



FACTS ABOUT ESSENTIAL TREMOR

WHAT IS ESSENTIAL TREMOR?

- Essential tremor (ET) is a neurological movement disorder that causes rhythmic, involuntary and uncontrollable shaking of the hands, but can also affect the head, voice, legs and trunk.
- ET is thought to be due to abnormal communication between certain areas of the brain, including the cerebellum, thalamus and brain stem. The exact cause is unknown.
- The tremor associated with ET is kinetic, meaning it presents itself during voluntary movement and disappears during rest.
- The tremor may be a rhythmic “back-and-forth” or “to-and-fro” movement produced by involuntary (unintentional) contractions of the muscle.
- Severity of the tremor can vary greatly from hour to hour and day-to-day.
- Though it is not life threatening, quality of life becomes a very serious issue for people with ET as daily activities (i.e. eating, grooming, writing) become extremely difficult if not impossible.
- ET is called “essential” because in medical terms essential means the cause is unknown.

WHAT IS THE EPIDEMIOLOGY OF ESSENTIAL TREMOR?

- As many as 1 in 20 people older than age 40, and 1 in 5 people over 65 may have ET, however the condition does not discriminate against age as it affects both men and women of all ages.
- There are approximately 10 million people with ET in the United States, and many more worldwide.
- ET is often misdiagnosed as Parkinson’s disease – a disorder characterized by resting tremor, stiffness and slowness of movement; it is estimated that ET is ten times more common than Parkinson’s disease.
- ET is the most common of all movement disorders. Of all neurologic diseases, ET is the most common with the exception of stroke.
- ET is often considered “familial” because it often runs in families. Children who have a parent with ET have approximately a 50 percent chance of also showing signs of the disorder in their lifetime. However, it is not a strictly genetic condition, as it also presents itself in individuals with no family history of ET.
- ET is not caused by another neurological condition, by injury, or as a side effect of a medication.

HOW IS ESSENTIAL TREMOR DIAGNOSED?

- Despite the vast number of people with ET, there is very little awareness of this disorder; the more people understand ET, the more likely they will seek help early if they exhibit symptoms.
- Doctors who are trained to evaluate tremor can accurately diagnose ET on the basis of the symptoms and a neurological examination. During this exam, the doctor will be gathering as much information as possible about the patient’s tremor because there are no blood, urine or other tests for ET. Before making a diagnosis of ET, a patient’s doctor may want to investigate other possible causes of tremor such as thyroid disease, excessive caffeine ingestion or medication side effects.



FACTS ABOUT THE INTERNATIONAL ESSENTIAL TREMOR FOUNDATION

ABOUT THE INTERNATIONAL ESSENTIAL TREMOR FOUNDATION

- The IETF is the leading organization in the world that provides global educational information, services and support to those affected by essential tremor (ET), and to health care providers, while promoting and funding ground-breaking ET research.
- To date, the IETF has donated more than half a million dollars through 12 research grants and a family assistance program with the goal of helping scientists research for better understanding of the disease, better treatments and a cure, and help families cope with ET physically and emotionally.
- The IETF creates and distributes educational literature, including two regular publications (The Scoop and Tremor Talk) for people who have ET, their loved ones, caregivers, physicians and the general public.
- The organization coordinates and conducts community education programs in many cities throughout the U.S. each year. The IETF has hosted nearly 150 community education events since its inception.
- The IETF actively lobbies Congress to adopt a National Essential Tremor Awareness Month to build a better national understanding of the disorder.
- A board of directors, medical advisory board, staff and seven community ambassadors guide IETF's membership, which consists of patients, physicians, educators, health care workers, parents, relatives, friends and volunteers.
- The IETF provides a database of physicians who specialize in the diagnosis and treatment of ET.
- The organization assists in forming and maintaining 80 local ET support groups.
- "Tulips for Tremor" is the organization's largest fundraising activity that runs in conjunction with the IETF's annual awareness campaign.
- The IETF was founded in 1988 and is an international 501(c)(3) non-profit membership organization.
- For further information surrounding ET, visit www.essentialtremor.org.

