

# FootSteps . . .

TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia  
Volume 5, Issue 1, March 2004, Published by The Erythromelalgia Association

## TEA Members Respond to EM Survey

By mid-March, more than 200 TEA members completed and returned the TEA survey about EM. TEA Vice President Beth Coimbra, who is handling the project, is now compiling the results. TEA developed the survey to gain a comprehensive picture of how people with EM deal with this troubling and painful condition

and how it affects their lives. All 420 TEA members were sent this first ever TEA-sponsored survey early this year.

Survey findings should provide valuable information for TEA members and the TEA Medical Advisory Committee. Information from the survey also will

serve as useful reference material for future research. Once compiled, results will be posted on the TEA web site and made available through the Networking Program.

Questions? Contact Ms.Coimbra at 200 Old Castle Lane, Wallingford, PA 19086, or [bcoimbra@comcast.net](mailto:bcoimbra@comcast.net).

## TEA Membership Directory to be Published

TEA will soon publish a membership directory in an effort to encourage communication among members.

The directory will appear first on our web site in a searchable listing that will allow you to find other TEA members in your hometown or nearby. It will contain street addresses, city, state, zip, country and email addresses (no phone numbers unless requested by the member).

It is hoped that our mem-

bers will take advantage of the directory to share information and build friendships.

If the web site directory is successful, we will make the directory available in printed form through the Networking Program, by request.

It is possible to choose not to be included in the directory. To not be included you will need to contact our Member Services Representative Ray Salza, or write to the webmaster@erythromelalgia.org.

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### *"A Hollywood Celebration"*

Raising money for EM Research

June 13, 2004

TEA sponsored event, proceeds to go towards the TEA Research Fund.

Tickets are \$30 per person, at the Club Hollywood Restaurant, Seattle Washington. See story on page 3.

# **What is Primary EM? and how does it differ from Secondary EM?**

By Lennia Machen with excerpts from Dr. Joost PH Drenth, in his paper titled *Autosomal dominant primary (familial) erythromelalgia A study aimed to identify the erythromelalgia gene*, September 2003.

As a person with erythromelalgia, I would like to know which type of EM I have. Two variations of EM have been identified with very different causes for this painful, burning condition. Primary, or idiopathic, EM is inherited and only affects a small percentage of EM sufferers. Secondary EM is more common and may be curable if the primary condition is found and successfully treated. However, EM is secondary to many primary illnesses and identifying them is not always so easy.

Dr. Drenth describes Primary EM in the following way: “Autosomal dominant primary (familial) erythromelalgia is a very rare (incurable) familial disorder presenting as painful attacks of red vasodilatation and congestion with elevated skin temperature. Attacks are provoked by heat and exercise and symptoms are relieved by cooling or elevating the affected extremities. Although the first cases have been described as early as in 1878, little progress has since been made in terms of elucidation of the mechanism of the disease.”

Another feature of Primary EM that differentiates it from Secondary EM is that it may be possible to identify the gene carrying EM from generation to generation. (See page 3 for information about the research being done at this time.) To further explain his research, Dr. Drenth offers the following: “Familial erythromelalgia is described as an autosomal dominant genetic disorder. This means that it takes only one abnormal gene copy to result in the disorder. Persons who are affected with familial erythromelalgia therefore have one

normal copy of the gene for erythromelalgia and one abnormal copy. The efforts described in our article in 2001 have managed to pinpoint a region on chromosome 2 that must contain the erythromelalgia gene. This interval still contains 81 genes, and we do not know which of these 81 genes is the precise gene involved in familial erythromelalgia.”

