Diann Shaddox Foundation
For Essential Tremor

2025 Year-End Review

Taking Action

2025 Taking Action
2026 Keeping the Momentum Going

We founded the Diann Shaddox Foundation Essential Tremor Research in 2014 with a strong commitment to uncovering new treatments and securing a cure for Essential Tremor.

Over the past 11 years, we have achieved significant milestones we long envisioned and pursued. We've proudly hosted the National Essential Tremor Conference and the "A Night to Shine for ET Gala:' We established our Scientific Advisory Board, a diverse network of leading experts and advisors committed to positioning ourselves as the foremost research organization focused on finding a cure for Essential Tremor (ET).

Along with the exciting news from Praxis Precision Medicine, which participated as a speaker at the ET Conference, making a groundbreaking announcement to unveil the first treatment, ulixacaltamide, specifically developed for people with ET since its identification in 1874.

We are keeping the momentum going and not slowing down. The Diann Shaddox Foundation is gearing up for:

- A groundbreaking 2026 in scientific research guided by our Scientific Advisory Board.
- Creating the largest Essential Tremor Patient Resource Database (PRD) that connects ET patients with the right researchers and investigators.
- Hosting the 2026 National Essential Tremor Conference that brings the ET patient community together with device companies, pharmaceuticals, and doctors who support ET.
- Expanding our Patient Council members who share their experiences with Essential Tremor and drive meaningful change in the fight against this disease.
- DSF Team Advocate Member who supports and defends Essential Tremor and advocates passionately for the rights, policies, and needs of all ET patients.

A Letter from the Executive Director & Founder/CEO

We are just getting started. These goals are not distant dreams; they are concrete realities coming to life right now, built on countless years of hard work and dedication from many. We recognize the commitment required to achieve them, and we will achieve them together.

With the unwavering backing of the Essential Tremor Community, advocates, scientists, doctors, donors, and the ET worldwide community, we are determined to take on Essential Tremor head-on and fight back with all our might!

Diann Shaddox
Founder/CEO

Randy Miles
Executive Director/Co-Founder

2025 - 2026

Mission & Goals

Research Studies

Data Metrics Research

Patients & ET Community

National ET Conference

Essential Tremor Research

Clinical Research Studies

Genetic Health Research

ET A Neurodegenerative Disorder

Scientific Advisory Board

Research Studies on Key Areas Affecting Health and Well-Being

ET Patient Resource Database, PRD

Tremor Guidelines: Diagnosis of Essential Tremor

Advancements in research, smartphones, & wearable devices.

Scientific Advisory Board.

Guided by our SAB, the Foundation conducts research focused on scientific and technological progress. The SAB ensures that our organization's work, whether in research, policy development, or product creation, remains scientifically rigorous and current.

Purpose:

The DSF Scientific Advisory Board gathers a diverse network of leading experts and advisors to provide expert guidance on scientific advancements, address the specific needs of the Essential Tremor community, and ensure that our policies, research, marketing, communications, and publications meet the highest standards of scientific rigor and accuracy.

Up-to-Date Information:

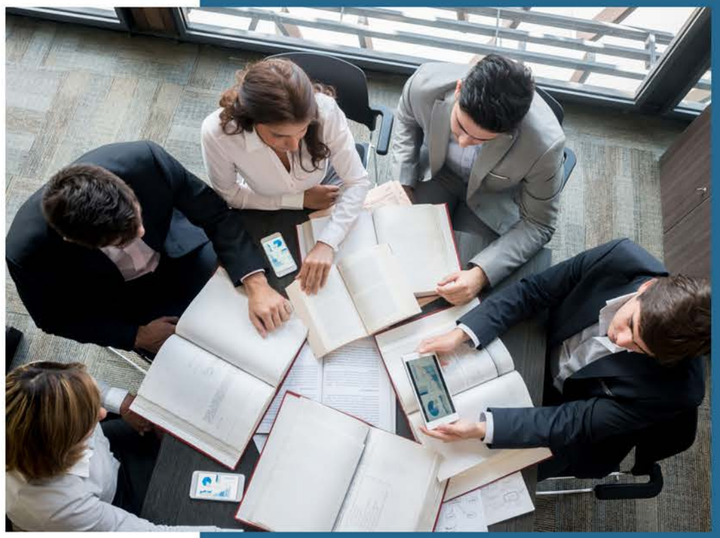
We share the latest news about Essential Tremor disease through our ET Talks, newsletters, and social media.

We have implemented our funding plans, including fundraisers, and continue to partner with world-renowned investigators, researchers, and industry leaders to move us closer to new treatments and a better quality of life for people with ET.

Focus:

We aim to become a world leader in Essential Tremor studies to leverage this information and advance treatment, thereby accelerating progress toward developing new therapies and a cure for ET. We will find new treatments and a cure for ET!

