

FootSteps

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

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Two drugs for EM pain in pipeline

People with inherited EM (IEM) recently participated in trials of two experimental drugs for EM pain. The drug companies developing these medications believe that if these drugs relieve the pain of IEM, they also will relieve pain associated with secondary EM and other forms of nerve pain. Both drugs have been in development for years and will not be available for general use probably for years to come. They are based on groundbreaking pain laboratory research done by scientists at Yale, among others.

Pfizer holds trial of new drug for EM pain

Pfizer Neusentis, a research unit of the global pharmaceutical company, recently conducted a clinical trial of an experimental drug to relieve the pain of inherited EM. Involving people with IEM, the study is another step in the process of developing this new drug and getting governmental approval for its use.

This drug trial was preceded by an enabler study, in collaboration with Stephen Waxman, M.D., Ph.D., and his group at Yale's Center for Neuroscience and Regeneration Research. The enabler study, also using people with IEM, helped Pfizer Neusentis learn more about the clinical features and natural history of the disease and design the drug study. "It was very interesting to see that patients vary in their experience, both in the duration and the intensity of pain," said Ruth McKernan, Ph.D., Chief Scientific Officer. Both studies were carried out at Pfizer's Clinical Research Unit in New Haven, CT, U.S. *(continued on PG3)*

Experimental drug XEN402 makes progress

During the past year, the experimental EM drug XEN402—now TV-45070—made significant progress toward eventual approval by government agencies like the U.S. Federal Drug Administration. Last December, Teva Pharmaceuticals, a global company, announced a worldwide exclusive license agreement in collaboration with Xenon, the Canadian biopharmaceutical company that discovered and initially developed the EM pain drug. Teva now is paying for developmental, regulatory, and marketing efforts for the experimental drug. *(continued on PG3)*



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.

Membership renewals up

TEA thanks all those who renewed their membership in 2013. Renewals are up 22 percent over 2012. This year's renewal donations totaled \$17,200 as of September 2013, and included several very generous gifts. Two members donated \$2,000 each and another \$1,020. Two other gifts were over \$400. Other donations averaged \$28, which is significantly more than the suggested donation "dues" of \$20. Unless designated as gifts to the Research Fund, this money will be for general use—for printing, mailing, website expenses and other programs. TEA has no paid staff, so has no salary expenses.

TEA now has 1,596 members. More than 1,000 are from the U.S., 215 from European countries, 84 Canada, 75 Australia and New Zealand, 10 Central and South America, 9 Africa, 3 Israel, 5 China, 2 Japan, and 4 from other Asian countries.

One member from Hawaii included this note with her renewal: "Thanks for the info about NOT using ice cold water to cool the feet. I have now broken that habit and my feet cool off on their own."

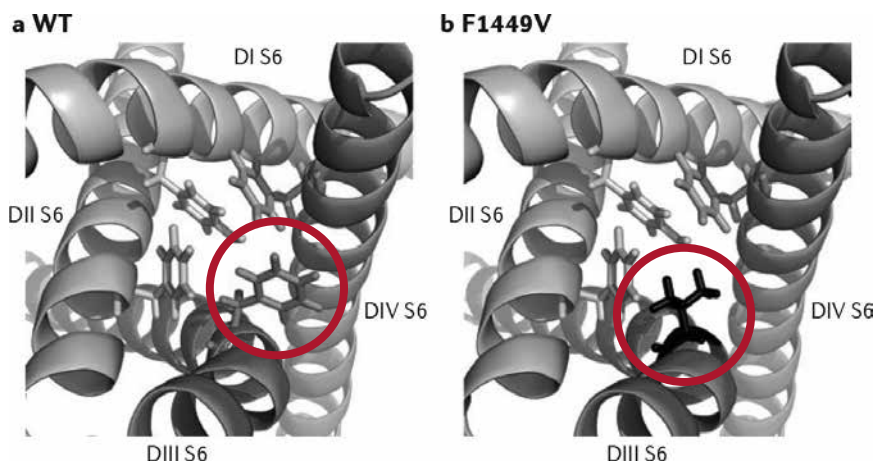
A grayscale world map is visible in the background of this section. Overlaid on the map is the text "TEA members span the globe" in a red, serif font.