To illustrate what’s involved in genetic research, Dr. Drenth uses an analogy. “Imagining that our hereditary information is contained in a set of encyclopedias which represent chromosomes. A volume is a single chromosome and each page represents the information encoded by a gene. These are the instructions for the production of a necessary product (a protein). The page must be printed perfectly to communicate its critical information. One misspelling or typo may interrupt production of the product. On one page there are many different misspellings which possibly can occur; these represent different mutations in the gene. To go back to familial erythromelalgia, the specific volume has been identified but the page number (mutation) has not. These misspellings in one erythromelalgia family are not likely to be the same as that in another family. Direct testing, which means looking specifically for the misspelling in the gene, may be offered once the gene has been discovered and has been well characterized. Such testing is already available for certain other genetic disor-

mial erythromelalgia we have first to identify the gene in order to develop a genetic test.”

Dr. Drenth also offers the following encouragement to people with Primary EM who have children or are planning to have them: “Every time a person with familial erythromelalgia has a child, there is a 50 percent chance to pass on the abnormal copy of the gene and thus, the disorder. There is also a 50 percent chance for a child to inherit the healthy gene copy and be unaffected.”

You can learn more about whether your own case of EM is primary or secondary by examining your family tree. If you notice other family members with EM symptoms, and you suspect these similar symptoms are not coincidental, you might want to check further to learn more about your relatives’ symptoms and lifestyles. Once Dr. Drenth’s research is complete, you may be able to have blood tests done to confirm your suspicions. As such testing is not possible at this time, and depends on Dr. Drenth’s success, please keep watching for future news

***So, how do you know which type of EM you have?*** Unfortunately, there are no tests yet, but there may be many indications of a primary condition—one that may cause Secondary EM. A primary disease may be diagnosed by various tests. (Please see your doctor.) Primary EM remains a very difficult condition to identify without a good family history and medical diagnoses of the other affected family members. But who knows? With the TEA Research Fund growing, we may soon be able to know more about this mystery.

## TEA Plans Seattle Fund Raising Event

“A Hollywood Celebration: Raising Money for EM Research,” featuring a silent and live auction and a raffle, is set for June 13, 2004, in the Piano Bar of Club Hollywood in Seattle, Washington, USA. All proceeds go to TEA. The event is the brainchild of Sarah Sundstrom, newly named Chairperson, TEA Fund Raising Committee.

Club Hollywood is a recently opened casino, bar/restaurant with an interior design dominated by motion picture paraphernalia, movie posters, and glass enclosed Hollywood collectibles. Club owners are charging TEA just \$10 per dinner, with use of the facility free. Ms. Sundstrom hopes to attract 150 attendees to the \$30-a-plate dinner. As many TEA members, friends and family members as possible are encouraged to donate handmade items, gift certificates, frequent flier miles or any other valuables to the auction.

You will receive a letter with more details about the event either by e-mail or enclosed with this newsletter. A copy also is posted on the TEA web site. Contact Ms. Sundstrom with questions, at [sarahsundstrom@comcast.net](mailto:sarahsundstrom@comcast.net) or #817, 152nd Place SW, Lynnwood, WA 98037, USA.

### 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 email [webmaster@erythromelalgia.org](mailto:webmaster@erythromelalgia.org). Let's fill up our TEA library!

## Search for EM Gene Continues

Research continues to isolate the gene thought to cause primary EM. Heading up the project is Dr. Joost PH Drenth who is working in conjunction with the National Institutes of Health (NIH) and his home hospital, Canisius Wilhelmina Hospital, The Netherlands.

Last fall, TEA members with family histories of EM supplied blood samples to Dr. Drenth for this study. Those with relatives who also have EM are thought to have Primary EM, a form of the disease that is inherited. (See “What is Primary EM?” also in this issue.) Dr. Drenth is still using these samples for this study and hopes to have some information for us soon, although DNA testing so far is not yielding consistent results. Other testing methods, however, also are being explored as the project continues.

Dr. Drenth is considered one of the world's most active physicians working with EM, with a number of studies already reported in the medical literature. While Dr. Drenth is not an official member of the TEA Medical Advisory Committee, we gratefully welcome his work and input into finding solutions to EM. TEA is pleased to be a part of his current groundbreaking project and will continue to keep in close contact with Dr. Drenth and pass along the results of his research to our membership.