ABOUT ET SUPPORT GROUPS IN LOCAL COMMUNITIES

- The IETF regularly provides assistance and support to 80 groups in local communities throughout the United States.
- Developed by the IETF and facilitated by local spokespersons for people who have ET or who have a family member or friend who has ET.
- Conducted in places where people feel welcome and accepted, and can openly talk and exchange ideas about the challenge of living with ET.
- Support groups are a vital resource to ET sufferers and their families, but are not a substitute for medical treatment or personal or health counseling.

ABOUT "TULIPS FOR TREMOR"

- "Tulips for Tremor" is the IETF's signature national fundraising campaign; proceeds from the event benefit the IETF's awareness programs and research initiatives into a cause and cure for ET.
- The fundraiser features high-quality tulip bulbs from the well-known and respected Dutch Mill Bulbs as well as various tulip merchandise including tulip pendants, shirts, caps and tote bags.



FREQUENTLY ASKED QUESTIONS

What is ET?

Essential tremor (ET) is a neurological movement disorder that causes rhythmic, involuntary and uncontrollable shaking of the hands, but can also affect the head, voice, legs and trunk.

What causes ET?

Essential tremor is thought to be due to abnormal communication between certain areas of the brain, including the cerebellum, thalamus and brain stem. The exact cause is unknown. The condition is often considered “familial” because it runs in families. Each child of a parent with ET has approximately a 50 percent chance of inheriting a gene that causes ET. However, it is important to note that not everyone who inherits a gene develops symptoms, and some people have ET and do not have a family history, which suggests other causes.

Does ET cause death or shorten life?

Although ET symptoms often progress, it neither causes death nor shortens lifespan; rather it directly affects one’s quality of life. At best ET is but a nuisance, and at worst ET can be extremely debilitating. Most cases of ET fall somewhere in between the two extremes.

Who gets ET and at what age does ET start?

While ET often runs in families, it is not exclusively genetic and appears in individuals with no known family history. It is not discriminatory and is found in all races and parts of the world, and affects men and women equally. The age and severity of onset varies, although diagnosis before the age of ten is rare. In most cases, symptoms begin after the after the age of 40. ET affects approximately one out of 100 people.

Does ET worsen with age?

It is uncertain whether or not ET will progress to debilitating levels; however, it is likely that the disorder will continue to worsen over time as people with ET get older.

How is ET diagnosed?

Despite the vast number of people with ET, there is very little awareness of this disorder; the more people understand ET, the more likely they will seek help early if they exhibit symptoms. Doctors who are trained to evaluate tremor can accurately diagnose ET on the basis of the symptoms and a neurological examination. During this exam, the doctor will be gathering as much information as possible about the patient’s tremor because there are no blood, urine or other tests for ET. Before making a diagnosis of ET, a patient’s doctor may want to investigate other possible causes of tremor such as thyroid disease, excessive caffeine ingestion or medication side effects.

Are all tremors caused by ET?

Excessive caffeine, alcohol withdrawal, problems with thyroid or copper metabolism or the use of certain medications may cause a tremor. A major difference between ET and other tremor types is that in ET, a tremor is the only symptom, and muscle tone, strength and balance are not usually affected. ET is also an active tremor, presenting itself during movement and desisting during rest, unlike many other tremors which appear during rest. Other conditions that may cause tremors include: enhanced physiologic tremor, Parkinson’s disease, cerebellar tremor, dystonic tremor, and tremor due to medications.



What medications help ET?

The main medications used to treat ET are Propranolol (Inderal™), a beta-blocker used to treat high blood pressure, and Primidone (Mysoline™), an anti-seizure drug used to treat epilepsy. Sixty percent of patients are helped by these medications. Currently, Propranolol is the only drug approved by the FDA for treatment of ET. It is most effective against hand tremor. Occasional dose adjustments may be needed. It is important to note that people with mild ET may not need treatment. There is no evidence that early treatment stops or slows the natural progression of ET symptoms.

