
The Erythromelalgia Association
Your EM Connection
TEA's Online Newsletter

March 2025

Attune Neurosciences Research Study to Treat Chronic Pain

Attune Neurosciences, Inc. has announced an exciting research study focused on evaluating a non-surgical, non-drug, wearable therapy using Low Intensity Focused Ultrasound Stimulation (LIFUS) to help alleviate chronic pain.

LIFUS is a non-invasive brain stimulation technique that uses sound waves, similar to those in prenatal ultrasound imaging, to target activity in the deep brain regions.

This precision technique aims to alter brain activity associated with pain without affecting surrounding tissues, potentially offering a breakthrough treatment for chronic pain sufferers.

Key Details of the Research Study:

Objective:

To evaluate the effectiveness of LIFUS in a novel wearable device, designed for both in-clinic and at-home use to reduce pain.

Eligibility:

- Adults aged 22 to 80 experiencing chronic pain persisting for at least 3 months.
- Must be able to undergo a brain MRI.
- Must be available to travel to San Francisco for study participation.

Location:

- The study will be conducted at Attune's office in Mission Bay, San Francisco, CA.

Visit Details:

- The study involves 4 required visits, each less than 2 hours long.
- Visits are scheduled at least a week apart.
- There are optional additional visits available.
- Attune provides flexible scheduling options, including weekends and outside standard work hours to accommodate participants.

Compensation:

compensation.

- Participants will receive $50 per visit.

NOTE: PLEASE ZOOM-IN TO ENLARGE FLIER BELOW.

This innovative study leverages the precision of FUS technology and builds on its application in various other medical conditions. Attune invites participants interested in this new approach to learn more and join the initiative, emphasizing the potential to contribute to the advancement of effective chronic pain treatments.

For those interested in participating or seeking further

information, please click on the link below.

www.attuneneuro.com

Note: TEA is only announcing the study but is not involved nor provides support for it.

Boston Children's Hospital Releases Results of Literature Study

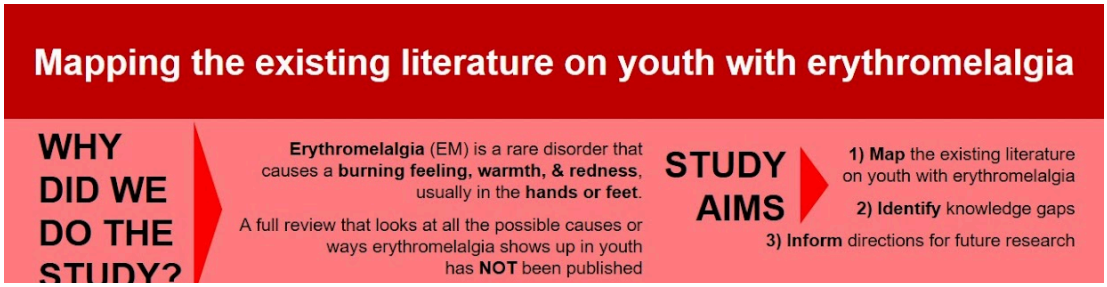
Boston Children's Hospital (BCH) conducted a study to examine existing research on erythromelalgia (EM) in children, aiming to map the available literature and identify knowledge gaps.

