

FootSteps

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

Winter 2017, Vol. 18, No. 1

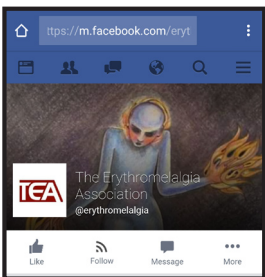
Statistics show TEA reaches many

Providing education, awareness and community through our website, member services program, newsletter, social media presence and networking programs is TEA's mission. But how do we know that's what TEA really does?



Website monthly reports

First, TEA gets a monthly report of exactly how many people visit TEA's website—erythromelalgia.org or burningfeet.org. During November 2016, there were 16,166 *visits*. Of those, 10,981 were *unique*, meaning they were visits from individuals who went to the site once or more than once. Yes, that means almost 11,000 people visited TEA's website during that one month!

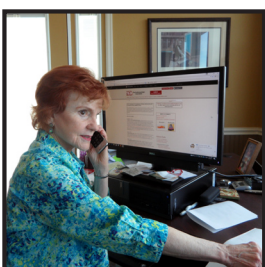


Facebook.com/erythromelalgia

Additionally, in December 2016, TEA's Facebook page reached a milestone—2,000 *likes*. When people like a page on FB, they will automatically see any new posts to that page in their *newsfeeds* when they open up their FB account. According to Facebook, TEA's three FB posts in November reached more than 3,200 people. During that month, 43 people visited our FB page, meaning they actually went to

TEA's page and may have viewed many earlier posts as well as the most recent one. Of those 43, 42 *liked* the page and will automatically receive new posts.

People who have *liked* the page receive TEA posts in their *newsfeeds* without visiting the page and then may share the posts with their FB friends. This is the beauty of FB—it gets the word out to more and more people with the help of other FB users. Individuals who receive shared posts may become interested in more information about EM or TEA and then visit our FB page, increasing TEA's reach.



TEA MemberServices

Our *MemberServices* volunteers also track their statistics. In November 2016, they responded to 12 phone calls and 46 email messages, providing one-to-one contact.

This issue of *FootSteps* was mailed to more than 2,500 people, about 750 of those living throughout the world, outside the U.S. *FootSteps* also may be read on TEA's website.



The Erythromelalgia
Association

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is published by



**The Erythromelalgia
Association**

www.erythromelalgia.org
www.burningfeet.org



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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 website to be redesigned

Proposals are currently being considered for the redesign of TEA's website in 2017 to better meet the needs of the organization and its members. TEA will hire a website design firm experienced in organizing and arranging website content to best present TEA's information to website visitors. The firm will also create an appearance for the site to deliver messages in an engaging way. A new website should be as easily used on smartphones and tablets as on desktop computers, "because mobile web usage is now greater than desktop browsing," according to TEA president Beth Coimbra.

Your stories: everyone has one



*Frank G. Wilkes
Pensacola FL, USA*

In 1995 I fell off a ladder and landed on my backside. Lumbar stenosis gradually developed and I had two fusion surgeries to relieve the resulting pain. After the second surgery I had a lingering neuropathy that evolved into the burning sensation of EM, particularly in my right foot. The pain occurred often after exercise and was most frequently in evidence at bedtime, thus hindering sleep. Gabapentin (Neurontin) worked well treating the EM at a dose of 2,400 to 3,000 mg per day, which was within the range observed by Backonja and Glanzman to be an effective dose for neuropathic pain.¹

My physician Trevor W. Turner, M.D., of the Andrews Institute in Gulf Breeze, Florida, U.S., decided to investigate the use of topical application of several chemicals suggested by Jay S. Cohen, M.D., to have potential for providing relief of EM symptoms. He prescribed a compounded lotion consisting of Voltaren (diclofenac) (0.25%), Lidocaine (2.25%) and Prilocaine (2.25%).² It achieved significant effectiveness, but was quite expensive. I then determined that a combination of Voltaren (4%), Lidocaine (4%) and trolamine salicylate (Aspercreme) (4%) provided relief equal to the more expensive lotion. Thus, in my case, gabapentin generally prevents EM's occurrence, but when it flares up, this less expensive lotion made up of two OTC lotions plus Voltaren provides several hours of relief.

¹Backonja, M. and R. L. Glanzman. 2003. Gabapentin dosing for neuropathic pain: evidence from randomized, placebo-controlled clinical trials. *Clin Ther* 25(1):81-104.

