

# FootSteps

Spring 2008

Vol. 9, No. 2

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)

## TEA Gives Yale Researchers \$45,000

After months of consideration by the Board of Directors, TEA gave Yale's EM research program \$45,000 in April. The money came out of TEA's Research Fund.

"TEA's gift will propel our international collaborations ... in a search to better understand and then cure EM," said Stephen G. Waxman, M.D., Ph.D., chairman and professor, Department of Neurology, Yale University School of Medicine.

TEA restricted Yale's use of the money to support current collaborative efforts with scientists from China and the Netherlands. (See

"What TEA's Gift Will Do," p. 2.)

Yon Yang, M.D., Ph.D., who directs EM research in Beijing, and Joost Drenth, M.D., Ph.D., Radboud University, Nijmegen, the Netherlands, are working with Yale's research group at the Center for Neuroscience and Regeneration Research, West Haven VA Medical Center. Dr. Waxman is center director.

TEA's gift will support Yale's direct EM research

costs, including part of Dr. Yang's salary and that of a Yale Ph.D., and laboratory supplies, among others.

Yale is currently hosting Dr. Yang as a visiting scientist working directly with Yale EM researchers.

"Without TEA's help these collaborations would move forward more slowly, in a piecemeal way," said Dr. Waxman.

In 2005, TEA gave \$60,000 to Yale for EM research.

## Members to Receive Surveys

TEA members will soon receive a request to participate in the 2008 TEA survey. Those with EM symptoms are urged to complete the paper questionnaire or the online version.

This research study aims to gather valuable information about persons with EM and their experiences. The last such survey was conducted by TEA in 2003.

TEA's Board of Directors hired an independent firm — Survey Design and Analysis — to conduct this study.

Responses will go to the survey firm, which will tabulate and report them. Just mail your survey in the return envelope or submit it online.

The results — to be available on the TEA Web site and in *FootSteps* — should help all of us better understand EM and give us helpful information to share with physicians.

"SDA has extensive experience in designing and doing surveys," says Meriwether Jones, one of the TEA board members coordinating the survey. "They helped us refine our objectives and then tailored questions that are easy to answer."

Questions cover symptoms, diagnosis, triggers, what treatments work and how well, and much more.

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# What TEA's Gift Will Do

*Special thanks to Lakshmi Bangalore, Ph.D., Scientific Liaison Officer, Center for Neuroscience and Regeneration Research, West Haven VA Medical Center and Yale University School of Medicine, who wrote this summary.*

TEA's gift will help our international collaborations, which are bringing together scientists from three continents.

Dr. Joost Drenth (Netherlands) and Dr. Yong Yang (China) have provided us with new mutations from their patients with adult-onset, inherited EM.

We are currently analyzing these mutations in our laboratory, using the same powerful techniques used to study EM mutations from childhood-onset EM in our previous studies.

We are studying adult-onset inherited EM to understand how the Nav1.7 (sodium) channel's structure and its firing behavior contribute to the

disease and how various parts of the channel determine its response to painkillers.

Additionally, our collaborations are pursuing new avenues of EM research. One will improve our knowledge of factors that increase or decrease an individual's susceptibility to chronic pain that is acquired in adulthood.

We are studying SNPs (pronounced snips), which are small variations in DNA found in many individuals. We have found several SNPs in the SCN9A gene that codes for Nav1.7.

We are interested in understanding how SNPs affect the function of Nav1.7 channels and an individual's susceptibility to pain.

Yet another area of research that we are pursuing is constructing an animal model of EM (a disease in animals that mimics EM). We need such a model to enable experimentation that can not be performed in people.

*Editor's Note: SCN9A, one of the 30,000+ human genes, includes codes (or instructions) for forming the Nav1.7 sodium channel, among many others. Nav1.7 governs the firing of signals by nerve cells, including signals experienced as pain.*

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## Exercise Tip

Exercise! Everyone knows how important it is, yet many with EM find that even a short walk, especially in the summer, is too painful.