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## Networking Program Expands

Designed in 2003 for TEA members without internet access, the Networking Program is such a great success that TEA is now welcoming any and all members to join. That's right—even if you have access to email, you're encouraged to join the Networking Program.

Presently the program has 24 members who have agreed to exchange names and addresses in order to communicate with one another about their EM and treatments, says TEA Board member Judy Reese, who coordinates the program. She says most current participants want to share experiences with others in their own geographical area and expanding the program will help members do just that.

To sign up for the program, use the application form on page 10 near the back of this newsletter, or contact:

Judy Reese  
1155 E. Wild Duck Lane  
Salt Lake City, UT 84117

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## Christmas Cards Inserts a Success! *Your support is appreciated!*

Many TEA members included the TEA donation cards in their Christmas Cards this last holiday season with outstanding results! Several hundreds of dollars were donated towards the TEA Research Fund. Thank you to those members who took the time and effort to include this important note in their greeting cards this year.



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## TEA Medical Advisor Featured in LA Times Story

TEA and Medical Advisory Committee member, Dr. Jay S. Cohen, was featured in an article appearing in the *Los Angeles Times* February 15, 2004, concerning the fate of a patient, Michael Hope, who suffers from complications stemming from overdoses of Lipitor.

The reporter interviewed Cohen for his perspective on the dosage of many commonly prescribed medications. Even though the patient was given the standard dose of Lipitor, it was much too high. Dr. Cohen has been a proponent of lowering "standard" doses for many years and has written extensively on the topic. His book *Over Dose* was

published in 2001. He now writes *The Underground Medication-Sense Newsletter*, a quarterly internet publication whose goal is providing an objective voice about medication use in America so consumers and doctors can make fully informed decisions about drug and alternative therapies.

Cohen cites a 1998 article in the *Journal of the American Medical Association* that reported prescription drugs cause more than 2.2 million severe medical reactions in hospitals and could kill more than 100,000 people a year. "We have a huge problem with side effects, year after year, decade after decade," Cohen says.

"Every family is affected by it. I don't know how many people have told me that their parents didn't die of disease; they died of drugs. The problem is solvable if we just pay attention to it."

We congratulate Dr. Cohen for exposing this problem in the medical community and thank him for bringing it to our attention. Dr. Cohen had severe EM for several years in the 1990s and pioneered the treatment of EM with magnesium. His EM now is in total remission. If you are interested in reading the *Times* story, it can be found on the Internet at: <http://www.latimes.com/features/health/medicine/la-tm-cohen07feb15,1,7784074.story>.

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## Does medical jargon give you indigestion? Need of help to decipher it?

By Jean Jeffery

When I first began work in a hospital I was taken aback by all the strange medical jargon. I had to find the quickest way to learn this new "language." I'll share with you I did—then you can learn it too!

I bought a pocket-size nurses' dictionary (the kind that is popular with nurses who carry one around in their pockets). They're not expensive—they cost less than your annual TEA dues.

I happen to use Churchill Livingstone's Dictionary of Nursing, but there are several others just as good to choose from. The dictionary contains the meanings of about 10,000 medical terms and abbreviations. (But, no surprise, you probably won't find erythromelalgia included.)

Its also VERY useful if the dictionary you buy includes a few pages (usually at the front or back) which list the common prefixes and suffixes (beginnings and endings of medical words) with their English meanings.

These prefixes and suffixes are the secret "code-words" that medics use! They are actually parts of Latin or Greek words, which are strung together to make up the names of medical conditions and diseases. I've found that a knowledge of these is the key to understanding the meaning of unfamiliar medical terms that I come across in medical papers.

Here are two examples:

cardiopathy (heart disease) is made up from the prefix "cardio" that means heart and the suffix "pathy" that means disease. Gastritis (inflammation of the stomach) is made up from the prefix "gastro" that means stomach, and the suffix "itis" that means inflammation of. And erythro-mel-algia (painful red extremities) is made up from the parts of three Greek words which are "erythro" = red, "melos" = limb/extremity and "algos" = pain.

