

FootSteps

The newsletter for members of The Erythromelalgia Association
FootSteps online: www.erythromelalgia.org or www.burningfeet.org

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Mayo pain relief gel now creamy

The topical gel for EM pain relief now is made as a cream, a Mayo Clinic pharmacist announced this spring. The 2% amitriptyline, 0.5% ketamine preparation is now compounded in a Lipoderm base, says Roger Warndahl, R.Ph., senior pharmacist at the Mayo Clinic's compounding pharmacy.

The change was made when recent studies showed the Lipoderm cream base absorbs more quickly into skin and actually helps the drugs penetrate the skin better. The new topical also has the cosmetic advantage of a creamier, non-oily feel. "Breathability should be better with the Lipoderm since you don't have the petrolatum base to deal with," Warndahl says.

"At Mayo we've adopted a starting base combination of amitriptyline 2%, ketamine 0.5% in Lipoderm. We do, at times, add into that one of the following: gabapentin 5%, lidocaine 5% or clonidine 0.2%, depending on what the prescribers wish," Warndahl says. (Note: This cream has to be prescribed by a doctor and prepared in a compounding pharmacy where pharmacists mix the ingredients by hand.) The original EM pain-relieving, oil-based gel was developed for EM at Mayo under the direction of Mark Davis, M.D., and Paola Sandroni, M.D. Dr. Davis says he prescribes the cream for his EM patients. If the pain-relieving effect is not strong enough, he may increase the ketamine up to 5%. Prescribing physicians have to specify the drugs and the base of the cream for the compounding pharmacy. Any compounding pharmacy in the patient's region can fill the prescription. *(Deborah Mosarski contributed to this story)*



The Erythromelalgia
Association

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TEA member Lauren Chapman touches the ice during the break between periods at a high school ice hockey game last winter. Playing helps her forget her EM pain. (Photos by Kyle Austin, Ann Arbor News) See PG 5 for full story.

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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.

TEA improves online directory

Check TEA's website for changes to the Member Directory—TEA's list of members and friends who have chosen to be listed for other TEA members to see. After you log in and click on "member directory," notice that you can now easily sort names by city or state. This feature helps those interested in finding other people in or near their hometowns.

While you're in the directory, check your listing. Need updating? Go back to "Home," and click on "Manage Account" (left of "Log Out.") Then click on "Edit Profile" in the blue font at the top of the page. That takes you to the "Manage Profile" page. First, please answer the new questions about whether you have EM symptoms or were diagnosed with EM or know someone who was. If you have EM, please select the age when your symptoms began and into what age group you fall. Last, click "Update" to save your information.

Gathering this new information will help TEA assist EM researchers who want to know numbers and ages of people with EM, diagnosed or not. TEA never releases names, addresses, or any personal information about members. While you are online, please also update your address, e-mail, phone number and don't forget to tell TEA if you want to appear in the online directory and what information to list. Remember, only members have access to the online directory. Be assured TEA holds confidential any personal information.

In Memoriam

William Fisher

Condolences to the friends and family of William Fisher of Denver, CO, USA, who died in April 2014. Bill served in the United States Navy in the 1950s and worked for United Air Lines for many years as an airline mechanic and a specialist in safety and training. An outdoors enthusiast, he cycled the Rocky Mountains, going for 20 to 30 mile rides and cycling in charity events. He is survived by Iris, his wife of 62 years, and a large extended family.

Janis Eisler

TEA is also saddened by the loss of Janis Eisler of Toledo, Ohio, USA, who died suddenly in January 2014. Janis had EM for a number of years. She was a longtime member of TEA and an active participant in the EM Yahoo group. Janis worked virtually full time as a volunteer for David's House, an organization that provides assistance to persons with AIDS. She also was a skilled craftsman who enjoying giving her work to others.

New Zealand study: EM underdiagnosed

By Elisabeth Antoine

In the 2013 article “Erythromelalgia? A Clinical Study of People Who Experience Red, Hot, Painful Feet in the Community,” researchers in Dunedin, New Zealand, propose that the incidence of EM may be greater than commonly accepted.

The study recruited 92 individuals in the Dunedin area who suffered from the typical symptoms of EM: red, hot, painful feet that are made worse by heat and improved by cooling. The goal was to better characterize this population and measure their quality of life. There was a 3:1 ratio of females to males, with an average age of 61.

Each participant was given the Medical Outcomes Study Short Form 36 Questionnaire (SF-36) and the Otago Condition Specific Questionnaire (OCSQ) to assess pain, discomfort, difficulty coping, perceived appearance, and fear, as well as impact on work, home life, relationships, mood, and leisure activities. Scores were then compared with those of the general New Zealand population. It was determined that the people in the EM study had a worse quality of life, as their scores were significantly lower in most categories.

