FootSteps...

TOWARDS PROGRESS

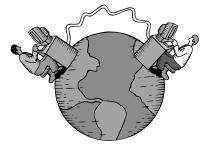
The Newsletter dedicated to finding a better way to live with erythromelalgia Volume 2, Issue 4, November/December 2001, Published by The Erythromelalgia Association

TEA Creates Medical Advisory Committee

The Erythromelalgia Association has created a Medical Advisory Committee (MAC) to address the medical aspects of EM. This is landmark news as it's the first ever collaboration of so many EM specialists in one "place." The members of this elite group will meet via email, and discuss matters that are of interest in furthering research and medical breakthroughs that could eventually help each one of us in our daily lives.

There are 6 members of the MAC at the time of publication, and it's possible that more could join us soon. Here's the list of current members:

- ◆ Jay. S. Cohen, M.D. University of California at San Diego, published author of Erythromelalgia: New theories and new therapies, and founding member of TEA
- Mark Davis, M.D., of Mayo Clinic, and published researcher of EM
- Knut Kvernebo, M.D., PhD, Professor of Cardiothoracic Surgery University of Oslo, Norway, published author of the extensive article about EM found in VASA: Erythromelalgia: A Condition Caused by Micro-Vascular Arteriovenous Shunting, as well as several other important articles about EM.
- ♦ Jan Jacques Michiels, M.D., Professor Hemostasis Thrombosis and Vascular Research at University Hospital Antwerp Belgium, Director of Goodheart Institute Rotterdam, The Netherlands, and one of the most published authors and researchers of EM known.
- Cato Mork, M.D., Department of Dermatology, Rikshospitalet University Hospital, Oslo, Norway, co-author with Dr. Kvernebo of Erythromelalgia: A Mysterious Condition?
- Ronald Schneeweiss, M.D., Family Medical Center, University of Washington.



TEA is very excited to see this outstanding and prestigious group of EM experts join together in discussion about this terrible condition we all share. The MAC will be chaired by Dr. Cohen, and facilitated by our new board member, Ann Sheehan. As the meetings take place, we will keep you apprised of their developments and progressive strides.

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T.E.A. for 'One'



This feature is the "get to know you" corner. Since we already know our members have an association to EM, we try to avoid that topic and focus on meeting the special person instead. So, pour yourself a nice tall glass of decaffeinated iced tea, and enjoy meeting Beth Coimbra, one of our new TEA Directors

meet Beth Coimbra

FootSteps: Tell us something about yourself that is special to your life... What is your favorite way to spend time?

Beth: My life is special because it is everything I could have dreamed for. I am mainly a stay-at-home Mom who works an average of 200 hours a year mostly during tax season. I recently began to advertise my services as a CPA in the hopes of starting a small practice in which I can be flexible in hours worked and place where I work. I am lucky to be available for my children's school and after school activities. I love to bake and cook and am thrilled when my family enjoys the fruits of my labor. We are currently building an apartment in our basement that will serve as living quarters for my parents who are doing well in their early 70s.

FootSteps: Introduce us to your family, hobbies, sports, activities, etc...

Beth: My husband is Firmino (he is of Portuguese decent and his parents and sister live in Portugal and we visit there every other year). Firmino is a management consultant who loves home (house) projects. He does all of our landscaping and has planned, designed and built an apartment for my parents in our basement. I have a 9



Here's Beth, with ther husband Firmino, and sons Jordan and Adam.

year old son, Adam, who is at the head of his class academically. He enjoys all sports even though he is not the star. He plays in Fall and Spring soccer, is a green belt in Karate and is taking saxophone lessons at school. I have another son, Jordan who is 6 years old. He is a very silly child who, thank goodness, always tunes it down at school and is a very good and obedient student. Jordan enjoys model trains and has an orange belt in Karate. We also have a smooth-haired fox terrier named Jake.

FootSteps: Tell us a little about your past, special skills, sports, hobbies, trips you've taken, or anything that you are glad that you did earlier in your life.

