FootSteps *TOWARD PROGRESS*

The newsletter dedicated to finding a better way to live with erythromelalgia
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Survey Says: Most Members Positive about TEA

Were you surprised to find this issue of *FootSteps* in your mailbox? If you were, you're among the two-thirds of members who have never before received a printed issue. TEA made the change to mailing newsletters to everyone as a result of the telephone member satisfaction survey conducted in May.

Almost 60 percent of those surveyed report getting the quarterly newsletter by going to the TEA Web site and reading it online or printing it from the Web. But just fewer than a third prefer getting it that way. And *FootSteps* will still be posted on the Web site as well as being mailed.

Those asking the questions completed surveys of 59 members whose names had been randomly chosen from the TEA membership list, which totaled 514. Surveying that size sample means we can be 90 percent confident the findings reflect the opinions of the entire membership.

The survey says almost 90 percent of rspondents agree that TEA provides useful information to them. But while more than two-thirds also agree TEA provides information to them as often as they want or need it, many say they would like to receive more in general from TEA.

A large percentage of those surveyed—almost 80 percent—say they read all or most of the newsletter.

When asked about the kinds of information in the newsletter, however, about 90 percent of respondents say they want more articles about treatments for EM and more articles about EM research.

Almost 60 percent of respondents would like to read more stories about members' personal experiences with EM. More than two-thirds say *Footsteps* should include about the same amount or less concerning association activities and fundraising.

Asked what other kinds of information they would like to get, respondents most often say they want TEA to provide names of physicians familiar with EM. Other suggestions made by respondents include "tips" about what other members do that help them and how others cope, more about medications, and more descriptions of EM symptoms including psychological effects.

An "Ask the Doctor" column, more articles by EM specialists, quick overviews of medical articles to take to doctors, more personal stories about people who have improved, and information aimed specifically at the newly diagnosed—all these and more are among the many suggestions made by respondents.

Half agree TEA provides services to them that they need. When asked what more TEA could do, however, many

Survey Results

ALSO IN THIS ISSUE

You're Not Alone

Networking Program Provides Support, Information

Would you like to contact others living near you who also have EM? Or get copies of articles from the TEA Library without using the Web site? TEA offers a service—the Networking Program—that helps you do both. Just fill out the form included on page 9 of this newsletter and send it to Judy Reese, Networking Chairperson, 1155 E. Wild Duck Lane, Salt Lake City, Utah 84117.

By signing the application form, you give TEA permission to provide your name and address to other TEA members who are a part of the program—and there are quite a few both in the U.S. and the U.K. TEA holds personal information about its members in strict confidence and will not disclose it unless you give TEA written permission.

Originally intended just for those without access to TEA's Web site, the program now is open to any member whether you're computer savvy or not. Initially members connected by writing letters and Reese provided information only available on the Web site.

A brief newsletter called "What's What" is sent to all those in the program. It includes personal stories submitted by members with contact information so any Networking Program member has a chance to respond. And Reese sends copies of any article in the TEA Library members request. (See page 9.) You just pay a small copying fee and the cost of the postage. As a service to the entire membership, Reese also mails VHS or DVD copies of TEA's video.

TEA Seeks Operational Funding, Sends Grant Proposals

Seeking general funding for operational expenses, TEA sent ten comprehensive grant proposals in late June to Connecticut, U.S., companies and foundations. The potential grantors were identified by Giovina Taraschi, a fellow EM sufferer and TEA member. Taraschi has extensive experience in marketing and development (fundraising) for nonprofit organizations, says TEA Vice President Beth Coimbra, who is coordinating the project.

Author of the "Greater Philadelphia Guide to Corporate Grantmaking," Taraschi wrote the TEA grant proposal and accompanying cover letter after identifying potential grantors in Connecticut, U.S., location of TEA's headquarters.

"As TEA grows and attempts to expand its programming for the benefit of people with EM and their families, our organization has reached a stage when it can no longer depend on volunteers alone," says Coimbra. Taraschi, who lives just a few miles from Coimbra in southeastern Pennsylvania, graciously volunteered to use her professional expertise to begin the process of seeking outside funding for TEA.

More potential grantors will be identified in other geographic areas and similar grant proposals will be sent out later this year, Coimbra says.

Yale Research: Journal Article Translated

By Jean Jeffery

Editor's Note: In June 2005, the Annals of Neurology *published an article by Yale Chair of Neurology Stephen G. Waxman, M.D., Ph.D., and Research Scientist in Neurology Sulayman D. Dib-Hajj, Ph.D., entitled "Erythromelalgia: A Hereditary Pain Syndrome Enters the Molecular Era." In this article the scientists review their studies into inherited (primary) EM and explain their findings.(Dr. Waxman is also chief of neurology at Yale New Haven Hospital and director of the Veteran Affairs Rehabilitation Research Center in West Haven , Conn.)*

What follows is a "translation" of this highly technical scientific article into language most should be able to understand. Thank you Jean!

