

# *FootSteps* TOWARD PROGRESS

The newsletter dedicated to finding a better way to live with erythromelalgia  
Volume 7, Issue 3, September 2006, Published by The Erythromelalgia Association

## TEA Web Site Redesigned, Updated

If you have visited TEA's Web site recently, you will have noticed some big changes. While member names and passwords remain the same, even the "log in" box has changed.

During the summer, Adam Coimbra "built" TEA a completely new Web site. Adam, 14, says he learned how to design Web sites on his own during four years of experimenting with computers. It's one of his hobbies.

Much of the information visitors to the site can "click on" has been updated, thanks to Adam's Mom, Beth Coimbra, TEA's president.

Adam integrated PayPal, an Internet financial management service, into the TEA site. PayPal allows TEA to accept—and immediately process—credit card payments online.

One big advantage of the new site is that individuals,

paying online using PayPal's secure service, can become paid members with full benefits immediately.

That means being able to gain access to the Article Archive and other member-only pages.

And donations and membership renewals can be done online as well. In fact, using the online service will save hours of volunteers' time spent processing checks sent to TEA's office.

Another feature of the new site is the TEA member directory that has been one of TEA's longtime goals. (See story, right.)

The backbone of any Web site is a database, Adam says.

For those of us who grew up before the dawn of the "Information Age," a database is "an organized body of related information."

In the jargon of computer science, it's "a collection of data arranged for ease and speed of search and retrieval."

In the case of Web sites, it's pages of information that users want to search through and "retrieve" what interests them most.

Adam also developed a content management system that holds all the information the TEA site offers to users as well as the association's administrative data.

TEA's site has more information about erythromelalgia in one place than any other resource available to people seeking answers about EM.

Visit the site soon. It's [www.erythromelalgia.org](http://www.erythromelalgia.org) or [www.burningfeet.org](http://www.burningfeet.org). If you don't have a computer, try your local library where a librarian should be able to assist you.

### ***Member Directory Now on Web Site***

A directory of TEA members is now available—to association members only—on TEA's updated Web site. Included are names, home addresses, countries, telephone numbers and e-mail addresses.

**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.**

Just call the new U.S. based Member Services number—

#### **Also In This Issue**

New Phone, Address .....	2
Neuropathy/Vasculopathy.	3
Meet the Board .....	4
Q and A .....	4
Research Update .....	5
Your Stories .....	6,7,8
Networking .....	9
Article Archive ..	10, 11, 12

(Continued on page 2)

---

## Member Directory on Web Site, Opt Out Now

(Continued from page 1)

610-566-0797—and leave a message. A member of the TEA board of directors will call you to confirm that your information is not visible on the Web site.

Creating a web-based members' directory has been one of TEA's published goals for several years. It is hoped that having such a directory will improve opportunities for communication among members of the association.

Members visiting the Web site will be able to sort the information in the directory by last name, U.S. state, and country. Then members can "network" with other members in their geographic areas.

Web site designer Adam Coimbra created the directory as a part of building the new TEA Web site. (See "Web Site Redesigned, Updated," p. 1.)

The new member database also makes administrative functions easier. Now when new members join TEA—if they answer "yes" to the member directory option—they will create their directory listings themselves.

If they answer "no," their information will be a part of the directory that will only be accessible for administrative purposes.

This new automatically generated directory listing means less work for volunteers behind the scenes who will only have to manually enter information for new members who join via

e-mail or traditional mail.

Renewal letters also will be generated automatically two months before your term of membership expires.

If you don't renew by your membership renewal date, your membership will lapse. If you then attempt to

log in to the site, you will get a message on your screen that you need to renew.

Because of these new automated functions, TEA now can begin to spend some valuable volunteer time on launching expanded educational services, a new organizational goal.

---

## TEA Has New Phone Number, Address

As of September 1, 2006, TEA's new telephone number is 610-566-0797. The business office address is 200 Old Castle Lane, Wallingford, PA 19086.

All three e-mail addresses remain the same: [re-search@erythromelalgia.org](mailto:research@erythromelalgia.org); [membership@erythromelalgia.org](mailto:membership@erythromelalgia.org); and [memberservices@erythromelalgia.org](mailto:memberservices@erythromelalgia.org)

The phone number is now a message line. Anyone who calls gets a recorded message, asking the caller to leave a message and promising a return call within 48 hours.

Three members of the board of directors—Meriwether Jones, Gayla Kanaster and Deborah Mosarski—are sharing the responsibility of making the return calls.

From now on, donations and membership correspondence should be sent to the PA address. The Networking Program is not affected by these changes.

After seven years as a board of directors' member and four years of responsibility for membership and member services, Ray Salza has given up his TEA duties for personal reasons.

