

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 40 | June 2023

*Shaky Hands
Are a Part of
Her Artistry*

**ET Research
Update**

Find an
Assistive
Technology
Center in
Your State



Your Voice for Essential Tremor



Update from the Executive Director



We completed a very successful National Essential Tremor Awareness Month campaign in March. A total of 659 donations were received, an increase of 144 from the same time in 2022, and more than \$46,000 in donations, which

is an increase of \$12,000 compared with 2022. You still have time to donate if you would like and receive 2023 awareness promotional items. For a donation of \$30 or more you will receive an IETF tablet/phone holder and for a gift of \$50 or more you will receive the tablet/phone holder and an awareness month umbrella. If you are donating online make sure to use the awareness month donation page to ensure you receive the tablet and/or umbrella.

Podcasts and Webinars

We are continuing our podcasts and webinar series. Our latest podcasts cover the Brain Donor Project, the long-term impact of focused ultrasound, new data on the Cala Trio and an interview with IETF scholarship winner Jillian Mars. We've recorded a new webinar with Praxis Precision Medicines discussing the results of their Phase 2B clinical trial for an ET specific medication.

To access these recorded education events, you can go to our website and click on What We Do/Educational Programs. The IETF would like to thank our corporate partners Medtronic, Boston Scientific, Insightec, Sage Therapeutics/Biogen, Jazz Pharmaceuticals, Cala Health, Praxis Precision Medicines, and Allevion Therapeutics for their support of these programs. We will continue to schedule a variety of podcasts and webinars and promote them through Tremor Gram and our social media channels.

In-Person Education Events

On April 1, the IETF held its first in-person education

event since November of 2019. It took place in Lee's Summit, MO. We had 136 reservations and 100 people in attendance the day of the event. Thank you to Dr. Rajesh Pahwa, from the University of Kansas Medical Center and member of the IETF Medical Advisory Board, and Kelli Ott, PT from Children's Mercy Hospital, for presenting at the event. Our plan is to continue our in-person education events moving forward. You will receive an email and postcard invite if we are hosting one in your area.

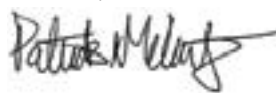
Clinical Trials

There are also some ET specific medication clinical trials currently taking place. If you live in an area where a trial site is located, you should have received an email from the IETF on how to sign up. If you don't have email, you can visit our website and click on the What We Do/Research buttons to find out more information or call our office for more details.

We hope you enjoy this issue of *Tremor Talk* which includes a feature on pianist Brianna Matzke, an update on the results of the Praxis clinical trial, and our newest medial advisory board member Dr. Emily Gantz, just to name a few topics.

As always, there is a lot going on at the IETF. But none of this happens without your support. Your donations are appreciated and allow us to continue to build on our mission to provide hope to the ET community through awareness, education, support, and research. We love to hear from you so please feel free to contact us with any questions, concerns, or ideas you might have. If you have moved recently or your email address has changed, please let us know so we can update our records and stay in touch. 🌍

Sincerely,



Patrick McCartney
Executive Director, IETF

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On the Cover:
Music Professor Brianna Matzke will be revealing her essential tremor as part of a commissioned arts project called TREMOR The Response Project.

Cover Photo by Marlene Rounds



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This publication is not intended to provide medical advice or be a substitute for qualified medical care. Appropriate treatment for your condition should be obtained from your physician. The content of this publication offers information to those with essential tremor. The IETF does not endorse any product advertised in this publication

unless otherwise stated.

Please send comments, questions, and story ideas to: IETF *Tremor Talk* Editor, PO Box 14005, Lenexa, Kansas 66285-4005 USA or call toll free 888-387-3667 or email tammy@essentialtremor.org.

HAVE YOU MOVED? Email us your new contact information, info@essentialtremor.org. Use the subject line "Change of Address."

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Making Day-to-Day Tasks Easier for People with ET

Look for an Assistive Technology Center in Your State

When you can't get your shaky hands to cooperate when performing everyday tasks, assistive technology may provide needed support. But which devices are best?

There are hundreds of assistive technology devices online and in stores. They include cooking and eating utensils, computer aids, writing devices and more. Because everyone's ET impacts them differently, a device that helps one person may not help the next in the same way.

A great resource for people looking for information and support in this area is the National Assistive Technology Act Technical Assistance and Training Center. In 1988, legislation was passed to help increase awareness, access and acquisition of assistive technology. Called the Assistive Technology Act, it supports State Assistive Technology (AT) Programs and Protection and Advocacy AT Programs.

In short, all 50 U.S. states, the District of Columbia, Puerto Rico and four U.S. territories (American Samoa, the Commonwealth of the Northern Mariana Island, Guam and the U.S. Virgin Islands) receive funding for assistive technology centers. These centers promote the ability of people with disabilities to know about, have access to and obtain assistive technology.

There are four state level activities authorized by the AT Act.

- *AT Demonstration* activities provide opportunities for people to become familiar with specific


types of AT by comparing and contrasting the functions and features of devices through hands-on exploration guided by a knowledgeable professional.

- *AT Device Loan* activities allow individuals to borrow AT for a limited time period to try it out and determine if a device will meet their needs before a purchase is made.
- *AT Reutilization activities* support the reuse of assistive technology that is no longer needed or used by its original owner and is acquired by a new owner at substantial cost savings.
- *AT State Financing* activities support the purchase/acquisition of AT through financial loans or other initiatives that directly provide AT to consumers at no cost using dollars from non-AT Act sources or save consumers money when purchasing AT.

Who is Served by AT Programs

All individuals of any age and with any type of disability, functional limitation or chronic health condition, are served by state AT programs.