What are the goals of ET treatment since there is no cure?

The goals of treatment are to reduce tremor severity, improve ability to function and decrease social handicap. Achieving these goals can sometimes take time so it is important to be patient. While almost 60 percent of people with ET benefit from medical therapies, a patient's doctor may have to try two or three different medicines before finding the one that works best.

Combination and other therapies

If the tremor is not well-controlled by one form of medication, one may experience better results when taking both Propranolol and Primidone together. If combination therapy is not helpful, the patient's doctor may then recommend one of the benzodiazepines such as clonazepam (Klonopin), diazepam (Valium), alprazolam (Xanax) or lorazepam (Ativan). If medications fail, injections of Botulinum toxin into muscles can be tried. Botulinum toxin injections have been useful in the treatment of some patients with head and voice tremors. While there are no scientific benefits confirmed, many ET sufferers receive temporary relief from alternative therapies including biofeedback and massage.

Can surgery help ET?

If treatment is impeding quality of life, disabling or is putting one's livelihood at risk, their doctor may suggest a surgical technique called Deep Brain Stimulation (DBS). Surgical procedures are expensive but often prove to be beneficial. Approximately 80 percent of patients have experienced improvement in their tremor after having DBS. When effective, medications may be reduced or even discontinued.

How can I minimize the effects of ET on my life?

Become informed about the condition and learn as much as possible about living with ET. Instead of restricting one's life because of what others may think, patients should explain their condition simply and honestly when they meet new people. If a child has ET, their parents should talk to teachers in person about the neurological basis for symptoms. Find ways to reduce stress and learn relaxation techniques. Avoid things that may worsen symptoms, such as caffeine and certain prescription medications. Contact the IETF at www.essentialtremor.org for a free information packet or information about joining or starting a support group for ET.

What does the IETF do to support those affected by ET?

The IETF is the leading organization dedicated to helping those affected by ET. Its goal is to spread awareness and fund research to identify effective treatments and, hopefully, a cure. The IETF has hosted nearly 150 community awareness events across the country to provide those affected with knowledge on how to live with ET. The IETF also provides for 80 local support groups and its website is the preeminent resource for information on ET. In addition, the IETF regularly produces two publications – The Scoop and Tremor Talk – to educate those affected by ET and their families. To date, the IETF has distributed more than half a million dollars in research grants to fund 12 promising research studies.

What can I do to support the IETF?

Contact the IETF at www.essentialtremor.org for information about joining or starting a support group for ET or making a donation.



WHAT ARE THE TREATMENT METHODS OF ESSENTIAL TREMOR?

- As ET affects each individual differently, treatment options vary greatly depending on the individual and can range from daily medications to brain surgery.
- Although there is no cure, the goals of treatment are to reduce tremor severity, improve ability to function in everyday tasks and better quality of life.
- The main medications used to treat ET are Propranolol (Inderal™), a beta-blocker used to treat high blood pressure, and Primidone (Mysoline™), an anti-seizure drug used to treat epilepsy. Both work by targeting the areas in the brain that cause symptoms. Currently, Propranolol is the only drug approved by the FDA for treatment of ET.
- Propranolol and Primidone are often used in combination therapy when either does not prove effective. Approximately 60 percent of people with ET are helped by using either medication.
- There is no evidence that early treatment stops or slows the natural progression of ET symptoms. With adequate knowledge, many people learn ways to cope with ET, both physically and emotionally.
- If treatment with medications is not effective, there are surgical techniques, the most popular being Deep Brain Stimulation (DBS). Approximately 80 percent of patients have experienced improvement in tremor after having DBS. When effective, medications may be reduced or even discontinued following this procedure.
- Some people with ET gain temporary relief from biofeedback and massage, though there is no scientific confirmation.

