

FootSteps...

TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia
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CURRENT INFORMATION ON TREATING ERYTHROMELALGIA

by Jay S. Cohen, M.D.

There appear to be several subtypes of erythromelalgia (EM) that respond to different therapies. Treatment consists of trying different approaches until the ideal one is determined, just as in treating hypertension and many other conditions. The diagnosis and treatments of EM are summarized in my review article, which is intended to inform patients and physicians about treatment options for EM: *Cohen, JS. Erythromelalgia: New Theories and New Therapies. Journal of the American Academy of Dermatology, Nov. 2000; 43:841-7.*

In my experience, two types of medications have demonstrated greatest effectiveness in treating EM:

1. **Calcium antagonists**, especially Diltiazem and Norvasc (amlodipine). These drugs, when effective, are the best treatment for EM. My experience is that about 50% of EM patients improve dramatically, 25% do not respond, and 25% worsen. In addition, patients unable to tolerate these drugs' side effects can obtain marked improvement with high doses of magnesium, which also is a calcium antagonist (see: Cohen, JS. High-Dose, Oral Magnesium in the Treatment of Chronic, Intractable Erythromelalgia. *Annals of Pharmacotherapy*, Feb. 2002;36:255-60). Calcium antagonists, including magnesium, should be started very carefully and increased gradually. Patients usually know very quickly whether calcium blockers are helpful or harmful. If helpful, increase dosage to tolerance for maximum effect. If the EM worsens, discontinue immediately. Use of magnesium requires normal renal function. Tolerance and absorption are highly variable with magnesium products. Best results are obtained with chelated magnesium pills or liquid magnesium solutions. These products can be obtained from most health food/vitamin stores. Chelated magnesium can be ordered from Miller Pharmacal Labs ("M2 Magnesium," 800-323-2935) and Carlson Labs (800-323-4141). Magnesium solutions can be obtained from Cardiovascular Research (800-888-4585) and Allergy Research Group (800-545-9960). Carlson makes a liquid magnesium in capsule form. Most vitamin and health food stores carry similar products. Magnesium doses can range from 400 to 1,000 mg/day or more. Start even lower, increase gradually with medical supervision.

2. **Selective serotonin reuptake inhibitors (SSRI's)**, especially Effexor (venlafaxine), but also Zoloft (sertraline) and others. Start with low doses (e.g., 1/4 or 1/2 of the usual initial dose) and increase gradually as the case requires.

Other treatments include:

Neurontin (gabapentin) often provides considerable relief of EM pain, but it does not help other symptoms. Neurontin can be used in combination with an SSRI or calcium antagonist or other treatments. Some patients are very sensitive to this drug initially, so it should be started at a low dosage and increased as necessary. Tegretol (carbamazepine) has also been reported helpful by one patient.

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Current Treatment Information on Treating Erythromelalgia, Cont. from page 1

Tricyclics such as amitriptyline, imipramine, or nortriptyline can reduce EM symptoms. Often used in combination with Neurontin. Some patients are very sensitive to these drugs -- start with 10 mg/day.

Prostaglandins, including intravenous PGE1 and oral Cytotec, have been reported effective by European researchers. Our members have reported some modest effects, but we have not seen dramatic improvement.

Antihistamines such as Benadryl and other first-generation antihistamines have been reported effective by some patients. Cyproheptadine (Periactin) has been reported as useful and may be used instead of standard antihistamines.

Ultram may be helpful for EM pain; avoid with SSRIs.

Responses to all of these drugs can be quite variable. Again, as with hypertension and other conditions, treatment is often a stepwise, trial and error process, but treatment can provide considerable pain relief and greatly improve EM patients' quality of life. Many patients are highly sensitive to these drugs and should be started with very low doses and titrated gradually.