As medicine advances, some new terms are being introduced which use these same "code-words". You can even make up your own examples. I think a good descriptive name for Raynaud's disease is leucomelalgia ("leuco" means white).

Happy reading, soon you'll be speaking and reading "medical eze"—with ease!

*From the President...*

## What To Expect in 2004

By Lennia Machen

This coming year may prove to be our busiest and most productive ever in working toward solving the mysteries of EM. You may have already read about the TEA survey being compiled as we speak, as well as the important research into the Primary EM gene being done by Dr. Drenth. But perhaps you didn't know about some of the other plans we are developing for 2004.

### **A Live Conference of the TEA Medical Advisory Committee**

TEA is in the process of planning our first face-to-face conference of the TEA Medical Advisory Committee. This first meeting will be an important one as the agenda will include standardization of basic nomenclature regarding EM. This conference also will serve as a foundation to build upon for future meetings and should spark interest in EM from the medical community, and thus prove to be productive in the long run for hundreds of EM sufferers around the world. The plan is to have physicians meet in Europe, possibly Norway, where the majority of the MAC members live and work. Currently the MAC is a relatively small committee with only five members, so TEA also plans to extend invitations to other prominent doctors with an interest in EM from around the world.

The expenses involved in financing a meeting of this sort are high, and we will need your help and support to be able to take this step. If you would be interested in helping finance our conference,

please send your contribution marked "MAC Conference" to our Member Services Representative, Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109, or write to Ray at [memberservices@erythromelalgia.org](mailto:memberservices@erythromelalgia.org). Donations are accepted via our web site donation form as well.

The TEA Board of Directors has discussed this expense at length and agreed that we must spend some money to promote communication about EM in the medical community and to generate immediate interest in TEA's objectives and goals—educating both physicians and the public about EM and finding treatments for EM. We know you share these immediate goals and will want to help support this concerted effort to take the first step.

*Help us find real solutions to Erythromelalgia—contribute to the MAC meeting.*

### **Fund Raising at the Membership and Community Level**

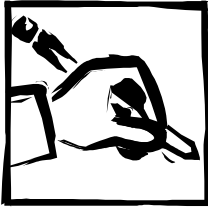
TEA is working on many fund raising efforts at a community or individual level. You will all receive more information about TEA's fund raising campaign soon. Fund Raising Committee Chair, Sarah Sundstrom, is planning a major event in her home town of Seattle, Washington, which will kick off the campaign this spring. (See the fund raising story on page 3.) The campaign

will offer many chances for all TEA members to join in this important task. We hope you will welcome the opportunity to help bring us that much closer to funding research projects and finding solutions to EM.

It's the welfare of our membership that causes TEA to continue working on the fight to solve the puzzles surrounding EM. We all have so much in common, even though it's a sad commonality. We all suffer from EM and have experienced firsthand the effect it has on our daily lives. That is why TEA continues to urge you to help us with fund raising. You are the best link to others who may be willing to give to our fund.

No one is ever comfortable with the task of asking for money, but this discomfort comes in a distant second to the uncomfortable lives we lead while plagued with EM. Won't you please consider the part you could play in this important project? Watch for the announcements about the fund raising campaign and ideas for how you can help in your communities. We all rely on each other and we must dedicate ourselves to stepping outside our comfort zones to help find the funds we need. It's time to get "down and dirty" and make every effort to promote this important activity.

If you would like more information, please contact Fund Raising Committee Chair Sarah Sundstrom, [sarahsundstrom@comcast.net](mailto:sarahsundstrom@comcast.net) or #817, 152nd Place SW, Lynnwood, WA 98037, USA.



## ***Your Stories... and everyone has one!***

TEA has asked its members to write brief stories about their EM or daily lives, and we would love to hear your story too! Many of you have already written, and we thank you for your effort and time in doing so. We all enjoy getting to know our fellow members and learning what they have done to live with their EM. This valuable information helps us all.

If you feel you are not a writer—*never fear*—we will be happy to help you write or edit your story.