Ray has given TEA thousands of hours of volunteer time AND WE THANK HIM!

---

### The Erythromelalgia Association

200 Old Castle Lane, Wallingford, PA 19086

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* Editor, [imdcomm@aol.com](mailto:imdcomm@aol.com)

*FootSteps* is the official publication of The Erythromelalgia Association and is published quarterly for its members. Any information contained in this publication is protected by copyright and may not be reproduced without express permission from the editor. The intent and purpose of this publication is to inform those with EM or their friends and families—not, in any way, to provide medical advice.

---

# Abnormal Blood Flow and Nerve Damage Coexist in EM

**By Jean Jeffery**

This paper, titled "EM: vasculopathy, neuropathy, or both?" is written by Dr. Mark Davis and colleagues at the Mayo Clinic in Rochester, Minnesota. The abstract can be found in TEA's Article Archive, Research No. 14. EM is regarded as a vasculopathy (disorder of the blood vessels) or a neuropathy (damage to the nerves). To evaluate the role of the blood vessels and nerves in EM, the Mayo scientists tested vascular and nerve function in 67 patients who came to the Mayo Clinic between 1999 - 2001.

## Studying blood flow

Measurements of skin temperature, blood flow and the amount of oxygen present in the skin of the feet were made in 13 patients with EM. These tests were done in the absence of symptoms, and again when red hot burning symptoms of EM were present. During symptoms the average toe skin temperature increased by 7.8C and there was a massive 10-fold increase in blood flow, but the amount of oxygen in the skin remained unchanged.

The findings when EM symptoms are present are thought to be due to an abnormal increase in "arteriovenous shunting". The arteriovenous blood vessels shunt large volumes of blood through the skin away from the capillary vessels, which become hypoxic (deficient in oxygen). The cap-

illary vessels demand more blood, but this only serves to worsen the situation because fresh supplies of blood continue to be shunted away from them.

## Testing nerve function

Electromyography (EMG) and nerve conduction studies were carried out on 24 patients with EM when symptoms were not present. EMG records electrical activity in the muscles and nerve conduction studies record the speed at which impulses travel along the nerve fibres. These tests detect the presence of neuropathy (nerve damage) in nerves with large fibres. Abnormal results occurred in 14 (58%) patients of which 4 had abnormal EMG results only.

Fifty-seven patients underwent autonomic reflex screening. This included evaluation of sweat production and recordings of changes in blood pressure and heart rate that are governed by the autonomic nervous system. Autonomic nerves regulate these "automatic" body functions that are not under our conscious control. The autonomic tests are more sensitive than the EMG and nerve conduction tests because they can detect neuropathy in nerves with small fibres. Abnormal results in autonomic reflex screening

were found in 49 (86%) patients. In this group of 49, 94% had absent or dramatically reduced sweat production, and 30% had abnormalities in the tests for blood pressure and heart rate.

The findings from all the nerve studies show that large-fibre neuropathy (58%) is fairly common whereas small-fibre neuropathy (involving mainly sympathetic nerves) occurs in most cases of EM (86%).

The Mayo team conclude that both vasculopathy (caused by increased blood flow with shunting) and neuropathy (of mainly small-fibre nerves) are involved in EM. However it is not known which disorder is primary (occurs first). Vasculopathy can cause neuropathy because the increase in arteriovenous blood shunting leads to hypoxemia (deficiency of oxygen). This damages the nerves. On the other hand neuropathy may cause the abnormal changes of blood flow.

*(Since this paper was written, new research has shown that the genetic mutation in the inherited form of EM is a neuropathy in which the sympathetic nerves cause abnormal changes of blood flow in the skin).*

---

Erythromelalgia: vasculopathy, neuropathy, or both? A prospective study of vascular and neurophysiologic studies in erythromelalgia. Davis MDP, Sandroni P, Rooke TW, Low PA. 2003. Archives of Dermatology 139: 1337-1343.

---

## Meet Your Board of Directors



### Deborah Mosarski

A member of TEA's board of directors since 2003, Deborah lives with her husband in Charlotte, NC, U.S.

Deborah worked as a flight attendant for 12 years and en-

***This is the first in series of articles featuring the individuals that serve on TEA's board of directors. Board members are volunteers. Most live with EM or support a spouse with EM.***

---

joyed running, traveling, and ballroom dancing before developing EM in 1994.

Involved with medical support groups on the Internet for several years, Deborah has extensively researched her symptoms and EM.

She believes that the best way to help oneself and others is through education.

She has found few physicians are well informed about EM and thinks increasing physicians' awareness of EM would be the first step toward advancements in research into this debilitating condition.

Deborah's hope is that, through research, progress can be made to help identify, treat, and possibly even heal EM.

