

# FootSteps . . .

TOWARD PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia  
Volume 5, Issue 3, September 2004, Published by The Erythromelalgia Association

## TEA to Fund Research through NORD Grant Program

For the first time in its six-year history, TEA will fund a research study seeking answers to the mystery of erythromelalgia (EM). The Board of Directors recently approved using \$35,000 of the TEA Research Fund to initiate a grant through the National Organization for Rare Disorders (NORD).

As a member of NORD, TEA can take advantage of that organization's expertise in requesting, evaluating, and selecting the best medical research projects to fund. Through its Clinical Research Grant Program, NORD provides small—\$35,000 is the minimum amount—one-year, “seed money” grants to academic scientists studying new treatments or diagnostic tests for rare diseases.

Early next year, NORD will prepare a Request for Proposals (RFP) for research studies into EM to be funded by TEA. NORD then will

advertise the RFP in leading medical journals and mail it to every university-affiliated hospital and medical school in the U.S. In addition, NORD will specifically contact researchers who have published journal articles about EM in the past two to five years and notify research institutes in Canada and Europe.

Medical researchers, who are typically physicians working at university-affiliated hospitals or medical schools, then have a period of several months to submit preliminary grant applications. NORD's Medical Advisory Committee of academic scientific experts assesses these proposals—using the same peer review system used by the National Institutes of Health—and selects several finalists. Finalists must then submit full grant applications, which are evalu-

ated before NORD selects the winner. Then the grant will be awarded probably in early fall 2005.

Although the process seems long and complicated, it is unbiased and independent. Awards are based solely on scientific merit. Because applicants from around the world compete for these grants, the chosen projects are the most likely to result in research breakthroughs. And NORD monitors the researchers' progress throughout the yearlong grant period. The scientists must submit interim reports and receive the funds in three installments.

Because NORD's Clinical Research Grant Program focuses on preliminary studies, TEA's grant will most likely fund a project testing a new drug or medical device through small clinical trials, which are scientifically designed studies involving people. If the data gathered show promise, the researchers can apply for large grants from the government or other sponsors like drug companies. So, what seems like a small grant in the world of expensive medical research may eventually help many people with EM in a big way.

## TEA Launches UK/Europe Networking Program

Beginning this fall, TEA members in Europe and the United Kingdom will have the chance to join a Networking (NW) Program meant just for them. Newly named UK/Europe NW Coordinator Nina Bunton is sending letters to TEA members in that region introducing herself and inviting them to join the Program.

Nina says she hopes people in the UK and other European countries will see her as a hub of information about EM that can be shared. With members' permission, she hopes to put people in the same geographical location in touch with each other and set up face-to-face

meetings.

Another one of Nina's jobs will be to mail copies of articles in TEA's library to NW Program members who request them.

Under the direction of TEA Board of Directors member Judy Reese, the NW Program was originally designed to help members without Internet access communicate with one another. Now with more than 40 members, the program is open to any TEA member with or without Internet access. An application to join the program is included at the end of this newsletter.

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## Auction's Final Total \$17,350

After accounting for expenses and adding late donations, the auction held in Seattle June 13, 2004, raised \$17,350 in funds for the TEA Research Fund. "A Hollywood Celebration," coordinated by TEA Fund-raising Chairperson Sarah Sundstrom, was the first ever fund-raising event held by TEA. Attended by 118 people, the \$30 a plate dinner at Club Hollywood in North Seattle featured both silent and live auctions. Sundstrom worked tirelessly for months acquiring donated items, producing an informational video about EM,

and making arrangements including enlisting a Seattle radio personality as guest auctioneer.

This event proved that volunteers—including people living with EM—can work magic when it comes to fund raising. TEA owes a huge debt of gratitude to Sundstrom for her efforts.

## Condolences

Longtime TEA member Mimosa Low of California died in April. The cause of death is unknown. TEA offers condolences to her family and friends.

## Credit Card Program a Success

TEA's credit card form on the web site is a resounding success. The one and a half year-old program makes it simple for TEA members and donors to send funds without the extra charges of international bank orders, checks, or transfers. This tool has helped TEA become *the* international organization for erythromelalgia information and support.

