

FootSteps

Winter 2008

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

First Appeal Draws Generous Support

Members gave generously in response to TEA's first ever direct-mail appeal for donations.

Mailed in Nov. 2007, the appeal had prompted gifts totaling \$8,695.00 by Dec. 31, 2007.

Checks continued to arrive as the new year began. By Jan. 21, 2008, the total was \$10,361.00.

TEA's board of directors plans to make this an end-of-year "annual" appeal.

"We are delighted by the generosity of our members, their families and friends," says Beth Coimbra, presi-

dent and treasurer of TEA.

The board intends to use most of the money to pay for special projects. The first on the list is an update of the 2003 member survey.

The results of that survey provided insights into symptoms and treatments that people with EM are still

sharing with their doctors.

The board is already considering survey firms to conduct the new survey in 2008.

"Another large project we hope to begin in the future is a coordinated awareness campaign directed at doctors as well as the general public," Beth says.

One-Woman Awareness Campaign

"Pain is just pain. I'm in pain sitting down, standing, sleeping. Why not do something that gives me hope and might help others?"

These are the words of Kate Conklin, now training daily for an Ironman triathlon in summer 2008. That's a 2.4 mile swim, 112 mile bike ride and 26 mile run.

She did a half Ironman in Sept. 2007, and then was one of six winners in of the Cadence Kona Challenge the following month.

She wears "Erythromelalgia Athlete" on her back, runs in sandals, and tells her story to everyone she can.

Sponsored by the Cadence Sports Center in New York City, their Oct. Kona Challenge was a triathlon in their new multisport center



Kate Conklin

followed by questions from judges. With her limbs swollen and bright red, Kate told her story. And won.

Her \$30,000 prize includes a year of training by Cadence trainers, a feature story in *Triathlete* magazine followed by monthly updates of her progress, a French

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Collaboration Results in EM Research Review

An article that summarizes the recent, major advances in EM research was published in Dec. 2007.

Co-authors are Joost P.H. Drenth, M.D., Ph.D., University Medical Center, St. Radboud, Nijmegen, the Netherlands, and Stephen G.

Q and A by Gayla Kanaster

Send answers and new questions to Gayla, 2532 N. Fremont St., Tacoma, WA, U. S. A. 98406, or GaylaKanaster@aol.com

Paula Smith of Chalfont, PA, U.S., sent these answers:

Q "Does humidity affect other people with EM?" (**Karen Kimble**)

A "Humidity is my worst enemy. Here in the Delaware Valley of southeastern PA, our summers are very humid. I spent last summer in the house with the A/C and even then my feet would flare several times a day. I need 65 degrees or cooler and low humidity to be able to go outside. I used to be a runner and triathlete, but that has all stopped. The only sport I can still do is swimming, as long as the pool water temperature is COOL."

Q "What food and drinks, including caffeine, have an effect on EM?" (**Nicki Greer**)

A "I am in the middle of a very rough menopause and the slightest bit of caffeine will cause a hot flash, which then 'ignites' my feet. I do not drink tea, coffee, or soda, so caffeine is not in my diet."

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

A "At my worst point with EM last winter I was completely sleep deprived because my hot feet prevented me from sleeping—keeping me up all night. Naps were impossible."

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Waxman, M.D., Ph.D., chairman and professor, Department of Neurology, Yale University, U.S.

"We now have a robust collaboration," says Dr. Waxman, who also is director of the Center for Neuroscience and Regeneration Research, West Haven VA Medical Center, where the Yale research is conducted.

Published in a prestigious medical journal, the article reviews the recent progress in scientific understanding of the genetic defects underlying the pain of primary EM, in addition to the effects of two other very rare inherited pain disorders.

This research provides an increased understanding of human pain, "one of the most pervasive symptoms in clinical medicine."

These recent findings also offer "a promising therapeutic option for the treatment of pain," and the "need for the design of ... genetically tailored pharmacological options for future testing," the article concludes.

