. Then, send it to Gayla Kanaster, GaylaKanaster@aol.com or 2532 N. Fremont St., Tacoma, WA, USA 98406.



*Jane Beattie
Oceanside CA USA*

Since the early '80s, I've had symptoms of peripheral neuropathy, specifically tingling spreading from my hands and feet. EM showed up in 2008 (at age 60) while walking around Rome for 10 days. (At least it was a fabulous trip!)

Now I always have swelling in my hands and feet, which gets worse when they are hot, and a couple of deep cracks on each of my feet. I have to ration the amount of time I spend using my hands and feet. I try to minimize contact with water. For several months I got very little sleep. When I changed my meds to 100 mg amitriptyline and 5 mg zolpidem tartrate (Ambien), I was able to stay in bed with only occasional applications of freezer-chilled "Hot Pockets." I mention "Hot Pockets" because I have found them to be the gentlest coolant (aside from fans). They are cloth beanbags designed to put around your shoulders. I found mine at a drug store. You need several because they don't keep their cool for long (pun intended). When my feet get super-heated, though, the only thing that cools them down is a plastic cold pack from the freezer—with an old kitchen towel between the cold pack and my skin. (EDITOR'S NOTE: The use of ice packs is not recommended.)

Skin care is also a problem for me since getting EM. I've found a routine that seems to work. After a quick lukewarm shower, I use a hypoallergenic lotion on my body (Aveeno with colloidal oatmeal). Eucerin cream works well on my feet, after which I put on clean cotton socks. I keep the socks

on until my feet start to "complain" (the tingling that precedes the heating up). For body soap and shampoo, I use Johnson's natural head-to-toe foaming baby wash. I've found the baby section is a good place to shop for gentle products.



*Starla Jackson
Huntsville TX USA*

I'll never forget awakening with EM last April. The symptoms have not ceased for a second. My hands and feet feel as though I am being stung by a hellacious jellyfish while simultaneously being placed in an open flame. I'm sure this is common. I tried months of Lyrica, Neurontin, and Chinese herbal capsules, none of which helped at all, as well as topical remedies—some prescribed and some of my own concoctions. I don't know how I ever found time to work. It seems that being disabled is at least a 60 hour per week job.

I use Lidoderm (five percent lidocaine) patches on other areas, and one day I slapped those on my feet just for the heck of it. They helped some. When I told my "brilliant" neurologist this, a light bulb went on. Oral lidocaine (Mexitil) had been relatively recently developed for heart patients. He put me on 150 mg twice daily. I felt some relief within 48 hours. After a week, I would say the burning was relieved by 40 percent. At least I was no longer suicidal nor was I desperate to amputate my limbs.

After 30 days of Mexitil at this dosage, he increased it to three times a day. However, I have not noticed any further relief.

Everyone Has One

Mexitil does have side effects. The primary one is nausea, which has not affected me one iota. What has affected me is extreme exhaustion as well as a bit of dizziness, but it's definitely a good trade-off.

I am a widow with no children. However, I "claim" hundreds of children—my piano students. I have a Master's of Music and served as a college piano faculty member, as well as operating a private piano studio, "Starnote Music." My most recent position was with the Houston, TX, Grand Opera. I'm now retired, due to my multiple neuro-progressive disorders. I am an avid baseball fan and peace activist. I'm also a volunteer pianist—even with slightly burning hands.



Jules Hunter
Noosa Queensland, AUS

I am 42 years old and was diagnosed with EM in September 2010 by a rheumatologist here in Noosa,

Queensland, Australia, which is one of the warmest states in "OZ." However, I would not live anywhere else but this special part of the world. I also have multiple sclerosis.

The burning started in my feet about four years ago. Exercise, walking, heat, and hot showers bring on the burning, throbbing, pain. This also occurs at night when resting, even without a sheet or blanket. I use A/C, a fan, and elevate my feet for relief and only wear open-topped sandals. I also have flares in my knees and on patches of my face and ear.

In high school, I played many sports and was on a music scholarship. I now know why I had burning pain, numbness, paralysis, vertigo, immense fatigue and frustration when unable to achieve my goals. I pushed myself more, thinking it would help. I'm no longer able to work, but I earned my diploma in Financial Planning two years ago.

I am able to cope with the MS as I know I can keep symptoms under control with diet, rest, exercise and limiting stress. I cannot control EM as easily. The pain and burning interrupts my love of walking and the lack of sleep is cruel. I'm sure many of you can relate. I was told I was given MS and EM as "gifts" because I can cope, with my positive attitude and love of life. My Mum always taught me "if you look good (which I always try to do), you feel good." I love life and wake each day in anticipation of what it will bring. Simple things like having coffee with my beautiful Mum and walks along the beach make me so happy. The support I have from my parents and close friends encourages me to achieve my goals.

I am so impressed with TEA, the staff, doctors and incredible range of articles available. My doctors and pharmacist refer to these constantly.



Erika Conrad
Tacoma WA USA

I am 19 years old and though I've had EM for about 10 years, I was only diagnosed a couple of

years ago. I haven't found any medication that helps the pain in my feet. The doctor now has me on Neurontin and Tramadol and I hope they help. Now even my face gets extremely red and hot when I am very stressed. I rarely leave the house due to the pain, which seems almost constant. I wish I had someone in my life who understands, but EM is almost impossible to describe. I've applied for disability, which I really need since I cannot work.

