

FootSteps

TOWARD PROGRESS

The newsletter dedicated to finding a better way to live with erythromelalgia
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Teleconference with Dr. Cohen Open to All

What's new in treating EM will be among the subjects discussed Saturday, May 20, at a teleconference featuring Jay S. Cohen, M.D., and benefiting TEA's Research Fund.

The session will start at 10 a.m. U.S. West Coast time, 1 p.m. on the East Coast.

Open to anyone interested in EM, the fee for this hourlong session is \$25 for TEA members and \$45 for non-members. Dr. Cohen is volunteering his time; funds go to support the growth of the Research Fund.

Named "Dr. Cohen on EM," the teleconference was suggested by Dr. Cohen, Adjunct Associate Professor of Family and Preventive Medicine at the University of California at San Diego.

Participants will listen to the teleconference on their home

telephones. Once registered, they will be given a toll free phone number and passcode to dial in to the teleconference.

During the first half hour, Dr. Cohen will be interviewed on various topics such as what causes EM, treatments for EM, and why there is so much variation among people with EM in their responses to treatment.

During the second half hour of the teleconference, Dr. Cohen will respond to call-in questions.

Dr. Cohen cannot diagnose over the phone, of course, and recommends that listeners check with their doctors about any suggestions he makes.

Dr. Cohen also will welcome comments from people who have done their own reading or who have tried different therapies for EM.

A founding member of TEA, Dr. Cohen was hit by debilitating EM in his early 50s. He researched EM extensively and developed therapies that he tried himself.

After five years he went into remission, only to relapse three years later. He will be glad to explain why this happened and to talk about the

new therapies he has found that help with EM.

Chairman of TEA's Medical Advisory Committee, Dr. Cohen first wrote "Current Information on Treating EM" in 2000. His most recent revision of this wide-ranging, practical review of treatments was in 2005. It is TR-25 in the Article Archive on TEA's Web site.

He has published articles about EM in medical journals as well.

The registration deadline is April 28. Those registering must include a phone number or e-mail address so TEA can contact you with teleconference details.

This first teleconference is targeted to participants in North America. Others are welcome, but can join in only by paying for a long distance call to Atlanta, GA, USA, for the duration of the event.

You can register on the TEA Web site and pay by credit card. (Check the home page for directions.)

You also may register by sending a check payable to TEA marked "teleconference" to TEA, 24 Pickering Lane, Wethersfield, CT 06109.

Questions may be sent to: research@erythromelalgia.org

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Board of Directors Elects Officers

In elections held in January, TEA's board of directors elected Beth Coimbra president. She replaces Lennia Machen and is just the second person to hold this office.

Machen served seven years as president, taking office when TEA was founded in 1999. She remains a member of the board of directors. (See story, p. 4)

Also elected to two-year terms were Isabelle Davis, vice president; Gayla Kanaster, secretary; and Ray Salza, treasurer.

Coimbra Has Experience

Coimbra, who has served as vice president since 2003, has performed various functions for TEA since joining the organization in late 1999. She conducted the member survey of treatments in 2004, compiling the results as computerized spread sheets. These results are in the Article Archive. (TEA-10)

Coimbra, a CPA with a degree in accounting, has served on the board of the National Organization for Rare Disorders since 2003. Her first job for TEA was handling membership services, which she did for two years.

Coimbra's full-time job experience includes two years with the University of Delaware in grant accounting as well as four years in public accounting.

Coimbra now works from her home; she lives near Philadelphia with her husband and

10- and 13-year-old sons. She has mild to moderate EM with a concentration of her symptoms in her feet.

A member of TEA since 2001, Davis joined the TEA board in 2003. With 20 years' experience in public relations and publication production, she became the editor of *FootSteps* in 2005.

She lives with her husband near Detroit, Mich., and holds a bachelor's degree in English and a master's degree in journalism. She has EM secondary to relatively benign multiple sclerosis.