Former TEA president, **Lennia Machen**, Idaho Falls, ID, U.S., wrote to *FootSteps* about a solution that works for her:

"I'm doing an exercise program that is getting me into shape without making me miserable or stirring up EM symptoms — Stott Pilates.

It's one of the original Pilates methods. In my basic level/essentials class, the main focus is on making the core muscles strong, strengthening the back, and becoming fit without impact.

There is stretching involved, but no moves that should cause problems with hands or feet.

Stott Pilates DVDs are available for those who prefer to try this at home. I think others with mild to medium EM would find this exercise helpful."

*Footsteps* would like to hear from other readers who have exercise tips. Please write to Gayla Kanaster (See "Q and A," p. 4.)

**FootSteps** is published quarterly by  
**The Erythromelalgia Association**

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## Genetic Research, Drugs discussed by MAC

Basic genetic research and potential studies of drug therapies were topics discussed during a meeting of TEA's Medical Advisory Committee (MAC) in February.

Made up of physicians who do research in EM and in some cases see EM patients, the MAC meets occasionally by e-mail. Jay S. Cohen, M.D., is chairman.

Joining the MAC in 2008 were Joost P. H. Drenth, M.D., Ph.D., and Stephen G. Waxman, M.D., Ph.D. Both were active participants in the meeting, which was moderated by Dr. Cohen.

Jan Jacque Michiels, M.D., Ph.D., and Mark D. P. Davis, M.D. added their insights to the discourse.

Much discussion followed Dr. Cohen's question: "Does the discovery of genetic factors in the familial group tell us anything about

the (approximately) 90 percent without a family history of EM? Can we assume the pathophysiology is the same?"

"The research group at Yale has discovered mutations that appear to cause EM in a small number of people with "sporadic" EM. These are not common, but still may hold lessons about non-inherited EM," wrote Dr. Waxman, Yale University School of Medicine.

"In my view, we can not assume the pathophysiology of inherited and non-inherited EM is the same. But I suspect Nav1.7 (a sodium channel) is a major player, nonetheless, in non-inherited EM," he wrote.

"It may not be the cause of non-inherited EM," but it must be involved when pain sensing nerve cells misfire."

"Knock-out of Nav1.7 results in loss of ability to

sense pain, suggesting that a block of Nav1.7 should be useful in a large number of disorders characterized by pain, including non-inherited EM," Dr. Waxman wrote.

His group at Yale is working with drug companies who hope to find agents to block pain without side effects. But, as with all new research ideas, there can be "no promises" for success.

Dr. Michiels, University Hospital, Antwerp, Belgium, concluded that research "should focus first on basic research studies regarding peripheral nerve biology and pathophysiology of the Nav1.7 mutants in search for new analgesics for treatment of EM."

Referring to the 2006 genetic explanation for the Pakistani boy who felt no pain, he noted the discovery that a mutation of the Nav1.7

*(Continued on page 6)*

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### EM Timeline *J.J. Michiels, M.D., Ph.D., chronicled these events during the MAC meeting.*

#### 1878

Mitchell described a broad spectrum of erythromelalgic manifestations in 16 patients.

#### 1932

Brown postulated five basic criteria for diagnosis of primary erythromelalgia.

#### 1938

Smith and Allen introduced the term erythromelalgia as a synonym for erythromelalgia.

#### 1985

Michiels discovered aspirin-sensitive erythromelalgia in thrombocythemia vera.

#### 1988-89

Michiels recognized erythromelalgia as a congenital disorder completely different from secondary erythromelalgia.

#### 1994

Brown, Michiels added four additional criteria for diagnosis of primary erythromelalgia to separate it from secondary erythromelalgia.

#### 2001

Drenth localized the primary erythromelalgia gene on chromosome 2q.

#### 2004

Yang identified mutations in

gene SCN9A in a single person and a family with primary erythromelalgia.

#### 2004

Drenth, Waxman identified additional mutations, including "founder" mutations that cause sporadic EM.

#### 2004

Waxman showed how mutations cause the pain of primary erythromelalgia.