If you have a VISA or MasterCard, the TEA form will accept funds for membership renewals, gifts, or donations. If you would like help in using the form or would like to use your credit card via telephone or regular mail, please contact Member Services. (See page 7.)

## Did You Know? *By TEA member Jean Jeffrey*



1. The name erythromelalgia was first used in 1878 by Silas Mitchell. He used the three Greek words erythros (red), melos (extremities), and algos (pain). Hence, it is sometimes referred to as "Mitchell's Disease."
2. Between 1952 and 2004, more than 300 papers from all over the world have been published on EM. Many are case reports on just one or two patients with EM.
3. Epidemics of EM have been reported from China since 1954, at intervals of 3 to 5 years during the winter and spring. The majority of sufferers were teenage female students.
4. One researcher in Oslo—Dr. Knut Kvernebo, a member of TEA's Medical Advisory Committee—received a gold medal from King Olav V of Norway in 1998 for his work on EM (VASA Article).

## Raise Money for TEA with Greeting Card Inserts

Available again this year are greeting card inserts that suggest making a donation to TEA. If you plan to send greeting cards during the upcoming holiday season, consider enclosing one of these cards. Full page copies of the inserts are provided on the web site as well as through the Networking Program. Examples of the cards are shown here and can be found in the online library.

The inserts come in two sizes. The larger card can be copied four times on an 8-1/2 x 11 inch page, then cut, or printed onto note card blanks. The smaller version is sized to be printed on standard, 10-per-page business card blanks available at office supply stores. You can print either style in color or black and white.

Several members who used the cards last year report remarkable success. What a great way to suggest a gift that could be so meaningful!



*Give a gift that says you care!*



**Donate to The Erythromelalgia Association.**

100% of your tax-deductible gift will go toward much needed research into finding a cure for the debilitating condition erythromelalgia. You can mail your donation directly to TEA or donate online at [www.erythromelalgia.org](http://www.erythromelalgia.org). Your gift will be truly appreciated by those who suffer daily from this painful disorder.

**The Erythromelalgia Association**

**24 Pickering Lane, Wethersfield, CT 06109**

If you wish to give in honor of someone, please include that person's name and address so TEA may mail them a card announcing your gift.

Small size card. 2 X 3-1/2" Print on standard business card (10 per page) stock available at office supply stores.

# A Special Thanks to Auction Donors

Listed here are the individuals and companies who made donations to the auction held in Seattle in June. TEA extends a very special "thank you" to each of these donors. You made raising \$17,350 possible and helped us get closer to funding research to find solutions to EM. (See related story on page 2.)

\* = TEA Member  
 \*\* = Monetary donation

Betz Family Winery  
 LFS  
 Treasure'd Glass  
 Trident Seafoods  
 W.S.U. Athletics  
 Microsoft  
 Dave & Julie Russell  
 Jennifer Barnes  
 Bayview Limosine  
 Anthony's Restaurants  
 Redhook Brewery  
 Julian Ward  
 Ballard Hardware  
 Brooks Sports  
 Gai's Bakery  
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 Landmark Vineyards  
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 Puyallup Fair  
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Northcoast Electric  
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 Onrax  
 Kurt & Dawn Geffe  
 Caruh Aveda Salon  
 W.S.U. Alumni Center  
 William Hubble  
 Bead World  
 Pat & Tanya Coyle  
 Mary Kay  
 Lowe's  
 Aqua Quip  
 Heather Lantz  
 Jennifer Biggs  
 Lara & Brent Huppert  
 Judy Reese\*  
 Starbucks  
 Eric & Beth Dann\*\*  
 Carolyn Slocum  
 And 1 Sports Gear  
 Rik & Annette Klevin  
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 Sharla & Dave Morgan\*\*  
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 Taildraggers Cafe



*You all have  
 found the  
 way to our  
 hearts!  
 Thank  
 You!!*



## Doctors Invited to Use Library

If your doctor would like access to our online library, please send the physician's name, specialty and e-mail address to Member Services. In keeping with TEA's goal of furthering education, we offer free access to any doctor who is interested.

## TEA Fundraising Videos Available for Use by Members

The informational video about EM produced for the Seattle auction now is available through the TEA Library, which has acquired three cassettes and three DVDs. The video features several TEA members, TEA President, Lennia Machen, and doctors all discussing EM and the difficulties of living with this debilitating condition. The video is designed as a fund raising tool.