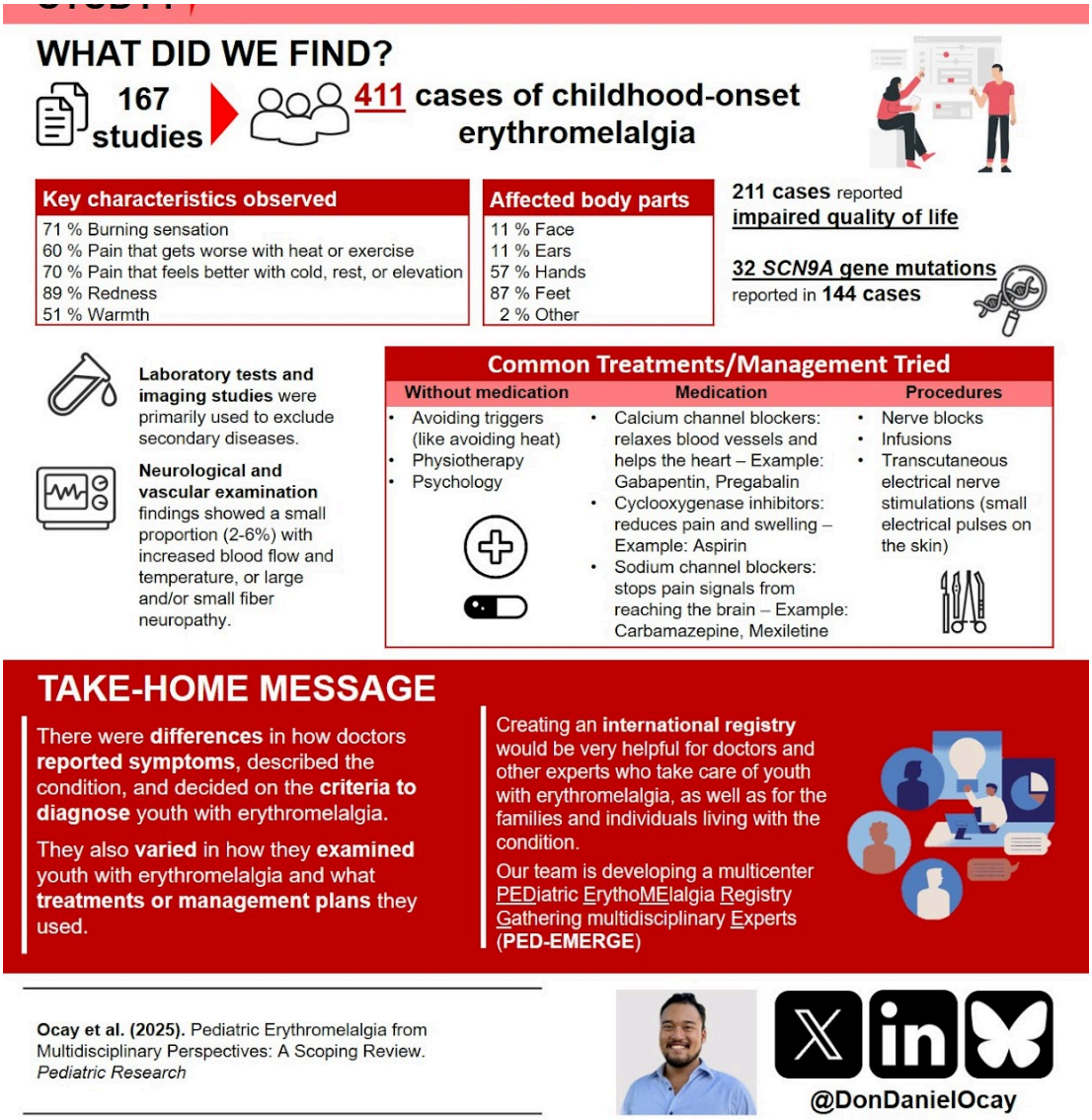
They analyzed 167 studies covering 411 cases of childhood-onset EM. Among these cases, 32 mutations of the SCN9A gene were reported in 144 instances, underscoring a genetic component to some cases of EM.

The study found that EM commonly affects the feet (87%), followed by the hands (57%), ears (11%), face (11%), and other parts (2%). Treatments for managing pain included trigger avoidance, physiotherapy, and medications like calcium channel blockers (e.g., gabapentin), cyclooxygenase inhibitors (e.g., aspirin), and sodium channel blockers (e.g., carbamazepine, mexiletine). Additional pain management approaches included nerve blocks, infusions, and transcutaneous electrical nerve stimulation (TENS).

A notable finding of the study was the variation in how healthcare professionals reported symptoms, described the condition, and established diagnostic criteria for youth with EM. There were also discrepancies in the examination and management plans implemented by different doctors.

To address these inconsistencies, the study proposed the creation of an international registry for healthcare professionals and experts who treat youth with EM as well as for patients and their families, aiming to standardize care and facilitate information-sharing. The Boston Children's Hospital team is developing a multicenter initiative known as the PEDiatric ErythroMElalgia Registry Gathering multidisciplinary Experts (PED-EMERGE) to coordinate these efforts.





Know Your TEA Board

- Angela Demerle -

Secretary

Angela Demerle has been an active member of The Erythromelalgia Association (TEA) for many years, motivated by her personal connection to the condition through her husband, Edward Dunlop, who was diagnosed with erythromelalgia (EM) in 2005. Angela and Edward discovered TEA online and graciously took on the task of responding to phone and email inquiries from patients seeking guidance and support.

