

# FootSteps

TOWARD PROGRESS

The newsletter dedicated to finding a better way to live with erythromelalgia

Volume 7, Issue 4, December 2006, Published by The Erythromelalgia Association, [www.erythromelalgia.org](http://www.erythromelalgia.org)

## Yale Researchers Collaborate with Dr. Drenth

“TEA members will be pleased to hear that we are now collaborating in some new work with Dr. Joost Drenth,” said Steven G. Waxman, M.D., Ph.D., director of the West Haven Veterans Administration Rehabilitation Research Center and chair of the Department of Neurology at Yale University School of Medicine.

Scientists at Yale have demonstrated certain genetic mutations can cause the pain and redness in the limbs of people with inherited EM. (See *FootSteps*, June 2006.)

Researchers at Yale and in The Netherlands are studying two families with members who developed EM as adults, but who do not have the same sort of genetic mutations as others in families with EM that starts in childhood.

The Yale team found one of these families and the second family was identified by Joost

Drenth, M.D., Ph.D., and colleagues at Radboud University Nijmegen Medical Center, The Netherlands. (See Research Update, *FootSteps*, September 2006.)

Both research groups are searching for another gene that is causing EM in these two families. If they can find the gene, it also may teach them about adult-onset, non-inherited EM, Yale researchers say.

### Non-inherited EM

While Yale researchers continue to focus on inherited EM, they are also interested—and are actively investigating—non-inherited EM.

An example is another technically challenging study under way at Yale into “polymorphisms,” which are small changes in genes.

Researchers theorize that these small changes do not cause families to have EM, but may predispose individuals to develop EM if exposed to an appropriate trigger.

Yet another study will examine the nerve fibers within the skin of people with non-inherited EM. Using biopsies from people with EM, scientists will look for defects at the molecular level.

Preparations for this effort-intensive study are just beginning.

### New Physician Contact

Yale has named Tanya Fischer, M.D., Ph.D., as the physician contact for people with EM who wish to volunteer to be part of the research. Yale is currently recruiting just people with inherited EM.

Those interested may e-mail her at [tanyafischer@yale.edu](mailto:tanyafischer@yale.edu) or, if you can't e-mail, call 203-937-3802.

## Yale Raises Doctors' Awareness of EM

Raising awareness of EM among doctors is one of TEA's long-term goals, and Yale's Dr. Waxman is proving to be one of our best ambassadors.

He and his research group this year have made approximately 15 EM-related presentations to doctors at scientific meetings and conferences around the world.

When describing their research findings, they always explain in detail what EM is.

EM awareness gets an increased boost when magazines like *Science* report on what Dr. Waxman says, as was the case

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# TEA's Redesigned Web Site In Use

In use since late summer, TEA's redesigned Web site offers members new services like the ability to search the new Member Directory for other people with EM in your geographic area.

The site's new technology means TEA can more easily and quickly update and add information, says TEA President Beth Coimbra.

The site already houses more information about EM than any other single resource.

Most new TEA members join while visiting the site. And the site's improved technology now allows newcomers to pay a membership donation and gain access to member-only pages immediately.

Membership renewals and donations also can be made online, saving hours of work for volunteers.

"It's very exciting to be able to administer the member accounts more efficiently and make changes more quickly and easily, Coimbra says.

Contact Us

Those visiting the site will notice a new "Contact Us" button on the navigation bar or menu that appears on the left side of the home page.

Clicking on "Contact Us" allows users to e-mail the Webmaster with any questions. E-mails are answered within 24 hours.

Members have e-mailed most frequently about password recognition issues or for help using the new Member

Directory, Coimbra said.

Edit Directory

Coimbra encourages members to review their listings in the directory. While online you can make any changes necessary to keep your information current.

Although members can view the entire directory, be assured you alone can access your listing to make changes.

This directory is the central and only database of information about members. It is used by TEA as the source of mailing addresses for this newsletter, for instance.

Members not wanting their listings visible to other members can request that their information be accessible only for administrative purposes.

**If you are currently a member of TEA and do not want directory information accessible to other members on the Web site, you need to**

**contact Member Services immediately.**

In addition, a new page now is available that links users to artists or other vendors who donate a portion of their proceeds to TEA.

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*(Continued from page 1)*

## EM Awareness

in its October 27, 2006 issue.

An article in that issue, "Unraveling Pain's DNA," features Dr. Waxman's talk at the Society for Neuroscience's meeting in Atlanta in October.

Just a few of the other EM-related presentations include the J.Z. Young Memorial Lecture, University College London, London, February 2006; a presentation at the Pain Research Conference, Grand Cayman Islands, April 2006; and another at the Oregon Health and Sciences University, Portland in October.