Beth: I grew up in Southeastern Pennsylvania and live in an area where I run into old schoolmates and friends in my daily travels. I also went to college in this same area. My husband, however, grew up in Africa and also lived in Portugal and Spain. We met at the international accounting firm where we both worked. It is then that I started to travel a bit. Of course, we've been to Portugal, but also we have traveled in the US and Canada. My two main hobbies are: caring for my houseplants (I found success with plants when I moved into a new home 3 yrs ago - with lots of light) and now take a lot of pride in them; cooking - now that my children are a little older and in school until 3:30pm I find I have more time for cooking and have been having lots of fun trying new things from the Light Cooking Magazines.

FootSteps: Share a dream for the future:

Beth: My dream for the future would be to continue as I am with my family in good health. Very simple and totally motivated by the fear that my EM will get worse and prohibit me from being such an active supporter and nurturer of my family. Part of this dream includes the good health of my children, who I worry will develop EM as they get older. But for now this family is very supportive of me when I cannot do certain things and we bring each other much joy on a day-to-day basis - I know I have been blessed.

ARE YOUR MEMBERSHIP DUES ... DUE?



A lot of our TEA members renew their yearly membership dues at this time of the year, so if you are one of those Winter Friends... send 'em in! The fee is still \$15* per year and can be paid by check or money order, or by using our new credit card service through "helping.org." (*this is the suggested donation and can be adjusted as needed.) Mail to: The Erythromelalgia Association, 4343 Roosevelt Way NE #305, Seattle, WA 98105 USA.

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We Still Need a Few Good Folks!

We still need your help! The TEA Board of Directors is in need to fill one more vacant Board Member Seat. While we have recently filled two seats, one more has come open, not to mention various other positions that need some attention. The TEA Board is a small group of members, some have EM, and others don't, who give of their time to work towards the education and research into erythromelalgia. We meet once a month, via the Internet, and typically handle issues like the governing of this non-profit organization, new items of interest to our members, and the advancement towards EM research and treatments. Won't you join us and be a part of this pioneering institution... dedicated to improving the lives of those who are afflicted with EM? We'd like to hear from you and answer any questions you may have about this task. The qualifications are simple...

- Must have Internet or e-mail capabilities.
- Must be a current TEA member.
- Must have interest and enthusiasm for the opportunity.
- Must be willing and able to dedicate adequate time to the job (may equal 2-6 hours per month).
- Helpful, ...but definitely not necessary, is to have some past experience in any type of non-profit or voluntary organization.



You say "Potato," I say "Potatoe"... or something like that

There are two definitions and spellings that have become notable regarding EM. Quoted from an article by Arnoldo Kraus, MD, and Donato Alarcon-Segovia, MD: "Some historic concepts may shed light on the two terms. Erythromelalgia was coined by Weir Mitchell in 1878. He constructed it from the 3 Greek words erythros (red), melos (extremities) and algos (pain) to describe a syndrome in which the extremities became red, painful and warm upon warming and/or dependency and improved with cooling and/or elevation... In 1938, Smith and Allen proposed the term erythermalgia as more appropriate since it included the Greek word thermos to cover the increased temperature which Mitchell's term had left out. In their own words: 'This term (erythromelalgia), however, is not entirely adequate because it does not denote the importance of heat..."

New Members

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



The following list is of the members that have newly joined since August 2001. This brings our membership to over 165 members. And, on this occasion, we would like to extend a great big hug of a welcome to them all!