Angela is also responsible for documenting Board Meeting minutes and contributing to TEA's online newsletter, *Your EM Connection*. Her 35-year career in the legal field has prepared her well for her role as a Board Member. Now in retirement, she resides in Rochester, New York, where she enjoys spending time with Edward, their daughter, son-in-law, and identical twin grandchildren.

Through articles written for the TEA newsletter and other publications, Angela has shared valuable insights into the role of caregiving for those living with chronic pain. Her dedication to The Erythromelalgia Association is centered on easing the burden for individuals with EM and their caregivers.

Thank you, Angela, for all you do to help the EM community!

FDA Approves Journavx, a Drug to Treat Pain without Opioid Effect

The Food and Drug Administration (FDA) has approved suzetrigine (sold as Journavx), a new pain medication (the first in 30 years) that promises relief without the risk of addiction. Unlike opioid-based pain relievers, this drug works on nerves outside the brain, blocking pain signals without affecting brain activity.

This is considered to be the first of a new generation of more powerful nonaddictive drugs to relieve pain. According to a New York Times article published on January 30, 2025, the conception of this new drug began when Dr. Stephen Waxman at Yale discovered that there are two electrical signals outside the brain that generate electrical nerve signals–NAV1.7 and NAV1.8. Dr. Waxman hypothesized that a drug capable of blocking these sodium channels could provide potent pain relief without affecting the brain, making it non-addictive. TEA has a longstanding association with Dr. Waxman, and has made several significant contributions to his research over the years. Furthermore, TEA was instrumental in informing Dr. Waxman about a family in Alabama who had chronic pain caused by EM. Upon investigation, Dr. Waxman discovered that the family members all had a mutation in the NAV1.7 channel, causing their pain nerves to fire constantly.

TEA's President, Beth Coimbra recently contacted Dr. Waxman for his thoughts on the new drug. He acknowledged the new drug as a significant breakthrough in pain treatment, but noted that it has not yet been tested for chronic pain. Dr. Waxman suggested that the medication be used initially for acute pain cases to assess its short-term tolerance and side effects, which could provide valuable insights into its potential for treating chronic pain in the future, particularly in EM patients.

NORD Announces its Living Rare Study

Living with a rare disease often brings challenges that affect every aspect of your life. Despite these serious struggles - which impact millions of people - rare diseases are not recognized as a public health issue due in part to a lack of data. The National Organization for Rare Disorders (NORD) is addressing this information gap with the launch of the Living Rare Study.

The Living Rare Study is the first large-scale, long-term research project in the United States dedicated to capturing the comprehensive experience of living with any rare disease over time. This study will collect data from thousands of

people over several years, providing essential insights into the real-world challenges and needs of individuals and families, from accessing care and treatments to managing daily tasks, finances and emotional well-being.

The data from the Living Rare Study is more than just statistics—it's the foundation for driving crucial changes in healthcare, policy and resources. The more EM community members who participate by sharing their lived experiences, the stronger our case for support and meaningful change for those living with rare diseases.

Key Facts About the Living Rare Study:

For Both Patients and Caregivers: Open to people living in the U.S. who are diagnosed with or suspect they have a rare disease, as well as their caregivers.

Comprehensive Research: NORD will collect patient experience data over several years to see how the impact of rare diseases changes over time.

Holistic Approach: Covers healthcare access, daily life impacts, emotional and physical well-being and financial challenges.

Flexible: Takes about 1 hour to complete and can be done at your own pace. NORD will send you a reminder each year to update your information.

Secure: Privacy is a priority. Data is stored securely on NORD's HIPAA-compliant platform, and responses are confidential.

For more information and to participate, visit

www.livingrarestudy.org.

Additions to TEA's Physicians List:

Do you have a physician who has diagnosed and/or treated your EM whose name you would like to share with other EM sufferers?

If so, please first ask your physician's permission to be listed on TEA's Physician Directory, and then submit their name, address, phone number and specialty to:

erythromelalgia.assoc@gmail.com

EM ZOOM Meetups:

The EM ZOOM Meetup meets on the 3rd Saturday of the month from

The EM ZOOM Meetup meets on the 3rd Saturday of the month from 11:00 am to 12:30 pm PST (2:00 pm to 3:30 pm EST). Everyone is welcome!

Please contact pk.agarwal3@gmail.com to be added to the notification list.

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*. We have developed a suggested outline for 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