Please send them to Gayla Kanaster, 2556 W. 234th St., Torrance, CA 90505, USA or [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com)

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***This issue we have received an important article (written by Dr. Costa's mother, Gayla Kanaster) concerning one treatment device used by several EM sufferers.***

Dr. Pamela Costa of University Place, Washington, who has Primary EM, recently tried the Intrathecal Pump, which is designed to reduce pain by delivering medication directly to the receptors in the spinal cord. Before making the decision to have the pump surgically implanted, Dr. Costa, a clinical psychologist and Chair of Behavioral Sciences at Tacoma Community College in Washington, discussed the procedure with two EM sufferers who had found relief with the pump. She also reviewed the pros and cons with the chief of surgery at University of Washington Medical Center before deciding to let him do the procedure.

The system consists of a pump and a catheter. The pump is surgically implanted in the abdominal area, near the belt-line. A thin flexible tube called a catheter connects to the pump and is tunneled under the skin to the site where medication is to be delivered. The first step was an operation under general anesthesia to insert a temporary pump to check how Dr. Costa would react.

She awoke with a painful spinal headache, nausea and vomiting. The next 10 days were a "nightmare." She had allergic reactions to morphine, dilaudid and sufentanyl, three pain medications administered through the pump. She had back pain from a tear in the spinal dura—the tough, fibrous membrane that covers the spinal cord—that occurred during surgery.

She was then given her regular oral dose of MS-Contin, intravenous morphine and caffeine to relieve her headache and back pain and Zofran to prevent the constant vomiting. On the fifth day a "blood patch" in her spine was performed to help with the headache and vomiting, without success.

When she finally returned home, she needed physical therapy for several weeks and has resumed her previous pain therapy of 15mg of MS-Contin twice a day, and 75 mg of Effexor at night. Born with severe EM, Dr. Costa had been part of an extensive study of familial erythromelalgia (Primary EM. See "What is Primary EM? on page 2.) conducted by the University of Alabama, Birmingham. She and her husband have a four-year-old adopted daughter.

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The intent and purpose of this publication is to bring information to those suffering from erythromelalgia or their friends and families, and not, in any way, to provide medical advice.

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## TEA Research Fund Donors



*Following is a list of the active members 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.*

Barbara Klazmer,\* Robert Self, Paul Hilder, Phil Pennington, Shan Guadagnoli, Isabelle Davis, Dolores Besch, Angela Gervasi, John Davidson, Dolores Besch, Rhonda Batts, Regina & Dieter Bayer,\* Willene Domenichelli,\* Georgia Stokowski, Don Bolton,\* Peter DeSpirt, Marion Walker, Beth Huston, Katherine Pelly, Lawrence Batlan, Margaret Miller, Linda Barr, James Read, Joyce Perkins, Erika Schon,\* Jodie Barr,\* Eloise Masters, Carol Boulais, Philip Coyle, Polly Vogel, Robert Self, James McKellican, Marilyn Wade, Shirley Miller,\* Lois Mavsar, Jeanne Golden, Paul Isacoff, Kathleen Rutledge,\* Thomas Simmons,\* Kathy Golden, Vincent Liscano,\* Cordell & Beverly Lawrence,\* Pam Costa,\* Madeline Steingut, Jennifer Jones, Denis & Sally Caravella,\* Aetna Foundation, William Reese,\* Amy Marcotullio, Derek Berman,\* Sandra Correa, and Robina Pritchard.