Procedures such as sympathetic blocks and high-potency topical capsaicin with epidural anesthesia have been useful in some people. The Mayo Clinic has had limited success with intravenous lidocaine and mexiletine; for atypical or unresponsive cases, the Mayo Clinic provides the most in-depth diagnostic evaluation of EM in the U.S. If sympathetic blocks provide temporary improvement, then a long-term epidural or sympathectomy might be considered. If a sympathetic block worsens symptoms, do not repeat. Early reports of the capsaicin therapy were very promising, but subsequent cases were less impressive. Spinal cord stimulation and morphine pumps have provided pain relief for some EM patients. Hyperbaric oxygen therapy caused severe worsening in one patient and is probably contraindicated for EM.

Children sometimes respond differently than adults. Nitroprusside infusions have been very helpful in some children, but not helpful in adults.

Further information about these approaches as well as references can be found in my other articles. This summary is for information purposes only.

The information herein should not be considered to be a substitute for the direct medical advice of your doctor, nor is it meant to encourage the diagnosis or treatment of any illness, disease, or other medical problem by lay persons. Readers should not change any drugs or dosages unless specifically directed to do so by their own doctors.

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June 2002*

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 or rejoined us since June 2002. And, on this occasion, we would like to extend a great big hug of a welcome to them all!

Marlene Smith, Judy Reese, Mrs. Ismay Wittig, Paul Hilder, Jacqueline Y. Oyster, Jean Jansen, Dr. Mihailescu-Stoica Mircea, Andrew Jones, M.D., Francine Harris, John Izzi, Janet Perrigo, Violet Harada, Lori Ann Stephenson, Marian Forschler, Ann Sturm, Magaret Martin, Elaine Blanchette, Barbara Johnson, Sylvia Ambrosini, Barbara Zolkower, Dolores Griffith, Lizabeth A. Warren, Bonnie Wirkus, Joy E. Knoll, Jill Baxter, Kris M. Evans, George R. Britt

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

Retirement of Our Founder

By Lennia Machen

Milt LeCouteur, one of the founding fathers of TEA, is retiring from his office of Secretary and Treasurer. Milt has played an important part in TEA's becoming organized, and single-handedly handled a lot of our original incorporation arrangements. We have been fortunate to have such a dedicated volunteer working for all of us in our search to find a solution to EM. Milt has continued to be a tireless and generous worker for the organization and is still helping, even though he has announced retirement.

While reflecting back to when I first "met" Milt over the Internet on the Harvard bulletin board, I also thought back to four years ago when TEA was officially "born," and realized how far TEA has come in our goals and objectives. It's quite an accomplishment, and one that took all of our collective efforts and talents to achieve, however, Milt was often at the forefront of TEA's activities and development. And to top it off... we all are dealing with a disability while doing all this "cool stuff." Seems, we are truly blessed with abilities and willingness.

Many kudos to Milt for the great strides he has made in making EM more understandable and livable! Just think how very far we have come from the days of "...soak the affected limb in ice water" as being the only known treatment. Milt, it was you who had the vision for TEA, and suggested we organize. Just look at the help we have been able to provide to people searching for information about this awful condition we share. The legacy will surely continue and keep providing many more sufferers with that help. And, think of the future research project... wow! Who would have thought this would come from a handful of people meeting on the Harvard Bulletin Board? Milt, you're the tops! We can't thank you enough for all your hard work and dedication!

New Offices filled on the TEA Board of Directors

The TEA Board of Directors has made a few changes in its officers. Beth Coimbra, our current Membership Chairman, has also taken on the post of Vice President. Ray Salza has stepped into the position of Secretary and Treasurer. Hearty "Thank You's" are in order as these volunteers assume their new offices.

As always, if you are interested in helping out on our board of directors, please contact us. We are always looking for volunteers for our several tasks and jobs. Inquiries are welcome, and we promise not to sign you up just because you asked what the job entails. One thing though... we are limiting our board members to only those members, or friends and family of TEA members, who have Internet and email access, as we hold our monthly board meetings via email.