"Mutations in sodium-channel gene SCN9A cause a spectrum of human genetic pain disorders" is now in TEA's Articles section on the Web site www.erythromelalgia.org or www.burningfeet.org. It is highly technical reading.

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Research Update

Research makes progress during 2007

Editor's note: *Special thanks to Lakshmi Bangalore, Ph.D., scientific liaison officer, Center for Neuroscience and Regeneration Research, West Haven VA Medical Center and Yale, who compiled the summary of Yale's 2007 EM research progress. (The research center houses the laboratories where the EM studies are done.)*

"The workload is immense," says Stephen G. Waxman, Center director and chairman and professor, Department of Neurology, Yale University School of Medicine.

At this point, the Yale researchers are turning their attention from inherited EM caused by single mutations (Patients develop pain in childhood.) to EM involving multiple genes, where the onset of pain occurs in adulthood, Dr. Waxman says.

"We are interested in these complex cases for a simple reason: They will tell us a lot about adult-onset sporadic (secondary) EM. We ... want to understand EM in all its dimensions, then cure it," he says.

The work at Yale already has unraveled some of the mystery of EM and improved the diagnosis and treatment of hereditary EM. It also is beginning to explain the most basic biologic processes involved in other neuropathic pain disorders.

The articles mentioned in the following summary are now available to members of TEA at www.burningfeet.org. Sign in and click "Articles."

- Yale now has active collaborations not only with Joost Drenth, M.D., Ph.D., in the Netherlands, (See story, p. 2.) but also with Yong Yang, M.D., Ph.D., who directs the research effort in Beijing, China.
- Research into the behavior of mutations in hereditary EM revealed the likely reason

painful symptoms are helped by cold. This study¹ was published in Jan. 2007 in the journal *Molecular Pain*.

- Another published study² provided clues as to why some people with inherited EM are helped by treatment with lidocaine while others are not. These findings should guide the researchers in developing treatments tailored to individual families. (Each EM family tends to have its own mutation.)
- One article³ published in April 2007 is a case study of a member of the large Alabama family with many members affected by EM. This paper should help physicians better diagnose and treat people with hereditary EM and provide genetic counseling. Stephen Novella, M.D., co-authored the article with his research colleagues. As previously announced, the Yale Department of Neurology (or Yale New Haven Hospital) has Dr. Novella available to evaluate and treat EM patients.
- Yale's published work has sparked much interest within the pharmaceutical industry toward the search for drugs that can target mutant Nav1.7 in EM, and it continues to seek the expertise of Yale scientists in the biology of Nav1.7 and its role in human painful disorders.
- Researchers are studying paroxysmal extreme pain disorder, a pain disorder which has also been linked to Nav1.7, for clues to better understand EM.

¹ Temperature dependence of erythromelalgia mutation L858F in sodium channel Nav1.7. Han C, Lampert A, Rush AM, Dib-Hajj SD, Wang X, Yang Y, Waxman SG. *Mol Pain*. Jan 2007.

² A Nav1.7 channel mutation associated with hereditary erythromelalgia contributes to neuronal hyperexcitability and displays reduced lidocaine sensitivity. Sheets PL, Jackson JO 2nd, Waxman SG, Dib-Hajj SD, Cummins TR. *J Physiol*. 2007 Jun 15;581 (Pt 3):1019-31.

³ A case of inherited erythromelalgia. Novella SP, Hisama FM, Dib-Hajj SD, Waxman SG. *Nat Clin Pract Neurol*. 2007 Apr;3 (4):229-34.

Your Stories—everyone has one!

Everyone can empathize with TEA members who have experienced the long road to an EM diagnosis and live with EM's continuing challenges. Most of us have tales to tell! TEA encourages you to write your story. Then, send it to Gayla Kanaster, gaylakanaster@aol.com or 2532 N. Fremont Street, Tacoma, WA, USA 98406.