Newly elected secretary Kanaster joined the TEA board in 2002. She is a member of the large extended family from Alabama most recently studied by the Yale researchers and has had EM from birth.

Her wide life experience includes serving as president

of a large, non-profit organization in Los Angeles, running a travel agency, and working as a flight attendant.

She recently moved to Tacoma, Wash., where she lives with her husband.

Salza Re-elected

Salza was re-elected treasurer, a job he has done for TEA for three years. Salza also handles membership and member services for TEA. His business and project management experience has been an important asset for TEA.

One of the founding directors of TEA, Salza is retired from a career with Aetna Financial Services where he managed the information technology department for the pension and retirement operations.

Unlike the other officers, Salza does not have EM; his wife Carol does. They live near Hartford, Conn.

The Erythromelalgia Association 24 Pickering Lane, Wethersfield, CT 06109

Beth Coimbra, President

Isabelle Davis, Vice President

Gayla Kanaster, Secretary

Ray Salza, Treasurer/Member Services

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EM and Raynaud's Phenomenon Can Occur Together

By Jean Jeffery

This paper¹ describes a patient with both EM and Raynaud's phenomenon (RP) and reviews the research into the causes of each disorder. It is No. E/R-59 in TEA Article Archive.

EM and RP appear to have opposite symptoms yet may coexist. In EM the episodes of redness and burning pain of the extremities are triggered by heat and relieved by cooling. In RP the extremities turn white on exposure to cold, then often blue, and finally red with temporary burning on return to a warm environment.

The patient, a 42-year old female, had a 4-year history of RP and a 3-year history of EM. After exposure to the cold all her fingers and toes exhibited the three color changes of RP. Her EM was mild and affected her toes in warm conditions. Her medical history included lupus of her nose, urticaria, and recent knee joint pain. A tentative diagnosis of primary RP and primary EM was made. The patient's symptoms improved significantly with daily application of nitroglycerin cream to her fingers and toes.

EM is rare whereas RP affects 5-10% of the population. However they are similar in that symptoms can affect the toes, fingers, ears or nose, are more common in females and can run in families. EM and RP also have primary and second-

ary forms. The secondary forms are associated with various disorders, especially autoimmune diseases such as rheumatoid arthritis and lupus. EM also occurs with thrombocythemia and peripheral neuropathy. RP responds to treatment with vasodilators such as calcium antagonists but these may either improve or worsen EM.

What Causes EM and RP?

Research has pointed to abnormal blood flow and nerve impairment in EM and RP. Temperature regulation of the skin is controlled by vasodilation and vasoconstriction (opening and closing of the blood vessels). The "arteriovenous" vessels in the skin of the extremities may behave abnormally in EM and RP. In EM they open too wide in hot conditions and shunt their blood deeper into the skin. This causes hyperemia (oversupply of blood) with red burning skin. In RP it is thought that these vessels go into vasospasm (close tightly) in cold conditions to cause cold white skin. On a return to warm conditions the vessels reopen and cause hyperemia. Many chemicals present in the blood may also trigger hyperemia or vasospasm. These include hormones, immune and inflammatory products, enzymes and nerve proteins.

The sympathetic nervous system plays an important role. These nerves release the potent vasoconstrictor norepinephrine (noradrenaline). Raynaud's sufferers have alpha-2 receptors in their blood vessels which react with the norepinephrine at cold temperatures to cause vasospasm. Many EM patients suffer with painful small-fibre neuropathy (damaged nerves) of the sympathetic system. (Since this paper was written it has also been found that a neuropathy with mutations of a sodium nerve channel cause the painful symptoms in inherited EM).

Some people with EM have cool extremities during the day followed by burning at night. Studies have shown that their blood vessels are constricted in the cool phase, then overdilate at night to cause hyperemia. This may explain why EM and RP can coexist: both disorders begin with vasospasm followed later by hyperemia. The hyperemic phase is more prominent in EM whereas the vasospastic phase is more prominent in RP. This does not however account for other EM patients who suffer constant burning day and night. It has therefore been proposed that different subtypes of EM exist, each requiring different treatment. The subtype that coexists with RP may respond to calcium antagonists, whereas the subtype with constant hyperemia may respond to beta blockers.

