FootSteps... TOWARD PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia Volume 5, Issue 4, December 2004, Published by The Erythromelalgia Association

TEA to Help Fund Yale Research into Primary EM

TEA's Research Fund will be put to use immediately by helping finance ongoing investigations into EM at a Yale University research center. TEA's Board of Directors in November approved donating \$60,000 to the Department of Neurology at Yale specifically to support a research study into primary (inherited) EM.

While this is laboratory—or what's known as basic—research, what they've discovered about EM is likely to open up "new and rationally based strategies for treatment of primary EM," the researchers say. That's because much less rare diseases like epilepsy and cardiac arrhythmias happen to result from malfunctions in proteins very similar to those that are altered in EM.

These proteins—called sodium channels—are found along the length of nerve fibers and act as molecular batteries in generating and transmitting nerve signals. Sodium-channel-blocking drugs already exist to treat the more commonly occurring illnesses like epilepsy. Although there are nine different sodium channels, there's a good chance that some of these drugs also might work to block the channel implicated in EM, according to Sulayman D. Dib-Haji, Ph.D., research scientist at the Center for Neuroscience and Regeneration Research at Yale, and the West Haven Veterans Affairs Medical Center, whose team is conducting the research under

the direction of Stephen Waxman, M.D., Yale chair and professor of neurology and director of the Center.

For almost 10 years, the relationship of sodium channels and pain—especially nerve pain—has been one of the Yale researchers' main interests. The center where they work is funded largely by the Veterans Administration and groups like the Paralyzed Veterans of America, the United Spinal Association and the Multiple Sclerosis Society. Their mission is ultimately to restore function in people with spinal cord injuries, nerve injuries and multiple sclerosis through basic research into the biology of abnormal nerve conduction.

Their finding in the recent EM study is consistent with their theories that dysfunction of one sodium channel can cause painsensing nerve cells in the skin to become hyper-excitable and overly sensitive to stimuli like heat, firing when they should not and causing pain.

TEA first helped the Yale researchers by asking members with primary EM—people with family members who also have EM—to give blood. The researchers then collected blood samples from these TEA members and their families. Analyzing blood cells from just one of the samples—with state-of-theart molecular biological tech-

niques—the team identified a genetic mutation linked to EM pain. This finding provides the first explanation of what happens at the cellular level in the bodies of people with inherited EM that causes their pain. An article by the Yale research team reporting their observations and laying the grounds for the current study was published in the *Journal of Neuroscience* last September.

TEA's monetary donation will help fund the next steps in the study, one of which is analyzing the blood of the other 26 members of this family to confirm the new mutation. Dr. Dib-Hajj says that members of the same families who have EM should all have the same mutation, and relatives without the disease should not. These scientists have been studying the biology of this one sodium chan-

Continued on page 2

ALSO IN THIS ISSUE

Partners with Yale2
Did You Know? 2
Fund Raising Videos2
President's Message 3
TEA to Attend Conference 3
TEA Annual Report 4
New Members 4
Your Stories 5-6
Raise Funds for TEA 6
Fund Donors7
Contact Information 7
Networking Program 8
Article Catalog 9-10
-

Yale Research Project, Cont.

nel since its discovery in 1995—the one they found to be altered in primary EM. And thus, when recent studies by Dr. Joost Drenth in the Netherlands and Dr. Y. Yang in China identified the gene associated with EM and two mutations in it, the Yale team was able to build upon these discoveries and determine how the mutations produce altered sodium channel function.

If you would like to learn more about the research at Yale, go to: http://info.med.yale.edu/ neurol/pva-epvacenter/info/ center.html

Editor's Note: When interviewed for this story, Dr. Dib-Hajj, on behalf of the research team, expressed its gratitude to the members of TEA for our support of their work. The funds we are donating are important, he said, but more important is the general support for Yale's research efforts that TEA is demonstrating.

Does EM Run in Your Family?

We are considering having a special section in *Footsteps* featuring members who have multiple generations of EM in their families. If your family shares this awful condition, we would like to hear about it. Please let us know. Send your story (or questions you may have) to GaylaKanaster@aol.com or Gayla Kanaster, 2556 W. 234th Street, Torrance, CA 90505-3115.