Learn More

Go to www.at3center.net/stateprogram to find an Assistive Technology (AT) program in your state, with websites and contact information. 

Information courtesy of the National Assistive Technology Act Technical Assistance and Training (AT3) Center website.

ASSISTIVE TECHNOLOGY (AT) SERVICES FLOW

How do you access information about and acquire assistive technology devices for yourself, family members, or clients to enhance life, work, and play?

Access

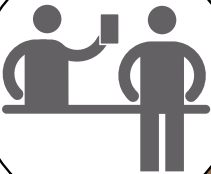
Information & Assistance

Contact your State Assistive Technology Program for more information on AT devices and usage.



Device Demonstration

AT professionals will demonstrate different devices according to your particular needs.



Device Loan

You can borrow devices to try at home, school, work, or play.



Reutilization

Acquisition

You can acquire the desired device. Some gently used devices may be acquired at little or no cost.



State Financing

Other financing options are also available. Contact your state AT program to learn about all your options.



Find your local AT program
<https://www.at3center.net/stateprogram>

See the IETF's listing of ET assistive devices online at www.essentialtremor.org/resource/assistive-devices/ or scan the QR code with your smartphone camera.



ESSENTIAL 1

Clinical Study Shows Potential in Essential Tremor

Update from Praxis Medicines about Ulixacaltamide for Essential Tremor

Earlier this spring, Praxis Precision Medicines reported topline results from its Phase 2 Essential1 clinical study of ulixacaltamide (formerly PRAX-944) to treat essential tremor (ET). Here, Monique Giroux, Praxis' Clinical Lead and Director of Neurology-Movement Disorders, helps answer questions about the study results and what they mean for people living with ET.

Q. Why is Praxis conducting research in ET?

Praxis is a clinical-stage biopharmaceutical company focused on developing potential treatments for people living with central nervous system disorders, including movement disorders and epilepsy. Through this work, we have come to understand that ET is so much more than tremor. We know how frustrating it can be to accomplish ordinary tasks like getting dressed, eating or holding a cup, and how symptoms can often lead to feelings of anxiety, depression and sometimes isolation. Because no medications have been developed specifically for ET, we've heard from many that they struggle to find relief, and that there is an urgent need for more and better treatment options specifically developed for people with ET.

Q. What is ulixacaltamide?

Ulixacaltamide is an investigational T-type calcium chan-

nel blocker being developed by Praxis. It's designed to calm the neurons in the brain that are too active in people with ET, potentially alleviating motor symptoms. Our goal is to develop ulixacaltamide with the ET community's needs in mind. For example, it's formulated as a once-daily oral medication that can be taken any time of day, with or without food, and is shaped as an oval capsule to help with administration.

Q. What was the goal of the Essential1 study?

Essential1 is a Phase 2 study of ulixacaltamide in people living with moderate to severe ET. It's the largest ET study to date, and its goal was to show functional and quality of life improvements. To do so, the study looked at the efficacy, safety, and tolerability of ulixacaltamide once-daily compared to placebo (a sugar pill). The main measurement was the change in ET symptoms after 56 days (or 8 weeks) of treatment, using scores on the modified Activities of Daily Living (mADL) scale. The study also looked at other measurements, including change in severity of symptoms across a range of other rating scales.

Q. What did the mADL scale measure in the study?

ADL scales are tools that score basic activities that have an impact on quality of life and independence, such as eating, drinking, pouring, using keys and other frequent



daily tasks. Additionally, the Essential1 study also looked at functional measurements including cursive handwriting and drawing spirals. All measures were individually scored on a 3-point scale where 0 represents no impact and 3 represents an inability to perform the task. Importantly, a single point improvement may indicate a positive impact on a person’s quality of life.

Q. What did the Essential1 study find?

In the study, people treated with ulixacaltamide saw their ET symptoms improve by over 3 (3.01) points after 56 days of treatment compared to less than 1.5 (1.44) points for those on placebo, as measured by the mADL score. While this is a numerical difference, it didn’t reach statistical significance.

Importantly, we did observe clinically meaningful improvements in Essential1. For instance, participants taking ulixacaltamide scored better than placebo on nearly all the ADL measures (10 of 12, including dressing, using keys, pouring, writing, drinking, among others). The functional measures of cursive handwriting and drawing spirals were not improved.


Additionally, participants and their doctors reported over-

all improvement with ulixacaltamide versus placebo, and it was generally well-tolerated. Side effects were generally mild to moderate with dizziness, constipation, headache, fatigue, anxiety, feeling abnormal and tingling sensation being the most common in the study.

Q. What’s next for Praxis in ET?

We are excited about the potential of ulixacaltamide and are committed to continuing to advance scientific understanding to develop new and better treatment options for ET. We are incredibly grateful to everyone who participated in the Essential1 study – your support has been critical in helping to advance our medical knowledge about ET. As a next step, we’ll be meeting with the FDA in June to discuss the Essential1 results and receive feedback on our plans for a Phase 3 trial to support a marketing application for ulixacaltamide.

* * * * *

For more information and updates from Praxis Precision Medicines about ET and future clinical trials, visit praxisessentialtremor.com. 



Thank you for your interest in *Tremor Talk*. We hope you enjoyed this free preview. If you would like to get this magazine in its entirety in your mailbox three times a year, just become an IETF donor.

To become a donor, call the IETF (toll free) at 888.387.3667 or donate online at www.essentialtremor.org/donate.



The mission of the International Essential Tremor Foundation (IETF) is to provide hope to the essential tremor community worldwide through awareness, education, support and research.

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