Erythromelalgia: A Hereditary Pain Syndrome Enters the Molecular Era

This paper describes the recent findings about erythromelalgia (EM) by the neuroscientists at the Yale University School of Medicine. The have discovered that the pain experienced in the inherited form of EM is caused by a defective sodium ion channel in the nervous system. The defect in the ion channel is due to the mutation of a gene on the second chromosome.

Sodium ion channels are tiny pores in the walls of nerve cells. They regulate the flow of sodium ions into nerve cells to generate and transmit electrical signals or nerve messages that travel in waves along the nerve fibers.

There are nine different sodium ion channels; the defective one in EM is channel 1.7. The sodium 1.7 channels are found in greatest numbers in the sensory nerve cells of the peripheral nerves close to the spinal cord and within clusters of nerves in the sympathetic nervous system. The peripheral nerves transmit to the spinal cord and brain nerve messages from sensory cells such as the pain receptors (pain-sensing nerve cells) in the skin.

"EM is the first human disorder in which it has been possible to associate an ion channel mutation with chronic neuropathic pain," the researchers write. It is by looking at what happens inside the cells, where the interactions among the actual molecules take place, that the Yale team has demonstrated the link between the defective sodium 1.7 channels and the pain of EM. In EM the sodium 1.7 channels trigger high numbers of abnormal electrical signals in the pain receptors (pain-sensing nerve cells) in the skin. The extremely hyperactive behavior of the pain receptors causes the painful burning symptoms of EM.

This new discovery about EM is a valuable contribution to the world of neurobiology as it should lead to greater understanding of the molecular basis for hyperexcitability of nerve and muscle cells. EM may be able to teach the medical community more about the role of sodium 1.7 channels in pain associated with inflammation and nerve injury, as well as more about other inherited and acquired (non-inherited) pain disorders.

Treatment of epilepsy and cardiac arrhythmias now involves the use of sodium channel blocker drugs. (Two sodium channel blocker drugs, lidocaine and mexiletine have given relief to some patients with EM.)

The scientists expect that further evaluation of existing sodium channel blocker drugs and of new ones that target specific defective ion channels will bring new successful treatment for EM.

Research Update

Researchers in Holland Search for Genes Causing EM

Submitted by J.P.H. Drenth, M.D., Ph.D.

Joost PH Drenth, who is a gastroenterologist at the Department of Gastroenterology and Hepatology in the Radboud University Medical Center, Nijmegen, The Netherlands, became interested in erythermalgia in the early nineties of the last century. A publication in the Dutch Medical Journal by Dr. Jan J. Michiels, who is from Rotterdam, The Netherlands, led to an intensive collaboration between these two researchers. Dr. Drenth, who at that time was a medical student, went on to describe several cases of patients suffering from erythermalgia. These accounts were published in several peer reviewed medical journals.

Gradually a picture emerged and it became clear that it was possible to categorize patients into several groups. We learned that although the symptoms of all patients are very similar (hot burning and painful feet and/or hands), the actual causes might differ.

Dr. Michiels had appreciated that patients with elevated platelets could have painful burning feet, in most instances restricted to a single foot. Aspirin he discovered reversed the symptoms. He labeled this entity as erythromelalgia, erytho for red, melas for extremities, and algos for pain.

Other patients, though, did not have high platelet counts but did have the same symptoms albeit mostly in both feet and/or hands. Apart from their burning feet, some had another disorder such as vasculitis, but many others did not have an underlying disease. This was called secondary erythermalgia.

The researchers reserved the term primary erythermalgia for patients from families in which several members shared the burning feet. We knew several families with primary erythermalgia and finally traced six families with this rare disease. The families stemmed from the United States, Canada, France and Holland. We first discovered that primary erythermalgia presents as an autosomal dominant disease, which means that a person must inherit one mutated copy of the gene from one affected parent in order to get the disease. During the genome-wide search that followed, we identified a region on the long arm of chromosome 2 associated with susceptibility to this form of inherited skin disease. This result was confirmed for all six families.

It was not until several years later that we were able to show that mutations in a gene that encoded for a sodium channel were responsible for the disease. These sodium channels are located in the nerve tissues in the skin. Most probably the mutations cause these sodium channels to over-perform so that the nerves are constantly triggered. Patients feel this as pain. We also found that although most families with primary erythermalgia have a mutation in that sodium channel, some did not.

Our future efforts are directed to investigate which other genes are involved in erythermalgia. Rene te Morsche, who is a senior technician in the Laboratory for Gastroenterology and Hepatology at the Radboud University Medical Center, Nijmegen, The Netherlands, will spearhead this effort.