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**The Erythromelalgia Association**  
200 Old Castle Lane, Wallingford, PA, USA 19086

[www.erythromelalgia.org](http://www.erythromelalgia.org)

Beth Coimbra, President

Isabelle Davis, Vice President

Gayla Kanaster, Secretary

**To contact: [memberservices@erythromelalgia.org](mailto:memberservices@erythromelalgia.org)  
or call 610-566-0797**

Gayla Kanaster, Co-Chairperson, Networking Program  
2532 N. Fremont St., Tacoma, WA, USA 98406

Judy Reese, Co-Chairperson, Networking Program  
1155 E. Duck Lane, Salt Lake City, Utah, USA 84117

Isabelle Davis, *FootSteps* Principal Writer/Editor  
[isabelle.davis@gmail.com](mailto:isabelle.davis@gmail.com)

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# *Serotonin Drugs Can Bring Rapid Relief from EM*

*By Jean Jeffery*

There are three reports in the medical journals that describe remarkable improvement of EM with the serotonin reuptake inhibitor venlafaxine (Effexor). These reports can be found in TEA's Article Archive.

Venlafaxine is a well known antidepressant and increases the amount of serotonin and norepinephrine (noradrenaline) in the nerves. Venlafaxine is also thought to play a role in the widening and narrowing of the blood vessels as it inhibits uptake of serotonin by the blood platelets.

DiCaudo's report<sup>1</sup> describes treatment of a 58-year old woman who had suffered with very severe EM in her feet for five years. Continual soaking in ice water had caused many large foot ulcers and confined her to a wheelchair. Many treatments had failed to provide relief.

The patient was prescribed extended-release capsules of venlafaxine (37.5 mg daily for one week, then 75mg each day). After three weeks medication her pain and redness had decreased, and by five weeks she had ceased soaking her feet and no longer needed her wheelchair. All ulcers healed completely by nine weeks. She has continued on 75 mg venlafaxine daily for more than nine months, during which she has experienced only mild discomfort of her feet after standing.

## ***Second Report of Improvement***

The second report<sup>2</sup> gives brief details of a pilot study in which ten patients with primary EM (cause unknown) were given venlafaxine (37.5 mg twice daily). After one week of treatment all participants experienced marked improvement in their burning pain and erythema (redness). These benefits contin-

ued during 6-18 months treatment. Only minor side effects of venlafaxine were reported (nausea, dry mouth and drowsiness).

## ***Third Paper Reports Relief***

The third paper<sup>3</sup> describes the rapid relief of EM in three women who used ice-cold water to relieve severe symptoms in their feet. They had each tried many different drugs without success.

Two of the women, aged 63 and 68, were given venlafaxine (37.5 mg twice daily). The first patient experienced rapid relief of her EM and then suffered no major attacks during the next 14 months. The EM symptoms of the second patient showed great improvement after three days treatment.

The third patient, aged 52, had EM in both her hands and feet. She was given the serotonin reuptake inhibitor fluoxetine (Prozac) 20 mg daily which gave no benefit. However sertraline (Zoloft) at 50 mg twice daily brought marked relief after three days. Fluoxetine and sertraline are different from venlafaxine in that they increase the levels of serotonin, but not of norepinephrine.

Improvement of EM with serotonin drugs was reported in the 2003 TEA Survey<sup>4</sup> in which over 200 members participated. Nearly 50% of 102 people with EM who tried venlafaxine, paroxetine (Paxil), or sertraline reported some relief of their symptoms. Three patients reported complete relief of their EM (two with paroxetine and one with sertraline). However with all three drugs there were some people who experienced wors-

ening of their EM symptoms.

Dr. Jay Cohen<sup>5</sup> writes that the serotonin drugs "provide substantial benefit for some, but not all, EM patients". He advises that treatment should begin on a very low dose, as some people with EM are very sensitive to these drugs and may not be able to tolerate the side effects of normal doses. He recommends beginning with the long-acting XR version of venlafaxine. The new serotonin drug duloxetine (Cymbalta), which is very similar to venlafaxine, has also given some good results.

