

# FootSteps

Winter 2009

Vol. 10, No. 1

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)

## Mayo study finds higher EM incidence

Researchers find overall EM rate 1.3 percent per 100,000 population.

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## Anticonvulsants, SNRIs lead drugs

An approximate 76 percent of the respondents to TEA's 2008 Survey reported often getting moderate to good relief from medication. But not the same one.

Drugs classified as "anticonvulsants" helped approximately 36 percent. They include Klonopin, Lyrica, Neurontin, and Trental. About 80 percent of those using this class of drugs said they got moderate or good relief.

Another 20 percent of respondents reported taking a sort of antidepressant classified as a SNRI. Cymbalta and Effexor are examples. And approximately 80 percent of them got moderate to good relief.

While aspirin has been classically considered a drug of choice for EM, it is among a group known as non-steroidal anti-inflammatories (NSAIDS) that includes ibuprofen (Advil) and Tylenol. Another 20 percent of respondents used NSAIDS, and 63 percent of them got moderate or good relief.

**TEA USED SURVEY FIRM.** An outside company – Survey Design and Analysis of Denver, Colo. — conducted the TEA survey in the summer and fall of 2008. The firm sent questionnaires to 647 TEA members either by e-mail or the U.S. Postal Service.

Members responded by returning 427 questionnaires to the survey company – a high response rate of 66 percent.

Almost 80 percent of respondents were female; 77 percent ranged in age from 41 to 80+. About 42 percent were over 50 when they first became aware of their symptoms.

*(Continued on page 2)*

## '08 Appeal exceeds '07

Despite dire economic conditions, TEA's generous donors answered the second annual appeal with donations 23 percent higher than last year.

Mailed in late November 2008, the appeal brought in a total of \$14,459 through Jan. 31, 2009. The appeal sent in 2007 resulted in \$11,757 in donations.

This time donors gave \$5,229 to the Research Fund. The TEA General Fund received \$9,230.

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## **Want to read *FootSteps* online?**

If you would prefer to read *FootSteps* online, TEA can take you off the *FootSteps* mailing list.

*FootSteps* is posted on TEA's Web site as soon as it is mailed. Just e-mail the editor and TEA will stop mailing *FootSteps* to you.

It's a "win-win," because TEA will save the cost of postage.

## **Survey findings** (Continued from page 1)

The survey revealed a potentially large percentage of respondents with a genetic basis for EM. While just five percent reported having a blood relative who also has been diagnosed with EM, another 20 percent believed they had relatives with EM symptoms who had not yet been diagnosed.

Just 46 percent said they have no relatives with symptoms. (Having close relatives with EM suggests that inherited genetic mutations are causing the disorder.)

Almost 64 percent of respondents reported EM is their only (or primary) disorder. Of those, 30 percent also have another disease they consider secondary to EM.

The 25 percent with the most probable familial connections (the respondents with a diagnosed relative plus those who thought relatives had EM) were generally younger when EM symptoms started and reported longer times to diagnosis. (These correlations are statistically significant.)

**DIAGNOSIS DELAYED.** About half of respondents said they had had their EM symptoms more than two years before being diagnosed with EM, and 11 percent more than 10 years.

Only 26 percent said their doctors were educated well enough about EM to diagnose and treat others with EM.

This survey confirmed the hallmark symptoms of EM and also described the painful, chronic nature of the disease.

Not surprisingly, 99 percent reported that flares affect their feet or hands, with 93 percent experiencing redness and burning. And 93 percent said hot weather made flares worse.

Almost 80 percent of respondents reported their worst flares cause an intense or excruciating degree of pain. Some 45 percent reported feeling their pain both at the skin level and deep into their bodies.

Most people with EM (84 percent of respondents) also reported they had chronic symptoms – those that had stayed about the same or gotten worse over time.

**FEW EVER SYMPTOM-FREE.** A majority (64 percent of respondents) said that since their symptoms started, they have had no symptom-free periods of more than few days.

If they did nothing to control flares, 80 percent of respondents said they would flare every day.

A hot environment (65 degrees F or above) causes EM flares or makes them worse for 93 percent of those respondents who said weather conditions exacerbate their flares.

Approximately 50 percent of respondents said they did not perspire at all or had reduced perspiration.

(Continued on page 3)

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## Mayo: EM not so rare, after all

A 2008 Mayo Medical School/Mayo Clinic study found the incidence of EM (how many people a year are diagnosed with EM) was 1.3 per 100,000 people per year.