Scientific Advisory Board Members



Darlene Lobel MD, FAANS
Elan Louis, M.D., M.S.
Kenneth Ecker
Dr. Neeraj Vij
Dr. Drew Christensen
James Martodam

Clinical Research Studies

By collaborating with experts at the forefront of clinical research, we aim to facilitate groundbreaking studies that could lead to the development of novel treatments for ET disease.

Our efforts focus on improving patient outcomes by ensuring that new therapies are effective and tailored to meet patients' diverse needs. Through this transformative research, we are committed to making significant advancements in the field of medicine for ET.

Genetic Health Research

Genetic health plays a crucial role in determining how a person's genes and DNA shape their traits and risk of diseases such as ET. It is essential to understand how genetic variations can lead to inherited conditions or increase the risk of complex diseases.

Proactive management of genetic health demands effective interventions, such as lifestyle changes, personalized treatments, and genetic testing, to accurately identify risks and direct medical care.

DSF Data Metrics

Healthcare Data Metrics Research

We are actively working to gather diverse information from healthcare experts and ET Patients. We aim to explore patients' many challenges, highlighting their experiences and struggles.
We strive to improve and enhance our support for those in need, ultimately transforming their healthcare journey.

Population Data Metric Research

We are currently developing a system to collect data on the population affected by ET Disease.

This effort aims to improve our understanding of the disease's prevalence and impact on individuals and communities.

ET Patient Resource Database

Creating the Largest ET Patient Resource Database. **PRD**

By systematically collecting and analyzing this information, we aim to provide valuable insights that inform future research, intervention strategies, and support initiatives for those affected by ET.

DSF Research Studies

Tremor Guidelines: Diagnosis

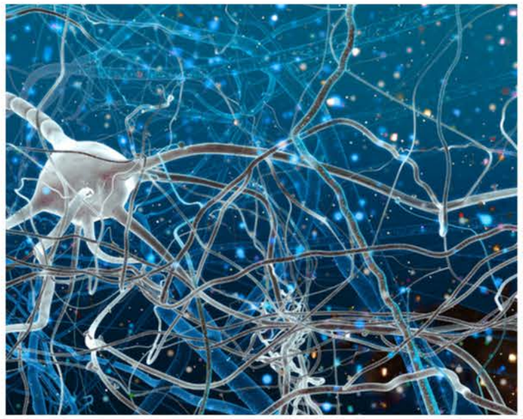
The Diann Shaddox Foundation is a part of the Tremor Guideline Committee. ET diagnosis remains a clinical diagnosis, as there are no validated diagnostic markers for ET.

The goal is to provide a more data-driven, empirically-guided approach to diagnosing ET, distinguishing it from other tremor disorders.

Smartphones & Wearable Devices.

Developing apps that monitor medication timing, wearable devices that assess tremor severity, and other technologies are providing support to people with ET in many aspects of daily life.

Neurodegenerative Disorder



Significant evidence suggests that ET is a neurodegenerative disorder involving abnormalities indicating neurodegeneration. ET also links to non-motor symptoms like mild cognitive impairments and faster cognitive decline, similar to other neurodegenerative diseases.

Research Studies on Affecting Health and Well-Being

Research on exercise, nutrition, gait, and speech/voice investigates their impacts on health. Exercise studies the benefits of physical activity; nutrition explores the role of diet; gait analysis examines movement for mobility and injury prevention; speech/voice research.

ET Patients are a vital cornerstone of our Foundation, being the heart of all our efforts.

Patients with Essential Tremor possess invaluable knowledge. By actively sharing experiences—specifically, what treatments have been effective and how they respond—patients can significantly influence research and improve our understanding by joining;

Patient Council

Support Groups & Webinars

Children Educational Initiative

Play a Role in ET Research

Advocate for ET Policies

Participating in research is not just an option; it's a powerful and impactful choice that makes a difference. You play a crucial role in advancing ET research discoveries and shaping the future of treatments.

We must come together to promote progress in treatment options.

"No one knows Essential Tremor better than those living with it."

The **Patient Council** is a prestigious network of Essential Tremor Patients who serve as advisors to help inform and guide DSF.

The goal of DSF is to prioritize the patient voice in the fight against ET.

The Patient Council fosters discussions that influence research, policy, and more. We aim to ensure that scientists, policymakers, and society understand patient needs. Through activities like educational resources and outreach, we strengthen our ET community.

The Patient Council is aware of the realities of living with ET and works closely with DSF to ensure that the "patient voice" is always at the forefront.

The Patient Council advises DSF on strategies to increase clinical trial participation and efficiently collect patient data. Council members also play a key role in building strong relationships with industry, legislators, regulatory agencies, and innovative fundraising initiatives.

Our progress relies on uniting the ET Community and listening to their voices. All the research in the world is meaningless without hearing from the only people who can truly answer whether science is helping — those living with the disease.

The Diann Shaddox Foundation remains committed to being that link, directing strategic funding to projects that matter most to patients.

Patient Council Members

-Diagnosed with Essential Tremor.