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<sup>1</sup>Alleviation of erythromelalgia with venlafaxine. DiCaudo DJ, Kelley LA. 2004. Archives of Dermatology 140:621-623. (TEA Article Archive, Treatment No. 21)

<sup>2</sup>Treatment of erythromelalgia with a serotonin/noradrenaline reuptake inhibitor. Moinn A, Yashar SS, Sanchez JE, Yashar B. 2002. British Journal of Dermatology 146: 336-337. (TEA Article Archive, Treatment No. 12)

<sup>3</sup>Erythromelalgia: response to serotonin reuptake inhibitors. Rudikoff D, Jaffe IA. 1997. Journal of American Academy of Dermatology 37: 281-283. (TEA Article Archive, Treatment No. 11)

<sup>4</sup>TEA EM Survey. 2003

<sup>5</sup>Current information on treating erythromelalgia. Cohen JS. 2005. TEA Article Archive, Treatment No. 9)

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## Your Stories—everyone has one!

We can all empathize with fellow members who face the daily challenges of living with EM. Because EM is so rare, most of us have tales of the often long and difficult diagnosis process and the ways we've found to cope.

**Jeanne Ginter writes:** Though my symptoms weren't severe enough to seek medical attention, there had been subtle signs for several years. Burning pressure in my heels or my feet "just being hot" at the end of a workday. I was an X-ray Tech in a busy orthopedic clinic, an avid hiker, beachcomber and kayaker. ...

In December 2004 my symptoms accelerated very quickly. By January my feet started to swell, were red and burning hot most of the time. ... My doctor suggested I try vitamin B Complex. My feet continued to worsen and after five weeks they were so swollen that when I stepped down the tight skin would split. Soon they were covered with open wounds. I was in constant pain and unable to sleep.

I searched the Internet and read everything the TEA website offered a non-member. I went to another doctor who diagnosed EM. You can imagine the feeling of relief to finally hear a diagnosis. ... I came home and joined TEA. I was referred to a dermatologist. He was familiar with EM, Dr. Jay Cohen and his research, and had even treated several cases during his residency at a large teaching university. I started gabapentin 300 mg at bedtime. ... At least I could sleep and the edema in my feet finally began to lessen and the open sores healed.

I realized my life would never be the same, but I was not going to let it be less, only different. I bought five small clip-on fans. ... Heeding warnings about soaking feet in ice water, I found just running cool water over mine for a couple of minutes then putting them under a fan seemed to cool them nicely. When all sores were healed, I joined a water aerobics class. Exercise really helps the circulation in my feet and legs and my mental attitude. ... No longer able to take my

beloved hikes, I took short walks on cleared trails or the beach during cool days.

Thanks to TEA's newsletter, article archive and a cooperative doctor, two years after being diagnosed with EM I have found a more comfortable life. For me, taking a combination of gabapentin and very low dose of amitriptyline has worked better than either separately. The unpleasant side effects have eased considerably. I also began taking magnesium and noticed a positive difference. ... Now I'm able to wear a pair of Croc's, with smooth inserts to cover the rough interior, for short periods of time. Sometimes I take short walks or hikes, then allow my feet a couple of days to recover. I still have symptoms from moderate to severe at times but am thankful that I have a very supportive husband and found ways to live with this condition.

**Bonnie Wirkus writes:** My problem started about 10 years ago when I felt like my toes were turning to wood. The pad behind my toes always seemed red; then the burning began. Cold winters, rainy weather and humidity made my life a nightmare. The warmer weather of south Arizona is far friendlier to my feet.

This is the first year I've been able to wear tennis shoes and walk for more than 20 minutes at a time. When my feet are cold, they end up cramping to the point they look twisted, and a very hard and sharp edge appears at the arch. After discovering TEA I took 1200 mg calcium and 1500 mg magnesium daily. My feet are also "happier" when potassium is added to the mix. By "happier," I mean the pain is tolerable. I am on a blood thinner, warfarin, so aspirin is not an option for pain. A trial with orthotics made things worse.

At the Cleveland Clinic nerve conduction and circulation tests were not helpful, but the doctor examined my feet and knew what it was. She

*(Continued on page 5)*

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## Your Stories—everyone has one!

TEA encourages you to share your experience by writing your story. If you think you're not a writer, never fear. We can help you write and edit your story. Please send it to Gayla Kanaster, [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com) or 2532 N. Fremont Street, Tacoma, WA, USA 98406

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suggested pain medicine, which I have resisted taking. From trial and error, I've found footwear with slick innersoles do not work for me. My feet slide around and there is friction and pain. Suede innersoles are better.

I'm told that I have good sensitivity in my feet, but I can cut them and not know until I see the blood. In reading other EM stories, I see many similarities in how mine started behind the big toe and on the ball of my foot. I have found no local doctor familiar with EM.

I worked for my best friend and dance teacher as a bookkeeper and costume maker for 30 years. I made 300-500 costumes a year for her performances. I painted huge backdrops; Disney characters, Wizard of OZ, and many others. In Pennsylvania, I was head seamstress at a bridal store and had an alteration business in my home. I also love painting and photography.