Yale: "We regard you as partners"

After reviewing this article, Dr. Waxman, Yale University chair and professor of neurology, sent the editor an email to add his "thanks to those of Dr. Dib-Hajj and the rest of our research team." He continued, "As you know, we are very excited about the progress that we have already made in the study of EM, but we want to move even further ahead, and your gift will make this possible. We are fortunate in housing, within our Research Center, a truly world-class, multidisciplinary team of researchers. Please know that we are working around the clock in our effort to develop new therapeutic approaches to chronic pain. We regard you as partners and I am confident that we will win this battle against EM."

Did You Know? By TEA President, Lennia Machen????



- 1. TEA is six years old! TEA was incorporated in 1999 and the TEA newsletter, FootSteps, has completed six years of publishing information about EM for it's members.
- 2. "Getting a diagnosis" of EM, is the number one complaint of TEA members.
- 3. Primary EM sufferers comprise about 1/4 of the people who are diagnosed with EM. Secondary EM is much more common among EM sufferers.
- 4. TEA has nearly 500 members and has raised over \$92,000 for EM research.

TEA Fund-raising Videos Available

The video about EM and TEA, produced this year for the Seattle auction, now is available to be purchased or rented as a DVD or VHS tape. Intended as a fund-raising tool, the video includes several TEA members describing very effectively the challenges they face living with EM. Two physicians also discuss EM and its symptoms. Beginning with an introduction by TEA President Lennia Machen, the video also includes information about TEA and its mission.

Members can obtain a copy by contacting Networking Program Chairperson Judy Reese. (See contact information p.7) A DVD costs \$14.50 plus \$2 shipping; a VHS tape \$24.00 plus shipping. Copies may also be rented for just the total two-way \$4.00 shipping cost. A deposit equaling the value of the DVD/tape or a credit card number also is required. The deposit will be returned to you when you return the video.

President's Message--a big difference in just one word

TEA has taken an important "first step" and crossed the line from "planning" to "participating." We will now and forever be *participants* in research into EM and never again be just *planning* to participate. A big difference in just one word. A change that cannot be undone—we are forever changed.

TEA's gifting money to Yale and funding a grant through NORD realizes the dream many of us have shared since the conception of TEA. It's because of everyone's donations that this dream is now a reality. To many, supporting research is the goal and purpose of TEA. It is largely through our members' generosity and tireless support that we are able to make this step into our future. We all thank you from the bottom of our hearts for the opportunity you have given us all.

What better time than the holiday season to acknowledge the special gift you all have given EM sufferers around the world? The gift of hope, a big difference in just one word. When we have *hope* that research may find solutions to our pain and suffering, we have a gift of huge proportions that lasts well after the gift wrappings and holiday offerings have been discarded. It is hope that keeps us looking forward toward the possibility of wellness. Imagine finding a solution to your EM! It gives me great hope that we may be supporting the research project that could do just that.

While we thank our generous members for their gifts in support of EM research, we must also look to our future. We need to see this as only the first of the numerous steps needed to reach our goal ... real help for all EM sufferers. Until we find the cure or an effective treatment for all who suffer from EM, our job is not finished. We now must not rest on our laurels and place all our hopes on these first projects, but rather begin planning on replenishing our research fund and searching for future projects. We still need your help.

I am asking for your continued support and donations to sustain our goals until we find those final solutions. Won't you please consider making a contribution to TEA's Research Fund? We have so much more work to do, and together, we can take more steps, and reach our goals.

Another—in some way more meaningful—way to keep hope alive is to contribute your time. Many of our board members see the hours and energy they volunteer as their way to contribute. If you are able and willing to volunteer your time, please contact our Member Services representative and ask about the jobs and committees that you might participate in. We're an all-volunteer organization and contributing time is greatly appreciated and can be very gratifying. And, you don't need to have EM to help. If you are a spouse or family member of a sufferer, what better way to take part in speeding up the solutions your loved one wishes for on a daily basis, than to take part in this cause? Consider helping us to help those with EM.

In conclusion, I thank each one of you who has contributed to this cause. I appreciate you. And I encourage you to continue your support. We have more work to do, and it can only happen with *your* support.

Lennia Machen

TEA Board Member to Attend NIH Regional Workshop

"Gaining Access to Research Resources" will be the focus of a workshop TEA Vice President Beth Coimbra will attend at the end of January. Sponsored by the Office of Rare Diseases of the National Institutes of Health, the three-day training meeting is intended for leaders of rare-disease patient organizations.