Mary Moulton writes: Like many others with EM, my history is one of trying to find a doctor who would work with me. I was 81 when my feet started to be painfully swollen and red in the daytime. The podiatrist and internist were stumped. A neurologist made the diagnosis, but I had to do most of the research. Over the next two years we tried everything, including two nerve blocks, various salves and Lidocaine patches. Mexitiline and misoprostol helped, but for only three months. Then he gave up.

Meanwhile, because I could not wear shoes, a weak metatarsal arch fell. I have had to be in a wheelchair to keep the bones from being bruised. Then the swelling and redness started elsewhere, the most distressing places being the face and tongue. Sleep has always been an issue. At present the internist has me on Lyrica, amitriptyline and Klonopin.

This spring a dermatologist and a rheumatologist each had nothing to offer. A hematologist took two pints of blood. Then he tried massive doses of aspirin. When I showed him the words: "rule out an underlying myeloproliferative disease," he perked up and did a bone biopsy, which was negative. The next stop was an allergist who suggested I might be allergic to the old fillings in my teeth. The dentist said this was highly unlikely.

Finally acupuncture, started a year ago, began to help. With the addition of mysterious Chinese herbs and toe exercises, I was free of pain. I have to keep my feet elevated most of the time, but the swelling and burning are absent or confined to short periods in the evening.

Hurrah!

Kris Evans writes: I was diagnosed with EM a little over 20 years ago. I'm now 51 and I am handling it well I think. I do have a pedestal fan at the end of my bed that I run every night and I also have a clip fan on my recliner in the living room. My parents and grown children know they need to have fans around for me when I visit—sad but true. Before I was diagnosed I would submerge my feet into cold water, but I was told by a few doctors that doing that could eventually kill the nerves so it wasn't a good idea. That's when I went to a fan.

I recently found a doctor in my new town who was willing to sit down and look at *Foot-Steps*. I had said I was interested in beta blockers but due to other medical problems he chose not to go that route. He did put me on antihistamines, which seem to have helped a little. I told him that I had noticed whenever I took Alka Seltzer Night Time Cold my feet didn't bother me as much and that's when he decided to try the antihistamines.

In Memorium

Condolences to the family and friends of Herbert C. Mansmann, Jr., M.D., who died last Sept. at 84. He had been a frequent contributor to the EM YahooGroup and was a well known magnesium researcher.

A 1951 graduate of the Jefferson Medical College in Philadelphia, PA, U.S., he went on to become Director of the Division of Allergy and Immunology at that school. He is survived by his wife of 69 years, one daughter and five sons, 13 grandchildren and one great-grandchild.

Our Most Sincere Thanks To Our Donors

TEA thanks the people and organizations who made donations to TEA in the six months from June 1, through December 31, 2007.

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John Ravetti Joins Board

John Ravetti of Stockton, CA, U.S., joined the TEA Board of Directors last fall.

John's interest in EM and TEA was sparked by his young daughter Danielle's EM diagnosis. (See John's story in "Your Stories," *FootSteps*, Fall 2007.)

He is a project manager for Waterproofing Associates, Mountain View, CA. As such he manages commercial roofing and waterproofing system installations, such as for stadiums, hotels and institutional buildings.

John assisted Danielle in the EM Awareness bracelet project. (See story, page 7.) He also has suggestions for other fundraising projects.

Raise Money Just by Searching the Web

by Gayla Kanaster

Editor's Note: Board of Directors' Secretary Gayla Kanaster heard about GoodSearch and suggested to the board that TEA become a GoodSearch charity. She also investigated what it took to become a member and did what was required. Then she wrote this story!

TEA members with computers can now help raise money by simply searching the web or shopping online.

Using GoodSearch—a new Yahoo-powered search engine and online shopping mall—you earn money for TEA.

Each search earns a one-cent donation. And, if you shop through GoodShop.com, TEA receives donations averaging three percent (and up to 37 percent) of the value of your online purchases.

It's easy to use. Go to GoodSearch.com, click on

“Who do you GoodSearch for?” Then enter “Erythromelalgia Association.” You only have to do this once.