#### 2006

Waxman showed how EM mutations can cause sympathetic dysfunction, such as redness.

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# Q and A by Gayla Kanaster

*Send your questions and answers to Gayla*

*2532 N. Fremont St., Tacoma, WA, USA 98406, or [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com)*

**Q** *"I have recently been diagnosed with bilateral carpal tunnel syndrome and surgery has been suggested. I've heard that after a surgical procedure, EM can sometimes get worse. Has anyone experienced this and if so, how bad did the EM get?" (Tammy Beck)*



**A Jane Bell Donald**, West Sussex, U.K.: "I had major surgery after suffering from EM, brought on, I think, by varicose veins surgery. My local doctor hoped the major operation might just reverse things and my EM would go away. No such luck, I'm

afraid. This disease is very individual. You will have to go with your gut instinct."

**A Sabine Shreves**, Burke, VA, U.S.: "My EM started after a major surgery and I am wondering if it was set off by that."



**A Sally Tobin**, San Francisco, CA, U.S.: "I experienced undiagnosed EM and carpal tunnel syndrome at the same time. I went to hand specialists and neurologists, but no one diagnosed my EM or could offer me anything but surgery, physical therapy, and ergo-

nomic analysis of my workplace. Looking back, I believe that overuse of a hot laptop computer made my EM symptoms worse, and the swelling then contributed to carpal tunnel. Once EM was diagnosed (diagnosis by Google using the TEA Web site followed by physician confirmation), I changed my work habits (ergonomic keyboard, auxiliary screen, shorter computer sessions, walking around, and sometimes even driving home early so that I could have a break and then resume work from home). Very gradually things have improved, but I will probably not be able to spend 12 hours per day at the keyboard

again. After the EM flare-ups subsided to their current level, my carpal tunnel symptoms went away nearly completely, though the strength in my hands has not returned to the previous level."

**Q** *"Has anyone else experienced fingernail separation after an EM episode? There wasn't any trauma to the fingernails, but they began to blacken and separate one by one." (Emi Nellenback)*

**A Jane Bell Donald**: "My toenails are yellow and thick. I have to hack at them rather than cut. We learn to live with these things."

**A Kate Pelly**, Petaluma, CA, U.S.: My dermatologist recommended Thymol. It's a liquid which I apply whenever my nail beds are becoming sore or swollen and red or nails become separated. It works! I wouldn't be without it. The condition is called perirynichia."

**Q** *"Do other readers tend to have allergies, especially to perfumes and household cleaner scents? Also, do others tend to be prone to infections, such as UTI's?" (Eileen Fanwick)*

**A Mary Moulton**, Sandy Spring, MD, U.S.: "Yes! I have allergies to airborne pollens and dust. I'm also sensitive to perfumes, smoke and "cleaner" scents. I avoid the UTI's now by taking cranberry powder in capsules three times daily (also comes in a gel). Cranberry juice—not wise. It contains sugar. Bacteria love sugar. If I do get a UTI, I try the herb UvaUrsi, which I order from Swanson's Health Products, before asking for an antibiotic."

**A Sally Tobin**: "Yes. I have been sensitive to perfumes and most household cleaners and some organic chemicals for years. I find that I can only use unscented products, especially on my skin. I use unscented detergents and do not

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## More Q and A

use dryer sheets, even the unscented ones. Certain exposures seem to trigger flare-ups. Recently I tried a new sunscreen from Aveeno that was supposed to be 'calming,' but it caused major facial flushing. When we have guests, we always ask them to avoid scented products during their stay.

I believe that I am more sensitive to carriers that are used in perfumes and fragrances than I am to the flower extracts themselves, but there are even some extracts that cause problems for me. I end up "sniffing" my way through the Aveda stores to find products that work. I have to hold my breath to go through the perfume gauntlet in department stores, and I cannot shop in stores with scented candles.

I don't tend to get UTIs, so I can't help there, but I understand that cranberry juice has a substance that helps keep the bacteria from attaching and reduces UTI frequency."