Beth hopes to gain information about how TEA might grow in the future and what potential sources for research money might be available during the workshop to be held in Philadelphia. Representatives of other patient organizations who attend may have ideas to share on subjects like recruiting members, she says.

Beth serves on the Board of Directors of the National Organization for Rare Disorders (NORD), which is coordinating the meeting. TEA is a member of NORD.

Annual Report: 2004 Accomplishments

2004 was a good year for TEA! Our organization—without any paid staff—accomplished a great deal in the past year. Here's a list of what we did.

- TEA members provided blood samples to researchers at Yale University, who identified a genetic mutation in one of those samples that they linked to EM pain. This discovery explains for the first time what happens in the bodies of people with primary EM that causes pain. These scientists at Yale's Center for Neuroscience and Regeneration Research say this finding is likely to open new strategies for treatment of primary EM. (See story p. 1)
- TEA's Research Fund grew to more than \$90,000, and the Board of Directors decided to put the money to use by funding two research projects in 2005. TEA will donate \$60,000 to Yale University's Center for Neuroscience and Regeneration Research specifically to help fund continued research into what goes wrong in the nerve cells of people with EM that causes pain.
- TEA also will fund a \$35,000 "seed money" grant through the National Organization for Rare Disorders (NORD). As a member of NORD, TEA is able to make use of NORD's Clinical Research Grant Program, which requests, evaluates, and awards grants on behalf of its numerous member organizations. In January 2005, NORD will issue to the worldwide research community a Request for Proposal for research studies into EM. The "winning" study will be chosen by early fall. (See *Footsteps*, September 2004 for the full story.)
- TEA sponsored its first major fund-raising event—a dinner and auction held in Seattle in June 2004. More than \$17,000 was raised for the Research Fund from this one event. Led by Sarah Sundstrom, TEA's newly appointed Fund-Raising Chairperson, volunteers spent countless hours organizing the auction and acquiring an impressive inventory of goods and services. They also produced an educational videotape about EM and took care of the myriad details involved in this successful \$30-dollar-a-plate dinner.
- Also in June, three members of TEA's Medical Advisory Committee (MAC) met face to face for the first time in Oslo, Norway. TEA President Lennia Machen was a participant in the meeting.
- Participation in the Networking Program was opened to all TEA members, and a Networking office was established in the UK to more effectively serve TEA's many European members.
- Results of the 2004 member survey were compiled and published to provide an up-to-date view of EM treatments for our members and medical professionals.

TEA's membership increased to 480 members in 17 countries.

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.

Lorraine Beard, Connie Blattner, Susan Burkett, Debra DeRue, Virginia Duffy, Kelley Durden, Mrs. Gwen Fisher, Kevin Green, Michele Grundstein MD, Steve Helm, Astrid Hasbrouck, Maria Koncewicz, Meg Lombardi, Shirley Longmire, Lisa Martin, Barbara Oehl, Timothy Prahlow, Marian Precht, Bonnie Pritchard, Carmella Roy, Phillip Sprules, Linda Sutton, Maggie Wallace, Kathy Weaver, William Wood

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



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 also have long and difficult tales to tell about the diagnosis process. TEA invites you to share your experience with EM by writing your story. If you think you're not a writer—

never fear. We can help you write and edit you story. Please send stories to Gayla Kanaster, gaylakanaster@aol.com or 2556 W. 234th Street, Torrance, CA 90505.

Jean's Story

I live in Nottingham, England and I've had EM for 14 years. During this time my life has taken some strange twists and turns. In 1994, I was in constant agony with burning, red, hot, swollen feet and could not wear any shoes. But now, just 10 years later, my feet feel very cold most of the day unless I wear slippers, and the EM symptoms have "migrated" to my head. The reason for these changes: I have both EM and Raynaud's Disease. Although the symptoms of these two conditions are exact opposites, the diseases are closely linked. The result: my life is ruled by the weather all year round.

But back to the beginning: I've had Raynaud's in my feet, hands and ears since I was 10. At the age of 44, I was glad to find my Raynaud's symptoms beginning to disappear. But they were replaced by something far worse: fiery burning toes! Despite using ice packs and cold fans I became housebound and had to give up work as a medical scientist. I was diagnosed with EM but no medication gave me any relief. I became depressed.