¹Coexistence of erythromelalgia and Raynaud's phenomenon. Berlin AL, Pehr K. 2004. Journal American Academy of Dermatology 50: 456-460.

Lennia Machen's Story: A Tribute to a Job Well Done

Editor's Note: Lennia Machen served as president of TEA from its founding in 1999 to January 2006. Beth Coimbra assumed the duties of president with Machen's full endorsement. (See Board of Directors Elects Officers, p. 2) Machen remains on the board of directors and is webmaster for TEA's Web site.

It was 1995 when EM hit single mom Lennia Machen "like a ton of bricks." An office administrator at the Idaho National Laboratory in Idaho Falls and part-time figure skating teacher, her EM symptoms were debilitating.

She remembers feeling weak, unable to stand up and having "no idea what was wrong." After her local doctor diagnosed a virus, she sought care in Portland, Oregon, where her parents lived.

The Chief of Staff at the hospital there researched her symptoms and diagnosed her EM. After a battery of tests and bad results from her first treatments, she realized she was on her own.

Turned to Internet

She turned to the Internet, then in its infancy. And there she found others with EM, including Milt LeCouteur and Karl Granat, on a medical "bulletin board."

Many, many e-mails later, TEA was born, formally incorporated as a nonprofit organization in the state of Washington in January 1999. Le-

Couteur, Granat, Machen and a handful of others had already worked hundreds of volunteer hours laying the foundation for TEA.

Machen is proud that she spearheaded the writing of organizational objectives and the mission statement early in TEA's existence.

She began writing *Foot-Steps* in early 2000, having already launched the Web site. Her first newsletter, available in the TEA Web site's Newsletter Archive, includes a complete early history of TEA.

In her typically humble way, Lennia insists that her seven years (and thousands of volunteer hours) as president of TEA were a learning experience for her. She says she's proud to "have been in TEA at the start."

Disabled by EM

Long before her work with TEA began, the debilitating EM symptoms she suffered meant she couldn't work. Struggling just to get through the day, she and her six-year-old son lived on disability pay provided by her employer.

Able to walk only short distances, she began taking college courses as rehabilitation. She pushed a specially modified wheelchair into classrooms, adjusted the chair so her legs could be elevated and sat down. She says, "Oh, the stares!"

Getting her EM to a much more benign level took sev-

eral years of trial and error with medications like magnesium and Neurontin.

It was biofeedback at the Pain Center at the Oregon Sciences Center in Portland that finally helped her the most.

These sessions taught her that it was striving to keep her hands and feet warm—not cold—that helped the most in warding off the painful EM flares.

Keep Constant Temperature

"EM is like a full-body migraine," she was told. In order to keep her blood vessels from constricting, she needed to do her best to keep her extremities at a constant temperature.

She also had to lose weight and avoid foods that cause vasoconstriction. By persevering through flares without cooling, she learned to avoid flares.

She completed her bachelor's degree in May 2000, and her master's in 2003. She now is an adjunct professor at Idaho State University, teaching Human Resources Training and Development classes part time.

No longer in a wheelchair, she most often teaches "Specialized Needs and Career Counseling Concepts," which is a class about how teachers should recognize and accommodate students with special needs.

Parlaying life experience as a special needs student into a course she now teaches. That's Machen's positive, enthusiastic attitude toward life in action.

Research Update

Dutch Researchers: Grant ‘Kickstarted’ Studies

“The award of the NORD grant meant a real breakthrough in our research efforts, and made us very proud,” said Joost PH Drenth, MD, Ph.D., recipient of the TEA \$30,000, one-year grant.

The grant is being administered by the National Organization for Rare Disorders for TEA.

“After we obtained the grant, we kickstarted our studies,” Dr. Drenth said. They decided, first, to test DNA samples from a single, large American family from whom they had previously obtained blood samples.