### Directors Needed

TEA's board has two open positions. You can bring your background and life experience to the board. Just send an e-mail briefly describing yourself to Gayla Kanaster@aol.com

---

## Q and A By Gayla Kanaster, 2532 N. Fremont St., Tacoma, WA, USA 98406

*Editor's Note: This column was a feature of the Networking Program's "What's What," which has been folded into FootSteps. You are encouraged to submit your answers and suggest new questions. E-mail Gayla at Gayla Kanaster@aol.com or write to her at the address above.*

**Q.** What do you do for EM relief that does not involve any changes of temperature?

**A.** Judy Reese of Salt Lake City, UT, U.S., says one of the best things she can do is to avoid stress. She admits this isn't always possible, but recently found that even a short getaway gave her almost immediate relief, after dealing with a stressful personal situa-

tion. She also takes 325 mg of aspirin daily, which "helps more than ibuprofen."

**A.** Bonnie Wirkus of Good-year, AZ, U.S., wears shoes with cloth or suede lining. She says, "If I wear shoes with slick leather or plastic soles my feet really burn and swell."

**Q.** What effects has menopause had on EM symptoms like flushing? Have any treatments helped?

**A.** Jean Jeffery, Nottingham, England: "I went through menopause in 1998-99, up to which point I'd had EM for eight years in my feet. I didn't suffer from the usual hot flushes and sweats. Instead,

the menopause triggered off new EM burning in my face and hands. It began with red burning ears, then cheeks, followed by occasional attacks of hot sweaty red palms and fingers during the day. Facial EM caused sleepless nights. Thankfully I tried HRT (combined oestrogen and progestogen) which has halted EM in my hands and reduced the frequency of facial attacks. I still take HRT. However, I have to avoid going out in the sun and also stay at temperatures below 22c/72F.

### Questions for next issue:

**Q.** What foods or drinks are likely to trigger EM flares?

**Q.** Have acupuncture or other "natural" therapies, including chiropractic, worked for you?.

---

## Research Update

# Dutch Researchers Busy Analyzing Results

by Joost P H Drenth, M.D., Ph.D.

*Editor's Note: Joost P H Drenth, M.D., Ph.D, Professor of Molecular Gastroenterology & Hepatology, Radboud University, Nijmegen Medical Center, in 2006 was the recipient of a \$30,000, one-year grant funded by TEA and administered by the National Organization of Rare Disorders. He submitted this report on the progress of the research.*

We, in Nijmegen, The Netherlands, are actively searching for genes that can cause erythralgia. Two years ago we were able to find a gene that if mutated caused EM. We tested this gene in six families, and all patients had one mutated gene, while all healthy siblings did not have anything wrong. At that point we thought that one gene caused all cases of familial EM.

We were wrong, because one family with EM from the USA did not have this gene mutated. We were puzzled and we carefully checked whether we made a mistake. The symptoms of the patients who had complaints were comparable to those families we already knew. We repeated our tests, and the same results came back, not the first gene, so a second gene had to be involved.

In the first months of 2006, we used a relatively new technique in order to pinpoint a possible second gene. We would not have been able to do this study without the support of TEA as this approach is very costly and labour intensive.

Only after receiving the funds could we start our investigations. The funds your members provided went into buying these DNA chips, performing the tests and analysing the data.

This new technique allows us to peek at 10,000 gene variants at the same time. Using this powerful technique we can compare the test results from patients with non-affected brothers and sisters. This will give us a profile that in the long run might tell us which gene is causing this form of EM.

As we write, we are busy with analyzing the results. You can compare this with finding a needle in the haystack as we have at least 100,000 pieces of information that we have to tie together. At this point we are further analyzing the results. In the end it will pay off.

---

## NORD Names Coimbra Audit Committee Chair

The National Organization for Rare Disorders (NORD) recently named TEA President Beth Coimbra chairman of its newly formed Audit Committee.

Like many other nonprofits, NORD is heeding the call to place more emphasis on financial and management internal controls.

Strengthening these controls should ensure proper oversight of organizations and was mandated for "for profit" entities.

A member of the board of directors of NORD since 2003, Coimbra will help chart the course for the new committee and NORD's audit process.

"The committee has been charged with writing an audit charter for NORD," said Coimbra.

She recently visited the corporate offices in Connecticut to further acquaint herself with NORD's business and management practices.

A CPA, Coimbra has extensive experience in the nonprofit sector.

She lives with her husband and two sons in Wallingford, PA, U.S.

---

## 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.

**Stacey Wilensky writes:** I am a 26-year-old female from Long Island, NY; blonde hair, blue eyes, fair skin—and red feet and hands since my late teens. I had never experienced any pain because of the redness, so I never considered that there might be something wrong with me. In January of this year, I suffered a bad case of bronchitis. Just as I thought I was getting better, out of nowhere I started having debilitating attacks of burning pain in my hands and feet. The attacks were so bad that I went to the emergency room twice in one week, only to be sent home with painkillers that did absolutely nothing for me. I visited every kind of doctor possible, had every test imaginable (including MRI and nerve conduction tests) and every single time I was told everything looked normal.

