

# 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)

Spring 2013, Vol. 14, No. 1

## Annual Appeal most successful yet

TEA's 2012 Annual Appeal raised 77 percent more than any other appeal during the past six years—\$25,714. TEA sends just one appeal for funds each year at the end of the year.

In recognition of those who support our organization on an ongoing basis, TEA this year set up several giving levels—Patron, Benefactor, Sponsor, and Supporter. And we were fortunate to receive gifts from eight Patrons (\$500 and up), seven Benefactors (\$250 to \$499), 59 Sponsors (\$100 to \$249), 78 Supporters (\$50 to \$99) and an additional 86 donors. See p. 6 for names of those who gave.

What makes the Annual Appeal so important is that funds received—unless designated for the Research Fund—will pay a majority of 2013's expenses. Donations are used to pay website expenses, postage, newsletter and other printing, etc.

The 2008 appeal formerly had raised the most—\$14,459. The first appeal in 2007 raised \$11,757. Appeal donations received through February 28, 2013, are included in the totals. Appeal donations continue to trickle in through the spring months.

## Wanted: volunteers

Did information on TEA's website help you better understand your symptoms? Did you receive a thorough answer to a question you asked MemberServices? Or just enjoy reading *FootSteps*?

TEA volunteers were responsible for making all those services happen. As you know, TEA is an all volunteer agency. Virtually all of the work of the organization falls to the members of the unpaid Board of Directors and a small group of dedicated TEA volunteers.

There is much more we could accomplish if we had more volunteers. The only qualifications you need to be a volunteer are a willingness to give your time to TEA, the ability to work with very little supervision and carry through on tasks.

We have a special need for new board members with experience in fundraising, or with legal, financial, public relations and marketing backgrounds.

Some projects TEA needs volunteer help with now:

1. Verify names and phone numbers for the Doctor Directory
2. Scan the web for articles about EM

To volunteer, contact Gayla Kanaster, [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com).



The Erythromelalgia  
Association

## INSIDE

### Beth Coimbra writes

Dr. Mark Davis presents  
Grand Rounds on EM

PG 3

### More of your stories

Four share their EM journeys

PG 4 and 5

### TEA salutes donors

Record Annual Appeal  
givers recognized

PG 6

### Qutenza patches

High-dose capsaicin treatment  
helps some

PG 7

## ALSO IN THIS ISSUE

### Member makes news

Canadian contest winner featured

PG 2

### Volunteer needed

Help wanted with Doctor Directory

PG 2

### New member joins board

Rebecca Fisher brings  
advocacy, other skills

PG 2

# FootSteps

is published by



## 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.

## Rebecca Fisher joins board

Bringing a wealth of experience to the TEA Board of Directors is its newest member Rebecca Fisher of Toms Brook, Virginia. A Congressional aide working on Capitol Hill in the 1980s, she found her real passion in the next phase of her career—working with the elderly.



*Rebecca Fisher*

Becky served as president of a nonprofit continuing care retirement community in the 1990s, where working with older adults proved very rewarding. In recent years she began working as a hospice volunteer, as well as doing other volunteer work.

Coping with two other rare disorders in addition to EM, Becky has learned to advocate on her own behalf—a valuable skill in TEA.

## Help wanted with doctor directory

One of the most frequently asked questions TEA gets is: “Can you recommend a doctor in my area? One who knows about EM?”

Currently, these inquiries are answered by TEA’s MemberServices’ volunteers, who respond to requests for doctors’ names individually. But TEA plans to put a Doctor Directory on the website. All we need now is a volunteer to verify names and phone numbers.

TEA keeps a list of doctors who have been recommended by TEA members. By no means comprehensive, the list was first compiled from responses to the 2008 Member Survey, which included a request for recommended doctors’ names.

The current list is only a start. TEA encourages any member wanting to add a doctor to the list to send the name and contact information to [memberservices@erythromelalgia.org](mailto:memberservices@erythromelalgia.org).