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

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

### TEA Contact Information:

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

**Network Program:** Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117  
or email to: [network@erythromelalgia.org](mailto:network@erythromelalgia.org)

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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.*

**Alice Bluhm, Katherine Collier, Eve Duncan, Kelly Hershey, Miss P.A.Hudson-Wallis, Rata Johnstone, Beverly & Cordell Lawrence, Shelly Loveland, James McKellican, Karen Nomura, Stephanie Pratola, Robina Pritchard, Gillian Turnbull, Raymond Gaskins Jr. M.D., Myron Goodman M.D., Malcolm Trevor King, Teresa Kjorvestad, Sue Moore, Rebecca Northover, Alan Pratt, Michael Ross, Jane Schwartz, Dolores Besch, Anne Birrell, Tracey Chouihni, Mr. R. S. Clark, Ann Forstater, Carolyn Quinn, and Megan Rung.**

*Welcome!... we're glad you've joined us!*







## TEA Library Articles and Documents Page 1

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 Thrombocythemia. Michiels, Abels, Steketee, Huub, VanVliet, Vuzevski 1985	8	\$2	
M012	Histopathology of EM in Thrombocythemia, Michiels, Abels, Vuzevski 1983	8	\$2	
M013	Pathological C-fibres in patients with a chronic painful condition. Rastavik, Weidner, Schmidt, Schmels, Hilliges, Jorum, Handwerker, Torebjork, 2003	1	\$1	
M014	Prevention and treatment of thrombotic complications in essential thrombocythaemia: efficacy and safety of aspirin. Van Genderen, Mulder, Waleboer, Van De Moesdijk, Michiels, 1996	8	\$2	
M015	A Way to Understand Erythromelalgia, Zoppi, Zamponi, Pagni, Buoncristiano, 1985	4	\$1	
M016	Autonomic Innervation of the Skin in Primary Erythermalgia. Uno, Parker, 1983	8	\$2	
M017	Coexistence of Raynaud's Syndrome and Erythromelalgia. Slutsker, 1990	1	\$1	
M018	Erythromelalgia: Case Report and Literature Review. Levine and Gustafson, 1987	5	\$1	
M019	Erythromelalgia Pain Managed with Gabapentin. McGraw, Kosek, 1997	5	\$1	
M020	Erythromelalgia: Symptom or Syndrome? Belch and Mackay, 1992	9	\$2	
M021	Impaired Skin Vasomotor Reflexes in Patients with EM. Littleford, Khan, Belch, 1999	8	\$2	
M022	Nitroprusside Treatment of EM in an Adolescent Female. Stone, Rivey, Allington, 1997	5	\$1	
M023	Pharmacotherapy of Raynaud's Phenomenon. Belch, Ho, 1996	1	\$1	
M024	Refractory Idiopathic Erythromelalgia. Rauck, Naveria, Speight, Smith, 1996	7	\$2	
M026	Temperature-associated Vascular Disorders: Raynaud's Phenon. and EM. J. Belch, 2001	26	\$6	
M027	Treatment Regimens and Patient Review. Text book excerpt (no date)	6	\$2	
M028	Unexpected Healing of Cutaneous Ulcers in a Short Child (with EM). Climaz, Rusconi, Fossali, Careddu, 2001	2	\$1	
M029	Erythromelalgia: Response to serotonin reuptake inhibitors. Rudikoff, Jaffe, 1997	3	\$1	
M030	Efficacy of IV Magnesium in Neuropathic Pain. Brill, Sedgwick, Hamann, Di Vadi, 2002	5	\$1	
M047	One Size Dose Does Not Fit All. Dr. Jay Cohen, 1999. Discusses prescription dosage	2	\$1	