-Share insights on the unmet needs of the ET Patient community.

-Provide feedback on Team DSF's programs and materials

- Review and provide feedback on Team DSF's programs and materials.

- Serve as ambassadors for the Foundation within the ET community and public.

- Facilitate sharing of the Foundation's resource information.

Get Involved

Essential Tremor Worldwide Facebook Group

The ET Worldwide Facebook Support Group is a social media private platform where individuals worldwide living with Essential Tremor come together to share their experiences and offer each other unwavering moral support and guidance.

ET Champions Support Group

ET Champions is a supportive community where you can share your experiences, ask Essential Tremor questions, and find encouragement from others.

We warmly welcome not only individuals living with Essential Tremor but also their family members, friends, coworkers, caregivers, and advocates to join.

Our ET Champions will facilitate private Zoom meetings and discussions, providing a platform for meaningful conversation.

ET Talks Webinar

ET Talks: Roundtable discussions, where you can explore different aspects of living with Essential Tremor (ET) and discover ways to enhance your quality of life.

This is an excellent opportunity to log on (Zoom), listen to expert discussions, and ask you Essential Tremor questions.

ET Patients

Play a Role in ET Research

Everyone plays a crucial role in progressing disease research and creating new treatments. Here's what you should know and how to get started.

- Data Metric Research
- Healthcare Data Research
- Studies Affecting Health & Well-Being
- Clinical Trials Research

Very Important

- Share your ET Story

Participating in research is not just an option; it's a powerful and impactful choice that makes a difference. You play a crucial role in advancing ET research discoveries and shaping the future of treatments.

We must come together to promote progress in treatment options.

Advocate for ET Policies

Grassroots advocacy serves as the backbone of our efforts and our foundation. By joining forces, we can effectively influence legislation and policy decisions to enhance the quality of life for everyone affected by ET.

Your involvement can help elevate the voices of those who often go unheard, ensuring that the needs of the ET community are prioritized.

Children Educational Initiative

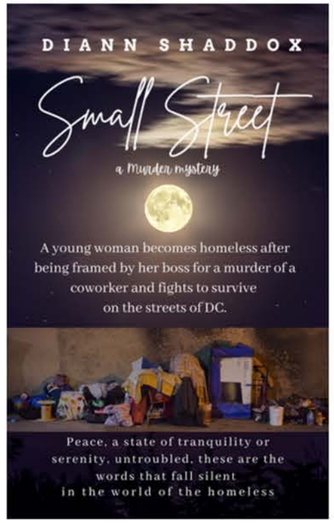
We are dedicated to advocating for parents and children, empowering them to navigate the educational system so that children with Essential Tremor can achieve their full academic potential.

National Essential Tremor Conference & “A Night to Shine for ET Gala

Exciting times in 2025 for the Diann Shaddox Foundation for ET Research & More to come in 2026

DSF National ET Conference

The Diann Shaddox Foundation for Essential Tremor Research hosted the National Essential Tremor Conference in Clearwater Beach, FL. This event brought together pharmaceutical companies, device manufacturers, hospitals, physicians, research scientists, and many other key players in the ET community from around the world.



The evening fundraiser, "A Night to Shine for ET Gala, Old Hollywood," was a vibrant celebration of unity, filled with engaging activities, camaraderie, and unwavering support for essential tremor awareness and the Foundation's mission.

In the spring of 2025, Diann Shaddox proudly released her eighth book, "Small Street," and is now actively working on her autobiography.

As 2026 approaches, Diann is poised to make a significant impact as a guest in magazines, book clubs, and at book signings, where she will share her experience living with Essential Tremor and discuss her compelling novels.

About the Diann Shaddox Foundation

Grassroots advocacy is the core of our mission and the driving force behind our foundation's initiative. By uniting, we can effectively influence legislation, shape policy, and drive medical research to enhance the quality of life for all affected by ET.

Who we are:

The Diann Shaddox Foundation (DSF) is a 501 (c)(3) non-profit organization dedicated to finding new treatments and a cure for Essential Tremor (ET).

Founded by author Diann Shaddox, who has lived with the challenges of Essential Tremor (ET) her entire life. the foundation educates the public and medical community about the disease, and supports research and patient care.

The Diann Shaddox Foundation is committed to relentlessly pursuing research to solve the mysteries of Essential Tremor and find a cure.

MISSION: To empower patients and find a cure for Essential Tremor.

Your involvement can help us make unprecedented progress in ET medical research to uncover the mystery and cause in order to find a cure.

Your support is crucial in making this vision a reality.

Join us by raising funds for our Scientific Advisory Board, a leading scientific collaboration and research initiative driven by distinguished scientists and investigators. Every dollar brings us closer to finding a cure for Essential Tremor. Join Team DSF now!

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Diann Shaddox Foundation
For Essential Tremor

Thank you for an *Amazing Year*

“2025 has been a journey of growth, resilience, and transformation. Let’s make 2026 even better — together.”