Affected members of this family had typical complaints of EM, such as red, hot and painful feet. However, previous testing had revealed that this family did not have the same genetic form of EM as did other families.

It was this finding that led the researchers to theorize that a defect in a second gene could cause EM. Thus, the goal of the TEA-funded study is investigating just that.

As of the end of February, the researchers report they have almost finished the “first run.” The greatest challenge is yet to come as they need to analyze the huge amount of data in order to extract the most valuable information.

How to find a second EM gene is enormously complex. It has been estimated that humans possess 20,000 to 30,000 genes. And finding a gene resembles finding a needle in the haystack.

Ideally, Dr. Drenth said, they should test each and every gene and compare EM patients with non-affected members from the same family. This is an Herculean task and seems impossible to do.

Fortunately, recent developments have opened up new ways to investigate genes. The Dutch researchers are using one such new method. The technique is very expensive, and they are proceeding carefully.

Those with inherited EM who wish to volunteer for the study should e-mail Dr. Drenth at JOOSTPHDRENTH@cs.com, or write to him at the Department of Medicine, Division of Gastroenterology and Hepatology, Radboud University Nijmegen Medical Center, P.O. Box 9101, 6500 HB Nijmegen, The Netherlands.

Nicholl, Friends Raise Money, Fund Pilot Study in UK

With quite a bit of help from her friends, TEA member Jayne Nicholl last fall raised £1,200—enough to fund an EM pilot study.

Jayne, 27, was born with EM and is one of TEA’s growing number of English members.

Her flatmate Sophie Williams is well acquainted with the effect EM has on Jayne’s life and knows Jayne will never be fine without lots of help from her friends.

Last year Sophie was training for a half marathon and raised £600 in sponsorships for her run.

“I was amazingly touched when she told me she had decided to donate her sponsorship money to help EM research,” Jayne said.

They donated the money to the UK Raynaud’s and Scleroderma Association with the specific request that the money would go to fund a pilot study into EM.

Jayne raised another £600 simply by asking for a donation from her employer Young & Co. Brewery. Jayne knew the brewery had a history of supporting charities and is delighted with her company’s generosity.

The £1,200 (about \$2,100) is now funding a pilot study examining the DNA from 30 patients with EM to see if they share some of the gene variations that have been found in Raynaud’s.

The Raynaud’s and Scleroderma Association awarded the grant to investigators Dr. C. P. Denton and Dr. D. J. Abraham, rheumatologists at the Royal Free Hospital in London.

2005 Annual Report: Accomplishments

2005 was a significant year for TEA—the year when the dream of actually funding research into EM became reality. TEA donated money from the Research Fund to help support the work of two groups of EM researchers.

Some of TEA's 2005 accomplishments include:

- TEA donated \$60,000 to help fund research into primary EM at Yale University's Center for Neuroscience and Regeneration Research. Yale doctors reported their research findings in four highly regarded medical journals.
- TEA agreed to fund a \$30,000, one-year grant for the study "Identification of a Second Erythromelalgia Susceptibility Gene" to be done in 2006 by Joost P. H. Drenth, MD, Ph.D., Radboud University, Nijmegen, The Netherlands. Awarded through the National Organization for Rare Disorders, the grant will be administered and monitored by NORD.
- A member satisfaction survey—performed by calling randomly selected members—revealed that a large majority of our membership think TEA provides useful information to them. However, the majority of survey respondents said they want more information about EM research and treatments and about members' personal experiences.
- Those surveyed also suggested other kinds of information they would like, such as names of doctors and overviews of medical journal articles to take to their doctors. In response to comments from a majority of survey participants that they would like to receive *FootSteps* via regular mail, in July, TEA began mailing the newsletter to all members.
- TEA's Article Archive—a growing library of documents and medical journal articles—was reorganized so articles are easier to find. A short description of the contents of each article also was added. (The complete listing of articles and documents in the reorganized Article Archive is included with this issue of *FootSteps*, pp.10, 11 and 12.)
- TEA received media exposure both in England and the U.S. Member Jayne Nicholl was featured in London's magazine *Best* and appeared on a morning TV talk show.
- TEA issued a release to the news media about its role in helping fund the Yale research in coordination with Yale's press release about their EM research findings. As a result, three members of the Powell family were interviewed about their EM on a Birmingham, Alabama TV news broadcast.
- TEA member Pamela Costa, Ph.D., was featured in two stories in the Tacoma News Tribune, Tacoma, Washington. She also was interviewed by the Discovery Health Channel for a documentary scheduled to air in 2006.
- A total of \$18, 223 was donated to the Research Fund. Some of these funds were raised by individual members who used a variety of methods from getting support from their employers to requesting donations to TEA instead of birthday gifts.