I searched my symptoms on the Internet and luckily found TEA's website. When I mentioned EM to a very kind rheumatologist, she confirmed that I did in fact have primary EM. Ever since, she has put me on different medications to try and control my EM flare-ups. Aspirin did nothing for me and Effexor made me feel like a zombie. Now I am on lopressor (a beta blocker) and amitriptyline at night. Amitriptyline has worked better than anything else I've tried. Unfortunately, it is meant for nighttime use since it causes extreme drowsiness. Some days I feel like my symptoms are under control and then some days I get flare-ups every hour, so it's very hard to tell what works and what doesn't. I hate having to plan my days based on how hot it will be outside or if there will be air conditioning where I'm going. It is so depressing to have to stay home sometimes when my friends are out at the beach or barbecuing in the summer. I miss taking my dog for long walks and I pray that someday there will be a miraculous treatment for all those who are suffering like I am.

On a happier note, I recently got engaged! The sparkling diamond looks gorgeous on my pink little finger! I am so appreciative of my fiancé's patience in dealing with me and this horrific nightmare that I have to live with. Because of TEA, we have learned so much together about possible remedies and we love to hear stories of remission. It has given us hope and we are so truly thankful that such a wealth of information is available to us. For our 2007 WINTER wedding (naturally!), we have decided to present a generous donation to TEA in lieu of wedding favors for our guests.

**Russell Jarret writes:** I am a 35-year-old male who led an active and productive life without any serious health problems until Feb. 26, 2000. After jogging six laps around a local college track, all of that changed. When I woke up the next morning and put my feet on the floor, I had severe pain in both my feet. I consulted a podiatrist and began treatment for plantar fasciitis. After getting no relief, I consulted a pedorthist (who works with devices to help foot problems) and began wearing "soft" orthotics, different shoes and limiting my daily activities.

I still had pain, so the next month I saw an orthopedic specialist and did eight weeks of physical therapy. When that didn't help, he referred me to an orthopedic surgeon, who gave me cortisone injections. I also began treatment with a chiropractor for pain in my lower back after prolonged sitting. After a nerve conduction study and MRI, with no diagnosis or relief from my foot pain, I was referred to two rheumatologists who started me on several medications.

In August 2002, I was released from my place of employment, partially because the pain in my feet and my back made it impossible for me to concentrate and perform my machinist work duties. I then got a passenger bus and log loader license, but I could not even concentrate on operat-

*(Continued on page 7)*



---

## 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

*(Continued from page 6)*

ing the tractor/trailer because of the pain.

I was prescribed 1800 mg of Neurotin daily for 60 days, had a full body bone scan, EMG, and more medication, tried the Lowdye Strapping Procedure (taping of the feet for support), and was diagnosed with "chronic" plantar fasciitis. After a tarsal tunnel release and a plantar fasciotomy on my left foot and 10 more weeks of physical therapy, my left foot hurt even more.

In June 2003, I began receiving treatment and medication for depression, short-term memory loss and lack of concentration. I tried to work as a telemarketer and began taking evening classes. Later that year, my car was repossessed. I finally had to withdraw from my classes. I was unemployed and had to go on Medicaid.

I've also tried prednisone, Cymbalta, lorazepam, Lyrica, Anodyne therapy, and nerve block shots in both feet. I had a spinal cord stimulator for seven days with only 25 percent improvement. After an increase in panic attacks and an elevation in stress, anxiety and anger, I was prescribed Clonazepam.

Last April I was diagnosed with erythromelalgia and I now have an appointment at the Cleveland Clinic with a neuromuscular doctor and dermatologist.

I have had 129 doctor visits, 126 psychological counseling sessions and 49 physical therapy appointments in the past six years and four months. I still have no relief from the chronic foot pain and am unable to sit for more than an hour at the time due to early arthritis of the disc in my back. I find it helps to wear flip-flops year-around, use calming techniques, and carry a folding stool.

**Mary Stuart-Menteth writes:** I am 67 years old and retired. My first unexplained symptoms were a loss of strength in my legs, poor tolerance of heat and getting tired, tingling in the soles of my feet, palms and face, progressing to burning. The burning would start if I got hot, stood up for too long or at night in bed.

Sometimes when I flare now, I get very thirsty and can feel unwell and panicky. I find both hot and cold weather hard to tolerate, as if I have lost my thermostat! It can be difficult to sleep, stand still or even sit with my legs down. I put my feet up a lot, sleep with neither blankets nor duvets to keep my feet, hands, legs and arms cool, wrapping my trunk up in sleeveless jumpers and shawls.