Jeanne Brown, Elaine Blanchette, Jane Richard, A. Ruth Starnes, Nancy Mabry, Sandra Correa, Brian Loeffler, Anne Durant, Brian Knight, Terri Miller, Robert Self, Ann Sheehan, Margaret Beleckis & Charles Kelly, Debbie Grayson, Carla Rosenau, Beth Coimbra, Debra & Gina Hirsch, Barbara Scott, Junior Ruf, Linda Watson, Margaret DeSpirt, Marsha Turney, Tibor Zemplenyi, Elizabeth Chalmers, Jane Faraca, Nancy Franklin, Mrs. J. Farish (Tom Fyfe), Illiana Bech, Lex Trelford, Tiiana Baumbach, Mary Stuart Menteth, Rhonda Batts, Ellen Schreivogel, Brian Whalen, Mark vanZessen, Marilyn Wade, Katherine Ballard, Gail McNitt, Michael & Joelle Marchio, Joan Studley, Cheryl Rody.

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

Two Types of Erythromelalgia?

Excerpts taken from "Erythromelalgia: New theories and new therapies" by Dr. Jay S. Cohen, and references to research by Dr. Jill Belch.

"Erythromelalgia has some similarities with RP. RP's most prominent symptom is the whiteness of digits from cold-induced vasoconstriction, but the greatest discomfort sometimes occurs with warming, which is described in terms that resemble erythromelalgia: intense heat, redness, vasodilation, and burning pain. It is hypothesized that similar dynamics underlie this aspect of RP and erythromelalgia: the hyperemia phase is more prominent in erythromelalgia, whereas the constriction phase is more prominent in RP. This might explain the puzzling reports of erythromelalgia and RP in the same patients.

Littleford, Khan, and Belch measured the skin temperature of patients with erythromelalgia, which, when not flaring, was lower than that of control subjects. This suggests a sub clinical vasoconstriction during the day with subsequent reactive hyperemia at night. Littleford, Khan, and Belch state: "We believe that, in erythromelalgia, vasoconstriction precedes reactive hyperemia, similar to that seen in Raynaud's phenomenon." (p 588) This may explain why some patients have noticeably cool, yet still erythematous limbs during the day as their symptoms progress. Normal skin temperature may disappear entirely, and the affected areas go from cool during the day to hot at night. Other patients do not exhibit this diurnal variation; instead they display typical symptoms of erythromelalgia and heat intolerance continuously."

What this information suggests is that there may be more than just the assumed one basic type of EM, but rather that there may be two very distinct types. One that causes the person to feel the burning and heat of vasodilation continuously, and another variety where patients experience the changes between a vasoconstriction (a cold feeling) to the rapid dilation with the known burning and redness. What this discovery may mean to you is that the treatments for one type may not be the same as for the other. As this could be a serious complication to your treatment and the information known to your doctor, you may want to note which type of EM you have.

Its possible that you may be able to tell your EM type by your symptoms; do your affected EM areas ever feel slightly cool and constricted, and later turn into the red and burning symptoms? Or, do you feel the burning and redness on a fairly consistent basis, with little or no relief? In some cases, the symptoms will be the same and you may need to actually test them using a couple of the types of medications. If this is the case, it's very important you work with your doctor before trying any medications or supplements. For example: if the EM is of the vasodilatory type or a combination of both, you may respond well to calcium antagonists and magnesium, whereas if you are of the vasoconstrictive type, you would not. It's not uncommon that some EM patients have noticed relief in their vasodilatory type symptoms with even small doses of magnesium.

This is just another reason to be very sure about your particular symptoms, and to discuss the appropriate treatments with your doctor. While diagnostic tests for the differences in the two types exist, they are only known at this writing to be available at the Mayo Clinic in the USA, through Dr. Belch in Scotland, or Dr. MacGrath in Sydney, Australia.

For more information please refer to Dr. Cohen's complete article, and Dr. J. L. Belch's article: Temperature-associated vascular disorders: Raynaud's phenomenon and erythromelalgia. In: Lowe, GD, Tooke, JE, editors. A textbook of vascular medicine. London: Oxford University Press; 1996. p. 339-52.



Hot



Flashes!