TEA members span the globe

You talk, it types

TEA former president Lennia Machen reports that she uses "a new tool that I have found to be hugely helpful in my work teaching. I talk and it types—what could be better? This one tool has eliminated a lot of my flares and allows me to work longer and more productively than just about anything I've tried. A colleague with dyslexia recommended it as it allowed him to write his dissertation without needing help."

The tool she uses is a computer software program Dragon Naturally Speaking made by Nuance. This company provides many varieties and price ranges of this product that allows you to dictate while the software types. It is compatible with most computer systems (PC, Mac, iPad, etc.) and needs only a microphone to help you begin communications without touching the keyboard. "Since I have installed Dragon I find my work time has greatly increased and I no longer have to schedule typing time and EM rest time to be able to get through my work. I have found that the software works with several other programs including QuickBooks, Excel, email and just about any forms of input boxes online. Find out more at: www.nuance.com.



This model shows the location of single atoms within mutant Nav 1.7 sodium channels. It demonstrates how much researchers have learned about EM and the molecules that drive it, according to Stephen G. Waxman, M.D. Ph.D. The model appears in a recent article in the journal Neuroscience. Go to TEA's online articles library at www.burningfeet.org to read "Nav 1.7 sodium channel: from molecule to man."

Pfizer holds trial of new drug for EM pain (continued from PG1)

"We would like to express our appreciation to the erythromelalgia community for their support in this work, particularly those who participated in our studies and travelled to the New Haven Clinical Research Unit. We greatly appreciate the commitment and motivation of the people who took part, gave generously of their time and shared their experiences of living with IEM with us. This is helping us learn more about this rare, painful condition and evaluate our investigational drug in the management of pain due to IEM," said Dr. McKernan.

Based on the research findings of the group at Yale, a small biopharmaceutical company Icagen

discovered and first developed this drug. Icagen began collaborating with Pfizer in 2007, was acquired by Pfizer in 2011 and became Pfizer Neusentis in 2012.

Some of the trial participants also donated blood samples for researchers to make into sensory neurons in the lab. "These experiments are just starting and will help us understand more about the properties of sensory nerves in erythromelalgia and how they are different from non-affected individuals. This effort could help us learn more about how the drug used in our study works in detail and how it might be improved," Dr. McKernan said.

Experimental drug XEN402 makes progress (continued from PG1)

In April, Teva and Xenon announced the U.S. FDA had granted orphan drug status to TV-45070 as a treatment for EM. This designation encourages the development of drugs to treat rare diseases and grants special incentives to drug developers. These can include tax credits toward the cost of clinical trials and prescription drug user fee waivers.

Xenon in 2011 held a small clinical trial of oral XEN402 in people with inherited EM. Published results show the substance may relieve EM pain. A topical form of XEN402 has also been trialed in people with shingles (post herpetic pain) and was found to relieve pain.

The experimental drug is a new chemical substance that inhibits the sodium channel Nav 1.7 that is encoded by gene SCN9A. Research at Yale and other medical schools in the past ten years proved that genetic mutations cause sensory nerve signals that pass through the channel to overexcite and cause the intense pain of inherited EM.

Headquartered in Israel, Teva is a world leader in generic drugs and also produces brand name and specialty pharmaceuticals. Xenon is a privately owned biopharmaceutical company focused on genetics-based drug discovery and development. It is headquartered in British Columbia, Canada.

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 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.



*Paula Smith
Chalfont, PA, US*

I was diagnosed with EM in my feet in 2007. My symptoms had begun in 1995 and gradually worsened with

the hormone imbalance of perimenopause. Flare-ups became unbearable when menopause began in 2005. I increasingly used cold water immersion for relief. DO NOT DO THIS. Cold water causes swelling; the body insulates itself from the cold. Swelling=more pain= VIOLENT CYCLE. By Jan. 2008 I was in a wheelchair with red, swollen feet, unable to walk. As a triathlete and marathon runner, I was devastated. Cold water no longer helped; pain was unbearable. My husband and I cried, and prayed. Fervently.