The longer-term payoff of this work is in terms of therapeutics, and it is a necessity that the results from these research efforts must be translated into treatment options for this enigmatic disease.

Research Update

Study of Alabama Family with Primary EM Published

Yale researchers had another medical journal article published in June 2005. The journal *Brain* released online the Yale scientists' report of their study of 25 members of one family, most of whom live in Alabama. (See "Powell's Burning Foot Disease," March 2005 *FootSteps*.) TEA led the researchers to this unusually large family affected by inherited EM. And funds donated by TEA helped make the research possible.

A total of 25 family members participated in the study; 17 have symptoms of primary EM. DNA analysis revealed all 17 affected family members carry a mutation in the gene that "codes for" sodium channel Nav1.7, one of the nine sodium channels known to be present in humans.

None of the family members without EM has the mutation. Nav1.7 is found in small-diameter nerve fibers and nerve endings within the peripheral nervous system and is associated with pain transmission. The mutation found in this family is now the third mutation found in this gene that is linked to primary EM.

The researchers also report they were able to demonstrate for the first time that this single mutation can trigger painful neuropathy in people with inherited EM. And they provide evidence that mutant human Nav1.7 predisposes the pain-sensing cells, in which it is found, to become hyperexcitable and fire rapid bursts of signals at lower than normal thresholds of activation—in other words, in reaction to low levels of stimuli (like temperature and exercise) that normally do not cause pain.

Hyperexcitability of pain-sensing neurons has long been considered a hallmark of painful neuropathies in which neurons turn on more easily and fire signals at higher than normal rates.

(The article is entitled "Gain-of-function mutation in Nav1.7 in familial erythromelalgia induces bursting of sensory neurons." Authors include Drs. Dib-Hajj and Waxman, among others.)

NORD Grant Process Proceeds

At least one researcher has been asked to prepare a full application for the $35,000 grant for research into EM being funded by TEA through the National Organization for Rare Disorders (NORD) Clinical Research Grant Program.

Using the same peer review system used by the National Institutes of Health, NORD's Medical Advisory Committee of academic scientific experts will evaluate the application. The grant is expected to be awarded sometime this fall. Watch for "Research Updates" in future issues for more information.

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FootSteps is the official publication of The Erythromelalgia Association and is published quarterly for its members. The intent and purpose of this publication is to inform those with erythromelalgia or their friends and families—not, in any way, to provide medical advice.

RESEARCH FUND DONORS

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

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From the President

TEA Loses A Best Friend

by Lennia Machen

We all go through our lives making personal best friends, those whose companionship and care we treasure. But, leaders and innovators who have created a better world for us all are also "best friends." Those who developed vaccines and invented things like the combustion engine affect my every step, every single day.

TEA has in its midst *best friends*—people who have contributed to the world's knowledge about EM and those who routinely give of themselves to give those with EM hope and help. Unfortunately, TEA recently lost a very best friend—Milton LeCouteur.

Milt was one of those special people who dedicated himself to helping others find relief from EM. Because of his own EM condition, he knew there were many others who would appreciate any progress made to help lessen the symptoms we all share. By recognizing this need, he and a few others founded TEA. Milt's dream was to fund research and to raise awareness of EM in the medical community. When TEA began, these goals were a long way off. Today, TEA is sponsoring research and more and more is known about EM in the medical community. We are gaining ground on Milt's dream.

There was a time not long ago when "apply ice or cool the affected limb," was the only treatment for EM. It wasn't until recent years that this advice has been intelligently challenged and overshadowed by medications and lifestyle changes that have helped many gain some control over EM symptoms. Milt was one of the pioneers who pressed the issue of there being a better way to treat EM. His dedication to finding solutions has caused TEA to become the world's center for information on EM. Milt was certainly one of our best friends.

I never had the privilege of meeting Milt face to face and we only spoke on the phone a few times. But through hundreds, maybe thousands, of e-mails over 10 years, I know the truly great contribution Milt made to TEA. Just like Milt, we all have something—advice, funds, time that we can give to help others. It will be in Milt's spirit that we continue to make progress by raising funds, raising awareness, and raising generosity. I hope you'll join me in this spirit of serving others and continue Milt's legacy of finding solutions to living with EM. Because you just cannot forget your best friends.

(Donations to the Research Fund in Milt's honor are being cheerfully accepted.)

A Guide to Help You Explore TEA's Library

By Jean Jeffery

There are nearly 50 items about EM in the TEA members' library (Article Archives) on the TEA Web site. Depending on your individual needs, you may want to read some of these articles yourself or print them to give to your doctor. This is a short guide to help you choose the kind of information you want.