Of these 92 individuals, 56 completed a face-to-face assessment with the study’s lead author. In this clinical evaluation, 24 (42%) showed strong evidence of EM. This diagnosis was made based on a clear history of erythema (redness), heat, and pain/discomfort of the extremities, made worse with heat and/or limb dependency and better with cooling. Most had only mild to moderate symptoms.

Forty-two participants (75%) had sought help from their primary care doctor, and 20 (36%) had consulted at least one specialist. Many commented that their doctors did not know what to make of their symptoms. Only 15 patients (27%) had received a diagnosis despite seeking help, and in only 9 cases (16%) was this diagnosis EM. (Other diagnoses included peripheral neuropathy, Raynaud’s syndrome, rheumatoid arthritis, restless legs syndrome, and peripheral nerve damage.) Thirty-four (61%) had tried medications to relieve their symptoms, the most common ones being amitriptyline, gabapentin, and paracetamol.

Eighteen participants (32%) reported having a first degree relative with similar symptoms. This figure is much higher than previous studies, which have reported an average of 7%, though the reason for this is unclear.



Based on the 42% who demonstrated strong evidence of having EM, it was estimated that the prevalence of EM in the Dunedin community is 15/100,000. A previous study by the Mayo Clinic in Olmsted County, Minnesota, reported a much lower 1.3/100,000. The discrepancy can perhaps be explained by the fact that the participants in the Mayo Clinic study were referred EM patients; it therefore did not take into account those who had symptoms but no diagnosis. The Dunedin study, on the other hand, aimed to recruit participants based on self-identified symptoms of red, hot, painful feet, rather than a current diagnosis of EM.

It is a significant finding that, while 42% of participants showed strong clinical evidence of EM symptoms, only 16% had previously received a diagnosis as such. These results suggest that the incidence of EM may be much greater than commonly accepted and that the majority of cases may go unrecognized. The assessment made it clear that many people had not received acknowledgment from the medical community. These individuals were surprised and pleased to learn that there might be a name for their condition and that there were others who also suffered from it. Researchers conclude that it is important for this population—those with red, hot, painful feet—to be better recognized, through raising awareness and understanding of EM.

The study was conducted by D. Friberg, T. Chen, G. Tarr, and A. van Rij at the Department of Surgical Sciences, Otago Medical School Dunedin, University of Otago, Dunedin, New Zealand. The full article, “Erythromelalgia? A Clinical Study of People Who Experience Red, Hot, Painful Feet in the Community,” is in TEA’s online archive.

Your stories: everyone has one

Everyone can empathize with those who have experienced difficulties 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.



*Ed Dunlop
Buffalo, NY, USA*

Like others I stumbled into EM by having surgery. In 2005, I had big-toe-joint surgery and right after that my foot

was on fire, bright red, ached and was swollen. The surgeon assured me all these symptoms would go away. They never did. After seeing dozens of specialists, one insisted I go to Cleveland Clinic where here I was told I had small fiber neuropathy and possibly EM. After two more toe operations, my foot was officially the hottest part of my body. Meanwhile, as with other EMers, my spouse continued taking over more of the responsibilities around the house and keeping my spirits up.

Through TEA I became aware of a neurologist at Yale University, who confirmed that I had EM. My GP arranged for me to be a part of the dermatology grand rounds at the University of Buffalo, one of five rare cases. Over 50 dermatologists looked at my foot and most had never seen EM and were somewhat stunned. I believe their exposure to EM benefitted our organization and EM recognition. I've tried over 40 different prescription drugs including methadone, and also a spinal stimulator, green light therapy, pain hypnosis, acupuncture and now iridology. The focus of the latter is to change my eating habits dramatically. I'm still working on that!

Dr. Kalb, a University at Buffalo dermatologist, told me I have a very rare case of EM. He suggested I look around for a research hospital. Meanwhile, belonging to a pain support group keeps me going. By accident I found out about using an Aircast canister that holds cool water and ice that circulates through a foot cyrocuff around each of my feet. It cools my feet just enough so that I can fall asleep. Before this I just used cool water, which

led to several ulcers. Our dogs are great at distracting me from the pain. We are active in the Bichon Rescue Society. I think it would be beneficial for EMers in the same area to plan get-togethers to share experiences, which I hope to do soon. To find people who live near you, sort the Member Directory by city or state.



*Elaine Sturton
Lincolnshire, UK*

After years of seeing many specialists and the frustration of having to live with debilitating conditions,

I finally was diagnosed with erythromelalgia and severe Raynaud's syndrome. I started having iloprost infusions at Kings College London to help with both conditions. I have since been transferred to The Royal Free in Hampstead and I now have ongoing three monthly infusions for a five-day course. It has effectively changed my life.

