



## 12 Month Annual Report

April 1, 2005 through March 31, 2006

Hope Through Research, Awareness and Support

The IETF is a proud member of:



INTERNATIONAL ESSENTIAL TREMOR FOUNDATION

PO Box 14005, Lenexa, Kansas 66285-4005 U.S.A.

Toll Free 888-387-3667 • 913-341-3880 • Fax 913-341-1296  
Email: [staff@essentialtremor.org](mailto:staff@essentialtremor.org) • Website: [www.essentialtremor.org](http://www.essentialtremor.org)

## From the Executive Director

Member support is the key to the IETF's success and in our ability to help those who are affected by essential tremor. Without our members we would not be able to —

- Fund research;
- Provide educational information to the newly diagnosed;
- Educate physicians about appropriate diagnosis and treatment;
- Develop a database of physicians who specialize in essential tremor;
- Encourage experts to join us on the chat line;
- Develop support groups across the country that work to improve the quality of life for those with essential tremor; or
- Engage in multiple activities to increase public awareness.



Catherine Rice,  
Executive Director

Because we have been touched by wonderful members, we would like to say “thank you” to everyone who made a donation, regardless of size, in FY06. Every cent helps further the mission. But great member support doesn't end with donations.

Support is also given through actions such as leading support groups, helping with patient events, supporting the staff in the office, and lending expertise on The Executive Board and on The Medical Advisory Board, and spreading the word about essential tremor and the IETF within communities. On the average, more than 210 hours are donated monthly by volunteers so you can see that without them it would be impossible to do what we do.

The past year has been an exciting time during which, once again, the IETF made great strides in increasing public awareness about essential tremor and in supporting people who are affected by this condition. New programs were initiated in marketing and public relations including the development of new support groups, the publication of new literature and the funding of basic research to find the cause or causes of essential tremor.

We are proud to provide you this annual report, which outlines all of these accomplishments and many more.

As the IETF prepares for another year, I personally want to express my appreciation to all those members who donated funds, time and talent. I want to say “thank you” to the support group leaders throughout the world who strive to make a difference in the lives of others as well as in their own lives; to the volunteers who work tirelessly in our Lenexa office to keep us on schedule; to the Medical Advisory Board members who contribute their expertise and valuable time to write for and provide information for the IETF's quarterly newsletter *Tremor Talk*; to the healthcare providers who educate patients about the IETF and essential tremor and; to the members of the Executive Board whose dedication and commitment to philanthropy makes this organization what it is.

I also thank the IETF staff: Kelly Schroeder, membership coordinator, who is responsible for the memberships and queries; Debbie Lovelace, marketing and public relations staff member responsible for the volunteers, support groups and the newsletter; and Judy Blankenship, marketing and public relations staff member for community relations and events.

All of us here at the IETF are excited to move forward to capitalize on all the accomplishments of 2005. We will strive to meet your expectations and look forward to serving you throughout FY06. I leave you with a quote from John W. Gardner, American Writer (1933-1982), *“The nonprofit sector enhances our creativity, enlivens our communities, nurtures individual responsibility, stirs life at the grassroots, and reminds us that we were born free.”*

A handwritten signature in cursive script that reads "Catherine Rice".

Catherine Rice  
Executive Director, IETF

## Shari Finsilver Steps Down as President

Dear ET Community,

It's hard to believe that my two year term as IETF president will be ending soon. What an incredible honor it was to serve. But it's especially gratifying when you can pass the baton to someone with experience, skills and knowledge; someone who cares deeply about both the IETF and essential tremor patients. I know that this organization will be in very good hands with Dr. Peter LeWitt serving as president.

I have learned so much from other essential tremor patients over the years leading a local support group and communicating with so many of you via e-mail and telephone. It's unfortunate that we are not only misunderstood by the general public when we shake uncontrollably, but we're often easily dismissed by the medical community. It's imperative that we continue our goal of increasing public awareness and educating both the public and professionals about essential tremor and how it can impact our daily lives and livelihood.

The embarrassment many of us feel when we shake is causing us to allow tremor to take over our lives. Instead, we must speak up about our tremor, letting people know that we shake and that our shaking is caused by a condition called essential tremor. In doing so, we make others and ourselves much more comfortable. We don't allow essential tremor to define us.

Please continue talking about your tremor, educating and helping others along the way. Remember what it felt like when no one understood you. Our collective voice will help us be heard. We're in this together!



Shari Finsilver  
IETF Past-President



Shari Finsilver,  
Past-President  
IETF Executive  
Board

## IETF Welcomes New Executive Board President

The IETF acknowledges the service of Shari Finsilver as the former president of The Executive Board, and welcomes Peter LeWitt, MD who has assumed the duties as executive board president.