ATTENTION SPINAL CORD STIMULATOR

USERS! Medtronic Neurological is issuing this Safety Alert to all physicians, patients and facilities involved with its implanted neurostimulation systems, which include: Spinal Cord and Peripheral Nerve Stimulation Systems. If you are using this device, please speak to your doctor about this warning immediately. The warning says: "Use of diathermy on patients with any implanted neurostimulation device can cause heating at the tissue/ stimulation electrode interface, which under certain circumstances can result in permanent tissue or nerve damage. Such tissue damage could lead to permanent injury or even death. The exact nature of the tissue or nerve damage depends on the location of the stimulation electrodes implanted in the patient (e.g. brain, spinal cord, sacral nerve, stomach), and the extent of the exposure to diathermy treatment." This pertains to the use of shortwave diathermy, microwave diathermy or therapeutic ultrasound diathermy in conjunction with the device.

A Book For Everyone!

Dr. Jay S. Cohen has published another new book, Over Dose: The Case Against The Drug Companies (Tarcher/ Putnam, New York). Over Dose explains why, although we have so many effective medications that help millions of people, these same medications provoke millions of serious reactions and more than 100,000 deaths annually (the #4 leading cause of death in America). In detail, Over Dose describes how widespread problems in drug company research and marketing, FDA oversight, and physicians' methods cause many patients, especially women and the elderly, to receive excessive doses of top-selling drugs, which too often results in unnecessary, avoidable side effects. Over Dose provides readers with multiple strategies for preventing medication side effects while working with their doctors to maximize the benefits of medication therapy.

Jay's research has been published in leading medical journals (Archives of Internal Medicine, Geriatrics, Drug Safety, Annals of Pharmacotherapy, etc.), and been featured in Newsweek, Consumer Reports, Women's Day, the New York Times, and People's Pharmacy (NPR). Over Dose can be found at local bookstores or at Amazon.com or

LIGHTEN UP!

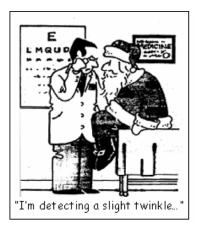
Send in your poems, jokes, stories, anything that can lighten up our day!

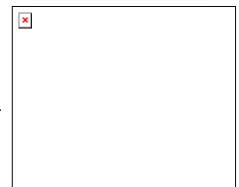
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The Erythromelalgia Association, 4343 Roosevelt Way NE, #305, Seattle, WA 98105, USA or contact us through our official website at http://www.erythromelalgia.org. C The intent and purpose of this publication is to bring information to those suffering from erythromelalgia or their friends and family, and not, in any way, to provide medical advice.

Hope is the belief that one hand reaching to another can eventually touch the moon, allowing the light to guide us through the night.

© Nicholas Mazza, Tallahassee FL, NAPT Board; Editor, Journal of Poetry Therapy





Rare Diseases Act... You can make a difference!

TEA has received the following information from The National Organization for Rare Disorders and would like to encourage you to contact your local representatives to discuss your interest in the Rare Disease Act.

Your letter or phone call can make a difference!

To find the addresses of your local representatives, look in your local phone book under government. To read more about this write to our secretary or search on http://www.rarediseases.org/ or http://www.hht.org/rare_disease.pdf for a sample letter.

(The following is from NORD) For the past ten years, NORD had advocated for increased funding for the Office of Rare Diseases (ORD) at the National Institutes of Health (NIH) and the Orphan Product Research Grants program at the Food and Drug Administration (FDA). Until now, those appeals have fallen on deaf ears. But it now appears that those years of hard work have begun to pay off, and people with all rare disorders need your help to make their dreams comes true.

On August 3, 2001, we are pleased to announce that Senators Orrin Hatch (R-UT) and Edward Kennedy (D-MA) introduced the Rare Diseases Act of 2001 (S. 1379). The proposed law says that:

For many years, the 25 million Americans suffering from over 6,000 rare disorders were denied access to effective medicines because prescription drug manufacturers could rarely make a profit from marketing drugs for such small groups of patients.