Members can obtain a copy by contacting TEA Networking Program Chairperson Judy Reese. (See contact information on page 7.) Copies may be purchased for \$24 for a DVD, or \$18 for VHS. (Prices include package and shipping, but not sales tax for Washington or Utah.) To borrow the video, send a deposit check or credit card number for the amount of the video, as well as a payment for shipping costs. The deposit will be returned to you upon receiving the borrowed item in the TEA office. Please plan to borrow the video for a week to 10 days only, longer terms need to be arranged with Judy prior to borrowing the item.

## Help Wanted!

As you know, TEA does not have a paid staff. All administrative functions are performed by volunteers. The officers and members of the Board of Directors are volunteers. However, TEA has identified some ambitious goals and needs volunteers if we are to achieve them. Interested in helping? Contact the appropriate address below.

WANTED: Internet-savvy TEA members—or family members/friends of TEA members—willing to volunteer their time to a project aimed at helping patients or members of the general public get accurate information about EM on the Internet. The project's objectives are:

1. Identify web sites that include medical subjects—especially those sites that list and explain diseases.
2. Contact the web sites and get accurate information about EM included.
3. Get web sites to create links to TEA's web site.

Prospective volunteers should contact Isabelle Davis, TEA Board of Trustees member at [imdcomm@aol.com](mailto:imdcomm@aol.com).

WANTED: Any member willing to raise funds for TEA by sending appeal letters and collecting donations to TEA. The letter already exists, it just needs to be personalized by someone with EM and sent. If interested, contact member Services or the NW program. (See page 7.)

WANTED: Web-page-experienced members who would like to be a part of our online library preparation. Some training is available but experience is helpful. HTML knowledge, knowledge of file types and how to work with photos and graphics, as well as basic desk-top publishing experience needed. The job will require the applicant to post articles and documents on the TEA web site and in the newsletter. Contact the webmaster and editor at [TEAwebmaster@erythromelalgia.org](mailto:TEAwebmaster@erythromelalgia.org)

WANTED: People with grant writing experience. TEA needs advice and help in this process and welcomes those who have any amount of experience to contact Member Services. (See page 7.)

## Congratulations

Sarah and Steve Sundstrom recently welcomed a baby girl to their home. Malena Katherine weighed 6 pounds and was 19 inches long. Both baby and her mom—TEA member and Fundraising Chairperson—are happy and healthy. Congratulations to the Sundstroms.

## Be a Library Contributor

Contact the TEA Library and learn how you can be a contributor to the growing library of articles about EM. Contact Member Services, or write [TEAwebmaster@erythromelalgia.org](mailto:TEAwebmaster@erythromelalgia.org)

# Alleviation of Erythromelalgia With Venlafaxine (Effexor XR)

Arch Dermatol. 2004;140:621-623.

Erythromelalgia is a rare disorder characterized by burning pain, warmth, and redness of the distal aspect of the extremities. Symptoms typically are precipitated by exposure to heat, and patients often soak their feet in ice water to alleviate the pain. We describe a woman with a 5-year history of intractable foot pain. With venlafaxine hydrochloride therapy, her symptoms improved markedly.

## Report of a Case

A 58-year-old woman complained of increasingly severe burning pain, warmth, and redness in her feet that had begun 5 years earlier. Exposure to heat exacerbated her pain, for which she continually soaked her feet in ice water. This constant immersion in water caused painful, nonhealing ulcers to develop on both feet. As a result, she confined herself to a wheelchair.

Before our evaluation, her treatment included 3-month trials of aspirin, amitriptyline hydrochloride, gabapentin, lidocaine ointment, and capsaicin cream. No treatment was effective, and all therapies were discontinued. The patient's medical history was significant for untreated hypertension. Physical examination revealed warmth, edema, and marked redness of the feet and ankles. About 20 ulcers, as large as 1 cm wide, were observed on the toes, dorsal aspect of the feet, and soles. Peripheral pulses were intact in both feet. The results of a complete blood cell count were within normal range. For treatment of the erythromelalgia, we prescribed extended-release capsules of venlafaxine hydrochloride (37.5 mg/d for 1 week, then 75 mg/d).