**Q** *"Besides having EM in my feet and legs, I believe it has caused swelling in my face, tongue and lips, to the point that it causes me to lisp. Has anyone experienced that?"* (Mary Moulton)

A **Marion Levy**, Los Angeles, CA, U.S.: "I experience a cold nose at night with a red patch under the nostrils. Vicks seems to help, if applied lightly. About 20 years ago, I had a salty taste in my mouth. My tongue and palate became red and sore. No tests indicated any disease. Eventually, I landed at the UCLA Dental Pain Center. They were familiar with this problem, which they attributed to trigeminal neuropathy. They prescribed Colgate Orabase gel, over the counter. Also, they made an appliance that fits on the palate. This seems to work quickly. The episodes are sporadic and exacerbated by stress. Maybe this was the start of EM, which did not appear for many years. My feet burn and hurt. They are not hot, but are swollen and light red. I take 0.5 mg Klonopin daily."

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## More Q and A

**Q** *"Does anyone else wake up with pain and redness in their feet and legs after sleeping a short time?"* (Pam Costa)



A **Sabine Shreves**, Burke, VA, U.S.: "My symptoms are always worse when I lie down and rest for a short period of time. They also worsen after I take a shower. I have EM in my toes, fingers, ears and cheeks. It flares most often in my hands. I'm still looking for a doctor willing to help."

A **Dottie Deline**, West Linn, OR, U.S.: "I can usually avoid an attack after a nap by elevating my feet when lying on the sofa or sitting in my "Lazyboy" type chair with my feet up, plus I keep the house as cool as I can stand it—63 to 65 degrees."

**Q** *"Do others experience a major flare right after a shower?"* (Pam Costa)

A **Yaeko Sheets**, Victorville, CA, U.S.: "The short answer is, 'Yes.' If there is one constant about EM it is that the trigger is heat or warmth as in a lukewarm shower. If your shower is in a tub you might try running cold water immediately after the shower to cool the feet, assuming it's the feet that are affected. Although warmth is the trigger for flaring EM, it would not surprise me for some to say they don't always have trouble after a warm shower. Perhaps EM could be best described as the most consistently inconsistent disorder known to medicine."

**Bonnie Lou Wirkus**, Good-year, AZ, U.S., submitted this:



**Q** *"Does anyone with EM have a very low white count? Mine is 2.5 and no one can find a reason for it."*

# 'Thank You' to Our Generous Donors

"We are very grateful and encouraged about our fundraising," said Beth Coimbra, TEA president. Donations to TEA more than doubled during the first three months of 2008 compared to 2007. Gifts totaled \$15,722.

TEA thanks the members, family, friends and organizations who made donations from January 1, through March 31, 2008.

*\*includes gifts to the first annual appeal*

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## MAC Discussions

*(Continued from page 3)*

sodium channel caused this complete loss of pain sensation was "of huge importance."

Dr. Cohen also asked members to discuss "the relative effectiveness of SSRIs and SNRIs and other medications ... in non-familial EM."

"The effectiveness of these drugs is a poor predictor of pathophysiology as many factors come into play," wrote Dr. Drenth, Radboud University, Nijmegen, Netherlands.

He sees about 12 new EM patients a year. They have the same groups of symptoms, but not necessarily for the same reasons, he wrote.

"Though many fulfill the criteria for EM, I doubt whether all share the same disease," he wrote. "Most patients with familial EM develop the disease at a young age in contrast to those with non-familial EM who develop symptoms when they are older."

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# *Erythromelalgia: a hypothesis*

by Jay S. Cohen, M.D.

*Dr. Cohen is the chairman of TEA's Medical Advisory Committee and an adjunct associate professor of Family and Preventive Medicine at the University of California, San Diego. He has had EM since 1995 and helped form TEA.*

What is erythromelalgia? Why does it occur? These are questions that have not been answered, but perhaps it is time to try.

One of the striking characteristics of EM is its response to heat and cold. Heat is the main trigger and cold is the antidote. I have not seen such immediate and extreme skin reactions with any other medical disorder.

