
FootSteps

TOWARD PROGRESS

The newsletter dedicated to finding a better way to live with erythromelalgia
Volume 7, Issue 2, June 2006, Published by The Erythromelalgia Association

70 Participate in TEA Teleconference

“There is really no place to find an expert in EM,” Jay S. Cohen, M.D., told the 70 participants during the May 20 teleconference “Dr. Cohen on EM.”

People with EM need to take the lead by gathering as much information about EM as they can and educating their doctors, said Dr. Cohen, Adjunct Associate Professor of Family and Preventive Medicine at the University of California, San Diego.

The first-ever TEA-sponsored teleconference was very well received by those who dialed in to the question-and-answer session, according to Meriwether Jones, event organizer.

During the first part of the session, co-moderator Deborah Mosarski posed some of the

most commonly asked questions sent in advance by participants. Later, individuals posed questions directly.

Dr. Cohen advised finding a doctor in your local area—possibly your internist—who is willing to work with you, has good judgment, and is patient enough to try one treatment at a time until you find one that works.

It is important to take articles and other information to

your doctor. These include Dr. Cohen’s “Current Information on Treating EM” (TR-25 in TEA’s Article Archive.) Referred to as Dr. Cohen’s “treatment guidelines,” this article is a broad overview that he revised in 2005.

There are many things to try, Dr. Cohen said, and “the key is to keep trying things.”

An EM patient himself, Dr. Cohen said he tried many,

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Teleconference Response Positive

“I found the teleconference very well organized and very useful.”

“I was delighted with the whole thing. I was amazed when he (Dr. Cohen) went 45 minutes over the planned hour.”

“Wow, ... I learned a lot from it.”

“THANK YOU to everyone involved....”

These are just a sampling of the e-mail messages received by event organizer Meriwether Jones and co-moderator Deborah Mosarski after the May 20 teleconference “Dr. Cohen on EM.”

Suggested by Jay Cohen, M.D., as a fundraiser, this was the first such event to be sponsored by TEA. Eighty people registered and 70 dialed in and listened to the conversation live.

Registrants unable to make the call had the chance to download a recording of the session from the Internet.

Money raised for the Research Fund totaled \$1,341.

“What resonated with me was just how much participants appreciated listening to a doctor who really understands EM, as well as hearing the voices of the people with EM who asked questions,” said Jones.

Other comments: “It does help to know that others are looking for a way to live as normal a life as possible.”

“Listening to Dr. Cohen has given me a renewed sense of hope that there might be something I can try to alleviate these vexing symptoms.”

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Teleconference

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many therapies until he found the ones that helped him most.

To make sure you're diagnosed correctly, he suggested seeing a dermatologist, "because some dermatologists have seen EM."

Equally important, dermatologists should be able to rule out other skin disorders and diagnose EM.

But if you're still uncertain that EM is your illness, in the U.S, he recommends the Mayo Clinic in Rochester, Minnesota.

Doctors there have seen hundreds of cases of EM and can perform all the definitive diagnostic tests.

Cohen Misdiagnosed

Dr. Cohen said he was misdiagnosed at first, told he had Reflex Sympathetic Dystrophy, a disease that at first may look exactly like EM.

When asked why people with EM can react so differently to different treatments, Dr. Cohen—whose area of expertise is in pharmacology and medication side effects—said individual reactions are a dilemma with all drugs.

"Some of us are very sensitive to some drugs," he said. However, he cautioned against giving up on a drug if you see no improvement after trying a low dosage for a short time.

If you do not get a response with a low dose of a medication, ask your doctor about gradually increasing the dose until you see some effect (either a beneficial effect or a side effect). Just as some peo-

ple respond to lower doses, others need higher doses.

He recommended that those just beginning treatment might first try the drug Effexor. (Effexor is one of a group of prescription antidepressant drugs.)

People Sensitive

Because some people are very sensitive to these drugs, again he advised starting at the lowest dose. Some people have responded even to a low dose of Effexor.