The rate for women was higher – 2.0 per 100,000 per year – than men, which was just 0.6. These statistics have a 95 percent confidence level.

Conducted by Mark D.P. Davis, M.D., and K.B. Reed, M.D., the study also found the number of new people diagnosed with EM increased in the study group during every ten-year period over the past 30 years.

Overall incidence also increased with age. The median age at diagnosis of those studied was 61.

The rates reported in this study were five times higher than those estimated by a 1998 Norwegian study, which is the only other known research describing EM incidence.

This is the first known population-based study of EM incidence. Using data from the Rochester Epidemiology Project, researchers drew the study group of 33 EM patients.

All were residents of Olmsted County, Minn., U. S., who were diagnosed with EM from 1967 through 2005. (None had inherited EM.) This rural Minnesota County includes the city of Rochester where the Mayo Clinic is located.

Incidence rates among patients in the study were sex- and age-adjusted to the structure of the U.S. white population in 2000, taken from U.S. census data.

By statistically adjusting for factors like age and sex, researchers can make meaningful comparisons between two very different groups like the population of Olmsted County and the population of the U.S.

Mayo researchers believed that the increased incidence during the last 30 years is real because physicians in Olmsted County have been aware of this disease for several decades.

The study was limited by the small number of patients and the potential differences among doctors in recognizing EM.

“Incidence of Erythromelalgia: a population-based study in Olmsted County, Minnesota.” is in TEA’s online archive.

## Abstract

**Objective:** To estimate the population-based incidence of erythromelalgia

**Background:** Only one report describing incidence of EM has been published before

**Study Design:** A population-based analysis of data from the Rochester Epidemiology Project

**Setting:** Mayo Medical School/Mayo Clinic in Olmsted County, Minnesota (a rural County in southeastern part of the state)

**Patients:** 33 residents of Olmsted County with a diagnosis of erythromelalgia in the study period (30 years)

**Methods:** Age- and sex-specific incidence rates of EM

**Main Outcome:** Population-based incidence rate

**Limits:** Small number of patients in study group; potential diagnostic differences

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### Survey findings *(continued from page 2)*

But almost half said they had some or a lot of control over the frequency of flares by controlling their environment.

About 87 percent reported knowing certain things triggered their EM symptoms or made them worse. After heat, exercise/physical exertion (79 percent), showering (50 percent), alcohol (42 percent), and elevated emotions (42 percent) topped the list of triggers.

More than half did not think their symptoms started after some sort of defining event like trauma or life change. But 28 percent reported that they did.

The full report of survey findings, and the doctor list, will be posted on the Web site.

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## Volunteers handle TEA information calls



**Sandii Berkshire**



**Jan McKim**

***I want to participate in the TEA Networking Program. (See page 12.)***

**Signature**

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**Mail to: Gayla Kanaster, 2532 N. Fremont St., Tacoma, WA, USA 98406**

Have you ever wondered who answers TEA's member services phone line — 610-566-0797?

TEA is now fortunate to have three capable volunteers – all with EM – who rotate months checking the TEA line for messages and returning calls.

This “telephone committee” handles an average of 15 calls a month. They answer questions about TEA services and the Web site. Some callers need help logging onto the site. Others inquire about membership.

One volunteer is Sandii Berkshire, Mukilteo, Wash., U.S. She works part time for a newspaper publishing company and also volunteers

at an animal shelter.

Another TEA telephone volunteer is Jan McKim, San Carlos, Calif., U.S.

A former TEA board member, she has a master's degree in counseling.

Justin Wedul, Denver, Colo., U.S., is the third volunteer. He works in financial services and is active in the EM Yahoo support group.

Before forming a committee, board of directors' members Deborah Mosarski and Gayla Kanaster returned most calls.

President Beth Coimbra answers e-mails sent to memberservices-@erythromelalgia.org – another way people can get information about TEA.

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### ***Former president, board member honored***

TEA recently sent clocks with engraved remembrance plaques to Lennia Machen, founding member and former president; and former board member Judy Reese.

“Being in TEA was one of the most important and meaningful things I have ever done in my life ... being associated with the others in founding TEA made all the difference to me in living with EM,” wrote Lennia in thanking TEA.

Lennia served as TEA's president from the founding in 1999 through 2005. She led the board of directors

through the start-up of TEA, launching the Web site, beginning the library of medical journal articles, etc. She also wrote and edited the newsletter for four years.