**Please use the order form on the previous page to order the above documents.**

## TEA Library Articles and Documents Page 2

Article #	Title, Author, Date	# Pages	Cost	Order?
M031	Hot Feet: Erythromelalgia and Related Disorders. Robert Layzer, 2001	5	\$2	
M032	Red Skin Re-read. Schechner, 2002	3	\$1	
M033	Treatment of Raynaud's Phenomenon with the Selective Serotonin Reuptake Inhibitor Fluoxetine. Coleiro, Marshall, Denton, Howell, Blann, Welsch and Black. 2001	8	\$2	
M034	Serotonin Reuptake Inhibitors, Raynaud's Phenomenon and erythromelalgia. Rey, Cretel, Jean, Pastor, Durand, 2003	2	\$1	
M035	Skin Blood Flow in Adult Human Thermoregulation: How it works, when it does not, and why. Charkoudian, 2003	12	\$3	
M036	Topical Antidepressants: the new local anesthetics? Strumper, Durieux, 2003	3	\$1	
M037	Topical amitriptyline in healthy volunteers. Gerner, Kao, Srinivasa, Narang, Wang, 2003	6	\$2.	
M038	Impaired Neurogenic Control of skin perfusion in EM. Mork, Kalgaard, Kvernebo, 2001	8	\$2	
M039	Treatment of erythromelalgia with a serotonin/noradrenaline reuptake inhibitor. Moiin, Yashar, Snachez, Yashar, 2002	2	\$1	
M040	Lidocaine patch for pain of erythromelalgia. Davis, Sandroni, 2002	4	\$1	
M041	Erythromelalgia an endothelial disorder responsive to sodium nitroprusside. Chan, Tucker, Madden, Golding, Atherton, Dillon, 2002	2	\$1	
M042	Poxviruses isolated from epidemic EM in China. Zheng, Zhang, Hu, Lui, Zhu, 1988	2	\$1	
M043	Skin Perfusion in patients with erythromelalgia. Littleford, Khan, Belch, 1999	7	\$2.	
M044	Treatment of primary erythromelalgia with cyclosporine. Sano, Itami, Yoshikawa, 2003	2	\$1	
M045	Resolution of refractory symptoms of secondary erythromelalgia with intermittent epidural Bupivacaine. Sticker, Green, 2001	5	\$1	
M046	Microvascular arteriovenous shunting is a probable pathogenetic mechanism in EM. Mork, Asker, Salgerud, Kvernebo, 2000. Reply, Davis, Rooke, Sandroni, 2000.	9	\$2	
M049	Natural history of erythromelalgia. Davis, O'Fallon, Rogers. Rooke, 2000	9	\$2	
M050	Aspirin Responsive painful syndrome in polycythemia vera associated with thrombocythemia. Michiels, Berneman, Schroyens and Van Urk, Abstract only, 2003	2	\$1	
P001	Disease has Midlander Crusading for Awareness. Templeton, 2002	2	\$1	
P002	Current Treatment for Erythromelalgia. Jay Cohen 2002	2	\$1	
P003	Lynnwood Woman Hobbled by Chronic Burning Foot Pain. O'Harran 2003	3	\$1	
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P005	Fighting Pain with Fire: Hot Chili Peppers Offer Relief—Capsaicin. Mike Field, 1994	1	\$1	
T001	TEA Introduction Letter. TEA, 2002	4	\$1	
T002	2002 TEA Financial Report	2	\$1	
T003	TEA Information Flyer, 2002	1	\$1	
T004	TEA Brochure (full color) 2003	2	\$1	
T005	TEA Bylaws. The complete bylaws used to operate TEA. 2003	8	\$2	
T006	TEA Policy & Procedure. Supplement document to the bylaws for the operation of TEA. 2003	7	\$2	
T007	TEA Christmas Card Insert, Business card size, color, 2003	1	\$1.50	
T008	TEA Christmas Card Insert, Note Card size, 4 1/4 X 5 1/2, color, 2003	1	\$1.50	
T009	TEA 2003 Financial Report	2	\$1	

**Please use the order form on the previous page to order the above documents.**



# The Erythromelalgia Association

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March 29, 2004

Dear Fellow TEA member:

Planning is now well under way for what is shaping up to be the largest fund raising event ever held to benefit The Erythromelalgia Association. The \$30-a-plate dinner will be held in North Seattle on June 13, 2004, from 5-8 pm. It will feature both a silent and live auction and a raffle. Dave Mahler, a celebrity sports radio DJ, will be the auctioneer.

The venue? The Piano Bar at Club Hollywood—a newly opened casino, restaurant/bar with movie posters, glass-encased Hollywood collectables, and motion picture paraphernalia decorating the walls. Use of the club is free to TEA and we will be charged just \$10 per meal served, which means that TEA will get \$20 of the \$30 charged per meal.