Three weeks later, the patient noticed gradual but marked improvement in the pain and redness in her feet. After the pain had begun to improve, she slowly discontinued soaking her feet in ice water until she had completely stopped soaking them approximately 5 weeks after the initiation of therapy. She resumed her regular activities without a wheelchair. Nine weeks after she began venlafaxine therapy, the ulcers healed completely. The patient has continued on a maintenance regimen of extended-release venlafaxine hydrochloride (75 mg/d) for more than 9 months. Her symptoms have been limited to mild discomfort of her feet after she stands.

## Comment

Erythromelalgia may occur as a primary condition or it may develop as a result of a systemic disease, such as polycythemia, thrombocythemia, or autoimmunity. Rather than a single diagnostic entity, erythromelalgia may be a clinical phenomenon associated with diverse causes in which peripheral vascular regulation is dysfunctional.<sup>1</sup> Theories of pathogenesis and summaries of new therapies are detailed in recent comprehensive reviews.<sup>2-4</sup> Aspirin therapy appears to be effective only in patients with an underlying hematoproliferative disorder.<sup>2</sup> For idiopathic erythromelalgia, numerous other treatments have had variable success in individual patients.<sup>2-6</sup> Venlafaxine is approved for the treatment of depression and generalized anxiety disorder. Its mechanism of action involves blockage of neuronal reuptake of serotonin and norepinephrine. Serotonin reuptake inhibitors such as venlafaxine have been reported to benefit some patients with erythromelalgia.<sup>2-5,7-8</sup>

The marked improvement in our patient, for whom other therapies failed, further suggests beneficial effects. Although the rarity of the condition may be a potential obstacle, randomized trials would be helpful in continuing to investigate the use of venlafaxine for erythromelalgia. The authors have no relevant financial interest in this article. Reprints are available from Dr DiCaudo.

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1. Kvernebo K. Erythromelalgia: a condition caused by microvascular arteriovenous shunting. *Vasa*. September 1998;suppl 51:1-39.
2. Cohen JS. Erythromelalgia: new theories and new therapies. *J Am Acad Dermatol*. 2000;43:841-847. CrossRef | ISI | MEDLINE
3. Mørk C, Kvernebo K. Erythromelalgia. In: Lebwohl M, Heymann WR, Berth-Jones J, Coulson I, eds. *Treatment of Skin Disease: Comprehensive Therapeutic Strategies*. St Louis, Mo: Mosby-Year Book Inc; 2002:212-214.
4. Davis MD, Rooke T. Erythromelalgia. *Curr Treat Options Cardiovasc Med*. 2002;4:207-222. MEDLINE
5. Davis MD, O'Fallon WM, Rogers RS III, Rooke TW. Natural history of erythromelalgia: presentation and outcome in 168 patients. *Arch Dermatol*. 2000;136:330-336. ABSTRACT/FULL TEXT
6. Cohen JS. High-dose oral magnesium treatment of chronic, intractable erythromelalgia. *Ann Pharmacother*. 2002;36:255-260. ABSTRACT/FULL TEXT
7. Moin A, Yashar SS, Sanchez JE, Yashar B. Treatment of erythromelalgia with a serotonin/noradrenaline reuptake inhibitor [letter]. *Br J Dermatol*. 2002;146:336-337. CrossRef | ISI | MEDLINE
8. Rudikoff D, Jaffe IA. Erythromelalgia: response to serotonin reuptake inhibitors. *J Am Acad Dermatol*. 1997;37:281-283. ISI | MEDLINE



# Your Stories— everyone has one!

TEA invites its members to share their experiences with EM by writing brief stories, **and we would love to hear your story too!** We all enjoy getting to know our fellow members and learning how they cope with the challenge of daily living with EM. If you think you are not a writer—never fear. We can help you write or edit your story.

Please send stories to Gayla Kanaster, 2556 W. 234<sup>th</sup> St., Torrance, CA 90505, or [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com).

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## Nina's Story

Nina Bunton, newly named TEA Networking Program UK/European Coordinator, writes:



To be diagnosed with erythromelalgia can be extremely distressing. Even after spending years trying to make sense of inexplicable symptoms, being dismissed by medical professionals and accused of “imagining” symptoms, it was enormously difficult to learn that the problem is EM—a chronic, painful, lifelong condition that is little understood in the medical world.