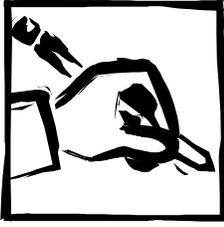
TEA Offices Move to New Addresses:

For Member Services and Business Office:

The Erythromelalgia Association c/o Ray Salza
24 Pickering Lane
Wethersfield, CT 06109
ray-paul@att.net

For General Information, or to Join TEA:

The Erythromelalgia Association c/o Beth Coimbra
200 Old Castle Lane
Wallingford, PA 19086
fcoimbra@comcast.net



Your Stories... and everyone has one!

TEA has been asking it's members to write brief stories about their EM or daily lives. Several members have responded and we are printing a few of them here for you. We would love to hear your story too! Please send them to Nancy Mabry at :209 Ridglea, Midland, TX 79701

My name is Kate Carless. I am a widow of 72 years. I live in a village near Bath, England. I developed EM when I was 32, but it was not diagnosed until I was 47. I suffered from burning soles of feet and palms of hands, and also tip of my tongue and lips and sometimes around my eyes, and swelling of hands, feet and sometimes gross swelling of arms and legs. Occasionally in very hot weather I get into a semi comatose condition, where my brain works, but I can only speak or move with great difficulty.

When I was 54, my youngest child developed schizophrenia, creating acute anxiety. My EM vanished - indeed I had very cold hands and feet! It is only now, 14 years after he sadly died, that my EM is back. It is not as bad as it used to be. I find that exercise to kick start the sweating mechanism helps. I have had a little stroke and take 1/2 an aspirin a day, which I think helps, too. (It was a VERY hot night that I had the stroke.)

I consider that fear and grief (my husband died of cancer in 1998) kept the EM away and that the chemicals produced by fear are involved in EM somehow. Luckily, here in England, we are having a cold summer - good for EM!

My name is Ismay Wittig. I live in Victoria, Australia. I am 59 years old. I have suffered with EM for 5 1/2 years. It started with a rash about the size of a 20 cent piece on the front and back of my legs near my ankles. I had on a new long skirt that was made of 100% viscose, and the rash was exactly where the skirt hit my leg. I went to my general practitioner and he put me on a steroid ointment. This caused my legs to go crazy! Little tiny lumps appeared all over my legs from the knees to the ankles. The doctor sent me to several specialists, and they did not want to know. I changed GP, and saw more specialists, and I finally got to see Dr. Peter Blombury, a Cardio-Vascular Surgeon. He changed my tablets and tried several different ones. Unfortunately, I cannot remember the names of all the tablets - more than half of which made no difference in my condition - but they included: Propranolol, Tegretol, Keyflex, Doxepin, and others. I am currently taking Deralin, 40mg, 2 tablets morning and night; Coversyl 4 mg, 1 tablet in the morning; Lasix, 40 mg, 2 tablets, morning and midday, and Murelax, 30 mg, 1/2 at night.

I have just come home from the hospital, after my legs broke out in blisters. Altogether I had 14 on both legs from the knee to the ankle, and the infection went through my body. The same thing happened 12 months ago.

The last specialist that I went to, about 2 years ago, told me what was wrong with my legs. I was sure I was the only person with EM!

I used to sit in front of the fan all day and night every day of the year. I was not going out, as I have not worn stockings for 5 years and have not been able to wear shoes for at least 3 years. I go barefoot around the house. My husband and I have been going out for lunch once a week, and I wear toweling scuffs. I even had to wear the scuffs to our daughter's wedding last year, and our son's wedding this year! I sometimes go to the shopping center with my husband. Our daughter got me a wheelchair through her work. It is great to get out of the house!!

Your Stories, Cont. from page 4

Hi, my name is Bonnie Wirkus, and I live in Boalsburg, Pennsylvania, USA. I am a seamstress and love working with brides and their parties. I sometimes make their dresses from scratch, or just alter what they have bought. I also do alterations for ladies and once in a while their husbands.