TEA will automatically show up each time you use GoodSearch thereafter.

The rewards can be great. If 100 members average two searches a day, TEA would earn approximately \$730.00 a year.

Even higher donations can be earned through GoodShop.com, a new online shopping mall featuring hundreds of stores including Amazon.com, Barnes & Noble, EBay, Home Depot, Macy's, and more.

To make GoodSearch appear every time you search, on the GoodSearch site, click on “Make GoodSearch your homepage” and follow the directions.

While on the site, you also can easily view total TEA donations. Sample e-mail letters to send to friends and family members are also available.

Many other charities have asked their members to switch to this new search engine. Through GoodSearch, the ASPCA has earned \$10,000, the Cystic Fibrosis Foundation \$7,100, and the Elephant Sanctuary \$6,300, to name a few.

TEA Member Rue Founds Pain Disorders Awareness Group



Jon Rue

TEA member Jon Rue last fall founded the Hollywood Cure for Pain, a movement of people in the entertainment industry whose goal it is to help raise awareness and fund research into chronic pain disorders.

The new group sponsored a red carpet gala in Nov. 2007, at Level 3 above the

Kodak Theater in Hollywood, CA, U.S.

About 70 attended the event that featured appearances by celebrities and musical performances by award-winning musicians.

Another TEA member, Melissa Karz, also helped at the event by selling EM Awareness bracelets, distributing TEA brochures and answering questions about EM.

The group held a subsequent awareness event at Bobby Trendy Designs, an upscale furniture store in Hollywood. Jon, who has both EM and RSD, said he hopes his group will continue to raise public awareness about rare pain disorders.

Bracelet Combines Fundraising, Awareness Goals

Raising money and EM awareness—two of TEA’s main goals—are combined in one simple red bracelet.

The brainchild of teenager Danielle Ravetti of Stockton, CA, U.S., the EM Awareness bracelets had raised \$1,261 for the TEA Research Fund by the end of 2007.

Danielle investigated companies on the Internet that sold awareness bracelets like the ones she’d seen for cancer. With the help of dad John, they ordered 1,000 red bracelets imprinted with “EM Awareness.”

They bagged them in lots

of 10. Danielle added a brief description of EM and a box of candies—Hot Tamales—to each bag.

Then they began selling them for \$20 donations to the TEA Research Fund. Purchasers also were asked to sell the bracelets for donations to TEA. (See the TEA Web site www.burning-feet.org to buy bracelets.)

A regional roller skating champion, Danielle began having hot burning feet at 13. After a year long odyssey of visits to various specialists, Danielle and her parents got a diagnosis of EM at the Lucille Packard



Danielle Ravetti

Children’s Hospital at Stanford University in Palo Alto, CA. (See John Ravetti’s story, *FootSteps* Fall 2007.)

Successfully treated in July 2007, Danielle was back on her feet in time to start her freshman year of high school last fall.

Triathlete Competes Despite Pain

(Continued from page 1)

top-of-the-line bicycle, and more.

Based on voting on the magazine’s Web site, one of the six winners will also receive an all-expense-paid trip to a July 2008 Ironman in Lake Placid, NY.

Kate’s story appears in the Jan. 2008 *Triathlete*. She hopes physician-athletes and others will read it and learn about EM.

The severe pain of primary EM struck suddenly at 28. In the year that followed, Kate thought about suicide, especially after getting the news that there was no cure for the disease. Or even an effective treatment.

She tried one drug therapy after another, getting little relief from any. Narcotics didn’t touch the pain, antidepressants didn’t help, other drugs had intolerable side effects.

Her doctors also told her that exercise would help her symptoms. Exercise in extreme pain? The thought depressed her. She prayed for strength.

She lost “everything.” A native of Omaha, NE, Kate was working as a CPA in Phoenix, AZ, when the pain started. After a year, she had to move back home.