Judy Reese joined the board in 2003 and served as Networking Chairperson for five years. She helped many members connect with others with EM.

“I appreciated working together for the thousands of EM sufferers. ... TEA's library is an amazing tool for those needing to understand all about erythromelalgia,” wrote Judy.

# 'Thank you' to our Donors

TEA thanks those who made donations from October 1, 2008, to January 31, 2009

<sup>^</sup> gifts made in honor or memory of someone + gifts made to the Research Fund

\* gifts made to the 2008 Annual Appeal (Gifts received after January 31, 2009, will be acknowledged in the Spring issue)

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Kate Conklin adjusts her swim cap before beginning the first leg of the Foster Grant Ironman World Championship — the 1.2-mile swim.



Kate smiles for the official post-race photo.

## EM's best ambassador Kate competes as "inspiring athlete"

2008 was an amazing year for TEA member Kate Conklin!

She was chosen to compete as an "inspiring athlete" with the best triathletes in the world in the Foster Grant Ironman World Championship 70.3, in Clearwater, Fla., in November. NBC will air race coverage in mid-April.

Kate's photo and a blurb about her, the Ironman and EM appeared in the "Faces in the Crowd" column in the Dec. 1, 2008, *Sports Illustrated*.

She was the subject of an eight-minute feature on ESPN TV SportsCenter that aired as she was competing in an Ironman in Kentucky in August.

Kate is a certified physical trainer for Sports Club LA, living in New York City. She has chronic, painful EM that she describes as feeling like she is on fire.

But her goal is unchanging: "I race in the Ironman to raise awareness about EM ... to help people live with extreme pain, help them not give up even though it seems there is no hope."

TEA recently named her an Awareness Ambassador and is providing her support in covering some of the expenses involved in competing.

NBC Sports cameras followed Kate from a helicopter during the world championship swim and bike ride. They gave her a bright orange swim cap so they could spot her.

And a camera crew filmed her from a motorcycle throughout the run. Kate appeared in sports reports the weekend of the race on NBC stations in Clearwater, New York City, and Omaha, Neb., where Kate grew up.

The mid-April U. S. national coverage of the world championships on NBC will include a feature on Kate as one of the "inspiring athletes."

The championship race was an Ironman 70.3 (miles). This means the distance was half that of an Ironman, which is 140.6 miles. That's a 2.4-mile swim, a 112-mile bike ride and a 26.2-mile run.

Kate was determined to finish the race. Even though her excruciating EM pain was compounded by pain from a stress fracture in her foot, she would not quit. She crossed the finish line limping, but with a Kate smile on her face.

"So here I go, testing myself again, embracing my pain and trying to make it work for me in the race," Kate wrote.

Kate races next in an April 26, 2009, marathon in Cali-

*(Continued on page 7)*

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**Kate competes** (continued from page 6)

fornia. *Runners World* magazine plans to do a feature on Kate.

Earlier in 2008, Kate ran a May mararthon in Rhode Island and competed in a July Ironman 70.3, also in Rhode Island.

For reports of just some of her endeavors see *FootSteps* Fall 2008, “Millions see Kate on ESPN TV Sportscenter;” *FootSteps* Spring 2008, “Cameras follow Kate running for EM awareness;” and Winter 2008, “One-woman awareness campaign.”

Read her blog — [KateConklin.blogspot.com](http://KateConklin.blogspot.com) — for links to her stories on ESPN and the news item in *Sports Illustrated*.



Kate Conklin, TEA Awareness Ambassador, runs and runs and (right) crosses the finish line — with a smile on her face. She competed as an inspiring athlete in the NBC-broadcast Foster Grant Ironman World Championship 70.3 in Clearwater, Fla., in Nov., 2008.

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## You, too, can be awareness ambassador

There’s only one Kate, but you could become an awareness ambassador, too.

TEA board member John Ravetti of Stockton, Calif., became an EM awareness ambassador last fall when he called his local Lion’s Club and asked to speak at one of the club’s luncheons.

He and daughter Danielle told Danielle’s EM story to the club and asked members to buy EM Awareness bracelets.

John and Danielle had previously done much to raise EM awareness and funds for research. The red awareness bracelets were 14-year-old Danielle’s idea.

John, a project manager for a waterproofing company, helped his daughter make the bracelet idea a reality in 2007.

You can still order bags of 20 bracelets from the TEA Web site for a \$20 donation to TEA’s Research Fund.