My recovery began with prescription pain meds to end my need for relief from cold water. Cymbalta and Ativan eased the peripheral neuropathy. Fighting back one step at a time, I began walking again...slowly. Then jogging, then running...at last! Key word: THRESHOLD. I found I could once again do what I loved because my feet would only "heat up" to a certain [tolerable] threshold, and not worsen. By the grace of God I did four short triathlons that summer, and by year's end, a half marathon. In 2009, I ran two marathons seven weeks apart, qualifying for Boston, which I ran in 2011 and 2013 (and I'm going back in 2014). I have EM, controlled by meds=tolerable threshold activity level. I walk barefoot at home 24/7. A small fan and metal cookie sheet are by the living room couch when flaring occurs. A/C and/or an air purifier circulates cool air over my feet at night so I can sleep. And when I lace up my running shoes, I feel free. Find your threshold—there's hope! If you would like more detailed information, please contact me at Paulapsalm103@yahoo.com.



*Laurie Southworth
Greensboro, NC, US*

I believe I have secondary EM in my hands, feet and face, in addition to Fibromyalgia and Chronic Fa-

tigue. Meg Edelsen's story on facial EM was especially interesting to me since my face is getting worse. My symptoms began right after a harsh chemical was used to remove a toenail from the skin of my toe. I was skeptical of having this procedure and expressed my reluctance to the doctor. [I will listen to my intuition regarding my body in the future.] I now have a painful, relentless itch that comes and goes with stress, heat, exhaustion, etc., with redness as well as swelling in my hands and feet. My face flushes and burns quickly in the heat.

I read that polyneuropathy meets the description of my symptoms. Now the latest theory on the cause of fibromyalgia is that it does not begin in the brain, but rather, it is a neurovascular disease that starts with vascular problems in the hands and then becomes a total body pain experience. I always wondered if the fact that I never sweat much indicated a problem and my research confirms that indeed, this is an important factor in identifying diseases. I still am not quite sure what I have but my neurologist does not want to put me through the painful neuropathy test, and there is no test for secondary EM, which the foot doctor said he thought I have. My close family is deceased, so I don't know if anyone else had these symptoms.

I invented a cigarette substitute called Better Quit, and have a company Health Solutions, Inc. I am still selling Better Quit to hospitals and cancer clinics

Everyone has one

around the country, but it is hard to work. I am a positive person and would love to correspond with anyone who has similar symptoms. We are an isolated group, unfortunately, and must make every effort to seek answers, try to help each other and make the best of our situation. My email address is BQNow@aol.com.



*Elisabeth Antoine
San Francisco, CA, US*

I am 44 years old, a former dancer and Pilates instructor, a cookbook author, and a mom to a 7-yr-old boy. My nightmare

began in the fall of 2010 when a pair of OTC insoles caused a pinched nerve in the arches of my feet. My podiatrist diagnosed bilateral tarsal tunnel syndrome (TTS) and recommended orthotics, which only made the pain worse. In September 2011, the pain spread to my heels, and I have not been able to walk at all since then. My neurologist dismissed the TTS diagnosis but prescribed nortriptyline for the pain. Within a few days of starting the drug, I developed the classic symptoms of EM. It came on gradually but got progressively worse later that year during a trial of HBO therapy. I tried a number of other treatments, medications, and supplements; none helped, and some made the flaring permanently worse. In a short amount of time, my EM had gone from mild to severe. I went from using cool washcloths and a fan to soaking my feet in cold water almost 24/7.

I had been bedridden for nearly a year when I finally found some relief. In January 2013, I had my first Qutenza (8% capsaicin patch) treatment. Despite the epidural anesthesia, it was extremely painful—but it left me with about 50% less flaring. Finally, I could get rid of those water buckets! In March, I had a second treatment—this time with an ankle block for anesthesia. It was much less painful than the first and has given me an additional 25% relief. My feet still flare daily—though less frequently and with much less pain—and I only use a fan for cool-

ing. For the most part, the improvement has lasted. I feel grateful to no longer be in constant, excruciating pain and that I can be there for my son again. I am now focused on a rehab program for my nerve injury; I try not to get my hopes up, but I dream of being able to walk someday without pain. Perhaps I may even consider a third Qutenza treatment as well.



