

FootSteps

The newsletter for members of The Erythromelgia Association
Footsteps online: www.erythromelgia.org or www.burningfeet.org

Spring 2012 Vol. 13, No. 1

TEA gifts Yale \$40,000

The TEA Board of Directors in March voted to gift \$40,000 to Yale University to support research on erythromelgia under the direction of Stephen G. Waxman, M.D., Ph.D.

According to Dr. Waxman, the funds will help the team at Yale's Center for Neuroscience and Regeneration Research move forward as rapidly as possible toward new treatments and cures for EM.

"Our team of talented cell and molecular biologists, geneticists, physiologists, pharmacologists, pain researchers and clinicians are working in a coordinated effort to fully understand EM, and to develop new and effective treatments for it. We have a lot of work to do but, as you know, we have already made rapid and important progress. The pace of progress is quickening. You are partners in this work, and we look forward to the day when we can celebrate, with you, victory in our battle against EM," Dr. Waxman wrote in his note to TEA acknowledging his receipt of TEA's check.

The funds will also support current collaborative efforts with Joost Drenth, M.D., Ph.D., in the Netherlands, and with other physicians who refer people with EM whose DNA is likely to be helpful "as we dissect this disorder molecule by molecule."

In 2005, TEA gave \$60,000 to Yale for EM research, another \$45,000 in 2008, and \$25,000 in 2010.

Paint your pain: an artistic challenge

Have a flair for art? TEA is challenging people with EM to depict their pain in a painting or drawing. The research team at Yale suggested the idea:

"In the pain field, there is a famous painting by Frida Kahlo de Rivera in which she draws herself with nails to describe her feeling of chronic pain. This painting is often used in presentations by pain researchers. Because our research is pretty specific to EM rather (*continued on pg 3*)



Stephen G. Waxman



The Erythromelgia
Association

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FootSteps

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The intent and purpose of this publication is to inform those with EM or their friends and families—not, in any way, to provide medical advice.

Mosarski elected TEA Secretary

Deborah Mosarski was recently elected Secretary of the TEA Board of Directors. As such, she records board meeting minutes and plays an active volunteer role in the organization.



Deborah Mosarski

A board member for nine years, Deborah serves as a liaison to online support groups and physicians. And she has played a leadership role in board programs like the 2009 Survey and the teleconference with Dr. Jay Cohen, among others.

A resident of South Carolina, she developed EM in 1994. Her symptoms are severe and led her to educate herself by searching the National Institutes of Health's Library of Medicine. She became active in online support groups before TEA was founded and has been a TEA member since its beginning.

Annual dues due

Members will soon receive a notice by email or U.S. mail that the annual dues donation of \$20.00 U.S. is due by June 15, 2012. Those who are able are encouraged to send TEA more than the suggested \$20.

Member dues finance TEA's day-to-day operations or go into the Research Fund if so designated. These annual donations are considered charitable gifts for U.S. tax purposes.

You can pay your dues online at TEA's website or send a check to TEA, 200 Old Castle Lane, Wallingford, PA, USA 19086.

Appeal raises more than \$10,000

TEA's generous donors answered last year's Annual Appeal with gifts totaling \$10,094. Of that total, donors designated \$1,885 to the Research Fund. This was the fifth year TEA sent an "annual appeal" letter – the only appeal TEA sends each year.

Arriving in mailboxes in December 2011, the appeal was sent to TEA's entire mailing list of members, friends, families and former donors.

The 2008 appeal raised the most – \$14,459. The first appeal in 2007 raised \$11,757; \$12,235 was raised in 2009; and \$11,407 in 2010.

Appeal donations received through March 31, 2012, are included in the totals. Appeal donations continue to trickle in through the spring months, said Beth Coimbra, Treasurer and President of TEA.

EM friends Facebook: support groups online

by Cindy Hockaday

Anyone who has EM knows the frustration of trying to find doctors who can recognize, diagnose and treat their condition. Some of us get lucky and find the right doctor. The rest of us are given a shrug of the shoulders and a shake of the head, or sent for countless tests, with no results.

Most eventually turn to the Internet and find TEA and all its information. But what about the emotional ups and downs of dealing with this strange disease on a daily basis?

Many now find the support they need by chatting online with virtual friends. During the past 12 years the EMYahoo group (founded at the same time as TEA) has helped many, many people.

And then there was Facebook. This hugely successful social media site now has at least five groups for people with EM.

