



The Erythromelalgia  
Association

# Your EM Connection

*TEA's Online Newsletter*

**- February 2024 -**

## **Dedicated TEA Vice-President Retires from TEA Board:**



With profound gratitude, TEA announces the retirement of our esteemed Board Member, Isabelle Davis, TEA Vice-President, effective January 1, 2024.

Isabelle joined the Board over twenty years ago, bringing with her an extensive background in academic medicine, public relations, writing skills and a wealth of life experience. Isabelle played a pivotal role in guiding the organization for many years; her significant contributions helped shape TEA into the vibrant entity it is today. Notably, Isabelle served as the writer and editor for TEA's publications, including *Footsteps*, the hard-copy newsletter, which has since transitioned to the online newsletter, *Your EM Connection*. Isabelle's guidance and expertise will be greatly missed, not only by the TEA Board of Directors, but also by the entire EM Community.

## **Pharmaceutical Research Initiatives** **for Erythromelalgia:**



TEA volunteers are often asked if there are companies working on potential EM Treatments. Currently, there are at least four such efforts:.

Note: Copy and paste the links below into your browser of choice.

**Winsantor** – is using atropine and pirenzepine (antimuscarinic drugs) which are already approved by the FDA to regenerate peripheral nerves. They are preparing to start their Phase 3 global study for diabetic peripheral neuropathy. <https://winsantor.com>

**AlgoTX** – is developing a topical amitriptyline. Phase 2 clinical development in chemotherapy-induced peripheral neuropathy, (the “ACT” study), is in progress in the US and Europe. In addition, a Phase 2 study of ATX01 in EM is under way in the US and Germany. <https://algotx.com>

**Adolore** – is developing a disease-modifying next generation non-opioid analgesic gene therapy for pain. <https://adolore.com>

**Axion Biosystems** – is using pharmacogenomics to study how genes affect a person's response to drugs. Their website mentions “Most patients with Inherited Erythromelalgia (IEM) are resistant to pharmacotherapy thus their pain cannot be relieved by common pain killers.” A major research goal is to figure out how to use a precision medicine approach to treat these patients based on their genetic background. <https://axionbiosystems.com>

Three of these companies have given presentations to TEA’s ZOOM Meet-Up, a ZOOM meeting for EM sufferers, meeting on the 3rd Saturday of the month. If you are interested in joining this ZOOM group, where you can access this type of valuable information and meet other EM sufferers, contact [pk.agarwal3@gmail.com](mailto:pk.agarwal3@gmail.com), who leads this Group.

## Member Stories for TEA Newsletter

Do you have a unique story about your life with EM to share with other EM sufferers? TEA is looking for member stories to publish in its online Newsletter, *Your EM Connection*. Here is a suggested outline for those considering a submission.



Tell us:

- Your first name, age and area of US (or overseas country) where you live.
- Describe your EM, when it began and how it was diagnosed.
- In 500 words or less, tell us your story that will be of interest to other EM sufferers.

Please e-mail your story to [erythromelalgia.assoc@gmail.com](mailto:erythromelalgia.assoc@gmail.com).