"But other people will need to work up to a higher dosage for the drug to work." If side effects develop, then you may need to give up and try something else.

The next most effective type of drug to try is a "calcium antagonist" or "calcium channel blocker." Diltiazem is the most effective prescription calcium antagonist for EM.

Start with short acting diltiazem in order to test your response. Some people obtain dramatic improvement with diltiazem, while others' EM can be made worse.

Magnesium is another calcium antagonist. Dr. Cohen himself received dramatic results with magnesium.

Magnesium Important

"Magnesium is an important mineral," he said. It relaxes blood vessels and can relieve migraines and other illnesses besides EM.

"Most magnesium products—sold over-the-counter—are of poor quality and often cause diarrhea. Find

a good brand that is well absorbed.

Magnesium, like diltiazem, can also worsen EM, so people should try these therapies very carefully. Alpha lipoic acid is a natural therapy that is also a calcium antagonist. It is used in Europe to treat neuropathies and nerve injuries, he said.

The doctors with the greatest knowledge of magnesium and alpha lipoic acid are the alternative practitioners. You can find an alternative doctor in your area by checking the Web site of the American College of Alternative Medicine (ACAM).

Check AHMA

To locate practitioners of all sorts of alternative therapies, many of whom are not M.D.s, check the American Holistic Medicine Association (AHMA) Web site.

When asked about his own experience with EM, Dr. Cohen said he was able to control the flaring of EM with magnesium. The addition of other therapies produced full remission for three years.

He relapsed because he cut back on his magnesium, and unknowingly, he was eating foods that had detrimental effects on his EM.

Dr. Cohen's recommendations are for informational purposes. This information should not be considered a substitute for the direct medical advice of your doctor. Readers should not change any dosages or drugs unless specifically directed to do so by their doctors.

Remission Of EM Using Cyproheptadine

By Jean Jeffery

This is a summary of a paper¹ from Japan which describes the treatment of primary EM in two female patients. Successful remission of EM was achieved with cyproheptadine (Periactin). Cyproheptadine is a serotonin and histamine antagonist (it works against serotonin and histamine).

The first patient, aged 48 years, had burning pain and numbness with redness and swelling of her toes which spread to her ankles. Her hands also became affected. All tests which included nerve conduction studies were normal, except for the lack of sweating in her feet. Aspirin and several other drugs failed to give relief. Midodrine slightly reduced the pain and hot skin temperature of the patient's hands only. Cyproheptadine, at the dosage of 24 mg daily, brought almost complete relief from the burning pain and hot skin. This remission continued over the patient's 17-month follow-up period.

The second patient, aged 20 years, experienced the same symptoms as the first patient in both her feet and hands for two weeks. All

tests were normal though she did not have a sweat test. Aspirin and other drugs were unhelpful. Ergotamine and dihydroergotamine slightly reduced the pain and hot skin temperature. A dosage of 12 mg cyproheptadine daily almost completely suppressed her burning pain and hot skin. Her remission from EM continued during her 12-month follow-up.

The authors of this paper discuss EM in the light of previous findings (abnormal blood flow in the skin and impairment of the nerves that control the diameter of the blood vessels). However no conclusions are reached on the mechanism of action of cyproheptadine.

Antihistamines Helpful

Dr Jay Cohen has reported that acrivastine (Benadryl) and cyproheptadine have helped people with EM. "Antihistamines are often overlooked in the treatment of EM, but these drugs have potent vascular effects and should be considered in difficult cases". (Current information on treating EM. 2005. No. TR-

25 in TEA's Article Archive).

Two EM members of the EMyahogroup have recently shared their success with antihistamines. (EMyahogroup is an online support group for EM at <http://www.groups.yahoo.com/>). The first lady has had complete remission of her EM with cyproheptadine. She had experienced painful burning with swelling and severe itching in her feet. Her EM has been controlled for over ten years by taking a daily maintenance dose (one quarter of one tablet) of cyproheptadine. On a rare occasion when an EM flare-up does occur she takes one 4 mg tablet three times daily, and then tapers this down to her maintenance dose as her EM symptoms recede.