*Lauren Frazer
Renfrewshire, UK*

My name is Lauren and I'm 19 years old. I was diagnosed with EM at age 12. I really don't have flare ups,

as I have severe pain 24 hours a day. I have no life, no qualifications and my nerve damage paralyzed me last year. In 2011, I had a life-threatening reaction to a medication for my EM (Steven-Johnson Syndrome). I woke up one day paralyzed from the knee and elbow down. Doctors told me I'd never walk or regain full sensation in my hands again. For seven weeks I was confined to one room with my Mum having to lift me. I was not going to accept this for the rest of my life. I had to fight; battle through no feeling in my legs, feet or hands to fully grip a walking frame. My burning feet swell up to 3-5 times their normal size. It seems like my sensory nerves and all the connecting nerves died on me. Sensory neuropathy also means the swollen feet are pressing even more on the sensory nerves. But I have defied medical odds! With good old determination, I am now able to walk with just one crutch. I may never walk unaided again, but I'm not going to stop trying. I still need a wheelchair for long distance. I now want to put my experiences to good use, so I created a Facebook (closed) support group last year that I'm so proud of, called Erythromelalgia-A helping hand. It has 84 members. I now keep going by helping others. If only I could put what I've overcome on job applications!

TEA's 2012 donors - thank you!

Listed here are those who gave to TEA in 2012. FootSteps 2013 Spring issue recognized 2012 Annual Appeal donors. Those who donated during 2013 will be featured next year.

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Ravetti family founded, funded EM bracelet awareness



TEA owes a debt of gratitude to the Ravetti family of Stockton, CA, U.S. For the past six years, they have bought, bagged and mailed EM awareness bracelets, donating their time and all money raised to the TEA Research Fund. And father John has served on TEA's Board of Directors.

At 14, daughter Danielle thought of the bracelet awareness fundraiser after enduring a grueling 18 months of relentless EM pain. The family had embarked on a long journey of seeing specialists and getting misdiagnoses before her EM was finally recognized at the Lucille Packard Children's Hospital at Stanford University, CA, U.S. She was then successfully treated with an adult procedure just being pioneered. After all that, she and her parents John and Karen decided to help others by raising funds for EM research.

They bought 1,000 red bracelets stamped with "EM Awareness," packaged them in bags of 10, attached a short description of EM and a box of Hot Tamales candies. Then they sold them for \$20 donations to TEA's

Research Fund. They also encouraged purchasers to sell individual bracelets for further donations. In 2013, funds raised total more than \$3,600.

Along the way Danielle became a junior member of TEA's Board of Directors, adding helping other children with EM to her busy school schedule. John just recently stepped down from his board position, but Danielle still encourages other young people with EM to contact her by email at danielleravetti@hotmail.com.

Danielle is continuing to live with EM. The effectiveness of her first successful treatment wore off. She was able to repeat the treatment but then had to stop because of side effects. She graduated from high school in 2011 and has begun online college courses studying to become a child life specialist. She volunteers at Stanford's children's hospital school, helping with art therapy, and assists in the training of her service dog Monty, who is close to being certified.

The Ravetti family recently turned over the bracelet fundraiser to TEA. Rebecca Fisher, TEA board member, at memberservices@burningfeet.org, is now handling orders for the bracelets embossed with "burningfeet.org"

Your stories *(continued from PG5)*



*Vivian Stafford
Schenectady, NY, US*

I started having EM symptoms about eight years ago with burning and red feet.

My doctor prescribed high blood pressure medicine and an antidepressant; however, these didn't help my EM. As time went by, it got worse and spread to my

hands, knees, legs, face and ears. I'm now taking gabapentin, trazodone, Ambien, plus six others for various health issues.

It's difficult living alone with this painful condition. I'm basically bedridden, so I thank God for my sister and a good friend. They do my shopping and pick up my medications so I don't have to leave my apartment. I'm fortunate to have a caring doctor. I don't have a computer, but would welcome phone calls or letters from TEA members. Please call weekends or after 9:00 PM EST (518) 281-6663. My address is 20-G Lincoln Heights, Schenectady, NY 12305.



The Erythromelalgia Association

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FootSteps

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www.erythromelalgia.org

Like us on Facebook

Last summer TEA joined the huge number of organizations on Facebook, one of the world's most popular social networking services. Environmental attorney and TEA board member Laura D. Beaton manages the page on behalf of TEA. Those who "like" TEA's page automatically notify their Facebook friends of their decision. Those friends then may choose to go see TEA's page and like it themselves, thus compounding the number of people made aware of EM.

TEA's page helps visitors learn about EM through descriptions of the condition, postings about research findings and links to vetted articles about EM—information that can be trusted because it's coming from TEA. When you "like" TEA on Facebook, updates from TEA will be added to your newsfeed, so you will know the latest developments about EM. Join TEA on Facebook by going to www.facebook.com/erythromelalgia and clicking "like."