2005 Annual Report: 2006 Goals

TEA began 2006 with optimism about the progress of EM research and our ability as an organization to make a difference in the lives of people with EM. The Board of Directors has set these goals for the year:

- Explore new communication methods. These could include teleconferences with physicians knowledgeable about EM, an “Ask the Doctor” column in *FootSteps* and improved Web site services
- Improve opportunities for communication among TEA members by creating a Web-site-based members’ directory and building the Networking Program
- Reach and support undiagnosed people with EM by making TEA’s Web site easier to find for those searching online and by adding new information
- Pursue alternative funding sources to support growing operational expenses by hiring a professional grantwriter
- Continue to increase public and physician awareness of EM through more media placements and increased MAC involvement

Financial Report

TEA’s income comes solely from membership dues and donations made by members and friends of the association. Thanks to their generosity in 2005, the Research Fund increased by \$18, 223. Donations designated for the Research Fund are held in segregated, interest-earning accounts. The Research Fund ended 2005 with a balance of \$30,052, including interest earnings.

During 2005, TEA donated \$60,000 from the Research Fund to Yale University’s Center for Neuroscience and Regeneration Research to help fund ongoing EM research. Another \$26,125 was paid to NORD to fund our grant.

Income from membership dues is deposited in TEA’s operating account and is used to pay expenses such as printing, postage, insurance, Web site operations and other office expenses necessary to provide member services. All directors, officers and MAC members are volunteers and receive no compensation.

During 2005, income from membership dues was \$8,985.17. Operating expenses were \$7,693.42. At the end of 2005, TEA’s operating account had a balance of \$6,757.77.

Our Mission

The Erythromelalgia Association is a nonprofit organization dedicated to supporting people with EM by maximizing their health outcomes and improving their quality of life; funding research into the causes and treatments of EM; and increasing awareness of EM among health care practitioners, patients, family members, and the general public.

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. 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 your story to Gayla Kanaster, gaylakanaster@aol.com or 2532 N. Fremont Street, Tacoma, WA, USA 98406

Stephen Snyder writes: I am 62 years old and my first EM symptoms appeared last August. I must add the caveat that I had many years of chemotherapy for chronic lymphocyte leukemia and also had a stem cell transplant in May 2004.

I was diagnosed by a dermatologist with EM in my feet and especially in my lower legs above the ankles. It seemed particularly bad when I was on my feet a lot, on very hot days, and if I wore socks that constricted my ankles.

Following my transplant I had leg cramps and took magnesium supplements and oral quinine pills. When I added an enteric aspirin everyday, my EM symptoms vanished with only a very occasional flare-up. When full blown, my EM was the most painful thing I have ever experienced.

I am writing to share my experience, particularly as it took a while for my oncologist and other doctors to recognize that I was not merely experiencing a side effect of the immunosuppressant and anti-viral medications I had taken, or past chemotherapies.

Walking around on college visits with my eldest, sitting at a baseball game, and hiking (even barefoot) in Wyoming's Wind River mountains caused excruciating EM pain.