I saw neurologists regarding my loss of strength, but they found no explanation. Later I got in touch with TEA, thanks to a friend who read about it. I spoke to Milton LeCouteur, a TEA board member at the time, who thought my symptoms were typical. It was wonderful getting some information and above all, feeling no longer alone.

When I last saw a neurologist, I took photographs of my flaring feet, thanks to Jean Jeffery's suggestion. He said that he had only seen one case of EM, but I didn't have it because my symptoms weren't severe enough! However, he did suggest I try acupuncture. I consulted the Dundee nurse "help line" and later found a very supportive acupuncturist locally.

I also had my hair analyzed for mineral deficiencies and have been taking magnesium, calcium, zinc and vitamin D supplements, partly because of the analysis but also because I have a degree of osteoporosis. The only other medicine I take is for osteoporosis. There are many medicines I cannot tolerate, including aspirin because I have a history of a pre-ulcerative condition. I try to eat as much organic food as possible to avoid insecticides and avoid hydrogenated vegetable fats.

*(Continued on page 8)*

---

## More Stories

Marie and Monica's husband are members of the Networking Program in the U.K. Their stories were submitted for publication in "What's What," which has been folded into *FootSteps*. Please send your story to Gayla Kanaster, [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com) or 2532 N. Fremont Street, Tacoma, WA, USA 98406

*(Continued from page 7)*

I have certainly had less flaring at nights and have slept better, but I think that I am also organizing my life progressively better. I try to keep my bedroom at a constant temperature with a thermostatically controlled heater in winter and a fan in summer. I keep peppermint cooling gel from the Body Shop and small plastic bottles of water by my bed and in the freezer.

The latter are a godsend whenever I travel as I can use them to cool myself and, as they thaw, drink and splash myself with cold water. I also find that walking on my cold kitchen floor tiles can be very helpful.

I should be interested to hear from anyone who has had similar experiences. Please feel free to phone at 01883 744389 or e-mail: - [ms\\_menteth@hotmail.co.uk](mailto:ms_menteth@hotmail.co.uk)

---

### IN MEMORIAM

By Judy Reese

Len Bishop, a longtime TEA member, died April 28, 2006, in Burlington, Wisconsin. Len was one of the first Networking Program members, joining in June 2003. Born in 1934, he was diagnosed at the age of 19 with erythromelalgia. He also had fibromyalgia and recently developed lung cancer. Len had been a special friend of mine these past few years. His humor during all his health problems has been not only his saving grace, but others as well. He laughed at himself and his pain. He will be missed.

**Monica Rowland writes:** I am the wife of Peter Rowland, the networking coordinator for the UK. I have been with Peter for about 30 years and he was diagnosed with erythromelalgia about 8 years ago. I would say that was the time that his condition started to affect us as a couple. We knew that there was something wrong, but until then, we did not know what.

Things that we used to enjoy together, I was doing on my own or with my sons, like going for walks in the country near the small rural village where we live. At first the changes were so subtle we hardly noticed them. On outings, his walking slowed down. By the time we got back to the car his feet would be aching, hot and itchy. Peter always insisted he was all right, but I knew he wasn't. I could tell by the pain in his eyes, the way he walked and all the other telltale signs. I was annoyed that he wasn't being truthful, but also felt guilty that I was making him suffer.

Then we had a breakthrough—the doctor gave him a spinal block. He was like a new man. He wanted to walk everywhere and do things he had not done in years without pain. His appearance even changed. It was like having my old husband back. Unfortunately, this treatment only lasted about 18 months as he became immune to the drug they used.

Then the doctors were at loose ends as to what to try next. A spinal cord implant was finally suggested, and Peter had to go for a psychological assessment before the operation. The psychologist made Peter face his fears for the first time. When he came home, we sat and talked and Peter finally opened up and told me how he really felt. He had been hiding so much from me. I knew when he was in pain but not how much.

Now we're a happy couple who have had to overcome a few obstacles. With the help of Peter's implant and a wheelchair we manage most things that come our way, with compromises being made on both sides.



---

## Networking Program Provides Support, Information

Are you a member without a computer and access to TEA's Web site? And would you like to contact others living near you who also have EM or get copies of articles from the Article Archive?

TEA offers a service—the Networking Program—that helps you do both. Just fill out the form below and send it to Judy Reese at the address below.

By signing the application form, you give TEA permission to provide your name and address to other TEA members who are a part of the program.

Networking Program members without access to the Internet can also order copies of articles in TEA's Article Archive. The list of articles in the archive is printed in this newsletter. Those ordering copies of articles are charged a small fee [GAYLA: HOW MUCH? SHOULD WE SET A FIXED FEE LIKE \$2?] to cover mailing costs and copying charges based on the length of the article. Just use the form below.