The Orphan Drug Act (ODA) created financial incentives for research and development of such "orphan drugs." Despite the tremendous success of the ODA, rare diseases and disorders deserve greater emphasis in the national biomedical research enterprise.

The National Institutes of Health (NIH) has received substantial increases in research funding from Congress for the purpose of expanding the national investment in behavioral and biomedical research. Notwithstanding such increases, funding for rare diseases and disorders at the NIH has not increased appreciably.

The Food and Drug Administration (FDA) supports small clinical trials on new treatments for rare disorders through Orphan Products Research Grants. Yet the appropriations in FY 2001 for such research grants were less than in FY 1995.

What does the Rare Diseases Act of 2001 do?

- Provides a statutory authorization for the existing Office of Rare Diseases (ORD) at the NIH.
- Increases the national investment in the development of diagnostics and treatments for patients with rare disorders.
- Authorizes regional centers of excellence for rare disease research and training.

Increases funding for the NIH Office for Rare Diseases to \$24 million for fiscal year 2002 and "such sums as may be necessary for each subsequent fiscal year." Increases the funding for the FDA's Orphan Product Research Grants program, which has provided vital support for clinical research on new treatments for rare disorders to \$25 million for fiscal year 2002, and "such sums as may be necessary for each subsequent fiscal year." Our work must now begin in earnest to ensure that the Rare Diseases Act of 2001 becomes law. This legislation will benefit the 25 million Americans -- every man, woman and child – who suffer with a rare disorder; therefore, we must ALL work together as one to ensure that the ORD and Orphan Product Research Grants program receive increased funding through the Rare Diseases Act of 2001. Contact your U. S. Senators today and ask them to cosponsor the Rare Diseases Act of 2001. Cite the name of the bill and the bill number. Tell them why passage of this bill is important to you and your family. Ask for a response. Ask for action.

Senators respond to constituents from their state. Please contact your members and chapters and ask them to write to the two U.S. Senators who represent their state in Washington, DC.

The language of the legislation, as well as Senator Kennedy's statement in the Congressional Record, can be found at NORD's web page under "What's New" at http://www.rarediseases.org. Diane Dorman, Senior Director for Public Policy, will be coordinating NORD's efforts. Contact her at (202) 496-1296 or via e-mail at ddorman@rarediseases.org to keep her apprised of your progress. Please forward copies of your letters to Diane at new address: 1050 17th St., NW, Suite 600, Washington, DC 20036.

SEPTEMBER BOARD MEETING

The September meeting was called to order at 10:25 am, MST, Sept. 10, 2001. Present were: Beth Coimbra, Milt LeCouteur, Nancy Mabry, Lennia Machen, Ray Salza, and Amy The. The meeting was closed on Sep. 14, 2001.

OLD BUSINESS: NORD Membership Application Requirements: MAC: Packets for invitation were sent out.

2. Open Director's seats; Ray reported concerning the filling of our open seats: "Nominations committee: 12 members were identified as candidates and were invited to join the board. Beth accepted.

REPORTS: Secretary/Treasurer report..."TEA has had twelve new inquiries between Aug 8 and Sept 9, 2001. During the same period there have been 15 memberships, 9 new, and 6 renewals. In addition there have been 8 research donations plus interest of \$40.43 totaling \$3,810.43. The Research Fund total was \$28,655.69. Together with the \$7,850.00 being held by NORD in escrow, the total Research Fund was \$36,505.69. The operational checking account on Sept 9, was \$2,057.95. During the month of Aug, 59 newsletters were sent to non-email members. There was one research donation of \$3,000.00. This enabled TEA to surpass its first research fund goal of \$35,000.00. Ray Salza and I wish to suggest that the \$28,655.00 be reinvested in a short term CD or mutual fund instrument." Motion was made and seconded, and voting proved to approve moving the research fund to a 31-day CD account.

4. Business Report: Ray had the following to report "Insurance: Our insurance agency's recommendation that we purchase a General Liability policy (additional \$521 annual premium) to supplement our Directors & Officers insurance policy has raised more questions that it has resolved.