I had been put on nifedipine by my GP for the Raynaud's; levothyroxine for underactive thyroid; duloxetine, prednisolone, amitriptyline, ibuprofen, B12, and paracetamol following acute autoimmune encephalitis in 2007. I now take losartan and hydroxychloroquine, which help with both chilblains and my skin problems. Dermax shampoo, Hydromol Intensive and Double Barrier gel are great for my very dry, cracked skin. Also E45.

Now with the treatments and understanding of my conditions, I can plan my days, what I'll be doing and where I'm going. With preplanning, I am now able to appear to lead a normal life.

It takes some effort and determination. I avoid certain fabrics and always *(continued on PG 5)*

Go to Mayo with Lauren: video documents EM evaluation

High school senior Lauren Chapman wanted to document her visit to the Mayo Clinic in November 2013. So she captured it on camera as it happened. Referred to Mayo's Mark Davis, M.D., by the doctor who diagnosed her EM, Lauren gives the viewer an inside look at the weeklong series of tests used at Mayo to evaluate EM. Lauren is a "natural" on camera describing her thoughts and feelings. From the anticipation of going to the esteemed medical center in Rochester, Minn., USA, through her appointments with Dr. Davis and the series of diagnostic tests, Lauren takes us through the steps. In reality TV style, she tells the camera what's happening and then narrates while the camera focuses on her undergoing the tests.



Lauren and her mother relax at home.

Lauren first felt the EM sensations when she was 10 during ice hockey practice. When she took off her skates, her feet were bright red. At first, the flares were infrequent but happened most often during and after exercise. Despite the burning, she kept on playing ice hockey and has been on the Pioneer High School's women's ice hockey team for three years. As a senior at this Ann Arbor, Mich. school, she is one of the team's fastest forwards with a "sniper" slapshot. It was while at a hospital being treated for a concussion suffered on the ice that a doctor actually saw her during a flare. The physician and his colleagues had never seen an EM flare before, but referred her to a rheumatologist. He looked up the symptoms, told Lauren about EM and sent her to Mayo.



Lauren Chapman applies compounded ketamine cream to help manage EM pain before hockey practice.

"I feel normal when I'm on the ice," she says. Back on the bench, the pain is there. On or off the ice, she experiences 50 to 70 flares a day and the heat, redness and pain seem to move from one part of her body to another. "It's like an internal third-degree burn every day," she says. "It's excruciating pain. It travels up my leg and feels like I'm being burned by an iron. None of the drugs has helped, not antidepressants, not over-the-counter pain meds, not Neurontin, not Lyrica, not anything. She's coped by moving her bedroom to the basement, using fans constantly, splashing cold water on her hands and face in the bathroom at school. After she released her video, she watched as classmates, teammates and friends saw for the first time what she's been living with for years.

She's planning on attending her local community college next year. And she'll keep competing on the ice in a AAA women's league in the Detroit area. But her passion now is to raise awareness about EM. It felt so good to finally tell her story that she's planning a senior project on the subject, thinking of speaking to community groups. Based on her first documentary, she's a natural for the job.

Watch Lauren's video on YouTube: <http://tinyurl.com/oz337sv>

Your stories *(continued from PG 4)*

layer my clothes so that I can quickly remove or add a layer. When I'm out, I look for an air-conditioned building to find relief. The Raynaud's and EM affect all my extremities, together with my nose, cheeks and ears, which can make life a bit rough some days. The constant pain is still there from the time I wake up until I go to bed. Together, the infusions and medications have enabled me to once again walk, go out and lead a relatively normal life. Life is for the living, they say, but it can throw spanners in the works for all of us. At age 58 I will keep trying to live my life as best and as cheerfully as I can, even though it can be a real struggle at times.

Faithful donors give to 2013 Annual Appeal

TEA thanks our generous members, family members and friends who gave generously again to our just once-a-year annual appeal. They are recognized below, listed by TEA's giving categories: Patron (\$500 and up); Benefactor (\$250 to \$499); Sponsor (\$100 to 249); Supporter (\$50 to \$99) and additional donors. (See PG 8.)

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Report from the Treasurer *By Beth Coimbra*

One important goal of a small nonprofit organization like TEA is to enable its existence for several years in the future. In other words, the organization needs to ensure that it has the funds to continue basic operations that carry out the stated mission. In the last few years, TEA has been able to grow the Operating Fund to approximately \$95,000, which would pay for normal operating expenses at current levels for several years to come and provides a reserve to fund new projects. This achievement occurred due to the generous giving of TEA members through membership renewal donations with additional general donations. The Operating Fund also gets a great boost each year with the generous contributions from the TEA family of members and friends during the Annual Appeal.