"Living with Erythromelalgia" is one large FB group (218 members). Discussions tend to center on symptoms, medications and doctors. You can join in at www.facebook.com/groups/35414575195/.

www.facebook.com/groups/EMExchange/, it is a closed group, so you will have to request membership acceptance.

"Erythromelalgia – Burning a Path to a Cure" provides discussions of symptoms and research. Located at www.facebook.com/groups/48920739782/, it is the largest group found, with 273 members.

"Fans of TEA," founded by an Australian couple, is a small group where discussions are mainly about symptoms. Current news from TEA and fundraising for research are other topics. It is located at www.facebook.com/groups/35414575195/.

TEA supports the mission of these groups but is not affiliated in any way and does not endorse the information found on the sites. Always consult your doctor before trying any new treatments.

Paint your pain: an artistic challenge (continued from PG1)

than general pain, I was wondering if there is any person in your EM community who would be willing to make a drawing/painting just like Frida Kahlo de Rivera's," Yang Yang, PhD., wrote on behalf of the research team.

Yale researchers are preparing presentations about their EM research for two, large scientific meetings in 2012, and have requested the right to use the painting/drawing selected in those and future presentations.

TEA will also award the winner one-year's free membership and 10 EM bracelets.

If you wish to submit artwork, please send a photograph of it by email to Deborah Mosarski, DeborahTEA@aol.com or Cindy Hockaday at TEA.cynthia.hockaday@gmail.com by June 1, 2012. Go to the TEA website www.erythromelalgia.org for details about this challenge.

The Broken Column: Frida Kahlo paints her suffering

In making their request for a painting/drawing done by someone with EM, the Yale researchers refer to the painting *The Broken Column* by famous Mexican painter Frida Kahlo de Rivera (July 6, 1907 to July 13, 1954).

At the age of eighteen, Kahlo was involved in a violent bus accident and her life was marked by chronic pain and health problems. She required numerous surgeries and was unable to carry a child to full term. In 1944 when Kahlo painted *The Broken Column*, her health had deteriorated to the point where she had to wear a steel corset for five months. She described it as a "punishment."

In the painting the straps of the corset seem to be all that is holding the artist's broken body together and upright. An Ionic column, broken in several places, symbolizes her damaged spine. The column appears to be on the verge of collapsing into rubble. Metal nails pierce Kahlo's face, breasts, arms, and torso, as well as her upper thigh, hidden behind a swath of cloth. Tears stream down her face. Set in an open landscape, the artist-sitter is exposed in more ways than one. The terrain on which she stands appears barren and cleaved. To see *The Broken Column*, go to <http://www.fridakahlofans.com/c0480.html>

Your Stories

Everyone can empathize with those who have experienced difficulties just getting an EM diagnosis and then living with EM's continuing challenges. TEA encourages you to write your story. Then, send it, along with a "head shot," to Gayla Kanaster, GaylaKanaster@aol.com or 2532 N. Fremont St., Tacoma, WA, USA 98406. Because our space is limited, we request that stories be no more than 350 words in length.



*Audrey C. Moser
Portland, OR USA*

I've never felt better in my life, more powerful or more in control and I want to share about learning a practice of "Riding the Waves." As I faced another summer, confined alone to my upstairs condo, sitting in front of the air conditioner until the outside temperature would get below 70 degrees and I could go outside, my usual, uninvited, annual depression began to take hold.

Then, in early May 2011, while attending my weekly "Easing into Yoga" class, my teacher spoke about a new class she is teaching – "Yoga of Awareness for Chronic Pain." She described the eight-week sessions – two-hour classes, based on gentle stretching, meditation, breathing practices, combined with the exploration of yogic wisdom and study of the relationship among yoga practice, experiences, and management of pain. She described all sensing as happening in waves and learning to "Ride the Waves" is imperative. Being definitely aware that I lived with chronic pain, I signed up.

The first class was May 6, 2011, and lo and behold, within two weeks, I needed no pain meds for my chronic neuropathic pain. ... I'm still in a learning process, still tuning into "riding the waves." The practice has produced marvelous results with my chronic pain and when used in response to acute pain, a softening and deepening peace ensues. As I write, summer (2011) is here and not one day has found me confined. I continue to seek shade, use some common sense, and take my daily medicinal routine of gabapetin, Zoloft, and Zyrtec.

This incredible class of empowerment was developed by a health educator, specializing in mind-body integration who works as a yoga therapist, mindfulness teacher, and teacher trainer at OHSU and Duke University Integrative Medicine.