How many disorders achieve almost instant control of all symptoms with exposure to cold? Ice may reduce the pain of a sunburn, but the inflammation and redness remain. Gradually the skin heals and the symptoms are gone. Unfortunately, EM does not follow the same healing pattern.

## *Not a Disease*

Ten years ago, our colleagues in Norway suggested that EM is not a distinct disease. Instead, they believed EM is a dysfunction causing abnormal activity of the blood vessels, mainly in

the heat exchange areas the body — feet, hands, face, ears, and nose. These doctors explained that even when a person who has had EM for decades is treated with an effective therapy, the EM can disappear overnight with no apparent damage to the tissues. Diseases tend to destroy, dysfunctions may not.

What is the nature of the dysfunction in EM? The doctors did not say, but here is one possibility. Based on EM's unique responses to heat and cold, my theory is that EM represents a dysfunction of the body's normal skin response to heat.

## *Hyperthermia Response*

The human system functions optimally within a narrow range of temperatures around 98.6 degrees F. What if the temperature rises too high, as can occur when a person runs a marathon or hikes in the desert in summer?

The body overheats — a condition known as hyperthermia. It is a dangerous, life-threatening state. The body activates mechanisms for reducing internal overheating. The blood vessels in the skin dilate to their maximum size. The result is massive blood flow, 30 times greater than under normal conditions. Thus, hyperthermia is a medical condition to

which the body responds appropriately with sudden, massive increases in blood flow to the skin. A similar increase in blood flow is seen in EM, except the response is triggered inappropriately by much lower temperatures and the massive flow is limited to EM areas of the skin. In EM, the vascular system in the skin reacts as if hyperthermia were occurring, yet it is not.

This model of the dysfunction in EM explains why vasodilation is so rapid and extreme. So, what is EM? It appears to be a dysfunction of the body's control mechanism for skin blood flow in hyperthermia. In EM, the mechanism triggers inappropriately at low temperatures, bringing the massive blood flow, redness and pain with which we are all too familiar.

This explanation is only a hypothesis, but it makes sense, and it offers EM patients and their doctors a way to understand this baffling disorder. Also, it may offer a new avenue for researchers to pursue.

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## Cameras Follow Kate Running for EM Awareness

“Let’s get loud! Let’s burn bright! Let’s show the world what EM sufferers can do!”

That’s just part of the inspirational message written by TEA board member Kate Conklin on her blog after running the Cox Providence Marathon May 4, in Providence, R.I., U.S.

Encouraged by an ESPN camera crew that followed her all the way to the finish, Kate kept going in her running sandals — most often smiling, laughing and encouraging others — despite the excruciating pain of inherited EM.

She finished in 4:52:50, feet bleeding from blisters. You can read her entire story including links to actual media coverage at <http://kateconklin.blogspot.com>.

ESPN — an international network — plans to air a “human interest” feature on Kate. Dates are uncertain as of now. ESPN also interviewed her on camera, taped her training for an upcoming Ironman, working as a personal trainer, and living through her typical day with EM.

On the May 2 evening news, NBC 10 in Providence, R.I., aired a segment featuring Kate,

her sandals and EM. The *Providence Journal* ran a story about Kate May 5, and the *Warwick Beacon* May 6.

Kate moved to New York City earlier this year. (See “One-Woman Awareness Campaign,” *FootSteps*, Winter 2008.)

She’s working as a personal trainer at the Sports Center L. A. in Rockefeller Center and training for the Ironman. That’s a 2.4 mile swim, 112 mile bike ride and 26 mile run.

She is also training for a “cycling-up-a-mountain” race in June on Whiteface Mountain, Lake Placid, NY. She cycles with a group of male competitive cyclists who ride through the streets of New York, across the George Washington Bridge into the hills of New Jersey.

Kate wills herself to forget the pain. That’s easy to do “when fighting the cabs in the city, dodging other cyclists on the bridge and beating the men to the top of hills.”

Kate was first featured in *Triathlete* magazine in January 2008. Now 33, she was disabled by EM pain at 28.