²Cohen, J. S. 2012 (Updated) The Medical Treatment of Erythromelalgia. MedicationSense.com.

Editor's Note: Compounded drugs are prepared by "compounding pharmacies," which are special kinds of drug stores.

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, e-mail your story along with a "head shot," to GaylaKanaster@aol.com or 2532 N. Fremont St., Tacoma WA, USA 98406. Because our space is limited, please limit stories to 350 words or less.



Research Continues on EM pain blockers

Pfizer ends trials; Chromocell tests new Nav1.7 blocker

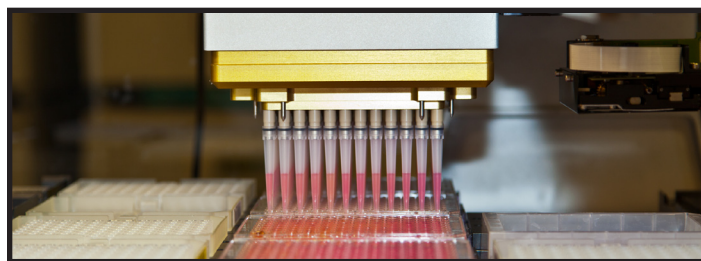
Worldwide drugs giant Pfizer has discontinued clinical trials of its Nav1.7 blocker drug despite encouraging results. But at least three other biotechnology companies are moving ahead with new drugs they have discovered. Each is designed to block the Nav1.7 sodium channel proven to be involved in the transmission of EM pain by Yale researchers.

One of those companies is New Jersey-based Chromocell Corporation, which last year began Phase I of the multiple-phase process of testing its drug for U.S. Federal Drug Administration approval, according to Kenneth Kashkin, M.D., chief operating officer. Chromocell's Nav1.7 sodium channel blocker is intended to treat neuropathic pain like the pain of EM. Similar to Pfizer's discontinued drug, it is anticipated to block the flow of sodium ions into nerve cells, resulting in a reduction in the transmission of pain signals to the brain. Nav 1.7 blocker drugs have been discovered and developed based on research findings—using inherited EM—of Stephen Waxman, M.D., Ph.D., and his team of researchers at Yale. Dr. Waxman is an advisor to the Chromocell project.



Also last year, the FDA granted Chromocell's drug its Fast Track designation for the treatment of idiopathic small fiber neuropathy (iSFN), a condition similar to EM. This FDA program is intended to ensure that therapies for serious conditions with current unmet treatment needs are expedited through the development process. Chromocell will conduct the stages of its drug's development through the Phase IIA "proof-of-concept"

clinical trial and then hand over further trials to Japanese pharmaceutical company Astellas Pharma Inc. The much larger Astellas will continue the research and development of this Nav1.7 blocker and lead further activities through to commercialization of the drug.



Phase I clinical trials are designed to evaluate the safety and tolerability of the oral formulation of the drug. While trials include only "normal" subjects in order to determine safe dosage levels, future trials will involve patients with iSFN. Dr. Kashkin stated that Phase I trials typically take one to two years to complete. While there are no current plans to test the new drug on any condition other than iSFN, both Drs. Kashkin and Waxman believe it may be a viable treatment for many other neuropathic pain conditions, including inherited EM. When asked if the drug will help people with non-inherited EM, Dr. Kashkin said this is a big unknown, though he remains optimistic that some people with EM not caused by genetic mutations will respond well to it. As Dr. Waxman has noted, the development of new medications such as Chromocell's will take time, but he regards the latest Nav1.7 studies as important breakthroughs. He emphasizes "as researchers, we share the goal of people with EM to find new therapies as soon as possible."

Founded in 2002, Chromocell is a life sciences company whose primary work has been the development of natural and synthetic taste enhancers for use in the food industry. Their unique cell-isolating technology enabled the company to expand into the field of therapeutics through the identification of compounds suited for pharmaceutical development. They are currently focusing their efforts on analgesics and rare diseases.



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www.burningfeet.org



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TEA cited in NIH website

Anyone searching for information about EM through the U.S. National Institutes of Health will find TEA described as a patient resource. The NIH website has information on many rare diseases, including EM. The EM page also cites *A Patient's Guide to Erythromelalgia*, published in 2016 by TEA, as one of its sources for the description of EM and its symptoms.

Go to the page by following this link:

<https://rarediseases.info.nih.gov/diseases/6377/erythromelalgia>