## Winning artist in the news

One of TEA’s winning artists was featured in media outlets throughout eastern Canada in February. Artist Heidi Grein, who has lived with EM for seven years, tied for third in TEA’s contest with her painting “Red Heat.”

Working as a TEA volunteer, Elisabeth Antoine wrote and distributed press releases about each of the winners of last year’s “Paint Your Pain” contest. One reporter was intrigued enough to arrange an interview with Heidi.

The story appeared in “The Daily Gleaner,” Heidi’s home town newspaper in Fredericton, New Brunswick, Canada, but also online and in as many as 19 other papers throughout New Brunswick province in eastern Canada. You can read the story about Heidi by clicking on “In the News” on TEA’s home page at [www.erythromelalgia.org](http://www.erythromelalgia.org).

# Dr. Mark Davis presents: Red, Hot and Painful

By Beth Coimbra  
TEA President and Treasurer

On March 8, 2013, I received an unexpected message from a friend who is a nurse at a local hospital: “Grand Rounds at Lankenau Hospital on March 10, 2013, will focus on erythromelalgia and Dr. Mark Davis from the Mayo Clinic will be presenting.” Lankenau is a medical center just outside of Philadelphia, about 20 minutes from my home. I was surprised that this teaching hospital was devoting a whole lecture for medical staff to this very rare disease and that the presenter was a member of TEA’s Medical Advisory Committee. Luckily, I was able to go on short notice.

I emailed Dr. Davis immediately to let him know that I live close to Lankenau and would be attending his presentation. He wrote back to say that he had planned to mention TEA during his presentation and show some of the artwork from TEA’s “Paint Your Pain” contest to help the audience of doctors better understand the suffering of EM patients.

Two days later, I watched as Dr. Davis was introduced to an auditorium of about 40 people (mostly internists) by Dr. David Cohen, Grand Rounds Coordinator at Lankenau. Dr. Cohen explained that he had seen a patient with EM symptoms recently and decided to devote a “grand rounds” to the rare disease. (“Grand Rounds” is a traditional teaching tool of medical continuing education to update physicians on important or evolving areas that are not part of their core practices.) Dr. Cohen searched for an expert on EM and found Dr. Davis, who has seen hundreds of EM patients, devoted his scientific research to EM, and published numerous medical journal articles about his research findings. Dr. Cohen invited Dr. Davis to speak to Lankenau’s physicians so that they would recognize EM if they had a patient with EM symptoms.

Dr. Davis began by expanding on his title slide that was seen by all upon arriving at the auditorium:

*Red, Hot and Painful:  
The curious syndrome of erythromelalgia.*

His presentation included photos of EM patients displaying red, swollen feet, legs, hands, ears and faces. Dr. Davis explained that a patient could come in with normal looking feet, but describe other times

when their feet are red and burning. He informed the audience that many patients are in so much pain they continuously soak their feet in ice water—something very detrimental to the patient’s skin and to the continuing cycle of burning flares. He highly recommended that physicians work to help the patient break that habit with the help of one of the drugs found to give relief to some. Or by using the topical treatment he prescribes for patients who come to see him at Mayo—a compound cream of amitriptyline and ketamine that has been found to reduce symptoms in some patients.

Dr. Davis ended his presentation with slides of the artwork from TEA’s art contest, held in 2012. Attendees expressed great appreciation for the insight provided by the images representing EM pain.

It was a wonderful event for me to witness: numerous physicians being made aware of the existence of erythromelalgia and learning to recognize, diagnose and begin treatment of a patient displaying symptoms of this rare condition.



*Mark Davis, M.D., Mayo Clinic’s EM specialist, with Beth Coimbra*

# Your stories

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, send it, along with a "head shot," to Gayla Kanaster, [GaylaKanaster@aol.com](mailto:GaylaKanaster@aol.com) or 2532 N. Fremont St., Tacoma, WA, US 98406. Because our space is limited, we request that stories be no more than 350 words in length.