We want as many of our membership to make it to the event as possible. If the \$30 is too much for any of you, please contact Sarah Sundstrom at the phone number or email address listed below. We will definitely be able to work something out.

We are aiming to attract at least 150 attendees to the event. All 18 Seattle-area TEA members have already received special invitations encouraging them to attend and bring friends and family members. Do you live far away from the Seattle area? You're encouraged to make Seattle a vacation destination this June and plan to attend. It's a beautiful city with predictably cool weather even in early summer.

Please let me know immediately if you decide to travel to attend the event. If there's enough interest among TEA out-of-towners, we will look into discounted accommodations.

Other ways you could help make the event a success:

- Donate to the auction some art or craft item you've made.
- Contact any family members or friends who work for large companies and could get gift certificates for the auction. Stores like Home Depot, Target, and Pier One and many chain restaurants do donate gift certificates to charity auctions.
- Ask those you know to donate frequent flier miles. People who travel frequently for work may also have points for hotel stays they might donate.

Anyone wanting more information should contact me at the addresses below. I am really excited about this event and know it's going to be a HUGE success.

Thanks for your support,  
Sarah Sundstrom  
Chairperson, TEA Fund Raising Committee

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# Creative Ideas for Supporting the TEA Auction

This is a great opportunity for those of you that would like to contribute to the auction. All you need is a little creativity. You can even do this with some friends and get them to donate a couple items to your basket.

The thing to keep in mind is that each basket should have a theme and be packaged well. People like to buy things that look good and many times, people like to buy things when they know that someone has made the items. Please don't feel as if you have to make the items for your basket, though. Feel free to make or purchase any of your items.

Here are some ideas that we've come up with, but there are a million things that you could do. Feel free to borrow an idea from this list or to come up with something on your own.

If you don't want to worry about the hassle of mailing the basket with your items, you can always include \$10 with your items and I will buy the basket.

## Baskets

- **Homemade Jam basket:** Could include a few jars of jam, packages of scones, cute spreading knife, book on how to make jam, recipe for homemade bread
- **Gardening theme:** Rather than having a basket this could be done in a pail, with a hand shovel, gloves, seeds, fertilizer, small pots
- **Summer Basket:** Could include a pair of thongs, funny sunglasses, beach towel, sunscreen, sun lotion, a disposable camera, a Frisbee and a good book or magazine
- **Book Basket:** Someone that enjoys reading could put a basket together of their favorite books and or poetry; perhaps something like a book review could be included in the basket
- **Coffee or Tea Basket:** You could include a few bags of great coffee, a couple nice mugs or even a commuter mug, and/or some specially flavored tea
- **Scrap booking Basket:** This could be filled with scrap booking things such as a cutter, adhesive tape, stickers, paper, a book on how to scrap book and a scrapbook
- **Knitting Basket:** Could include yarn, a book on how to knit, some needles and maybe a scarf
- **Recipe Basket:** This could include a nice box to hold recipes along with some of your favorite recipes.
- **Spa Basket:** Fill it with lotions, soaps, bath salts and candles
- **Card Basket:** Filled with different types of thank you, birthday cards, and blank cards along with envelopes, pretty paper, a nice pen and some stamps

## Homemade Items

- ◆ For anyone that crochets or knits: You could make a quilt, baby blanket, hat and glove set
- ◆ Homemade soaps, lotions, or candles
- ◆ Homemade cards
- ◆ Framed Painting
- ◆ Framed Photograph

## Gift Certificates to Chain Stores or Restaurants

If you know someone that works at a chain store or restaurant, ask them if they can get a gift certificate donated to our auction.

## Frequent Flyer Miles

If you or someone you know has to fly a lot, chances are you have racked up a lot of frequent flyer miles. Most airlines will let the owner of these miles "donate" them to someone else. Ask your family members if they have extra miles that they would like to donate. It would be great if we could auction off two round trip tickets to somewhere warm. (Remember, Seattle doesn't get that warm, so people love to head out of town for a few days to see sunshine.)