“I lost my job, my friends, my dreams, my fu-

(Continued on page 8)

Wedding Fundraiser Tops \$3,500

The total dollars donated to TEA in lieu of wedding gifts for Todd and Karen Kanaster now tops \$3,500, according to Gayla Kanaster, step-mother of the groom.

As reported in the fall 2007 *FootSteps*, the couple requested donations to TEA instead of gifts for their Sept. 2007 wedding.

Kate Competes for EM Awareness

(Continued from page 7)

ture,” Kate says. She prayed through it all, “Why?”

She decided to swim. She knew how—two years on her college swimming team meant she once had been a competitive swimmer.

Her first try—a five-minute swim—was excruciatingly painful. She persisted. After a year she could swim for 30 to 40 minutes.

“Maybe I can live with this disease,” she concluded. After swimming, she began biking—in sandals. In another year she could bike for an hour, and in yet another year also run for an hour.

Then she saw an Ironman on TV with people with disabilities competing.

She realized this was how she could help people with undiagnosed EM. And how she could “get the name of my disease out there.”

Competing might also give others with EM hope.

“You can run in sandals. It is possible to do a triathlon with our disease.”

That’s when she entered her first half Ironman.

Winter 2008 finds her being coached by a New York trainer, riding her new French bike, and all the time putting up with the pain.

She’s become a certified personal trainer and hopes to move to New York and work there.

She takes most pride in running—something the doctors said she never could do. She is also proud about motivating others and increasing awareness of EM.

She’s determined to continue—this is the race she’s “supposed to run.”

You can read her blog at kateconklin.blogspot.com.

You can learn much more about Ironman competitions and what it takes to train to be a triathlete at

www.triathletemagazine.com

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Treatment Articles

- [A case of inherited erythromelalgia.](#) Novella SP, Hisama FM, Dib-Hajj SD, Waxman SG. *Nature Clinical Practice Neurology* 2007, 3:229-234. Case study of 15-year old boy with a sodium channel 1.7 mutation. Includes technical information on sodium nerve channels.
- [Erythromelalgia.](#) Davis MD, Rooke T. *Current Treatment Options in Cardiovascular Medicine* 2006, 8:153-165. An update of their 2002 paper with new information on treatment of EM.
- [Lidocaine patch for pain of erythromelalgia: follow-up of 34 patients.](#) Davis MD, Sandroni P. *Archives of Dermatology* 2005, 141(10):1320-1321. Improvement in pain of EM for 18 out of 34 patients.
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[Erythromelalgia a mysterious condition?](#) Mork C, Kvernebo. Archives of Dermatology 2000, 136:406-409. Short review of diagnosis, classification and prognosis of EM.

[Erythromelalgia A condition caused by microvascular arteriovenous shunting.](#) Kvernebo K. VASA Journal of Vascular Diseases 1998, 51:1-39. This covers all aspects of EM and how it is caused by abnormal blood circulation. Very technical.

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[Poxviruses isolated from epidemic erythromelalgia in China.](#) Zheng ZM, Zhang JH, Hu JM, Liu S, Zhu WP. Lancet 1988, 1:296. EM epidemic associated with throat viral infection.

Q and A

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New Questions

Readers sent many fascinating new questions for this issue. If any one of these strikes a chord with you, submit an answer to GaylaKanaster@aol.com or Gayla, 2532 N. Fremont St., Tacoma, WA, USA 98406.

Q Does anyone else find their feet jerk during a flare?" (Submitted by **Janice Eisler**, Toledo, OH, U.S.)

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? (Submitted by **Tammy Beck**, Litchfield, IL, U.S.)

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." (Submitted by **Emi Nellenbach**, Federal Way, WA, U.S.)

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? (Submitted by **Eileen Fanwick**, Oceanside, NY, U.S.)

Q "Has anyone with EM been tested for food intolerance?" (Submitted by **Nicki Greer**, Aurora, OH, U.S.)

Q "Do others experience a major flare right after a shower (lukewarm water of course)?" (Submitted by **Pam Costa**, University Place, WA, U.S.)