P.S. It's 2012 and I'm still "Riding the Waves," still amazed and delighted with the calming results and still free of chronic neuropathic pain. (Audrey may be contacted at acmoser2@juno.com.)



*Bill Fisher
Denver, CO USA*

I developed peripheral neuropathy in both feet five years ago at the age of 75. It came on so suddenly it was startling and very painful. Approximately eight weeks later my feet started turning red and burning and well, I'm sure you know the rest. My current medications taken daily for EM and peripheral neuropathy are: Lyrica 300 mg, Cymbalta 30mg and pentoxifylline 1200mg. In other member stories in FootSteps, I noticed one common denominator — having trouble sleeping at night with so much pain. I used to dread bedtime, but now I look forward to it. I bought a portable (free-standing) room air conditioner that is at just the right level for my feet when I position its adjustable horizontal louvers next to the bed. I only need to use it for 15 or 20 minutes and my feet are ice cold. The unit has a three-speed blower that is much more effective than room fans (which I have tried) and is so quiet that it's conducive to sleep. Most of the

Everyone Has One

time I just keep the fan on low speed all night, with no air conditioning. The operating cost is very low here in Denver where the humidity is low. It has made a remarkable change in my life. ... I hope this information is helpful to some. Please feel free to contact me by email for any questions you have at Fishersare3@comcast.net.



*Bill Bracks
Te Puke, New Zealand*

I'm 80 and finally retired from my job as a company chairman. My first symptoms appeared with hot, swollen, burning feet 25 years ago. I photographed them for my GP who could not diagnose or research the complaint. So, I was off to numerous consultations with specialists. The burning feet were preferable to their prescriptions. I finally decided what you cannot cure you must endure! In the early days I would get out of bed and stand on the tile floor to get some relief and hopefully sleep. I also found that bare feet on the lawn brought relief ... Colleagues at board meetings often passed snide remarks about the Chairman being unable to afford shoes when I was sitting barefoot in meetings. If only they knew!! You cannot feel others' pain and in the case of EM it is even more so. My remedy today is off with the shoes and socks as soon as is practicable. If that means having worn them for three or four hours, then it's a bowl of cold water to cool them down before retiring or a stroll on the lawn if the weather allows. In bed, cold wet towels keep my uncovered feet cool enough. Not an ideal situation but it makes life a little more bearable. ... When undergoing a recent heart valve operation it was a nightly fight with the nursing staff to let me keep my feet sticking out of bed. My sympathy goes out to all those who suffer from this rare disease. It is fantastic to have a dedicated band of people in TEA who

care enough to form this worldwide association. The idea of forming support groups in countries outside the U.S. may just be the best means of accessing the resources to fund more research into this nasty condition. Blessings from Kiwiland.



*Vera Last
Sydney, Australia*

My EM seems to have had two apparently weird side effects which I have never seen reported. ... My EM now involves my feet, legs, hands, arms, face, and ears. My legs swell after too much walking. Heat and exercise make the EM so much worse. I am now stabilized (hopefully) on 60mg Cymbalta and 100mg of Neurontin. Meanwhile, my blood pressure has emerged into a pattern of being moderately high when I get up, normal most of the day, then zooming up in the late afternoon to a very high systolic pressure (but normal diastolic pressure and heart rate) in spite of having my blood pressure tablets quadrupled and my beta blockers doubled. I'm wondering if there is a connection to my EM, which also gets worse in the evenings. Last year, we visited our grandchildren in Boston. When I was fingerprinted on entering the USA, my fingerprints didn't duplicate my previous ones. I was fingerprinted about four times. I finally had to rub in moisturizer and that version was acceptable. I wondered if that could be connected to my EM? Has anyone else had these weird blood pressure and fingerprint anomalies? Members, researchers, anyone? My email address is: Lastfam@ozemail.com.au.

TEA recognizes our generous donors

TEA thanks all those who made donations during our 2011 Annual Appeal.

Donnis Sakran	Joan Crouch	Kathy Golden	Dorothy Leidig	Faith Payne
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Donor thanks TEA

Here are excerpts from an email sent to TEA by Teresa and Dave Eckert: "Appreciate everyone's efforts to get the verification of Dave and my donation to us. ... Also want to let you know how much we appreciate all the volunteer work everyone does for the association. We especially appreciate the information in FootSteps. ... Everyone please continue what you do that supports and informs the members and those they pass their information on to. You make a big difference in our lives."