Just six months later, I saw a new doctor at my hospital who recognized my EM. He had trained with Professor Jill Belch, the United Kingdom's EM expert! In November 1995, I traveled to Scotland to see Prof. Belch. After many tests she gave me a prostacyclin iloprost infusion (drip) for 5 days. With great surprise I watched my burning recede so that my feet began to look and feel normal again! I was told this benefit could last up to 6 months, after which I'd need repeated infusions.

Back home I reveled in wearing shoes again and putting my feet inside my bedcovers. Then sadly the burning re-appeared after four months, and my Raynaud's symptoms also returned. My toes now lurched between painful episodes of cold Raynaud's and burning EM. I was housebound again. I tried two more infusions in Nottingham but they did nothing! Thankfully, I found great support from EM members of the UK Raynaud's and Scleroderma Association. Since then I have been helping many other EM members all over the UK who contact me for help and support.

In winter 1997, my Raynaud's became so severe that my hospital made me a special pair of warm shoes lined with sheepskin, which were extra large to avoid rubbing my sore toes. I began to get out of my house again. But the following year, EM attacked my ears and cheeks. My burning red ears were incredibly painful and caused sleepless nights with my feet tucked up in a warm bed, but with cold fans blowing on my head. Soon after, my hands began to turn red and hot.

The EM symptoms affecting my face seemed to have been triggered by menopause. So I began hormone replacement therapy (HRT), which actually halted the EM in my hands and reduced the frequency of facial attacks. (I still take HRT to prevent my hands from burning.)

In 2001 I joined TEA and the EMyahoogroup, which gave my life a new focus and brought valued friends. At present I'm happiest indoors where the temperature never rises above 21C/69F. Above this my ears and cheeks always turn red and become painful. As well as HRT I have found that small doses of amlodipine/ Norvasc are very helpful for my feet. Time doesn't drag too much because I like to spend hours with my nose in medical books. I also write to my new EM friends. On cool, cloudy days I'm glad to get out in my car or to work in my garden. At the back of my mind, I do wonder what tricks my EM and Raynaud's will play on me next. I just hope I shall be able to handle them.

Raise Funds for TEA

Now that TEA has committed almost all of its Research Fund to help finance the work at Yale and sponsor a grant through the National Organization for Rare Disorders (NORD), we need to raise more money.

As you know, TEA has no paid staff. During the five years since our founding, TEA—through the work of volunteers—raised more than \$90,000 for the Research Fund. And these volunteers were primarily TEA members, many living with the challenges of EM and often other illnesses as well.

How did we do it? And how can we help to raise more? Here's how one member contributed to the effort—a method that could work for you. TEA board member Gayla Kanaster asked a group of her friends to make donations to TEA instead of buying her birthday gifts. "A group of us have been getting together to celebrate our birthdays for about 20 years. We have a

potluck dinner or go to a restaurant and have always exchanged presents. This year I asked that instead of buying me a gift, they make a donation to TEA," Gayla says.

She printed the donation cards from the web site, glued them on 3 x 5 inch cards and gave one to each friend. She also showed them the TEA fund-raising video. (See Fund-raising Videos Available, p. 4)

Your friends and family know about your rare disease and would no doubt give generously just as hers did, she says. "The TEA cards make it easy since they provide the needed information for donations. My friends were happy to no longer have to shop for 'just the right gift.' It's so much more meaningful," she added.

Other members have gotten generous responses by placing TEA donation inserts in their holiday cards. Debbie Mosarski, another TEA board member, raised \$495 by including the inserts in her cards in 2003. TEA donation cards, designed to be inserted into greeting cards, are available through the Networking Program as well as on the TEA web site.

TEA Fund Raising Chairperson Sarah Sundstrom and many of her friends and family members spent countless hours working on the dinner and auction held in Seattle last June. The first ever TEA fund-raising event, it raised \$17,350. Sarah would be glad to advise anyone who wants to plan an auction in 2005. At home now caring for her infant daughter born last September, she can be reached at

sarahsunstrom@comcast.net

If you have a fund-raising method to suggest, please contact the editor, (See TEA Contact Information, p.7) so we can include it in a future issue of *Footsteps*.

Your Stories, Continued

Marion's Story

I am a 69-year-old woman who first experienced a strange, itching sensation on the outer edge of my right foot. Gradually the sensation became more painful, red and burning. The other foot was also affected as were the fourth and fifth fingers and outer edge of my right hand. Using the Internet, I learned my condition was described as erythromelalgia.