*Meg Edelson  
Mill Valley, CA US*

I suffer from a rare case of Facial EM, characterized by severe flushing of the face/ears, which get red, hot and excruciatingly painful. My flushing started after taking a medication. Because of the immense pain, I sought medical help. I was told my symptoms would subside when I stopped the medication, but the flushing and agonizing pain only worsened. I was frequently misdiagnosed with rosacea, psychological or hormonal issues. Eventually, a doctor observed me during a flare. Alarmed, she rushed me off to be tested for illnesses that have facial flushing as a symptom. After testing negative to the flushing disorders, I was given the blanket diagnosis of "vasomotor instability." This began my quest for a meaningful diagnosis.

Next, I traveled to the Mayo Clinic where the autonomic neurology group discovered that I had also stopped sweating. These tests constituted proof that something was "officially wrong." I did not have rosacea, hormonal or psychological issues. Finally, I had a diagnosis: "Idiopathic Erythromelalgia-like Syndrome of the Face along with Total Body Anhidrosis." Though vague, this diagnosis meant everything, since by this time I had forfeited my career and social life due to overwhelming pain.

Facial EM feels like putting your face directly into a fire. It causes permanent, disfiguring swelling. I no longer look like me, even when not flaring, which feels humiliating. The first nine years of my 14+ year illness I was bedbound, trying to cool my face and warm my body. I couldn't do basic tasks. Heat or movement caused unrelenting pain. I was on fire 24/7 and unable to sleep. The pain was so agonizing, I often felt I could not live another day, but hung on for my daughter. When in despair, I made tolerating each moment my goal, forgetting about tomorrow.

Eventually, I found intermittent relief with medications, supplements, Five Element acupuncture, VBeam Perfecta Laser and an air-conditioned house. Life remains limited: 14+ years without travel, social events, even missing my daughter's college graduation. Although disabled, I have discovered new ways to enjoy life. With my daughter and husband's support, I endure a life arguably worse than death, suspended between not dying, but not getting well. However, I never stop trying to get better. I still seek out new doctors, treatments and medications, working toward an improved life. I will never get back my original face, or be the woman I was before Facial EM, but I must keep trying. (For more information about facial EM, see Meg's article on TEA's website.)

*Irene Kellough  
Toronto, ON CA*

As a new TEA member, I am so happy to know that I am not alone with EM. I am an 89-year-old widow living alone, but fortunate to have family nearby. My EM started about six years ago.

I noticed a TEA member once asked if anyone experienced EM stopping during an illness or injury. When I fractured my right ankle two years ago, my feet stopped hurting for about 10 days, then returned worse than before. Now I flare constantly. My right foot and ankle where the skin was damaged are very sensitive, dry, swell more and stiffen when I stand. I also have heel cracks and toenail problems, heavy freckling on the front of my legs, ankle to knee, darker on my ankles, but no discomfort there. I wonder if others experience this.

I'm using creams, a camphor, as recommended by some members, fans, air conditioner and cool wraps at night, but sleeping is still difficult. I keep my shoes and socks in the refrigerator.

# Everyone has one

I enjoy reading and doing crossword puzzles. I have been volunteering at a nursing home for over 15 years. I like to speak on the phone with family and friends. I also keep busy with housework, grocery shopping, and doing exercises in my home. And, of course, I spend a lot of time trying to keep my feet cool—a full time job!

But, I am happier and grateful to be part of the TEA group and thank everyone for their support. I would welcome hearing from others at anytime (416-694-8313).



*Denni David  
Chicago, IL US*

My journey began in 2007 when my EM symptoms first appeared. For about two years they were mild, but by 2009 I was miserable in the summer

and it was clear I had to become more proactive. I made appointments with numerous physicians and every test was normal until one vascular doctor was baffled by my blue feet and referred me to Mayo Clinic. The Mayo doctor, Dr. Rooke, considered EM but did not diagnose me. He thought my symptoms were not classic EM. I was becoming increasing more uncomfortable and was determined to get some answers.