TEA sends special 'thank you'

TEA is especially grateful to Joanne Lochmiller Olsen of Los Altos, Calif., USA, and her family for requesting donations in her memory be sent to TEA. Joanne died January 26, 2012, at the age of 67 after a long battle with cancer and a decade of EM.

A college graduate in computer science, Joanne worked as a computer programmer for 36 years. Married for 43 years, she was an avid cyclist and cross country skier. She is survived by her husband and two brothers and their families.

2011 Financials: TEA manages funds carefully

by Beth Coimbra

TEA manages its funds very carefully. As a 501(c)(3) corporation – a nonprofit – TEA's income comes almost entirely from donations and membership fees. As an organization, TEA seeks to be transparent and fully inform members of its status. To the right is a report of TEA's 2011 financial year.

The top portion of the financial document (the Balance Sheet) is a snapshot of the financial condition of TEA on December 31, 2011. It shows that TEA's Operating Fund totaled \$82,777, which is approximately \$10,000 more than the Operating Fund's total was on December 31, 2010, due to the low level of expenses during the 2011 year. TEA's Research Fund also increased during the prior year by about \$5,000 due to generous donations throughout the 2011 year.

The second section of this financial document (the Statement of Activity) shows the sources of income during the year ended December 31, 2011, and the cash used by TEA during the same year. TEA kept spending to just the bare minimum needed to keep programs and operations running.



Financial Statements were prepared by Beth Coimbra, CPA. Beth serves as Treasurer and President of TEA.

THE ERYTHROMELALGIA ASSOCIATION BALANCE SHEET December 31, 2011

ASSETS	
Cash and Marketable Securities	\$ <u>89,362</u>
Total Assets	\$ <u><u>89,362</u></u>
LIABILITIES AND CAPITAL	
Total Liabilities	\$ <u>0</u>
Fund Balance - Operating	\$ 82,777
Fund Balance - Research	\$ <u>6,585</u>
Total Fund Balances	\$ <u>89,362</u>
Total Liabilities & Fund Balances	\$ <u><u>89,362</u></u>

STATEMENT OF ACTIVITY FOR THE YEAR ENDED DECEMBER 31, 2011

	OPERATING FUND	RESEARCH FUND
Revenues		
Membership	\$ 7,316	
General Contributions	\$ 5,548	
In Honor Donations	\$ 3,075	\$ 100
Research Fund Donations		\$ 3,340
Bracelet Fundraiser	\$ 400	
Annual Appeal-Rsch		\$ 1,175
Annual Appeal - Unrestricted	\$ 12,020	
In Memoriam	\$ 400	
Network for Good	\$ 352	
Interest Income	\$ 30	
	<u>\$ 29,141</u>	<u>\$ 4,615</u>
Expenses		
Printing	\$ 6,926	
Postage	\$ 4,618	
Office Supplies	\$ 81	
Teleconference Phone	\$ 392	
Membership Phone	\$ 398	
Paypal Fees	\$ 144	
Graphic Design	\$ 2,000	
Website	\$ 1,538	
Insurance	\$ 998	
Bank Charges	\$ 70	
Memberships	\$ 75	
Corporate Fees	\$ 10	
Total Expenses	<u>\$ 17,250</u>	<u>\$ 0</u>
Net Income	<u>\$ 11,891</u>	<u>\$ 4,615</u>



The Erythromelalgia Association

FootSteps

Raising Awareness.
Raising Research Funds.
Raising Hope.

www.erythromelalgia.org

Legislative alert: Join NORD in supporting TREAT and FAST

Proposed legislation has been introduced recently in the U.S. Senate and House of Representatives to modernize and expand the Accelerated Approval pathway of the U.S. Food and Drug Administration (FDA), according to the National Organization for Rare Disorders. TEA is a member of NORD.

The bills are Transforming the Regulatory Environment to Accelerate Access to Treatments (TREAT) in the Senate and Faster Access to Specialized Treatments (FAST) in the House.

NORD believes that TREAT and FAST would speed the development of treatments for rare diseases while still maintaining standards for safety and efficacy. FAST includes language suggested by NORD.

To send letters of support for FAST and TREAT to your elected officials, go to NORD's website www.rarediseases.org and go to their Legislative Action Center. You'll find sample letters and help in sending the letters to your senator and representative.



200 Old Castle Lane,
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The Erythromelalgia Association

