

# FootSteps

The newsletter for members of The Erythromelalgia Association  
FootSteps online: [erythromelalgia.org](http://erythromelalgia.org) or [burningfeet.org](http://burningfeet.org)

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## TEA makes awareness video

TEA is producing a three-minute video to raise the general public's awareness of erythromelalgia, which is often not recognized by physicians or is misdiagnosed. The video also is intended to make more people aware of TEA's comprehensive website as the prime resource for those seeking accurate information about EM. The organization contracted with a video production company to ensure the result is professional and effective.

Explaining TEA's mission—empowering those with EM to improve their lives—is another goal of the video. President Beth Coimbra lets viewers know that since its founding in 1999, TEA has sought to empower those with EM by making accurate information about EM readily available. Because EM is frequently not recognized by physicians, those with EM often consult a number of different doctors seeking answers. TEA Vice President Isabelle Davis adds on camera that TEA's comprehensive website—[burningfeet.org](http://burningfeet.org)—is a powerful resource TEA offers. Easy to navigate, the site has answers to frequently asked questions, a full text copy of *A Patient's Guide to Erythromelalgia*, TEA's thorough guidebook to EM, a library of more than 100 medical journal articles and news media feature stories about EM, a doctor directory and much more.

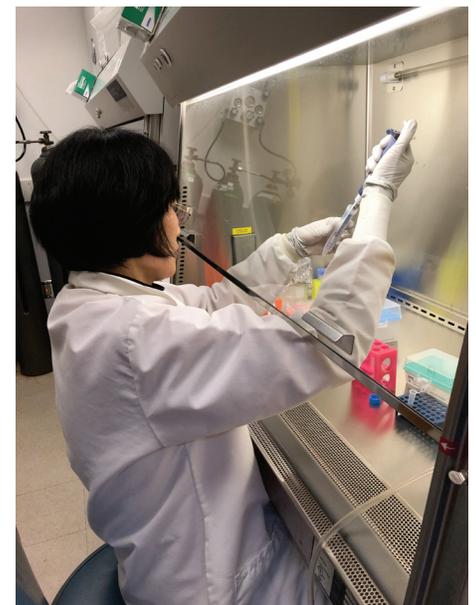
Filmed at the Center for Neuroscience and Regeneration Research at Yale, the video features EM researcher Stephen Waxman, M.D., Ph.D., director of the center, describing EM's symptoms and the differences among people with EM. Only about five percent of people with EM have the inherited form, which is a chronic pain syndrome and the focus of Yale's research. Most people with EM have the symptoms as a result of other diseases or for no apparent reason, Dr. Waxman explains. Inherited EM is caused by a genetic mutation and continues to be a "model" disease used by pain researchers worldwide in their search for an effective medication for neuropathic pain. When research leads to a drug that relieves the pain of EM, the same substance should help other kinds of chronic pain like diabetic neuropathy and shingles, he says.

It is fitting that the video was filmed at this research center at Yale. Using blood samples donated by TEA members, researchers about 15 years ago identified mutations to the EM gene and then proved that the mutations caused the pain of inherited EM.

When completed the video will be placed on TEA's website and Facebook page and sent to other pages whose subject is EM.



Yale research director Stephen G. Waxman, M.D., Ph.D. being filmed for TEA video.



Cell biologist Peng Zhao, Ph.D., prepares EM pain-signaling neurons for detailed analysis of their firing patterns.

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is published by



## The Erythromelalgia Association

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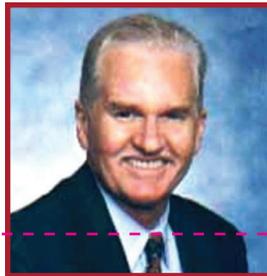
The intent and purpose of this publication is to inform those with EM or their friends and families—not, in any way, to provide medical advice.

## Angela Demerle joins board

Retired lawyer Angela Demerle recently joined TEA's Board of Directors. She lives in Buffalo, New York, with her husband Edward, who has dealt with EM since 2005. They have a daughter, Jessica, and three Bichon Frise, one of which is an active therapy dog. Angela and Ed have volunteered for TEA for several years, responding to messages left on the memberservices phone line. Raised in Buffalo, she practiced Public Utility and Environmental Law in West Virginia, Texas and New York for more than thirty years. She earned a B.A. in English Literature from SUNY at Buffalo, a M.L.S. from the University of Pittsburgh and a J.D. from West Virginia School of Law.



## Your stories: everyone has one



*Amberson McCulloch  
Port Ludlow, WA, USA*

About eight years ago I began to notice my feet were hot and tingling when I took off my shoes after playing tennis. These sensations steadily got worse over the course of a couple of years and I started having to soak my feet in cold water before going to bed and again in the middle of the night in order to sleep. The condition continued to worsen gradually. At that point I went to see the first of four neurologists I sought help from during the following years. The first diagnosed peripheral neuropathy and prescribed Lyrica, which initially helped a bit. The severity of the disease continued to worsen to the point where I needed to cool my feet with ice packs or stand in cold water every couple of hours. I became very depressed as my symptoms continued to get more severe. I tried everything in order to get relief—massage, acupuncture, marijuana, Chinese herbs, numerous oils that I rubbed on my feet, etc., etc. The only thing that provided immediate help was cold water, ice packs, or a cooling fan. The disease was finally diagnosed correctly as erythromelalgia, but no effective treatment was forthcoming. I was pretty much confined to the house to be close to cold water or my ice packs.

