



The Erythromelalgia
Association

Your EM Connection

TEA's Online Newsletter

First Edition, November 17, 2022



Welcome to TEA's online newsletter 1.0: 'Your EM Connection'

'Your EM Connection' replaces TEA's Footsteps newsletter which was first sent hardcopy to TEA member homes for many years. As time went by, more and more members opted to view the newsletter online and asked TEA to stop sending the hardcopies. This trend can be seen across industries with a huge reduction in printing and mailing costs not to mention carbon footprint.

TEA decided to join the majority of nonprofits in the trend of going completely digital with communications this year and converted to using Mailjet as our platform for mass emails and distribution of our newsletter.

TEA changed the name of the newsletter to be sure that all with EM are represented whether their symptoms are in their feet, hands and/or face. The new name allows all with EM to feel included and enhance our sense of community.

TEA hopes to be able to have more frequent touchpoints with TEA members going forward using this platform.

Please see below for this edition's articles.



EM Research: Behind the Scenes an interview with Dr. Stephen Waxman

On July 21, 2022, TEA held an informational webinar with Dr. Stephen G. Waxman, MD, PhD, and Professor of Neurology, Neurobiology and Pharmacology at Yale University, who has led an international coalition that identified sodium channel mutations as causes of peripheral neuropathy, one of the conditions of erythromelalgia (“EM”).

Dr. Waxman works with a talented team of 35 scientists at the Yale Research Center on one unified goal: to capitalize on the current molecular revolution to develop gene therapies with respect to neuropathic pain. Specifically, the Yale team is working on sodium channel NAV 1.7, which is now known to be a master switch for nerve pain, working like a volume knob. Mutations of NAV 1.7 make it overactive in sufferers of EM. Even without mutations, NAV 1.7 is a controller of nerve pain, so is applicable to all those with this type of pain.

Dr. Waxman disclosed in the interview that his research facility (along with the National Institute of Health “NIH”, and other research centers around the world) has just received a grant to research whether NAV 1.7 can be edited to alter this master switch on pain.

When asked about the seemingly slow pace of research, Dr. Waxman said he felt his research, (which is done outside the more challenging pharmaceutical industry framework) is moving along more quickly than research on other more well-known disorders. Moreover, pain research is attracting more interest in the research community. As a result, there are multiple studies looking at neuropathic pain from different angles—a multi-faceted attack on the problem.

In conclusion, webinar participants heard the good news from Dr. Waxman that there is realistic hope for new and successful treatments for EM---it is just a matter of time.

TEA has contributed to Dr. Waxman’s ongoing research related to erythromelalgia when fiscally able over the last twenty years. Another donation is scheduled before the end of

2022. The webinar can be viewed on TEA's recently established youtube account: [Dr. Waxman Interview](#)

Please go to our website: <https://erythromelalgia.org/> and click Donate on top menu to support our Research Fund.



TEA Launches Zoom Meet Ups for Members

TEA launched its first TEA Zoom Meet Up in February 2022! The Zoom Meet Up provides those with EM with a monthly dose of valuable information, community and fun! Each meeting features a monthly topic, such as pain management, homeopathy, footwear and research insights. The meetings often wrap up by sharing updates and helping those in need.

An immense amount of sharing takes place during each Zoom. Many participants have said that it's a great relief to finally connect with other people who truly understand what EM feels like and the struggles associated with trying to manage the symptoms and pain. They feel grateful knowing they are not alone and thus, there is a growing sense of family.

The idea for the TEA Zoom Meet Up originated in the EM Google Group, an EM online support group. One of the group's members, PK Agarwal, has provided leadership for the TEA Zoom Meet Up group by overseeing the program in collaboration with TEA, including coordinating and moderating the meetings. PK kicks off the meetings by sharing the agenda, any TEA or community updates, and a meaningful quote or two. The Meet Ups last about 90 minutes and are scheduled on the third Saturday of the month. Future plans include guest speakers.

TEA leadership has been extremely supportive of this Zoom Meet Up initiative. Beth Coimbra, TEA president, was instrumental in launching the program by extending invitations to the EM Google Group members, as well as all of TEA's West Coast members and by generously providing TEA's Zoom Account for the Meet Ups.

On average, 20 people attend monthly, from with invitations sent to a growing portion of the US and Canada as time passes. There has been international (Israel) participants, too.

If numbers warrant, a second TEA Zoom Meet Up group will be created.

If you are interested in joining this Meet-Up, please contact PK Agarwal at pk.agarwal3@gmail.com.