NEW BUSINESS: Vice President, Wendy Baker has resigned. Ray Salza was nominated and voted into the position.

OCTOBER BOARD MEETING The meeting opened on 10/10/01, Present were: Beth Coimbra, Milt LeCouteur, Nancy Mabry, Lennia Machen, Ray Salza, and Amy The. The meeting was closed on 10/17/01.

OLD BUSINESS 1. NORD Membership Application Requirements: No changes were reported since the announcement of Dr. Mark Davis as being the first MAC candidate to accept, and Dr. Mansmann declining.

2. Open Director's Seats: The board voted unanimously to accept both Helen and Ann into our Board of Directors. **REPORTS** Secretary/Treasurer Report: Between Sept 10 and Oct 10, 2001, TEA has received 11 payments for membership, including 5 renewals and 6 new. TEA has also received 7 research donations totaling \$740, bringing the research fund total to \$29,484.09. When added to the \$7,850.00 in escrow at NORD, the total research dollars available are \$37,334.09. The operational checking account on Oct 11, was \$2,246.97. On Sept 17, 2001, \$28,704.03 from the research fund was invested in a 31 day certificate of deposit at Home Street Bank, Seattle, at an interest rate of 3.70%. If the rate drops below 3%, I will investigate other possibilities.

NEW BUSINESS: Board member's Bios. The Bio's will be included into the new board member packages and added into an informative section with the Member's Page on the site. 7. Web Site Changes. Lennia distributed a brief proposal regarding some suggested changes for the TEA web site. 8. The Rare Diseases Act. The discussion on this topic has left off in agreeing that TEA needs to send out information to our membership as to how to write to their congressional representatives about support of the Act.

NOVEMBER BOARD MEETING Present were: B. Coimbra, M. LeCouteur, N. Mabry, L. Machen, H. Normandin, R. Salza, A. Sheehan, and A. The. Called to order Nov. 14, 2001, and adjourned Nov. 17, 2001. OLD BUSINESS: NORD/MAC: We have received six replies of acceptance: Dr. Mark Davis, Dr. Cato Mork, Dr. Jay Cohen, Dr. Knut Kvernebo, Dr. J. Michiels, and Dr. Schneeweiss. Ann Sheehan has graciously agreed to facilitate the meetings, and Dr. Cohen will act Chairman. 2. Open Director's seats; We welcomed two new board members to our group this month: Ann Sheehan and Helen Normandin. With Beth Coimbra joining us only two months before this, we have a total of three new members just recently. However, we will continue the "talent search" to find another person to fill one open seat.

REPORTS: Secretary/Treasurer report: Between Oct. 10 and Nov 13, 2001, TEA received 16 payments for memberships, three renewals and 13 new. In addition we have had eight inquires that may become members. TEA has also received six research donations totaling \$220.00 bringing the total to \$29,704.09. When added to the NORD escrow of \$7,850.00 the grand total is now \$37,554.09. The operational checking account balance on Nov. 13 was \$2,473.57. Though there have been expenditures during the period they have not as yet been reimbursed. The research fund 31 day CD came due on 10/23/2001. The interest rate for such investments has fallen below 2%, therefore the funds remain in the TEA Checking Account. I will attempt to find a short term investment at 3% or better during the next 30 days. In addition to the routine secretarial tasks a letter from Lennia announcing the formation of the MAC and soliciting memberships was sent by email to all the EMyahoogroups (250+) and to a list of about 40 other non-members. Lennia's letter was also sent to 63 non-members by US mail. Together with Lennia's letter, a letter from Nancy Mabry asking members to submit their EM stories for future publication was sent to all 165 members. By the way, from January 1, to November 13, 2001, 165 people have joined or renewed their membership. 2001 has been near 100% better than 2000



The Erythromelalgia Association 4343 Roosevelt Way, NE, #305 Seattle, WA 98105