

FootSteps

The newsletter for members of The Erythromelgia Association
FootSteps online: www.erythromelgia.org or www.burningfeet.org

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Drug company video explains pain research

If you have not seen the drug-company-produced video "The Passionate Pursuit of Nav 1.7," search YouTube or go to www.facebook.com/erythromelgia, March 3, 2016, and take a look. It begins and ends with TEA member Lauren Chapmen playing ice hockey (See *FootSteps* June 2014) and talking about her inherited EM and its effect on her life. Neuroscientist Stephen Waxman, M.D., Ph.D., Yale professor and researcher, explains on camera that in the early 2000s finding families of people whose pain is caused by genetic mutations was key to moving pain research forward. Yale's search turned up the rare pain syndrome EM. Using blood donated by TEA members, he and his group at Yale identified a mutation in the gene for sodium channel Nav 1.7, the nerve pathway that plays a major role in the firing of pain signals. Nav 1.7 became the "molecular target" that neuroscientists at universities and biopharmaceutical companies all over the world now aim for to develop new medications for chronic pain. So far none of what will be a new class of pain medications is through the developmental stage. But because of EM's role, hope for new pain relief is on the horizon.

Amgen, the company that made the video, is one biopharmaceutical company exploring this kind of new therapy for pain. Their scientists are using unconventional methods like isolating the sodium channel Nav 1.7 from an electric eel and designing substances from tarantula venom.

Dr. Waxman commented: "I am pleased that the video "The Passionate Pursuit of Nav1.7" is educating the community about EM, and about the search for Nav1.7 blockers as treatments for it. My comments in that video reflect my belief that there is a good chance that, ultimately, Nav1.7 blockers will alleviate pain in EM and related disorders."



This Chilean tarantula is the source of venom being used by a biopharmaceutical company to develop a potential new pain drug targeting Nav 1.7. Watch "The Passionate Pursuit of Nav 1.7" on YouTube to learn more.



The Erythromelgia
Association

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1945 — 2015

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nationally respected expert

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new TEA resource
on all things EM
now available

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FootSteps

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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.

Thank you: appeal results best ever

Results of TEA's 2015 Annual Appeal equaled the best campaign TEA has ever held with a total of \$25,710 donated. At the end of each year TEA sends an appeal to our EM community for support for our ongoing operations and Research Fund. This year we asked for special contributions for the soon-to-be-published, 28-page *A Patient's Guide to Erythromelalgia*—a new resource for people with EM. TEA collected \$8,359 dedicated to the patient guide, \$13,786 in general donations, and \$3,565 for the Research Fund.

General donations are used to pay website expenses, postage, newsletter and other printing costs, among others. Appeal donations received through March 15, 2016, are included in the totals, and contributions should continue to trickle in through the spring months.

"We thank everyone who donated for this overwhelming support for the work TEA does to empower those affected by EM to improve the quality of their lives," said President Beth Coimbra.

Your stories: everyone has one



Liz Ericksen
Salt Lake City, Utah, USA

I can remember the moment I realized that something funny was going on with my feet. I was eight months pregnant and standing outside in late August filling up a kiddie pool for my sister's kids. I remember the incredible urge to stand inside the pool to cool down. As I looked down at my feet (not an easy thing to do) I remember noticing how red they were! That was 33 years ago. It took a while for my problem to be diagnosed. I was probably in my 30s when a dermatologist figured out I had erythromelalgia. Now besides the pain and discomfort, my hands swell and un-swell all day! (Does everyone else experience this?) I would love to recommend something helpful to anyone reading this, but like you, I've tried most medications and creams to no avail. I have noticed that the better shape I'm in the less severe my pain is. It has helped somewhat to omit caffeine. I don't drink or smoke and try to keep my weight down because I figure the less pressure on my feet the better. My EM is definitely linked to my hormones. It seems to get especially bad when I'm having my period or ovulating and isn't subsiding now that I am in the thick of menopause. Here's one thing I can tell you—I tried injecting Botox into my heels to see if that would help. **DO NOT DO IT!** Getting the needle through the tough skin of the heel was not fun! And the Botox had no effect whatsoever.

I feel incredibly blessed because I'm still able to function somewhat normally. My husband is a physician so he is a little more understanding than most. My dream is to be able to wear anything but a sandal in the winter.