The second woman has used three antihistamines to prevent the EM burning in her feet. She has found that chlorphenamine (Piriton) is effective for a period of four hours, while desloratadine (Clarinet) helps to control her EM for up to 24 hours. At night she sometimes takes Benadryl for its sedative effect and because it prevents her feet from burning under the bed covers.

Editor's Note: EMyahogroup is not affiliated with TEA.

¹Treatment of primary erythromelalgia with cyproheptadine. Sakakibara R, Fukutake T, Kita K, Hattori T. 1996. Journal of the Autonomic Nervous System 58: 121-122.

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.

Patricia Michaux writes: I live in France and am a new member of TEA. I wanted to inform the members that I have had an improvement of my EM symptoms of about 50 to 70 percent from a method called auriculotherapy (also known as ear acupuncture).

After the first treatment last July, the improvement lasted for two months despite the warmth of summer. I had a second treatment last November. After several months, the improvement lasted only about six weeks. In my case, I only suffer when I walk, so the treatments are not really useful. If one day my illness increases, I will go back to this doctor.

The doctor had successfully treated persons with Raynaud's. She explained that, among other things, with Raynaud's she uses the therapy to increase the temperature of the body and that with me she diminishes it.

For persons who suffer without walking, for example during the night, or all day long, I think they may wish to consider auriculotherapy.

I want to say also that my EM has nevertheless diminished a lot. I don't know if it is the effect of auriculotherapy. I have to walk for about one hour to begin to feel pain. My English is really awful (because not practicing it, I'm losing it!) Excuse me for it.

Danielle Sullivan writes: I am a 25-year-old woman from London, England. I first felt the pain of erythromelalgia when I was 13 years old. As a child I was taken to my general practitioner who sent me home with a flea in my ear for wasting their time with hot itchy feet.

Throughout my teenage years my feet would burn and itch. My parents had no idea what caused it. At times I would beg my Dad to scratch my feet with wire brushes to stop the itching and then sit for hours on the side of the bath with my feet in ice water. By the age of 15 my hands were the same.

Unfortunately, my EM is progressive. Since turning 20 both my hands and feet have become very painful to the point where I cannot use my hands or walk without severe pain. The itching has given way to intense pain and the thought of my Dad scrubbing at my feet now is terrible. I wonder if any one else had an onset of this disease where it started with a hot itching?

I am currently on amlodipine and clopidogrel, plus a cocktail of pain killers. My Dad suffers with Raynaud's. He remembers his great aunt constantly rubbing her hands that were always swollen and red, just like mine, so I know my EM is inherited.

I am always trying to find new treatments, but as yet have not had good results. This is where *Footsteps* is so great. I took my first issue to my GP and rheumatologist and we are using the information to try different treatments.

For now though, I will continue to keep the house cold and sleep with my feet sticking out of the bed covers and my tower fan blowing directly onto them, whilst my poor husband shivers the night away, in two pairs of pajamas and the duvet pulled up under his chin!

Your Stories—everyone has one!

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 it to Gayla Kanaster, gaylakanaster@aol.com or 2532 N. Fremont Street, Tacoma, WA, USA 98406

Jim Read writes: I'm now 59 years old and I love it. I started feeling like my feet were warm after walking or running in about 1974.

Slowly the warmth in my feet increased over the next decade. I just figured pounding my feet into the pavement every day made them feel a little warm.

My feet looked perfectly normal, but I began to have more difficulty when I started doing hundreds of lectures and workshops. I'd stand all day in front of a class, and my feet started to feel warmer and warmer.

In 1990 I was diagnosed and a name came up: erythromelalgia. The diagnostician? A social worker. The wife of a psychologist colleague with whom I and three others shared office space. She found a very consistent description in some printed literature from NORD.