My rheumatologist didn't believe I had EM until I showed him photos of my inflamed feet. This year I visited the Mayo Clinic, a very stressful experience. The physicians there diagnosed my condition as mild EM in my hands and attributed the pain in my feet and other problems to fibromyalgia, osteoarthritis, and other medical conditions. I take19mg of Effexor daily, a low dose of Wellbutrin, and use 5% Lidocaine patches, plus apply "Zeel" ointment twice daily and "Pain Buster Two" ointment at night. I have tried acupuncture, which gives me temporary relief, and massage, with mixed results.

My attitude has changed about my physical problems—it's more positive and I feel less self-pity. I attended a pain management clinic at Cedars Sinai Hospital and learned some tools for relaxation.

My shoe choices are limited because of swelling in several toes. I have a small portable foot stool from the "Relax the Back" store that I use on airplanes and at my desk. I try to walk several times a week wearing orthotics in shoes I got at a "New Balance" store.

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.

John Allen, Lawrence Batlan, Dolores Besch, James Bronson, Virginia Bullock, Sandra Campbell*, Mr. R. S. Clark, Douglas Cotner, Mildred Daniels*, William Davenport*, Maureen Davies, Debra DeRue, Willene Domenichelli, Phyllis Dorminy, Catherine Erickson*, Nancy Farish, Ann Forstater, Mrs. N. Forsyth*, Angela Gervasi, Austin Haller*, John Hicks MD, Derek Humphry, Barbara Klazmer*, Sharon Landry*, Patricia LeVasseur, Virginia Meldrum, Verity McGregor*, Colleen McKay*, Charles Parker, Virginia Phillips*, Robert Self, Linda Sutton, Margaret Turner, Marsha Turney, Marilyn Wade, Maggie Wallace, Morrie Zagha

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

Our Many Thanks to Each One of You!

TEA needs your help! There are several jobs and tasks that TEA needs help with. If you would like to volunteer to help those with EM, please contact Member Services and find out how you can volunteer. Some tasks that have immediate openings include Fund Raising Committee, Board of Directors Member position, web site support, and more. TEA is a non-profit, all-volunteer organization.

TEA Contact Information:

Member Services: Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109.

Or e-mail to: memberservices@erythromelalgia.org 860-529-5261

Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117 **Networking Program:**

Or e-mail to: judy@dataquest.com (801) 631-3833

FootSteps: Isabelle Davis, 24 Pickering Lane, Wethersfield, CT 06109

Or email to: imdcomm@aol.com

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

^{**}Donors supporting the MAC Conference

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		<u>a</u>	
-		Mail this form to:	

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

DVD Fund Raising Video \$14.50 VHS Fund Raising Video \$24.00 Shipping \$4

To rent the Videos you must purchase them first, then your cost will be refunded when the video is returned.

Mail to: Judy Reese, NW Program 1155 E. Wild Duck Lane Salt Lake City, UT 84117 1-5 pages is \$1 6-10 pages is \$2 11-15 is \$3 16-20 is \$4 21-25 is \$5 26-30 is \$6 31-35 is \$7 36-40 is \$8

International shipping charge: \$2 extra shipping charge (except Canada)

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

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 arteriouvenous 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	Histopathy 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	Coexistance 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	
M031	Hot Feet: Erythromelalgia and Related Disorders. Robert Layzer, 2001	5	\$2	
M032	Red Skin Re-read. Schechner, 2002	3	\$1	

TEA Library Articles and Documents Page 2

Article #	Title, Author, Date	# Pages	Cost	Order?
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 erythromelalga with cyclosporine. Sano, Itami, Yoshikawa, 2003	2	\$1	
M045	Resolution of refractory symptoms of secondary erythermalgia 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	
M047	One Size Dose Does Not Fit All. Dr. Jay Cohen, 1999. Discusses prescription dosage	2	\$1	
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	
M051	Erythromelalgia: Studies on pathogenesis and therapy. Mork, C. 2004	25	\$6	
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	
P004	Causative Symptoms in Erythromelalgia Identified. Veronica Rose, 2002	1	\$1	
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	
T010	TEA 2004 EM Survey (Spread Sheets)	8	\$2	

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

Page 10