I was diagnosed with EM in 2003 after suffering symptoms for 14 years. I found that any information about EM was as rare and contradictory as the disease itself. I felt very lost, alone and confused. I felt as if I were the only person in the UK to have this disease. After extensive searching on the Internet, I found The Erythromelalgia Association web site and joined TEA.

I have another chronic condition, which apparently caused the EM, and had made many new friends and contacts with the same illness on the Internet. I realized the feeling that I'm not so alone is very reassuring. And there is a need in the UK for people with EM to begin networking.

I volunteered to coordinate a new EM UK/European Networking Program. With your help the new program will grow and give support and reassurance to others with this disease, as well as their families and care givers.

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## Susan's Story

My name is Susana Rubinstein. I am a 52-year-old single working Mom. I was an Assistant Principal at an elementary school when my school nurse noticed my legs and feet turning bright red. I really thought at that time that it was too much yard duty in the hot weather. (The school was open year round.) I was 49 at the time. I then started noticing that my feet were tingling and hurting while they turned red. The nurse told me to put them up on my desk, and the pain and redness disappeared—until I started to walk again.

Then, I had to take a job in a school with a traditional calendar at a substantial salary cut and restrict my yard-duty time. My doctor referred me to a dermatologist who had done her thesis on EM. She started me on one aspirin a day, which upsets my stomach. I feel as if I'm doomed with or without it. I live in Malibu, California with two young daughters. They find their lives affected by this disease as I sometimes need a wheelchair when activities require a lot of walking. I am all my little girls have and I have to keep healthy and working. I am now seeking doctors and others with more information on EM treatments.



# TEA Research Fund Donors



*Following is a list of the donors who have given to the Research Fund in the past three months. We thank each one of you for helping us all step that much closer to finding relief from EM.*

Aetna Foundation, Tiina Baumbach, Dolores Besch, Mrs D. Brisley, Dale Brower, Peter Clark, Zack Collar, Annette Conder-Prill, Stephanie Curran-Frenzl, Peggy Davis, Willene Domenichelli, Jane Donald, Yvonne Donaldson, Seymour Ellis, Catherine Erickson, Barbara Ernst, Ruud Grootveld, Marian Forschler, Jacqueline Fox, Jennifer Harris, Catherine Heckel, Katherine Henriksen, Jane Hrynio, Janice Hutson\*, Paul Isacoff, John Izzi, Jean Jansen, Shannon Justis, Vivian Kammerer, Gayla Kanaster\*, Barbara Klazmer\*, Marion Levy, Wendy Macdonald, Lois Mavsar, Douglas McDonald, Rhonda McElroy, Elizabeth McGrath, Michelle McQuade, Ann Nestor, Mrs. D F Parker, Phil Pennington\*, Hilary Pethybridge, Mary Randa, Larry Russell, Priscilla Sebeniecher, Frankie Shepherd\*, Tom Stocks, Robert Subias, Lex Trelford, Marilyn Wade, Steve Webber, Donna Weber\*

\*Donors to TEA's "in memory of" and "in honor of" programs.

\*\*Donors supporting the MAC Conference

***Our Many Thanks to Each One of You!***

## TEA Contact Information:

**Member Services:** **Ray Salza**, 24 Pickering Lane, Wethersfield, CT 06109.  
Or e-mail to: [memberservices@erythromelalgia.org](mailto:memberservices@erythromelalgia.org) 860-529-5261

**Networking Program:** **Judy Reese**, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117  
Or e-mail to: [judy@dataquest.com](mailto:judy@dataquest.com) (801) 631-3833

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## ***New Members***



*"Make new friends, but keep the old,  
One is Silver and the other Gold"*

*The following are members that have joined TEA in the past three months.*

Caroline Bell, Eleanor Briscoe, Dale Brower, Holly Burke, Annette Conder-Prill, Joan Crouch, Peggy Davis, Barbara Dettmer, Wadine Faye Gibbons, Lucien Gobeil, Rose Hammond, Jeanne Hansen, Donna Hodge, Meriwether Jones, Shannon Justis, Robert F. Kremer Sr., Anne Lack, Agnes Loukinas, Wendy Macdonald, Sally Maisano, Douglas McDonald, Thomas Miller III, Donald G. Murphy, Eleanora Palmitessa, Jill Penney, Mary Riordan, Andreas Roer, Barbara Rothschild, Susana Rubinstein, Mario Selman, Alyson Shaffer, Sarah Simpson, Delores Smith, Linda Spivey, Dianne St. Clair, Darrell Talley, Giovina Taraschi, Steve Webber

***Welcome! We're glad you've joined us!***

# TEA Networking Program Application Form

Yes, I want to participate in the EM Networking Program, I agree to the following rules, and I give TEA permission to distribute my contact information to other members of the program.