Four months ago I went back onto the TEA website where I had been before looking for new treatments. Noodling around on the site I noticed a link to a couple of support group Facebook pages and went to the "Fight Fire with Fire" Facebook page. That is where I read about Bob's Protocol. The protocol is simply to soak your feet in hot water for a half hour per night and stop using ALL cooling devices. Four months into the protocol I'm 90% better; not cured, but I have my life back! No guarantees on the hot water protocol, but it's DEFINITELY worth a week's trial. Google Bob's protocol for testimonials and feel free to contact me at [ambersonmacculloch@gmail.com](mailto:ambersonmacculloch@gmail.com) for further information.



## Yale researchers find pain tolerance genes

Among many other findings, researchers at Yale recently showed that the frequency and severity of pain attacks in people with inherited EM can vary considerably. Even among members of the same family carrying the same genetic mutation some suffer significant pain between attacks while others are relatively pain free.

In 2018, TEA donated \$75,000 to Yale researchers studying inherited EM and related pain disorders. Yale’s work focuses on inherited EM, which is now viewed by pain researchers worldwide as a human genetic model of chronic pain. Using TEA’s donation, the researchers at the Yale Neuroscience and Regeneration Research Center homed in on what makes one person able to tolerate pain better than another and tracked down genes that make pain more tolerable. Tapping into the database of EM families, they studied a mother and son pair—both with the same genetic mutation but with markedly different pain experiences. They showed for the first time that it is possible to pinpoint genes that are responsible for individual differences in pain (Mis et al., 2018). This study identified a “pain resilience gene” that acts like a brake, slowing down the firing of pain-signaling neurons.

“TEA funds have, indeed, been immensely helpful” in carrying out this research, said Stephen G. Waxman, M.D., Ph.D., director of the research center. “Private dollars (like those from TEA) give us stability, allow us to move more rapidly, and give us the flexibility to try new things.”

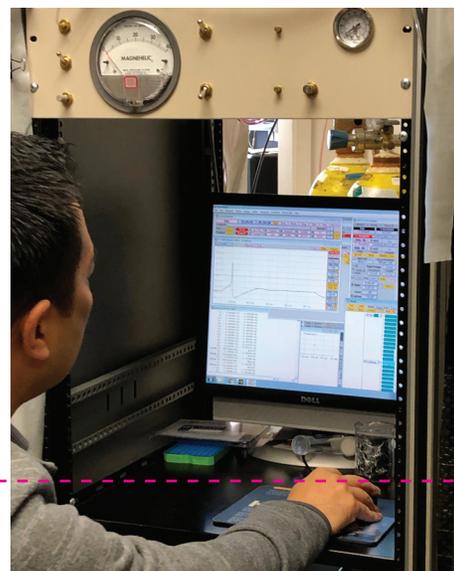
Researchers at the center are now extending their efforts to identify additional genes responsible for pain tolerance. Each additional gene identified represents a potential new therapeutic target. The power of stem cell technology combined with next-generation genome sequencing is making it possible to move closer than ever to better treatments for pain in people with EM.

In 2004, TEA began supporting research into inherited EM at this center with a gift of \$60,000 when this research group was the first to link mutations to a single gene with the pain of inherited EM. Before that TEA helped the scientists collect blood samples from members with inherited EM and their family members. Analyzing blood cells showed genetic mutations that made pain-sensing nerve cells hyper-excitable, firing off pain signals when they should not. Next the researchers proved that these mutations caused the pain of inherited EM. Study results were published in 2005. (See Medical Articles on TEA’s website [erythromelalgia.org](http://erythromelalgia.org).)

Reference: Mis MA, Yang Y, Tanaka BS, Gomis-Perez C, Liu S, Dib-Hajj F, Adi T, Garcia-Milian R, Schulman BR, Dib-Hajj SD, Waxman SG. Resilience to Pain: A Peripheral Component Identified Using Induced Pluripotent Stem Cells and Dynamic Clamp. *J Neurosci*. 2019 Jan 16;39(3):382-392. doi: 10.1523/JNEUROSCI.2433-18.2018. Epub 2018 Nov 20.



Molecular Biology Research Specialist Daniel Sosniak, Ph.D., at work in Yale lab.



Electrophysiologist Brian Tanaka, Ph.D., analyzes data collected from pain-signaling neurons that carry EM mutations.



Molecular Biology research Specialist Fadia Dib-Hajj, Ph.D. at work in Yale Lab.



## The Erythromelalgia Association

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Or donate using a check and  
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Share your story about how EM has  
affected your life. Send a head shot  
and your story (350 words or less) to  
[memberservices@burningfeet.org](mailto:memberservices@burningfeet.org) or mail to  
200 Old Castle Lane, Wallingford, PA, 19086.



# TEA FootSteps

## Wanted: volunteers to help TEA

TEA depends on volunteers to make its services happen—from providing accurate information about EM by phone in response to memberservices phone line questions to mailing new member packets. And more volunteers are needed.

What do you need to bring to the table? Caring about those affected by EM and a willingness to learn whatever the volunteer job requires.

**Interested?** Please send an email to [memberservices@burningfeet.org](mailto:memberservices@burningfeet.org) with the subject Volunteer and let us know you would like to discuss volunteer opportunities further.

**Raising Awareness.**

**Raising Research Funds.**

**Raising Hope.**

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20  
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