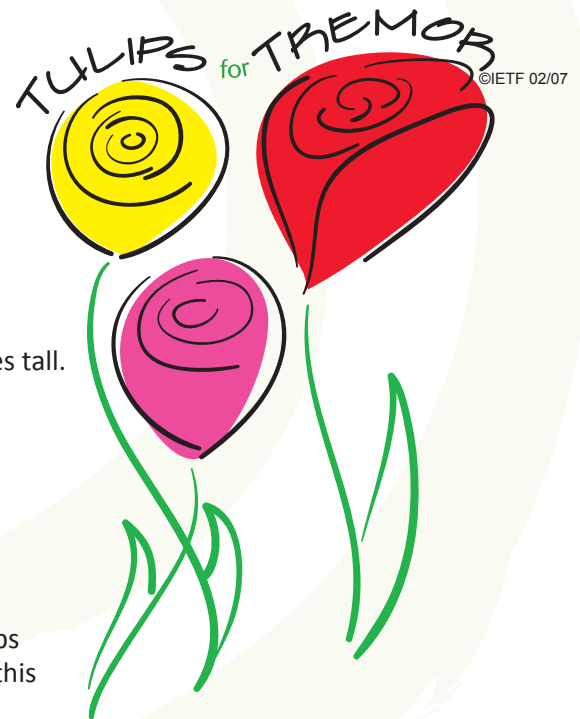


INTERNATIONAL ESSENTIAL TREMOR FOUNDATION TULIPS FOR TREMOR

- Tulips for Tremor is the International Essential Tremor Foundation's largest annual national fundraising activity and complements the IETF's annual awareness campaign.
- All proceeds from Tulips for Tremor benefit research initiatives and awareness programs that support those affected by essential tremor (ET) as well as health care providers.
- Tulips for Tremor efforts have helped the IETF raise money to fund 12 research grants and a family assistance program with the goal of helping scientists conduct research that provides a better understanding, new treatments and a cure for ET.
- The fundraiser features high-quality tulip bulbs from Dutch Mill Bulbs, as well as various tulip merchandise including tulip pendants, shirts, caps and tote bags.
- Those looking to support the IETF can order bulbs online at <http://www.essentialtremor.org>.

Tulips available for purchase through the IETF website include:

- **Angelique Tulips:** Delicate, soft pink petals and delicate scent. Blooms in May. Grows 18 inches tall.
- **General Eisenhower Tulips:** The "granddaddy" of the tulip family. Makes a statement in traditional red with blooms on sturdy stems that last. Blooms in April/May. Grows 30 inches tall.
- **Giant Dutch Tulips:** A stunning colorful display of the most popular solid color and bi-color midseason varieties. These sturdy-stemmed tulips will flower for years. Blooms in April/May. Grows 20 to 24 inches tall.
- **Washington Tulips:** Eye-catching marbled blend of yellow and red. Blooms in May. Grows 16 to 18 inches tall.
- **Pastel Tulip Mix:** Soft-colored midseason tulips. Blooms in April/May. Grows 18 to 24 inches tall.
- **Queen of the Night Tulips:** The "black tulip" — lush green foliage helps contrast the exceptionally dark bloom to enhance the uniqueness of this extremely popular variety. Blooms in May. Grows 22 to 24 inches tall.





International Essential Tremor Foundation Executive Director

Catherine Rice, executive director

Catherine is Executive Director of the International Essential Tremor Foundation (IETF). She received her Bachelor's Degree in Business Administration from Baker University in Baldwin City, KS and graduated with her Masters in Nonprofit Management with honors at Regis University School for Professional Studies in Denver, CO.

Prior to joining IETF in 1997, Catherine was the Administrator for the Department of Neurology at the University of Kansas Medical Center. IETF was founded by the Chairman of Neurology for whom Catherine worked. When she was ready to leave her job at the University of Kansas Medical Center it was a natural transition to take on the role of executive director because she already had experience working with patients who were diagnosed with essential tremor (ET), had 14 years experience managing the nonprofit portion of the Neurology Department and had established a strong working relationship with the founder and IETF board.

Catherine has been a manager of healthcare related businesses in the nonprofit field for 25 years. She is accustomed to the challenges that managing a nonprofit can have. Catherine prefers to work in the nonprofit arena because the opportunity to help others gives her greater satisfaction. As Catherine has so often said, "everyday I leave my office feeling as though I have had a huge positive impact in someone's life".