1. You must be a member of TEA with annual dues paid up to date.
2. You must sign and submit the form giving TEA permission to disclose your name and address to other participants in the program.
3. You must agree to respond to all correspondence from other Network Program members who write to you.

Signature: \_\_\_\_\_  
 Name \_\_\_\_\_ Date \_\_\_\_\_  
 Street Address \_\_\_\_\_  
 City \_\_\_\_\_ State/Province \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_  
 Country \_\_\_\_\_ (optional) Phone (\_\_\_\_) \_\_\_\_\_  
 (optional) E-mail address \_\_\_\_\_ @ \_\_\_\_\_

**Mail this form to:**  
**Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117**

## TEA Articles—Order Form

Name: \_\_\_\_\_  
 Address \_\_\_\_\_  
 City \_\_\_\_\_  
 State/Province: \_\_\_\_\_ Zip/Post Code.: \_\_\_\_\_  
 Country: \_\_\_\_\_ Date: \_\_\_\_\_  
 Are you a TEA Member?  Yes  No  
 Are you a TEA Network Program Member?  Yes  No  
**Method of payment: (Make Checks payable to TEA.)**  
 Check enclosed  Other : \_\_\_\_\_  
 VISA/MC **Exp. Date:** \_\_\_\_\_  
**Credit Card Number:** \_\_\_\_\_

**Mail to:** **Judy Reese, Network-**  
**ing Program**

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Document #	Charge
<b>Cost Sub-Total</b>	
<b>Non-TEA Member Charge</b> <small>(If you are <u>not</u> a member of TEA, there is a service charge of \$5.00 for each order)</small>	
<b>International Shipping Charge</b>	
<b>Total</b>	



**TEA Library Articles and Documents Page 1 (new items in bold)**

Article #	Title, Author, Date	# Pages	Cost	Order?
M001	Erythromelalgia: New Theories and New Therapies, Jay Cohen, 2000	10	\$2	
M002	Erythromelalgia, Dr. Mark Davis, 2002	14	\$3	
M003	Erythromelalgia: A Clinical Study of 87 Cases, Kalgaard, Seem, Kvernebo, 1997	8	\$2	
M004	Reduced Skin Capillary Density During Attacks of Erythromelalgia Implies Arteriovenous Shunting as Pathogenetic Mechanism, Mork, Kvernebo, Asker, Salerud, 2002	1	\$1	
M005	High-Dose Oral Magnesium Treatment of Chronic Intractable EM, Jay Cohen, 2002	8	\$2	
M006	EM: a condition caused by microvascular arteriovenous shunting, Kvernebo, 1998	36	\$8	
M007	AAPM: Lidocaine Patch Enhances Chronic Pain Therapy, Bruce Sylvester 2003	2	\$1	
M008	Erythromelalgia: A Mysterious Condition? Mørk, Kvernebo, Archives of Dermatology, 2000	7	\$2	
M009	Refractory Primary EM in a Child Using Continuous Epidural Infusion, Pain Clinic, 1996	2	\$1	
M010	The Primary Erythromelalgia-suseceptability Gene is Located on Chromosome 2q31-32 2, Drenth, Finley, Breedveld, Testers, Michiels, Guillet, Taieb, Kirby, and Heutink, 2001	7	\$2	
M011	Erythromelalgia Caused by Platelet-Mediated Arteriolar Inflammation and Thrombosis in Thrombocytopenia. Michiels, Abels, Steketee, Huub, VanVliet, Vuzevski 1985	8	\$2	
M012	Histopathology of EM in Thrombocytopenia, Michiels, Abels, Vuzevski 1983	8	\$2	
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