I have led a very full life and plan to continue enjoying it as much as I can. I walk my friend's dog every morning. I swear he keeps me motivated to walk. I feel very guilty if I have to miss a day for any reason. Knowing there are others out there with problems similar to mine has been a help. I think I am one of the lucky ones, since my EM hasn't gotten worse. I only have a few days a week when I have "unhappy" red, burning feet.

**Dorothy Rosi writes:** I am a 78-year-old retired elementary school teacher. I'm single with two grown children, grandchildren and recently a great grandchild. I'm fortunate to live in an ideal climate along the beach north of San Diego in Cardiff, California.

I was diagnosed with EM only recently, but about 20 years ago I had my first symptoms, painful areas on the soles of my feet. I have seen a variety of doctors and for years I was treated by neurologists. They had me try a variety of medications, but I had only minimal relief using elavil and clonazepam.

Over the years, my symptoms worsened and I've had to learn what to do for myself. I've relied on wearing soft thong sandals, elevating my feet whenever possible, trying to stay in an environment below 75 degrees, having fans by my bed and couch, etc.

I had air conditioning installed in my home, then carpeting throughout with the thickest padding available to allow me to be barefoot the entire day. Last year I purchased an electric scooter and lift for the back of my car so I can continue to market and get to appointments. Sunshine (even if it's cool), any lotions at all, and even soap impact my feet.

Five years ago I was so worn down by pain that my neurologist prescribed an opiate, morphine sulfate. It gave me some relief at night, but was barely worth the side effects and after a couple of years I stopped using it. More recently I've been prescribed Lyrica, which is a great help, especially during the day. I've also started taking Cymbalta, which further lessens the pain in my feet.

It's been a wonderful revelation to learn about TEA and the work that is being done. I suspect it's a bit late for me to learn what might cure my EM, but it's great there is hope for sufferers in the future. I appreciate the many people who are actively working to support TEA.

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# Meet Your TEA Board of Directors



## Meriwether Jones

*This is the second in a series of articles featuring the individuals that serve on TEA's board of directors. Board members are volunteers.*

If you took part in May's "Teleconference with Dr.

Cohen," you already know "Meri."

As the project leader of that TEA educational event, board of director's member Meriwether Jones phoned each person who registered.

And he made all teleconference arrangements. As a volunteer, of course.

TEA is very fortunate to have Jones on the board. Currently an independent consultant, he specializes in the design and facilitation of "peer learning" retreats for organizations engaged in philanthropy and/or community economic development.

He has a bachelor's degree

in economics and a master's of business administration and has served on numerous boards.

His career experience includes posts as executive director of the Community Strategies Group of the Aspen Institute. He also served as manager of Venture Development & Finance for the State of South Carolina, among other posts.

Jones has a true motivation for finding solutions to living with EM. His wife has EM.

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## Q and A

*This column was a feature of the Networking Program's "What's What," which has been folded into FootSteps. Submit your answers and suggest new questions to Gayla Kanaster at [Gayla.Kanaster@aol.com](mailto:Gayla.Kanaster@aol.com) or write to her at 2532 Fremont St., Tacoma, WA, USA 98406*

**Karen Kimble** of South Bend, Indiana, U.S., writes:

"I have suffered with EM for 19 years, and in the past few years I have noticed that humidity exacerbates the pain both for me and for my daughter who has developed EM in the last four years." They pose this issue's question:

**Q. Does humidity affect other people with EM?**

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### *Directors Needed*

TEA's board has two open positions. Just send an e-mail to Gayla Kanaster at [Gayla.Kanaster@aol.com](mailto:Gayla.Kanaster@aol.com) if you want to become a director.

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## *A Code of Our Own*

As we all know, EM is a very rare disease. Most doctors don't recognize its symptoms and can't diagnose it. Some who know about it doubt that EM is really a disease at all.

But, in the U.S., if doctors' offices can bill insurance companies for treating EM, then it must be a disease. And now they can do just that.

Back in October 2005, EM for the first time got its own ICD-9-CM code.

In the labyrinthine system that is health care financing in the U.S., every diagnosis noted by a doctor in a patient's medical record must be "coded" by the doctor's (or the hospital's) billing specialist.

With the code, the patient's insurance company can be billed for the care provided. And the provider will get paid. That's why codes are important.

ICD-9-CM stands for International Classification of Diseases, Ninth Revision, Clinical Modification.

The listing is based on the World Health Organization's International Classification of Diseases.