To order email Gayla Kanaster at [GaylaKanaster@aol.com](mailto:GaylaKanaster@aol.com) or write to her at 2532 N. Fremont St., Tacoma, WA, USA, 98406.

---

### TEA Networking Program Application

I want to participate in the TEA Networking Program and I give TEA permission to distribute my contact information to other members.

Signature \_\_\_\_\_  
Name \_\_\_\_\_ Date \_\_\_\_\_  
Street \_\_\_\_\_  
City \_\_\_\_\_ Province \_\_\_\_\_  
Country \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_  
(Optional) Phone \_\_\_\_\_ E-mail \_\_\_\_\_

Mail to: Judy Reese, 1155 E. Duck Lane, Salt Lake City, Utah, USA 84117

---

### TEA Articles—Order Form

Name \_\_\_\_\_ Date \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_  
State/Province \_\_\_\_\_ Zip/Post Code \_\_\_\_\_  
Country \_\_\_\_\_ Date \_\_\_\_\_

Are You a TEA Member? ☐ Yes ☐ No  
(*\$5 Nonmember Service Charge for Each Order*)

Method of payment: (Make Checks Payable to TEA)

☐ Check enclosed ☐ Other  
☐ VISA/MC Exp. Date \_\_\_\_\_

Credit Card Number \_\_\_\_\_

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

*Members with computers should print articles from the Web site*

Document #	Charge
Cost Sub-Total	
Nonmember Fee	
\$2 International Shipping Charge	
Total	

## EM/Raynaud's

1. Coexistence of Raynaud's Syndrome and Erythromelalgia: two letters published in The Lancet 1999. Brief discussion on association of Raynaud's with EM.
2. Treatment of Raynaud's phenomenon with the selective serotonin reuptake inhibitor fluoxetine. Coleiro B, Marshall S, Denton C, Howell K, Blann A, Welsh K, Black C. Published in Rheumatology, 2001. Comparison of fluoxetine with nifedipine in 53 patients with Raynaud's.
3. Temperature-Associated Vascular Disorders: Raynaud's Phenomenon and Erythromelalgia. Belch J. Long thorough account of all aspects of Raynaud's and EM including cause, diagnosis, and treatments for different forms and types of EM.
4. Serotonin Reuptake Inhibitors, Raynaud's Phenomenon and Erythromelalgia. Rey J, Cretel E, Jean R, Pastor M, Durand J. Published in Rheumatology 2003. Sertraline and fluoxetine relieve Raynaud's but induce EM in 2 adults
5. Coexistence of Erythromelalgia and Raynaud's Phenomenon. Berlin, Pehr. Amer Acad of Dermatol 2004. A case report and comparison of the underlying causes of EM and Raynaud's
6. Pharmacotherapy of Raynaud's Phenomenon. J. Belch, M. Ho, published in Drugs, 1996. Cause of Raynaud's and choice of drugs for treating it.

## General

1. Erythromelalgia: A Clinical Study of 87 Cases. Kalgaard OM, Seem E, Kvernebo K. J Int Med 242:191-197. 1997 Study of symptoms and prognosis for 87 patients.
2. Erythromelalgia: A Condition Caused by Microvascular Arteriovenous Shunting. Kvernbo K, VASA, Journal of Vascular Medicine, Nov. 1998. This long paper covers all aspects of EM and how it is caused by abnormal blood circulation. Very technical.
3. Erythromelalgia: A Mysterious Condition? Short review of diagnosis, classification and prognosis of EM.
4. Erythromelalgia Caused by Platelet-Mediated Arteriolar Inflammation & Thrombosis in Thrombocythemia. Jan J. Michiels.
5. Erythromelalgia: Symptom or Syndrome? Belch J, Mackay I, Ninewells Hospital and Medical School, Dundee, Scotland, published in Vascular Medicine Review, 1992. This covers all aspects of EM and includes treatment for different sub-types.
6. Hot Feet: Erythromelalgia and Related Disorders. Layzer R, presented at the 23rd Carrell-Krusen Neuromuscular Symposium. Short review of symptoms and a neurological cause of EM.
7. Poxviruses Isolated From Epidemic Erythromelalgia In China. Z. Zheng, J Zhang, J. Hu, S. Liu, W. Zhu. Published in Lancet, 1988. EM epidemic associated with throat viral infection
8. A Refractory Case of Erythromelalgia Involving the Ears. Ramierz, Kirsner. American Journal of Otolaryngology 2004. Detailed report of one EM patient who remained resistant to all treatment.
9. Erythromelalgia: An Unrecognized Manifestation of Small-Fiber Neuropathy. Creating awareness that erythromelalgia can be a manifestation of small-fiber neuropathy
10. Natural History of Erythromelalgia, Presentation and Outcome in 168 Patients. M Davis, W O'Fallon, R Rogers T Rooke, Arch Dermatol. 2000. Review of 168 EM patients examined at Mayo Clinic between 1970-1994.