In Memoriam: Jay S. Cohen, M.D.

TEA mourns the loss of founding member Jay S. Cohen, M.D., who died in December 2015. Dr. Cohen was among the few people with EM who connected on the Internet in the mid-1990s and helped found TEA in 1999. He served on TEA's original board of directors as Medical Consultant and became Chairman of the Medical Advisory Board Committee when it was formed in 2001, a position he retained until his death. He fought the often disabling effects of EM for 20 years, using his medical expertise to investigate the syndrome and theorize treatments. He published his first article about EM—"Erythromelalgia, new theories and new therapies"—in the *Journal of the American Academy of Dermatology* in Nov. 2000.

Lennia Machen, TEA's former president, remembers Dr. Cohen: "I recall his commitment to learning about EM and sharing his findings with all of us. The use of magnesium was a life-saving discovery. Both Jay and another one of the original group were completely bedridden, and the magnesium treatment restored their lives to ambulatory and productive again. Even though it was not a help for everyone, his discovery was one of the first to show the many varieties of EM."

Dr. Cohen counseled many TEA members by phone and email throughout the years and conducted a very successful TEA-sponsored teleconference "Dr. Cohen on EM" in 2006. He wrote "Current information on treating erythromelalgia," in 2002, an article made available to TEA members and revised several times in the next ten years. His most recent articles about EM are "Medical treatment of erythromelalgia," (updated in January 2012); "What is erythromelalgia?" "Supplements and herbs in the treatment of erythromelalgia;" and "Biorhythms and erythromelalgia: Why EM symptoms worsen in the evening and night." These articles are on Dr. Cohen's website www.medicationsense.com.

Dr. Cohen was a nationally respected expert on prescription medications and natural therapies.

His training and interest in pharmacology led to independent research on the causes of medication side effects that result in more than 100,000 deaths and 2 million hospitalizations each year. He noted that a substantial number of people are medication-sensitive, and starting in 1996, he published his findings in eight books and several medical journals. His book *Over Dose: The Case Against The Drug Companies* (Tarcher/Putnam, 2001) is considered one of his best and was favorably reviewed by *Publishers Weekly*, *Library Journal*, and the *Journal of the American Medical Association*. His findings were also featured in the news media including the *New York Times*, *Washington Post*, *Consumer Reports*, and *Wall Street Journal*, among others. He also did more than 100 radio programs.



He earned his medical degree at Temple University in 1971. After completing medical residencies, he practiced general medicine and conducted research at UCLA in acupuncture and pain. In 1974, he did a residency in psychiatry and psychopharmacology at the University of California at San Diego, where he later was an Adjunct Associate Professor of Psychiatry. He is a Fellow of the American College of Nutrition. Dr. Cohen lived in Del Mar, CA, for more than 40 years and is survived by his son Rory Cohen, daughter-in law Alana Cohen, and a nephew Hal Cohen.

TEA Patient Guide Order Form

☐ Please send me a FREE copy of *A Patient's Guide to Erythromelalgia*

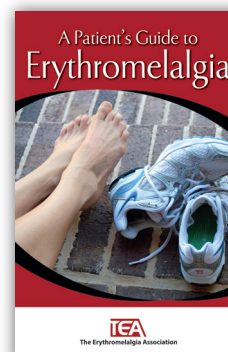
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Order your FREE patient guide now

Hot off the press is the 28-page book *A Patient's Guide to Erythromelalgia*. Copies are FREE to anyone who orders them. (Orders received by April 29 will be sent first.) TEA is accepting orders by mail with the order form on p. 3, at www.erythromelalgia.org, by e-mail to memberservices@burningfeet.org or phone (610) 566-0797. (Leave messages with names and addresses.) It may also be downloaded from the website.

The guide is a comprehensive overview of EM, carefully documented to verify its accuracy. It is intended for those living with EM, the newly diagnosed, and health care providers. It covers such topics as common symptoms, finding a doctor, reaching a diagnosis, symptom relief, lifestyle modifications, and includes a detailed list of treatments. The guide was written by Elisabeth Antoine and owes its existence to TEA Board Member Laura Beaton, who gave numerous volunteer hours overseeing the project.