My sewing, however, is becoming increasingly more difficult due to erythromelalgia. Some days my feet are normal color and with little pain. I call these my "happy feet days"...but they seem to occur less and less often.

My problems first started with a feeling of a very thick and uncomfortable callus behind my toes back in February of 1998. They have since continued to get worse, beginning with electric shocks running through my feet for no apparent reason at all. I said it felt like being shocked with a cattle prod. For those of you who live on a farm, you will probably understand this one! My feet would also go into cramps when I was doing a fitting or when I was asleep at night. I tried going to the orthotics, but that only seemed to make the feet hurt even more. The friction from the inner soles seemed to irritate my feet. I had molds taken of my feet to insure a proper fit back in March of 1999. After trying to adjust to the inner soles, I found my feet turning purple or bright red. At this point I became worried that it had something to do with circulation problems. Doctor after doctor assured me it was not this, but neuropathy.

On August 29, 2002, I tried a trip to Cleveland Clinic. There, they did nerve conduction tests, which proved to be very normal. Therefore, there does not appear to be any nerve damage. I do, however, have a loss of sensitivity in my feet. We also did a vascular test which proved there was not a problem with the circulation in my feet. It was at this time that Dr. Carmen suggested that I probably had Erythromelalgia, but other than pain killers, she didn't have any suggestions for me. Then she told me she had just read an article which was written by Jay Cohen, MD, Chairman of TEA's Medical Advisory Committee. With the help of my husband, we found your web site. After reading your information on the web site, I decided to join TEA.

I sleep with my feet uncovered and with a fan blowing directly on them. We air condition our house during the summer, so that helps; and I like to sleep with the window open in the winter and do not heat our bedroom. It doesn't matter if I wear tennies or sandals, my feet get just as miserable one way or the other. They tend to be happiest when I am barefoot. I do go barefoot most all year now. I no longer use ice packs on my feet to cool them, as the icy cold seems to make them burn even more than usual!

Walking is becoming more and more difficult for me. Some days it seems to be okay to walk ("happy feet days"), but on bad days I would like to just sit and cry. However, doing so would only make my eyes burn and my head hurt, so that is not a practical thing to do! I know I cannot let this beat me, but I also have to find some relief for the pain. I have tried numerous pain killers, but they tend to leave me groggy and disoriented. I am a person who needs to be in control of my emotions, and that means I need to learn better methods of controlling my pain with my head, rather than drugs.

I just picked up an article on a lady from Des Moines, Iowa who has come up with a topical herbal pain medication. I do think I will try this, and if I have any success with it, I will let you know.

My name is Len Bishop. I live in Burlington, Wisconsin, USA. My whole life is around this word - Erythromelalgia, which I have secondary to Raynauds Syndrome. At age 19 I was sent to the University of Wisconsin Clinic with a right side badly swollen red, etc, and my whole right side bigger than the left side. I was diagnosed with Erythromelalgia in right hand and a vascular block in my neck, adhesions growing on a vein and cutting off blood. This blockage was surgically taken care of, but I had to continue with EM. I am now 67 years old and my whole body has EM, fibromyalgia, and other related age problems like heart surgery, etc. I have been through the old and new times with this and it is certainly a relief to be in these times compared to the old. Nobody knew anything then and it was treated like something that didn't exist. Today that is all different.

Your Stories, Len Bishop, Cont. from page 5

EM has changed my whole life, such as causing me to retire early. The illness caused my divorce. It was very hard on my family. Now, though I have some family ties, it is still hard for them to understand.

Medications have been so many, because, due to body tolerance they only help for a while. There were so many, that would be a whole story of its own! I went to the University of Wisconsin Clinic 10 years, and then Columbia Hospital and Milwaukee Rheumatic Disease Center there until recent years here in Burlington. Coping is very hard. I have been bedridden seven times, but new tactics have made me active again to where I am bowling for exercise, but still very, very difficult. After heart surgery, my left leg was swollen to 5 times the normal size! Cortizone creams were used under a doctor's care. I was bedridden for a month. I also have cluster headaches, ringing of the ears, and my eyes burn.