It wasn't until 1997 that I went to a pain specialist. An anesthesiologist. He just gave me a prescription for Neurontin (gabapentin). It helped a little—maybe 20 percent less pain. The red and swollen look was here to stay. I stopped running and in 1998 I started cycling every day, a lot! It was nice.

We cooled our house and I began sleeping with my feet sticking out from under the bed sheets, and with an open window at night. Later, in January of 1999, I started the EM list. We now have nearly 500 subscribers.

Fortunately, my job as a clinical psychologist is sedentary and I don't have to stand or walk much.

I first stopped wearing shoes and switched to Birkenstock sandals with thin socks. Then just the socks, and three years ago I stopped wearing socks. Meet the barefoot shrink!

I think my obviously red feet (all the time) have been more tolerable than some because I walk so little.

Perhaps being in good physical condition otherwise helps. That's not to mention the recent

diagnoses of rheumatoid arthritis and ALS (Lou Gehrig's disease, usually fatal within two to five years). I don't think I have ALS. What could two neurologists know anyhow? ;-)

I'm happily married to the lovely six-foot-tall Heidi for 36 years. We have two adult children (27 and 31). I like my work, and I feel fortunate to have a job that allows me to sit in a cool office and walk very little (but talk a lot!).

Friends, family, cycling and work I enjoy makes life with erythromelalgia (not to mention RA and ALS) quite tolerable. I'm not depressed (on the contrary I'm quite happy! Really), and I wouldn't change a thing. My life is good.

That's my story and I'm sticking to it!

Your Stories in the Media

by Gayla Kanaster

Erythromelalgia is not exactly a household word, but it's showing up in newspapers, magazines and on television, thanks to the efforts of some TEA members.

England's "Real People" magazine featured member Jayne Nicholl in May. The article ("I Had an Epidural for My Feet!") chronicled her challenges in dealing with EM since childhood, complete with photos. (Another story about the 27-year-old Londoner appeared last year in "Best" magazine.)

TEA President Beth Coimbra was featured in the *Wilmington News Journal*, Wilmington, Delaware, in January 2006. Titled "Rare Disorder Keeps Woman Off Her Feet," the story described Beth's first painful episode and how she continues to deal with EM and included a photo showing her red feet next to her sons' normal ones.

Meanwhile, the TV feature story about Dr. Pamela Costa aired several times in April, May and June as part of the Discovery Health channel's series "Medical Incredibles."

From the President

TEA Was There for Me; Let's Reach Out to Others

By Beth Coimbra

As I communicate to members for the first time as president of TEA, I would like to recognize Lennia Machen, president for the past seven years. Lennia is a founding member of TEA, which began in 1999 with six people. Today TEA has more than 500 members in 17 countries and Lennia has positively impacted most of those members in their struggle with EM. I hope that our organization continues to flourish with the help of everyone in this community.

In 1999, at age 35, my bout with EM began. Every evening my feet would mysteriously turn red and burn so I had to crawl around to prepare my children for bed.

My general practitioner treated me unsuccessfully for athlete's foot. He sent me to a dermatologist who recalled my symptoms described in an old medical textbook.

Armed with the term "erythromelalgia," I went online and found TEA. Lennia, then president of the newly formed organization, shared her treatment failures and successes.

I sought help from numerous specialists, including a vascular surgeon, rheumatoid arthritis physician, pain management specialist, dermatologist, acupuncturist and neurologist.

My symptoms worsened.

Some days I could barely stand. One such day, I was sitting with my feet elevated, playing with my young son. I was thinking how lucky I was to have his companionship and love.

I realized that without EM, I would not be limited to sitting on the sofa and would be busy performing household chores—not sitting with my precious son. There was a blessing to my painful syndrome! It caused me to slow down and enjoy the most important thing in my life—my family. From then on, I looked at my limited lifestyle differently, although there are days when the pain is severe and it is hard to put this problem into perspective.