The opportunity to continue to work in the field of neurology has been a blessing because ET also runs in Catherine's family. While she has not personally developed a tremor, she remembers that two of her aunts' hands would shake uncontrollably. At the time, she was not aware that it was ET, but does remember that it was hard for them to do things in the kitchen. This makes working for IETF truly rewarding because her involvement not only helps those within her family but it also allows her to continue working in a field she loves.



International Essential Tremor Foundation Board Members

Kelly Lyons, PhD, president

Kelly is director of research and education for the Parkinson's Disease and Movement Disorder Center at the University Of Kansas Medical Center. She received her B.A., M.A., and Ph.D. in experimental psychology/cognitive aging from the University Of Kansas. Kelly's primary areas of research are Parkinson's disease and essential tremor, and she has published extensively on both. She is secretary/treasurer for the Tremor Research Group and co-editor in chief of the International Journal of Neuroscience.

In addition to research, Kelly is interested in patient support and has been involved in multiple educational initiatives for patients who have ET and Parkinson's disease. Her goal as IETF President is to help increase patient support, research initiatives and collaborations, and ET awareness both nationally and internationally.

Peter LeWitt, MD, vice-president

Peter is a board-certified neurologist specializing in movement disorders in Southfield, MI. He is also currently a professor of neurology and psychiatry at Wayne State University School of Medicine in Detroit, MI. As a Brown University Medical School graduate, he received additional medical and research training at the University Of Pennsylvania, Stanford University, and the National Institutes of Health.

Dr. LeWitt says he is honored to be a part of the IETF and sees it as an opportunity to translate his expertise to as broad an audience as possible. He hopes to return to those served by the IETF some measure of the experience he gains.

Russ Rosen, MS, secretary/interim treasurer

Russ brings an awareness of ET through his wife Arlene, with whom he's been married for almost 42 years. Approximately eleven years ago, Arlene was diagnosed with ET and began to take a variety of medications. He was concerned but with limited experience and knowledge he could only be ineptly supportive.

After attending the support group meetings in Dayton, OH, he began to better understand what Arlene was experiencing. He was especially struck by the high level of emotional support and help with coping skills.

Russ brings his strength as an individual with a Master's degree in Social Work administration. He has had 25 years of experience working in the not-for-profit setting as a volunteer as well as a staff person working with boards of directors and committees, planning, management and networking. Russ hopes to further strengthen these support groups to help as many people as possible.

Russ wants to help the IETF accomplish its mission to improve the quality of the lives of those afflicted with ET. He thinks it important to continue supporting those with ET in ways that improve self esteem, physical and mental health.



Shari Finsilver, past president

Shari's career, both professionally & as a volunteer, has been focused on healthcare. With an M.S. degree in Industrial & Operations Engineering from the University Of Michigan, she worked as a Management Engineer in a hospital setting. Living with essential tremor (ET) since childhood, coupled with her passion for healthcare led Shari to become active in the International Essential Tremor Foundation.

In 2001, Shari founded the first support group in Michigan, which she led for 6 years. She has served on the IETF board since 2002 & was honored to be elected board president during 2004 – 2006. Shari is also actively involved with Henry Ford Health System, particularly in the Neuroscience Institute & the Breast Care & Wellness Center.

Shari's goal is to increase public awareness about ET & the IETF, as well as to educate patients, families and the medical community about ET diagnosis and treatment, along with the importance of emotional support.

Edward M. Block, PhD, board member and past secretary

With more than 30 years in the pharmaceutical industry, Ed has led several drug development projects involving prescription and over-the-counter (OTC) products as well as transitioning prescription products to OTC. His experience includes international assignments, notably in the Pacific Rim.

Ed has ET and can trace it through several generations of his family. In addition, as a result of his professional expertise, he understands the limited options for treating the condition. The IETF relies on his understanding of drug development, including regulatory and political processes, to help determine and reach both short-and long-term goals. Ed has experience in marketing/evaluating business development opportunities for potential ET treatment options based on and using credible medical evidence.