I hope other transplant patients do not develop EM, and if they do, they will know what to do. Perhaps some of the chemotherapy I took or the transplant played a role in the onset of my EM. It is a mystery. But I am thankful for TEA's support for research to figure out its cause. My heart goes out to anyone coping with the symptoms of EM.

Barbara Berridge writes: I am 73 years old and live in Christchurch, Dorset in the U.K. I was born and brought up in Peterborough, a town near East Anglia where in the winter we said the weather came straight from Siberia.

In my teens I developed chilblains on my feet which became so bad they cracked and bled, causing pain enough for me to cry. My only relief came when I carried both my children through the winter months. I had no chilblains during either pregnancy.

Gradually, through the adult years, my chilblains subsided only to be replaced by "hot feet." I put up with the pain for a long time—my only relief being placing them on a freezer pad before going to bed. Sometimes I'm awakened when the covers accidentally touch my feet causing pain and heat.

My GP finally admitted I was a "puzzlement" and sent me to a specialist. He was able to give me a name for my hot feet—erythromelalgia! After so many years I could have kissed him.

I don't have a computer, but my son found the TEA website and joined for me. I now receive *Footsteps* and it has helped tremendously to know I'm not the only one with this condition. (I was very surprised and sorry to read in the December issue about the young boys with EM.) My doctor prescribed diltiazem 60 mg, which I now take once a day and my symptoms have improved.

I have written about my chilblains wondering if this could be relevant to my later developing EM, although I have not read of anyone else having the same.

I do not drive, but walk and ride my bike. I look forward to the next *Footsteps*.

Networking Program Provides Support, Information

Would you like to contact others living near you who also have EM? Or get copies of articles from the Article Archive without using the Web site? TEA offers a service—the Networking Program—that helps you do both. Just fill out the form below and send it to Judy Reese, 1155 E. Duck Lane, Salt Lake City, Utah, USA 84117

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. And there are quite a few both in the U.S. and the U.K. TEA holds personal information about its members in strict confidence and will not disclose it unless you give TEA written permission.

You must be a member of TEA to participate in the Networking Program. And you must agree to respond to any letters or other communications you receive from other members.