Someone I met while traveling referred me to a family doctor, Dr. Richard Shoemaker, who specializes in bio-toxin illnesses. During the period of time that I worked with this doctor, I learned I had inflammation and toxins. For six months I was on a prescribed medication (cholestyramine) that safely removed some of the toxins (I was told it binds with toxins in the intestines). I began to feel somewhat better so it appeared I was on the right track. Last June I started juicing. I purchased a masticating juicer and, since then, begin each morning with freshly juiced vegetables and some fruit (carrots, beets, kale, spinach, Swiss chard, small piece of apple). I am now seeing an alternative medicine M.D. who prescribed amitriptyline and suggested an anti-inflammatory supplement called AKBA, which I am currently taking.

I am feeling significantly better and am convinced juicing is the major contributor. My hands would occasionally

turn red, but that doesn't happen anymore and my feet don't burn at all. My particular EM symptoms are related to inflammation and I remain hopeful that I will continue to improve well into 2013. I am happy to share my entire story, so if you are interested, please email me at DSD3500@yahoo.com.



*Pam Allen  
Perth, AU*

“What is going on with your feet?” asked the man sitting next to me at dinner. We were out in the open enjoying African hospitality in the

middle of the Okavango Delta. Embarrassed, I looked down at my very red, swollen and burning feet bulging out of my sturdy sandals. Of course everyone else was wearing hiking boots and thick socks—it was cold! “I have no idea, but for the last two years this problem has plagued me 24 hours a day.”

“Well,” said this man's wife, “you need to see a neurologist ASAP when you return home.” Little did I know that this husband and wife were specialist doctors from the Royal Alfred Hospital back in Australia. I explained that three doctors and various other health professionals had either dismissed my pain or had just shrugged their shoulders. And that every night, even in winter, I stood for long periods of time in a tray of water next to my bed trying to find relief. Finally, these wonderful, caring doctors gave me direction in finding someone who potentially could help. “First, find a new doctor and tell him/her what we have said.” And the doctor I chose did not blink an eye. (He said later that he wasn't going to go against such highly qualified practitioners.)

The neurologist already had a patient with EM so immediately put me on amitriptyline (10mg). What a change! I was actually able to get through that first night without my trusty tray of water. I'm grateful that after five years I can now tolerate enclosed shoes for a short time. Yes, I am one of the lucky ones to receive relief from medication (now 75mg). I still have flare-ups (Neurontin helps), but (*continued on PG7*)

# TEA salutes 2012 Annual Appeal donors

TEA salutes all those who gave during our 2012 Annual Appeal, our most successful appeal to date. For the first time, TEA is recognizing donors in four giving-level categories-Patron, Benefactor, Sponsor and Supporter. (See pg 1 story for more.)

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# Qutenza: The High-Dose Capsaicin Patch

By Elisabeth Antoine

In 2000, Robert B. Layzer, M.D., University of California, San Francisco, theorized that perhaps the mechanism common to all forms of EM was over-sensitization of the skin's heat-sensing receptors.<sup>1</sup> These receptors (called TRPV1, vanilloid, or capsaicin receptors) are sensitive to extreme heat (over 43°C), as well as to capsaicin, the chemical in chili peppers that causes the sensation of burning pain. When tissue is damaged, it may become over-sensitized through the release of inflammatory chemicals. In addition, low pH that occurs in areas of reduced blood flow can also cause sensitization of TRPV1. With this comes a reduction in the heat threshold, leading to an increased pain response at lower temperatures.

Today, we know that genetic mutations affecting the sodium channel Nav1.7 play a role in some cases of EM; however, Dr. Layzer's theory may still hold merit, particularly in patients whose EM was caused by localized nerve or tissue damage. For these patients, the answer may lie in desensitizing the TRPV1 receptors. Although capsaicin is a TRPV1 agonist, prolonged exposure will paradoxically cause TRPV1 desensitization.