By selling individual bracelets for donations to the research fund, you can become an EM awareness ambassador yourself.

## Your Stories — everyone has one!

**Susan Burkett writes:** My EM symptoms started about 30 years ago. I am now 61, totally EM free and would like to share my story in the hope that others might be helped.

Once EM took hold I suffered a general intolerance to heat, while my feet/toes and hands were constantly fiery red, burning hot and prone to blistering. Wearing anything on my feet was impossible, even in Canberra's subzero winters. Doctors were baffled by my symptoms.

All this was complicated by co-existing medical conditions, including Raynaud's, a T-cell defect and chronic renal failure requiring dialysis.

In 2000 I embarked on my

own research. As a music librarian, researching things has always been in my nature and part of my job as a cataloguer at the Australian National University. I had long suspected that certain medications and foods were aggravating if not causative factors.

The culprits were all cheeses and yogurts, chocolate, yeast, processed meats, alcohol, gelatin (incl. capsules), pectin, citric acid, the B vitamins, Vitamin C and aspartate.

Ingestion of either fermented products or additives/preservatives manufactured by a fermentation process will quickly provoke flares. By eliminating these from my

diet I am now totally symptom free. Fresh foods and commercially prepared foods free of additives cause no symptoms. Sugar as such is fine.

The reason that I originally suspected a connection between EM and food was my knowledge of horses. They suffer a similar debilitating condition resulting in hot/cold feet called laminitis, which is directly related to diet.

Although the exact mechanism is unclear, it is known that abnormal fermentation in the gut, possibly caused by the release of vasoactive amines/glutamates, is a key factor.

### TEA Articles

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# TEA Articles

**Please note: Members with access to computers are urged to print copies from the Web site.**

## Treatment

[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.

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[Researchers find the right combination to unlock neuropathic pain.](#) *Medical News Today*, 16 Sep 2006. Pain relief with a combination of oxycodone and gabapentin.

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[Treatment of primary erythromelalgia with cyclosporine.](#) Sano S, Itami S, Yoshikawa K. *New England Journal of Medicine* 2003, 349:816-817. Successful treatment with cyclosporine in adult with inherited EM.

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[Treatment of erythromelalgia with a serotonin/noradrenaline reuptake inhibitor.](#) Moiin A, Yashar SS, Sanchez JE, Yashar B. *British Journal of Dermatology* 2002, 146:336-337. Improvement of EM in 10 patients treated with venlafaxine.

[Erythromelalgia: response to serotonin reuptake inhibitors.](#) Rudikoff D, Jaffe IA. *Journal of American Academy of Dermatology* 1997, 37:281-283. Rapid relief of EM in 3 adults with venlafaxine or sertraline.

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[Erythromelalgia pain managed with gabapentin.](#) McGraw T, Kosek P. *Anesthesiology* 1997, 86:988-990. Successful treatment with gabapentin for one child and one adult.

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## Treatment

*(Continued from page 9)*

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## Research

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## ***Thanks for Goodsearching***

Members, family and friends earned money for TEA in 2008 simply by searching the Internet using Goodsearch.

TEA received a check for \$150.70 from Goodsearch.org for 2008. That means more than 11,000 searches were made with TEA as the beneficiary.

Goodsearch is a fund-raising, Yahoo-powered search engine and online shopping Web site. Each search earns TEA a one-cent donation.

By shopping through GoodShop.com, TEA earns donations averaging three percent (and up to 37 percent) of the value of your purchases.

It's easy to use. Go to GoodSearch.com, click on "Who do you Good-Search for?" Then enter "Erythromelalgia Association." Follow directions for making Goodsearch your homepage.

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## **Canadian coordinator named**

TEA members who live in Canada now have a Canadian Networking coordinator — Gillian Birrell, Barrie, Ontario.

The TEA Networking Program helps members without computers contact other networking members living nearby.

To network, Canadian members now can contact Gillian. All others still contact Networking Chairperson Gayla Kanaster.

Receiving hard copies of medical journal articles from TEA's Web site archive is an additional service for those without access to the Internet. There is a nominal charge for printing and postage. (See page 8.)

To become a Networking Program member, complete the application form on page 4.

You can write to Gillian at 51-490 Veteran's Drive, Barrie, ON, Canada L4N 9N4.

Write to Gayla at Gayla Kanaster, 2532 N. Fremont St., Tacoma, WA, USA 98406.