I recently went for a walk with my three-year-old daughter to get some fresh air. She had been begging to go out for a week. After about 15
(continued on PG 7)

TEA members now more than blood samples to researchers



Seated (from right) are Gayla Kanaster, Pamela Costa, Ph.D., and Stephen Waxman, M. D., Ph.D., with the team of EM researchers in their laboratories after lunch with the visitors.

By Gayla Kanaster

Seeing the Yale University Center for Neuroscience and Regeneration Research and meeting Stephen Waxman, M.D., Ph.D., and the team of approximately 30 researchers studying inherited EM highlighted my trip to New Haven, CT, USA, in August. My daughter, Pam Costa, Ph.D., and I felt honored to meet Dr. Waxman and the international scientists whose published EM articles are posted on TEA's website.

Dr. Waxman led our tour of the research labs where scientists explained the "patch-clamp robots" and the latest dual laser microscopes.

People with inherited EM have mutations in SCN9A, the gene for the human Nav1.7 sodium channel. EM is the first inherited pain disorder in which it is possible to link these mutations with an abnormality in ion channel function that increases firing of pain signaling neurons.

We actually saw these neurons under the microscope, which brought Pam to tears after a lifetime of trying to understand what was going on in her body.

We actually saw these neurons under the microscope, which brought Pam to tears after a lifetime of trying to understand what was going on in her body.

Dr. Waxman told us they have a truly world-class, multidisciplinary team with most of the researchers working 60 hours a week to develop new therapeutic approaches to chronic pain.

I sensed the collaborative spirit of the lab immediately. Whiteboards and chalkboards on the hallway walls were filled with scientific notations that the team shares with each other.

Following lunch with the researchers, Pam was asked to give a talk about her life with EM. She explained how it has affected generations of our family, each person since birth, and how debilitating it can be. I was then asked about my symptoms, which are less severe than hers.

One of the scientists, Sulayman D. Dib-Hajj, Ph.D., commented how helpful it was to meet people who actually carry the mutation affecting the Nav1.7 sodium channel, after studying it in the laboratory for so long.

As an integral part of Yale University, the labs are located at the West Haven Veterans Affairs Medical Center and funded largely by the Veterans

Administration and the Paralyzed Veterans of America. A cure or treatment for EM will help others with neuropathic pain, including veterans with phantom limb pain and other forms of pain after nerve injury, traumatic limb amputation and burn injury.

We also were fortunate to meet two other special people: Dr. Waxman's gracious wife, Merle, a Yale Associate Dean, and TEA's *FootSteps* Editor Isabelle Davis who drove to New Haven from her home nearby to join us for dinner one evening.

It was an unforgettable trip that even added to my appreciation for Dr. Waxman and his team for their diligent EM research for so many years. As one of the researchers, Yang Yang, Ph.D., includes on his emails, "When there is a will, there is a way."

EDITOR'S NOTE: Gayla Kanaster and her daughter Pam Costa, Ph.D., are part of a large, extended family of people who carry a genetic mutation that causes EM. Blood samples from members of this family were part of the Yale team's original experiments that showed that the mutation caused their chronic pain and the accompanying symptoms.



Gayla Kanaster and Pam Costa (from left) stop for a picture with Steve Waxman and his wife Merle outside the art museum on the Yale campus.

(*Your Stories - Continued from PG 5*) minutes, she suddenly said her feet hurt. We sat down at a bus stop and I just started crying when I thought about her little feet hurting the way mine do. On the way home, I stopped at our mailbox and found TEA's *FootSteps*. When I read others' experiences with EM, it was comforting to know that I'm not alone and there actually are people out there who understand and want to help.



*Jean Warwick
Sydenham Oxon UK*

My problem began four years ago when I was 73, shortly after a knee replacement operation. I have all the usual EM symptoms—burning feet and lower legs with redness, swelling and flare-ups, but also only the back of one hand. All are worse at night. I can't walk or stand for long as the pain increases to the "razor blades" sensation in the soles of my

feet. My bedroom is unheated even in winter. I can only take paracetamol or co-codamol (for sleep) as my stomach does not tolerate aspirin-based medication.

We tried the tricyclic antidepressants, but I was like a zombie. I now take 20 mg citalopram, which helps a little. The skin on my legs and feet is very dry and flaky and I have rashes which defy all creams. I am always tired and can not do many of the things I used to do. I go barefoot inside and wear sandals outside, even in the snow here in Oxford, England. My husband of 59 years is very supportive and, being a Quaker, I have many Friends who commiserate with me and are very kind. Most people's eyes glaze over when I try to answer their questions, including local doctors. Nobody really understands the causes or knows what to do. I just soldier on and very bravely (I think). I have agreed to go on a train trip across to Greece and the Islands, as I refuse to let my EM win. I imagine that I shall see more of the hotel lounges than the museums and antiquities!! I have been assured that there is air conditioning and plenty of ice in the ice-boxes!



The Erythromelalgia
Association

www.erythromelalgia.org

FootSteps

Welcome to a redesigned, more lively and inviting *FootSteps*. TEA hopes this new look will draw your attention to the newsletter, lead you to open it and read what's inside. This issue has news about fundraising and a promising experimental ointment, five of "Your Stories," a trip to Yale, and more.

Raising Awareness. Raising Research Funds. Raising Hope.

Rather
read FootSteps
online and save
TEA the postage?
See the "How to edit your
online 'Profile'" story on
pg 2 for details.

200 Old Castle Lane,
Wallingford, PA, USA 19086

The Erythromelalgia
Association