Since OTC capsaicin creams typically take weeks to show any benefit—and are too painful for most EM patients to tolerate—the 8 percent capsaicin patch Qutenza is now a practical alternative. Developed by Stanford University's Wendye R. Robbins, M.D., the patch has only been FDA-approved in the U.S. to treat postherpetic neuralgia (shingles), but is increasingly being prescribed for other conditions, including EM. Dr. Robbins has so far treated more than two dozen EM patients with Qutenza, and she says that the majority have had successful results.

Research has shown that capsaicin acts as a neurotoxin, essentially killing off nerve endings and rendering

them nonfunctional.<sup>2</sup> Because capsaicin is highly selective to TRPV1, only those receptors that perceive heat are affected. Other sensory nerves remain intact and functional. Over a period of about three months, these damaged nerves do regenerate. Some patients continue to enjoy pain relief, while others require repeated treatments.

The Qutenza patch is quite painful and must be applied with some sort of anesthesia—an epidural, IV narcotics, local lidocaine injections, and topical numbing cream are some of the options. The patches are applied for a period of 60–90 minutes, after which the capsaicin is removed from the skin with an oil-based cleansing gel. Some patients experience residual burning for about a week following the treatment.

Despite the pain involved in the procedure, Qutenza's benefit lies in the fact that only one application is necessary to “de-functionalize” the nerves, compared to weeks of torture using an OTC capsaicin cream. The bottom line: Qutenza may not be appropriate for every patient, but it is a viable yet underutilized treatment that may provide relief for many of us who suffer from EM.

**EDITOR'S NOTE:** For more detailed information about Qutenza and capsaicin patches, you will find a longer, more technical article on TEA's website. The author, Elisabeth Antoine, is a freelance writer and a person with EM. You will find Elisabeth's personal story on the “Member Stories” page.

1 Layzer, R.B. “Hot feet: erythromelalgia and related disorders.” *Journal of Child Neurology* 2001; 16:199-202.

2 Anand, P., and Bley, K. “Topical Capsaicin for Pain Management: therapeutic potential and mechanisms of action of the new high-concentration capsaicin 8% patch.” *British Journal of Anaesthesia* August 17, 2011; doi:10.1093/bja/aer260.

## Your stories. Everyone has one *(continued from PG5)*

mentally it is so much easier to cope. Recently my hands have started to turn bright red, very hot, but no painful burning. As with fellow EM sufferers, my story is ongoing but I remain positive and hopeful that

researchers will find ways of helping those who suffer such debilitating pain. My wish is also for more information about EM to be highlighted in the media.



The Erythromelalgia  
Association

# FootSteps

Spring 2013, Vol. 14, No. 1

## **NORD celebrates 30-year anniversary**

This year is the 30-year anniversary of the founding of the National Organization for Rare Disorders (NORD), made up of more than 150 patient organizations including TEA. What came first was the Orphan Drug Act, signed into U.S. law also 30 years ago by President Ronald Reagan, to encourage development of treatments for rare diseases affecting millions of Americans.

NORD was formed by a coalition of rare disease patient organization leaders who had worked together with Congress, the media and other supporters to get this landmark law passed. These leaders established the nonprofit NORD to provide advocacy, education, research and patient/family services to for all Americans affected by rare diseases.

NORD addresses the challenges of people living with rare diseases like diagnosis delay, too little research, too few treatments, limited access to treatments. One of NORD's recent achievements was passage of the 2012 U.S. FDA Safety and Innovation Act, which includes major provisions related to rare disorders.

NORD will focus during this anniversary year on accomplishments and also the fact that most people with a rare disorder do not have an FDA-approved treatment. And, even when treatments exist, many patients have trouble accessing them.

**Raising Awareness.**

**Raising Research Funds.**

**Raising Hope.**

[www.erythromelalgia.org](http://www.erythromelalgia.org)



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