I eventually found a cardiologist with a special interest

in my condition who has been able to stabilize my flaring and pooling of blood using a combination of medications. I still get flare-ups every day, but the symptoms are much more manageable.

Throughout this ordeal the members of TEA provided me with invaluable hope and information. Many others must be suffering alone and our intent is to reach those people to provide them with the support and information they need. Like me, so many of our members are thankful to talk with someone who understands their pain and distress.

I am proud to represent the individuals who started TEA. Their dedication to reach those affected by EM has inspired my commitment to carry on their mission.

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Research Update

Yale Researchers Report New Findings

Yale researchers in May reported that a single genetic mutation causes not only the pain of inherited EM but also the redness.

“We have now made important progress understanding the defect of vasomotor control, which causes the redness in EM. This was technically extremely challenging—we are one of the few labs anywhere in the world that can do this type of work—but our experiments succeeded, and have given us important new insights,” said Stephen G. Waxman, M.D., Ph.D., director of the West Haven Veterans Administration Rehabilitation Research Center and chair of the Department of Neurology at Yale University School of Medicine.

Published in the May 2006 *Proceedings of the National Academy of Sciences*, this study shows a single mutation can produce opposing effects depending on the nerve cells in which it operates, and thus can produce multiple symptoms. Researchers show the EM genetic mutation (that results in a defect in the sodium channel Nav 1.7) causes over-excitability in one type of neuron (nerve cell) and under-excitability in another type of neuron.

These neuroscientists previously demonstrated that the pain people with inherited EM experience is caused by this defective sodium ion channel. They proved it causes pain-signaling nerve cells to be over-excitabile, firing when they should not and causing pain.

Titled “A single sodium channel mutation produces hyper- or hypoexcitability in different types of neurons,” this new study proves that the same defective ion channel can also affect nerve cells that control blood flow, making them under-excitabile. This effect causes the redness in EM.

Identification of the precise role of mutant Nav 1.7 in pain sensing neurons as well as in neurons that control blood flow should enable the development of therapies to alleviate pain and inflammation in people with EM and related neuropathic disorders.

These results may also be relevant to non-

inherited pain syndromes because work at Yale and elsewhere has shown that the Nav 1.7 channel is also involved in acquired inflammatory pain.

Research Fund Donors

TEA thanks the people and organizations who made donations to the Research Fund in the six months from December 1, 2005 through May 31, 2006. Thank you all!

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U.K. Networking Program Coordinator Named

Networking Program members residing in Europe—especially those in the United Kingdom—now have a local coordinator.

Peter Rowland of Cleveland in the U.K. is now the person Networking Program members should contact for names and addresses of other program members in their areas.

Peter also is handling requests for copies of articles in TEA's Article Archive—a service for those unable to access the articles on the Internet. Judy Reese and Gayla Kanaster remain co-coordinators for U.S. and other international Networking Program members.

Retired after working 33 years as a steelworker for British Steel (now Corus), Peter has had EM for about 25 years. He recently had a spinal cord stimulator surgically implanted to control his pain.

Networking members give TEA permission to share their contact information with other TEA members who live near them and are part of the program.

You can reach Peter by writing to him at PeterJRowland@msn.com or at 1 Wilton Village, Redcar, Cleveland TS10 4QX UK; or calling his home phone: 01642 468091 or mobil phone: 07900 828667.

Teleconference Recordings Available

Either a 100MB downloadable version or a two-CD set recording of the May 20 teleconference “Dr. Cohen on EM” is now available to all TEA members through Judy Reese, Networking Program co-coordinator. For \$20, the downloadable version can be played directly or burned onto audio CDs.

The two-CD set costs \$22.50 U.S.; \$25 international (shipping and handling included). Circle “downloadable” or “two-CD set” in this article; make sure your address information is correct on the other half of this page. (Add your e-mail address if you're buying the downloadable version.) Enclose this page of *FootSteps* with your check made payable to TEA and mail to Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, Utah USA 84117.