## Research

1. Skin Blood Flow in Adult Human Thermoregulation: How It Works, When It Does Not, and Why. Charkoudian N, Mayo Clinic Procedures. 2003. Review of many studies on temperature regulation of blood flow in the skin. Long technical paper.
2. Reduced skin capillary density during attacks of erythromelalgia implies arteriovenous shunting as pathogenetic mechanism. Mork C, Kvernebo K, Asker CL, Salerud EG. J Invest Dermatol 119:949-953. 2002 Abstract only. Abnormal blood flow in the skin capillary vessels.
3. A single sodium channel mutation produces hyper- or hypoexcitability in different types of neurons. Results of studies of the functional effects of a mutation of sodium channel Nav1.7 associated with a neuropathic pain syndrome, erythromelalgia, within sensory and sympathetic ganglion neurons, two cell types where Nav1.7 is normally expressed.
4. Pathological C-fibres in patients with a chronic painful condition. Rastavik K, Weidner C, Schmidt R, Schmelz M, Hilliges M, Jorum E, Handwerker H, Torebjork E. 2003. Changes in nerve condition in chronic EM.
5. Impaired Skin Vasomotor Reflexes In Patients With Erythromelalgia. Littleford R, Khan F, Belch J, The Biochemical Society and the Medical Research Society, 1999. The effect of the sympathetic nerves on skin blood flow in EM patients.
6. Red Skin Re-read. Schechner J, The Journal of Investigative Dermatology, 2002. Short summary of findings by Kvernebo and Mork on skin blood flow in EM. Very technical.
7. Impaired Neurogenic Control of Skin Perfusion in Erythromelalgia. Mork C, Kalgaard O, Kvernbo K, The Society for Investigative Dermatology, Inc. 2002. Nerve regulation of skin blood flow in EM patients.
8. Skin perfusion in patients with erythromelalgia. R. Littleford, F Khan, J. Belch, European Journal of Clinical Investi-

- gation in 1999. Detailed study of blood flow in the skin of EM patients.
9. Microvascular Arteriovenous Shunting is a Probable Pathogenetic Mechanism in Erythromelalgia. C Mork, C Asker, E.Salerud, K Kvernebo, Journal of Investigative Dermatology, 2000. Following the article is two replies by Drs. Davis, Rooke, and Sandroni, and a second reply by Mork and Kvernebo. Abnormal blood flow in the skin (shunting vessels) of EM patients.
  10. Erythromelalgia: Studies on pathogenesis and therapy. C Mork. Summary of earlier research in Norway on vascular and neurological causes of EM. Useful list of 200 other EM papers.
  11. Erythromelalgia: A hereditary pain syndrome enters the molecular era. Waxman, Dib-Hajj. Yale Research Project. Annals of Neurology, June 2005. Painful symptoms of EM caused by defective sodium ion nerve channel 1.7
  12. Gain-of-function mutation in Nav1.7 in familial erythromelalgia induces bursting of sensory neurons. Dib-Hajj, Rush, Cummins, Hisama, Novella, Tyrrell, Marshall, Waxman. Brain, June 2005. Study of third mutation in the gene for sodium channel 1.7 in Alabama Family
  13. Genetic heterogeneity and exclusion of a modifying locus at 2q in a family with autosomal dominant primary erythromelalgia. T.M. Burns, R.H.M. Te Morsche,\* J.B.M.J. Jansen\* and J.P.H. Drenth\*
  14. SCN9A Mutations Define Primary Erythromelalgia as a Neuropathic Disorder of Voltage Gated Sodium Channels. Drenth, te Morsche, Guillet, Taieb, Kirby,
  15. Erythromelalgia: vasculopathy, neuropathy, or both? A prospective study of vascular and neurophysiologic studies in erythromelalgia. Davis; Sandroni; Rooke; Low . Published in Arch Dermatol 2003 Detailed study of nerve abnormalities in EM patients
  16. Autosomal Dominant Erythromelalgia. W. Finley, J. Lindsey, Jr., J Fine, G. Dixon, M.Burbank. 1992, American Journal of Medical Genetics Study of Alabama family with inherited EM.
  17. Mutations in SCN9A, encoding a sodium channel alpha subunit, in patients with primary erythromelalgia. Y Yang\*, Y Wang\*, S Li\*, Z Xu, H Li, L Ma, J Fan, D Bu, B Liu, Z Fan, G Wu, J Jin, B Ding, X Zhu, Y Shen. J Med Genet 2004. Discovery of 2 mutations in sodium channel 1.7 gene in Chinese family.