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

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 Tacoma, WA, USA 98406**

Those with computers may access articles at TEA's Web site

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TEA Articles and Documents

| No. | Title, author, date | Pages | Cost |
|-------|--|-------|------|
| G-03 | Erythromelalgia: A Clinical Study of 87 Cases. Kalgaard, Seem, Kvernebo, 1997. Symptoms and prognosis of 87 patients. | 8 | \$2 |
| G-06 | EM: a condition caused by microvascular arteriovenous shunting. Kvernebo, 1998. This long paper covers all aspects of EM and how it is caused by abnormal blood circulation. Very technical. | 36 | \$8 |
| G-08 | Erythromelalgia: A Mysterious Condition? Mørk, Kvernebo, <i>Archives of Dermatology</i> , 2000. Short review of diagnosis, classification and prognosis of EM. | 7 | \$2 |
| G-11 | Erythromelalgia Caused by Platelet-Mediated Arteriolar Inflammation and Thrombosis in Thrombocytopenia. Michiels, Abels, Steketee, Huub, VanVliet, Vuzevski, 1985. EM and thrombocytopenia | 8 | \$2 |
| G-20 | Erythromelalgia: Symptom or Syndrome? Belch and Mackay, 1992. This covers all aspects of EM and includes treatment for different subtypes. | 9 | \$2 |
| G-31 | Hot Feet: Erythromelalgia and Related Disorders. Layzer, 2001. Short review of symptoms and a neurological cause | 5 | \$2 |
| G-42 | Poxviruses isolated from epidemic EM in China. Zheng, Zhang, Hu, Lui, Zhu, 1988. EM epidemic associated with throat viral infection. | 2 | \$1 |
| G-49 | Natural history of erythromelalgia. Davis, O'Fallon, Rogers. Rooke, 2000. Review of 168 EM patients examined at Mayo Clinic between 1970-1994. | 9 | \$2 |
| G-60 | A refractory case of erythromelalgia involving the ears. Ramires, Kirsner, 2004. Detailed report of one EM patient who remained resistant to all treatment. | 4 | \$1 |
| TR-01 | Erythromelalgia: New Theories and New Therapies. Dr. Cohen, 2000. Excellent review of treatment and all aspects of EM with survey of 41 patients. Easier reading for non-medics. | 10 | \$2 |
| TR-02 | Erythromelalgia. Davis, 2002. Survey of 99 patients' response to treatment. | 14 | \$3 |
| TR-05 | High-Dose Oral Magnesium Treatment of Chronic Intractable EM. Dr. Cohen, 2002. Author's remission of EM and the response of 12 other patients to magnesium. | 8 | \$2 |
| TR-09 | Refractory Primary EM in a Child Using Continuous Epidural Infusion. Pain Clinic, 1996. Improvement of EM with bupivacaine and clonidine in 4-year-old boy. | 2 | \$1 |
| TR-15 | A Way to Understand Erythromelalgia. Zoppi, Zamponi, Pagni, Buoncristiano, 1985. Successful treatment of 3 EM patients with 10 daily sympathetic nerve blocks. | 4 | \$1 |
| TR-19 | Erythromelalgia Pain Managed with Gabapentin. McGraw, Kosek, 1997. Successful treatment with gabapentin for one child and one adult. | 5 | \$1 |
| TR-22 | Nitroprusside Treatment of EM in an Adolescent Female. Stone, Rivey, Allington, 1997. Remission of EM in 15 year old using nitroprusside infusion. | 5 | \$1 |
| TR-24 | Refractory Idiopathic Erythromelalgia. Rauck, Naveria, Speight, Smith, 1996. Remission of primary EM in 2 adolescent males using various epidural infusions. | 7 | \$2 |
| TR-25 | Current Treatment for Erythromelalgia. Jay Dr. Cohen 2005. Excellent review of treatment and all aspects of EM. Easier reading for non-medics. | 2 | \$1 |
| TR-28 | Unexpected Healing of Cutaneous Ulcers in a Short Child (with EM). Climaz, Rusconi, Fossali, Careddu, 2001. Cessation of EM and associated ulcers with growth hormone in a 12 year old boy. | 2 | \$1 |
| TR-29 | Erythromelalgia: Response to serotonin reuptake inhibitors. Rudikoff, Jaffe, 1997. Rapid relief of EM in 3 adults with venlafaxine or sertraline. | 3 | \$1 |
| TR-39 | Treatment of erythromelalgia with a serotonin/noradrenaline reuptake inhibitor. Moiin, Yashar, Snachez, Yashar, 2002. Improvement of EM in 10 patients treated with venlafaxine. | 2 | \$1 |
| TR-40 | Lidocaine patch for pain of erythromelalgia. Davis, Sandroni, 2002. Successful pain relief for 15-year-old girl with EM. | 4 | \$1 |
| TR-41 | Erythromelalgia an endothelial disorder responsive to sodium nitroprusside. Chan, Tucker, Madden, Golding, Atherton, Dillon, 2002. Dramatic response by 2 children to nitroprusside. | 2 | \$1 |
| TR-44 | Treatment of primary erythromelalgia with cyclosporine. Sano, Itami, Yoshikawa, 2003. Successful treatment with cyclosporine in adult with inherited EM. | 2 | \$1 |
| TR-45 | Resolution of refractory symptoms of secondary erythromelalgia with intermittent epidural Bupivacaine. Sticker, Green, 2001. Remission of EM in 28-year-old female. | 5 | \$1 |
| TR-47 | One Size Dose Does Not Fit All. Dr. Cohen, 1999. Advice on prescription dosages. | 2 | \$1 |
| TR-50 | Aspirin responsive painful syndrome in polycythemia vera associated with thrombocytopenia. Michiels, Berneman, Schroyens and Van Urk. Abstract only, 2003. Success with aspirin for 3 EM patients. | 2 | \$1 |

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