Each article has a number, "M051," for example. I've included the numbers in this guide so you can enter the number you want in the archive search box on the Web site and then print the article from the Web yourself. Or if you don't use the Internet, you need to use the number when requesting an article be sent to you by post. A TEA articles order form and the complete list of articles are included at the end this issue. (See pages 10,11.)

I've listed the papers under three main sections—General, Treatment, and Research. Many of these papers are difficult to understand without some knowledge of medical jargon. So I've included a Section 4, which suggests easier articles to read.

SECTION 1—General
These articles give wide-ranging information on all aspects of EM. Most of them define and describe EM, discuss various causes and associated diseases, and sometimes treatments. I particularly recommend three papers:

1. M001 by Jay Cohen. New Theories and Therapies, 2000. Short and packed full of information, this is the best one to give to your doctor. This also is an easier paper to read for non-medics. All the rest are far more technical.
2. M049 by Mark Davis, 2000. A review of 168 patients with EM.
3. M006 by Knut Kvernebo, 1998. Very technical and thorough 40-page treatise on EM.

SECTION 2—Treatment
This section includes 13 papers that give details about individual treatments including lidocaine, magnesium, nitroprusside, and serotonin antidepressants). Other papers cover surveys with many treatments used by large numbers of patients. I recommend:

1. M002 by Mark Davis, 2002. Current Treatment Options. Survey of 99 patients. (Long article)
2. M001 by Jay Cohen, 2000. Survey of 41 patients.
3. T010. TEA Survey, 2004, of 222 patients.
4. P002 by Jay Cohen, 2002. Current Treatments for EM—a very helpful short guide to treatment for you and your doctor to read.

SECTION 3—Research (All very technical)
1. M051 by Cato Mork, 2004. Excellent latest research—summarizes earlier research papers on vascular and neurological causes of EM. Useful list of 200 other EM papers. (Long article)
2. M010 by Joost Drenth, 2001. The EM gene.

SECTION 4—Articles Easier to Understand.
These include T004, the 2-page brochure that is full of information on EM and about TEA. An alternative larger print version is T001, the TEA introduction letter.

Doctors unfamiliar with EM appreciate the brochure as well as the pages from the TEA Web site homepage on EM symptoms and on diagnosis. These include color photos of red burning feet, hands, and faces.

Also take a look at M001, Jay Cohen's 2000 paper New Theories and Therapies, listed in Section 1. For two members' personal stories read P001 and P003.

Your Stories—everyone has one!

We can all empathize with fellow members who face the daily challenges of living with EM. Because EM is so rare, most of us have tales of the often long and difficult diagnosis process and the ways we've found to cope. TEA encourages you to share your experience by writing your story. If you think you're not a writer, never fear. We can help you write and edit your story. Please send your story to Gayla Kanaster, gaylakanaster@aol.com or 2556 W. 234 Street, Torrance, CA 90505.

Editor's Note: Nicholl was the subject of an article in the June 28 edition of the British magazine Best. *Nicholl also wrote her story for the Raynaud's and Scleroderma Association newsletter, which was published recently along with a description of EM written by TEA member Jean Jeffery. Thank you Jayne for doing your best to raise awareness of EM among the general public!*

Jayne Nicholl writes: I read with interest the latest newsletter about the research at Yale on EM. I have had primary EM since birth and it has varied in degrees of severity over the years. As a child, my EM was manageable, although no one could really explain my "hot feet." By age 16 I was constantly bathing my feet and legs in cold water. My skin broke down, became infected, and a biopsy turned into an ulcer. I spent a month in hospital where an epidural and spinal infusion of Cholodine and Bupivocaine allowed my skin to heal and temporarily relieve the burning.

It was during my fourth year at University that I discovered TEA, while searching the Internet. I cried when I realized that I wasn't the only one with these symptoms. At 26, my life is pretty great. I have a wonderfully supportive family and friends, plus a great job in marketing in London, which I love. But, my EM is getting worse. I try to live an active life and I'm determined not to let my hot feet get in the way. I have learned what I can and can't reasonably do and enjoy swimming and cooking. Unfortunately, my sleep suffers and I have high blood pressure.

At the other extreme, my Raynaud's is worse and it's a constant battle keeping my feet cool and hands warms. I am currently seeing a Chinese herbal doctor and brewing the foul teas that she prescribes. That helped at first, but I no longer notice any difference. I've tried acupuncture with some success. These alternative remedies are very expensive so I can only try one at a time.

While no one else in my family suffers from the same degree of pain and erythema that I do, my father and brother often remove their socks and sleep with their feet uncovered. My mother and her sister also suffer from redness and burning flushing that creeps up the chest and face. Perhaps the combination of these on both sides of my family has lead to my EM?

(Continued from page 6)

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

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

TEA Library Articles and Documents Page 2

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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	
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