State Senator Terry Link, board member

Senator Link, D-Waukegan, was re-elected in 2002 to a third term as state senator of the 30th District. He serves as the majority caucus chair, and as vice-chairman of the Senate Revenue Committee. He began his career in government with the Illinois State Treasurer and the Secretary of State's offices.

Link has received many awards including, the Psychological Society of Illinois Legislator of the Year Award; the Helmet Award from the Associate Fire Fighters of Illinois in recognition of his efforts on behalf of fire fighters across the state; and the Citizen of the Year Award from the National Association of Social Workers – Northeastern District.

As a member of the executive board of IETF, Link offers hope to others through his personal story. He has lived with the effects of ET for most of his life, and despite its hardships, he has been able to overcome the symptoms and rise to high-profile position within state government. Using his position in office, he wishes to raise public awareness of the disorder and allow others to believe that they too can accomplish any goal they wish to achieve. Senator Link embraces the opportunity to serve on the Executive Board of IETF as a state senator.

Link attended Stout State University, now University Of Wisconsin - Stout. He is married to Susan McCall Link, and has four children: Lisa, Leah, Kelly, and Jennifer.



Celeste Fralick, board member

Celeste has had shaking of her dominant hand since puberty. At the age of 34 she was properly diagnosed by a neurologist and placed on Inderal®. As the symptoms continued over the next few years, she eventually added Primidone®. By her late forties she was diagnosed with a rare parallel disease, spasmodic dysphonia (SD), which robbed her of her voice for more than six months. She still suffers occasionally from the SD, but the ET continues to escalate the older she gets. Her family members have also identified similar characteristics and clear genetic dominance is becoming apparent.

For Celeste, it's been a long acceptance of ET because of the social stigma, but as a biomedical engineer she has been able to approach it from a left-brain, more pragmatic and scientific approach. She's learned the typical things to avoid – hormonal changes bring on more shakiness, as does speaking engagements, carrying cups of hot liquid, eating soup.

Celeste brings to the board her primary strengths of strategic development, biomedical engineering, ideation, and being a learner. Her secondary strengths include her 30-year background in the industry and systemic look at challenging issues. As a board member she would like to see ET as well-known and as well-funded as Parkinson's disease using strategic collaborations with academia, research, and industry.

Celeste understands that there are many different approaches for personally dealing with ET – what's best for someone else might not work with you. However, Celeste insists that it's important not to give up; and states that as new technology unfolds it is inevitable that someday, somehow, ET can be brought much further into the awareness of the general public, and improved coping mechanisms will emerge for more effective treatment and quicker diagnosis.

Doug Ward, PhD, board member

Doug first became aware of his tremor during his mid 30s, although he may have had the disorder long before. Initially, he was a science teacher, then he taught curriculum in a teacher education program and presented speeches to state board of education meetings; the state legislature; and other highly visible settings. His tremor would sometimes overcome him and if he didn't have some place to set his papers they would spill onto the floor.

Doug's mother had severe ET as did his father. Doug has identified ET in at least six generations of his family with numerous cousins, uncles and aunts exhibiting various levels of the condition.

ET led Doug to start a support group in memory of his mother that has now entered its fifth year. As a support group leader, he has spoken at senior health fairs, Kiwanis Clubs and other local venues.

Doug brings his experience in serving on local, national, international and state level boards for more than 40 years. Doug notes that there is a responsibility to become knowledgeable and to be an active advocate for IETF and its various initiatives. He continually seeks to expand the activities of the groups he has been involved with by recruiting members, developing new programs, and significantly expanding revenues.

Doug initially sought to educate himself on the operations of the board itself, and the existing expertise that is found within the board. He plans to assist in the development and promotion of a major fundraising activity and explore the current state of knowledge and activity regarding education about ET throughout the osteopathic medical colleges and postgraduate training programs. He also plans to distribute ET information throughout that system of 60,000 physicians and students.