I now live in a government owned apartment complex, which helps my financial situation. I have two children (a boy and a girl), and 5 grandchildren.

EM is from the top of my head to my toes - every inch of me! Others can learn to cope with this, but it takes close friends, family, endurance, stress training, and anything you can have available to you.

Thanks to those who took the time to write to us with their stories of dealing with EM. We all learn from sharing with each other and we sincerely hope the above information will be taken in that light... as a helpful approach to dealing with EM.

SUMMER BOARD MEETINGS

Over the summer, the TEA Board met and looked into issues such as Fund Raising, and the creation of a new web site. Expect much more information regarding both topics as they both are still in the development stage.

The fund raising efforts will include the creation of a committee that will be involved in raising funds for the research fund. If you are interested in joining in on this mammoth and important effort, please contact us and we can answer any questions you may have or help you get started. Our new board member, Jan McKim is the person to contact for this information: Jan McKim, 1717 Greenwood Ave., San Carlos, CA 94070

The new Web Site should be launched in the next few months. The new features will include personalized passwords to enter the member's area, a searchable tool for the articles and newsletters, and the expansion of EM articles available, printable tools (a TEA brochure, or informational flyer). We are striving for a more professional look as well as a more user friendly design and layout. Your comments and suggestions for the new site are very welcome, please contact Lennia Machen at: 11591 North 5th East, Idaho Falls, ID 83401.

With the changes in office positions, our board has also been busy with all the transitions needed to make these changes. During this time, several board members have taken on extra jobs, additional tasks, etc., to make these needed adjustments. As the dust settles, you will be hearing more about TEA's plans for future goals and events.

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Coming soon to a computer near you!...

You may want to make note of the following information to pass along to your family members, your doctor, or other health professionals like your health insurance agent, etc.

We offer free memberships to doctors wishing to treat patients for EM, and we may be able to help your doctor. Remember these addresses:

www.erythromelalgia.org or write to me at erythro@ida.net

Hot



Flashes!

TEA Welcomes a new Board Member: "Jan McKim lives in the San Francisco Bay Area and was recently diagnosed with EM this year. She has her Masters degree in counseling and has counseled and taught students in colleges and universities, and counseled clients with disabilities for the Department of Rehabilitation. Her love of traveling has taken her to Latin America where she has traveled and studied Spanish in Mexico, Guatemala and Costa Rica. Jan recently retired and will volunteer her time to raise funds for TEA sponsored research." *Jan will be heading up our new efforts in Fund Raising.... Welcome Jan!!*

Update your Membership File... TEA is building a new database of all of its members. If you have not updated your information and you have moved, changed your email addresses, or other membership information, please contact us. This is a large task, and your help will be greatly appreciated.

Contact: The Erythromelalgia Association, c/o Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109



A New Brochure Just For You... TEA has created a new brochure that you can print using your own computer. The brochure prints out onto an 8 1/2" X 14" (21.5cm X 35.5cm) sized paper, two sided, and in color. Once you have printed it, the brochure folds into four panels, and can be used to help your medical professionals, offer to people you know who may have EM, for your own information, etc. Contact Ray Salza for a copy at: The Erythromelalgia Association, c/o Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109

Translators Needed!

TEA is an International organization and has members in many countries. If you are bilingual or multilingual, and would like to help translate messages from new contacts, please let us know. While our plans don't include publishing in several languages at this time, we are presently interested in being able to read the initial messages from those with EM in non-English speaking countries. If you would like to help, write to TEA at 24 Pickering Lane, Wethersfield, CT 06109, and be sure to tell us what languages you are willing to help us with.

Are your
Membership
Dues Due?

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. You can contact the editor through:
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.

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