## Treatment

1. A Way To Understand Erythromelalgia. Zoppi M, Zamponi A, Pagni E, Buoncristiano U, Journal of the American Nervous System, 1985. Successful treatment of 3 EM patients with 10 daily sympathetic nerve blocks.
2. Erythromelalgia Pain Managed with Gabapentin. McGraw T, Kosek P, published in Anesthesiology, 1997. Successful treatment with gabapentin for 1 child and 1 adult.
3. Nitroprusside Treatment Of Erythromelalgia In An Adolescent Female. Stone J, Rivey M, Allington D, Annals of Pharmacotherapy, 1997. Remission of EM is 15 year old using nitroprusside infusion.
4. Refractory Idiopathic Erythromelalgia. Ratzck R, Naveira F, Speight K, Smith B, Anesthesia Analog, 1996. Remission of primary EM in 2 adolescent males using various epidural infusions.
5. Erythromelalgia. Davis MD, Rooke T. Curr Treat Options Cardiovasc Med 4:207-222. 2002 Survey of 99 patients response to treatment.
6. High-dose oral magnesium treatment of chronic, intractable erythromelalgia. Cohen JS. Ann Pharmacother 36:255-260. 2002 Author's remission of EM & response of 12 other patients to magnesium.
7. Treatment of refractory primary erythromelalgia in a child using a continuous epidural infusion. The Pain Clinic, 2000. Improvement of EM with bupivacaine and clonidine in 4 year old boy.
8. Current Treatments for EM. J Cohen, 2005. A summary of treatment information about EM.
9. Growth Hormone & Erythromelalgia. Unexpected healing of cutaneous ulcers in a short child (with EM), Cimaz R, Rusconi R,
10. Erythromelalgia: Response to Serotonin Reuptake Inhibitors. Rudikoff D, Jaffe
11. Treatment of erythromelalgia with a serotonin/noradrenaline reuptake inhibitor. A.Moiin, S.S. Yashar, J.E. Sanchez, B. Yashar. A letter to the editor of the 2002 British Association of Dermatologists, British Journal of Dermatology. Improvement of Em in 10 patients treated with venlafaxine.
12. Lidocaine Patch for Pain of Erythromelalgia. Davis M, Sandroni P, Published by Arch Dermatology/ Vol. 138, Jan 2002. Successful pain relief for 15 year old girl with EM.
13. Resolution of Refractory Symptoms of Secondary Erythromelalgia With Intermittent Epidural Bupivacaine. L Stricker, C Green, American Society of Regional Anesthesia and Pain Medicine, 2001. Remission of EM in 28 year old female.

14. Erythromelalgia: an endothelial disorder responsive to sodium nitroprusside. by M Chan, A Tucker, S Madden, C Golding, D Atherton, M Dillon, Arch Dis Child 2002. Dramatic response by 2 children to nitroprusside.
15. Treatment of Primary Erythromelalgia with Cyclosporine. S Sano, S Itarni, K Yoshikawa, New England Journal of Medicine 2003. Successful treatment with cyproheptadine in adult with inherited EM.
15. One-Size Dose Does Not Fit All. J Cohen. Physicians and patients should look beyond the guidelines recommended by drug manufacturers. Newsweek, December 6, 1999. Advice on prescription dosage.
16. Aspirin-responsive painful red, blue, black toe, or finger syndrome in polycythemia vera associated with thrombocythemia. J.Michiels, Z. Berneman, W. Schroyens, H. van Urk, Springer-Verlag 2003 ABSTRACT ONLY- No full article. Success with aspirin for 3 EM patients.
17. The Prostaglandin E1 Analog Misoprostol Reduces Symptoms and Microvascular Arteriovenous Shunting in Erythromelalgia: A Double-Blind, Crossover, Placebo-Compared Study. Mork, Salerud, Asker, and Kvernebo. 2004 J invest Dermatol. Improvement of EM in 14 out of 21 patients.
18. Fighting Pain with Fire: Hot Chili Peppers Offer Relief - Capsaicin. by Mike Field, The Gazette, Johns Hopkins University, July 25, 1994.
19. Alleviation of Erythromelalgia With Venlafaxine. DiCaudo, Kelly, 2004. A case study of a woman treating EM with Effexor (Venlafaxine)
20. Combination Gel of 1% Amitriptyline and 0.5% Ketamine to Treat Refractory Erythromelalgia Pain. Paola Sandroni, MD, PhD; Mark D. P. Davis, MD
21. Pregabalin and Gabapentin for Neuropathic Pain and CRPS/RSD. Stacey, Campbell, 2006.