In 2012, TEA depleted the Research Fund with a \$40,000 gift to Yale's EM Research Team, but has begun to replenish the fund through contributions that are restricted by the donors to be used for supporting research only. The Research Fund currently has a balance of about \$16,000.

Painless fundraising: donate to TEA online *By Gayla Kanaster*

Asking family and friends to make donations to TEA can be awkward. Even when they mention other charities they support, it's sometimes hard to ask them to also donate to one that helps us. However, there is an easy way that won't cost them an extra penny: Goodsearch and Goodshop. We (and they) can support TEA by just doing the things you may already do, such as searching the Internet and shopping online.

I confess, I forgot about using Goodsearch.com and Goodshop.com. I could have been earning money for TEA every time I googled George Clooney and other important information. I'm now back to earning a penny for TEA each time I use this Yahoo-powered search engine. It doesn't sound like much, but if just 100 members averaged two searches a day, TEA would earn approximately \$730 a year. And we have about 1,000 members!

Even higher donations can be earned through Goodshop.com, an online shopping mall with 2,800 par-

ticipating stores, including Amazon.com, Barnes & Noble, Ebay, Home Depot, Macy's and many more. Using it does not cost you a thing. You can also enroll in the Gooddining program. Choose from over 10,000 restaurants nationwide and earn up to 6 percent of every dollar spent on the meal as a TEA donation. Plus, you can find more than 100,000 coupons on the site. It's been six years since TEA signed up to be a part of the Goodsearch/Goodshop fundraising program. Perhaps some of you forgot like I did. So, this is a reminder to you and easy sign-up directions for those who recently joined TEA.

Go to www.Goodsearch.com, click on "Who do you Goodsearch for?" Then enter "Erythromelalgia Association." You only have to enter that once. It will appear from then on with each new search, plus the total TEA donations so far. You can click on Goodshop here or go directly to www.Goodshop.com. Believe me, from now on I'll be using it.

Grand rounds: raising doctors' EM awareness *By Laura Beaton*

Anyone with EM knows that getting diagnosed can be a years-long ordeal, and finding a treatment that helps can take even longer. So, it is no wonder that most of us would not be very enthusiastic about adding yet another doctor's appointment to our schedule. This is exactly how I felt when my dermatologist asked me if I would be interested in attending dermatology grand rounds at the local academic medical center. But I am glad I went. "Grand rounds" is the term for a regular conference of doctors, where they learn about the latest important issues in their field and rare or unusual cases, and put their heads together to try to figure out difficult cases. Part of this involves bringing in patients to be examined by the doctors.

My experience meant spending a morning in an exam room at the medical center. Before they came to see me, my doctor presented my case to the other doctors. Then, around 40 doctors – residents, attending physicians, and private practice doctors – came into the exam room in small groups to look at me, look at photos of my hands and feet flaring, and ask me questions about my EM and what it's like to live with it. The whole process took about two hours.

After I left, the doctors had a discussion about my case and what treatments might be helpful, especially for my facial EM, which is the most troublesome aspect of my EM. A few days later, my doctor called me to tell me about the discussion and give me some new treatment ideas. Happily, one of the suggestions proved helpful, and my facial EM is much milder than it used to be. I provided a large group of doctors, including students and younger doctors, with a chance to see and learn about EM from someone with EM. With many doctors going their whole career without seeing EM, I feel it is important to raise awareness of this condition when possible. Seeing it in person once can lead a doctor to making the right diagnosis for someone else in the future.

Editor's Note: Laura is a member of TEA's Board of Directors.



The Erythromelalgia Association

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*Raising Awareness.
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FootSteps

Annual Appeal raises \$22,996

Thanks to our generous donors, TEA's 2013 Annual Appeal raised \$22,996 as of May 10, 2014. TEA sends just one appeal for funds each year in December. In recognition of those who support our organization on an ongoing basis, TEA designates several giving levels—Patron, Benefactor, Sponsor and Supporter. We were fortunate to receive gifts from 10 Patrons (\$500 and up), 8 Benefactors (\$250 to \$499), 44 Sponsors (\$100 to \$249), 54 Supporters (\$50 to \$99) and an additional 57 donors. See p. 6 for names of those who gave.

What makes the Annual Appeal so important is that funds received—unless designated for the Research Fund—will pay a majority of 2014's expenses and ensure basic operations continue for several years in the future. Donations are used to pay website expenses, postage, newsletter and other printing, etc.