How did EM get a code? Former TEA President Lenina Machen found and completed the U.S. governmental paperwork needed.

Tell your doctors. EM has a code.

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# TEA Thanks Those Who Donate

*TEA thanks the people and organizations who made donations to the association and the Research Fund in the six months from June 1, 2006 through November 30, 2006.*

Aetna Foundation	Sheila Kirchmann
John Allen	Effie Mae Lamont
Sylvia Ambrosini+	Sharon Landry*
Patricia Anderson+	John Langford+
Kathy Baldridge+	Eleanor Latham+
Michael Bame+	Pamela Levitt+
Regina & Dieter Bayer*	Marion Levy
Caroline Bell+	Sheldon Levy*
Dolores Besch+	Sue Lockwood
Elaine Blanchette	Meg Lombardi
Corina Blouin+	Maureen Loughton+
Mrs. D. Brisley+	Debra Lybrand+
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Holly Burke+	Isabelle W. Manwiller*
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Stephanie Curran+	Elizabeth Miller+
Charles Daniel	Fran Mishler+
Keith Darby+	M. Mouthaan+
Isabelle Davis	Laura O'Brien+
Kathleen DeFrehn+	H. Ruth O'Rourke+
Peter DeSpirt	Jacqueline Oyster+
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Nancy Franklin+	Abbie Scarpulla
Nancy Gaseau+	Vivian Stafford+
Nicolette Greer+	Sandra Steed+
Dolores Griffith	Tom Stock+
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Dawn Hamer	Sharon Sugar
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Michelle Howard+	Mrs. O. Tomlins+
Jane Hrynio+	Marilyn Wade+
Derek Humphry	State of Washington
John Izzi+	Suzanne Wildman-Chard+
Mrs. G. Knifton+	Rolf & Nancee Wirthgren+
Renee Kalisvert	
Vivian Kammerer	

\*Indicates donations made in memory or in honor of someone.

+Indicates gifts to the Research Fund.

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## ***Consider Donation Options***

When you donate money to TEA you now have options. You can give to the Research Fund or to the association's General Fund.

The TEA board of directors has become increasingly aware of the need for funds for uses other than supporting medical research.

The board plans to develop programs to increase the flow of information about EM both to people with EM and their families, and to health care practitioners. These goals are an important part of our mission.

The "Teleconference with Dr. Cohen" in May 2006 was one such informational program. It got such an enthusiastic response from our members that we want to offer more like it.

We also hope to develop a full-blown campaign to inform health care practitioners about EM. These are the initiatives your donations to the General Fund might support.

### **Membership**

The board intentionally keeps membership dues low so that almost anyone needing the information TEA already provides can get it.

Our policy has been to use the money collected as membership donations to fund TEA's day-to-day expenses like the telephone bill and the cost of printing and mailing *FootSteps*.

However, the cost of these services continues to rise and TEA needs more funds to cover its operating expenses.

### **In Honor, In Memory**

Donors have been able to make donations in memory or in honor of someone special since 2003. These gifts traditionally have gone to the Research Fund.

Now those donating these gifts will be able to specify General Fund or Research Fund. Unspecified gifts will go to the General Fund.

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## Use Directory to Network; Existing Program Continues

New member Linda Reger lives in a small town in eastern Washington, U.S. She doesn't have access to a neurologist or other specialists and wanted to connect with other people with EM.

Using the new Member Directory on TEA's Web site, she e-mailed all 22 members in Washington state. Eight members responded and she is getting the information she sought.

"By networking with fellow sufferers, I have found that we can help each other," she says. Corresponding with others also helps her feel that she is not alone.

Only TEA members have access to the Member Directory. It can be sorted by last name, U.S. state, and country.

### Networking Without Computers

Are you a member without a computer or computer skills—without access to TEA's Web site? And would you also like to contact others living near you who have EM?

TEA still offers the Networking Program, a service for people who don't have easy

access to the Web site. Program co-chairperson Judy Reese will give you the names of other members in the Networking Program who live in your geographic area. Just fill out the form below and send it to Judy, **1155 E. Duck Lane, Salt Lake City, Utah, USA 84117.**

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### I want to participate in the TEA Networking Program.

**Signature** \_\_\_\_\_

**Name (Please print)**

\_\_\_\_\_

**Street** \_\_\_\_\_

\_\_\_\_\_

**City** \_\_\_\_\_

**Province** \_\_\_\_\_

**Country** \_\_\_\_\_

**Zip/Postal code** \_\_\_\_\_

**(Optional) Phone** \_\_\_\_\_

**E-mail** \_\_\_\_\_