During Shari's two-year term, she had many accomplishments including organizing the IETF's first fundraiser, recruiting three new executive board members, participating in the creation of the IETF's support group leader's training video and assisting Catherine Rice, the IETF executive director with fund development.

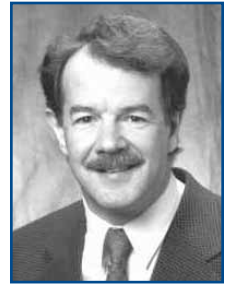
According to Catherine, Shari approached her duties as board president with, "a great passion for increasing public awareness about ET."

Mark Hallet, MD, IETF executive board member, was "impressed with Shari's leadership," and he found her to be, "thoughtful, resourceful and energetic."

Dean Cavey, IETF executive board treasurer, believed that Shari "was the right president for the right time in the development cycle of the IETF. Her enthusiasm, commitment and leadership were instrumental in moving the board and the entire organization to a new level."

Dr. LeWitt, incoming president, is a professor of neurology and psychiatry at Wayne State University School of Medicine in Detroit, MI, and is a board-certified neurologist sub-specializing in movement disorders in Southfield, MI. 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.

As a new member of the executive board, Dr. LeWitt said that he "hopes to return to those served by this organization (the IETF) some measure of the experience I have gained."



Peter, LeWitt, MD  
President IETF  
Executive Board

“We welcome Dr. LeWitt to The IETF Executive Board and look forward to his guidance and his leadership,” says Dean Cavey, “Dr. LeWitt’s professional experience will be extremely important to the IETF as the organization takes another step in its maturation process.”

Dr. Hallett adds, “Peter has a long standing commitment to patients with ET, and should be able to bring his medical expertise in promoting the goals of the organization.”

According to Catherine, the IETF is “extremely fortunate to have someone of Dr. LeWitt’s stature as president and we all look forward to working with him.”

## **Illinois state senator new IETF Executive Board member**

The IETF is pleased to welcome its newest Executive Board member, Illinois state Sen. Terry Link.



Sen. Terry Link

Link, D-Waukegan, was re-elected in 2002 to a 3rd 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.

As a new member of the executive board of the IETF, Link has several objectives: “First I want to get my story out to the public. I have been afflicted with ET for most of my life. Despite being exposed to this disorder, I have been able to overcome the symptoms and rise to an outstanding position within state government.

Using my position in office, I want to raise public awareness of the disorder and allow others to believe that even one diagnosed with ET can accomplish any goal they wish to achieve. I feel that it is extremely important for the public to be aware of the symptoms of ET, and the effects the disorder can cause within an individual’s life.

I will embrace the opportunity to serve on the Executive Board of IETF as a state senator and educate the public of this disease so we can build a common goal of identifying this affliction and finding a way to deal with it.”

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.

## IETF founder remembered

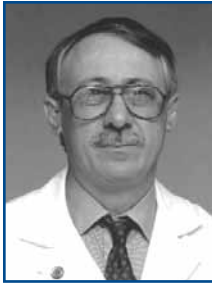
William (Bill) Koller, MD, founder of the IETF, died unexpectedly on October 3, 2005. He was 60 years old.

Born in Milwaukee, WI, July 12th, 1945, he received a PhD in Pharmacology from Northwestern University in Chicago in 1974 and a MD degree in 1976.

Koller founded the IETF in 1987 while serving as professor and chairman of neurology at the University of Kansas City Medical Center in Kansas City, KS.

More recently, he served as the National Research Director for the National Parkinson's Foundation at the University of Miami, and director of the movement disorders program at Mount Sinai Medical Center, New York City. His final position was at the University of North Carolina — Chapel Hill, NC where he was developing a movement disorder program.

IETF Executive Board members and staff remember Dr. Koller's contributions to the foundation and to the field of movement disorders:



William Koller, MD  
IETF Founder

*"I knew Bill for 18 years. I worked with him for 11 years at the University of Kansas Medical Center (KUMC) as the Administrator of Neurology while Bill was Chairman of Neurology. Seven years ago Bill provided me the opportunity to become involved with the IETF. I appreciate the confidence he had in my abilities to lead, and appreciate the opportunity I had to work with him. During those years, he founded the IETF and worked tirelessly to improve the lives of those with essential tremor. He developed the first Parkinson's Disease Center of Excellence at KUMC and was instrumental in helping obtain FDA approval of the deep brain stimulation device used in essential tremor today. Bill was heavily involved in the research of essential tremor and worked tirelessly to find better treatment. For those of us who knew and worked with Bill, he will never be forgotten and will be greatly missed. His legacy will live on."*

Catherine Rice, IETF executive director

*Death comes to all  
But great achievements build a monument  
Which shall endure until the sun grows cold.*

**Georg Fabricius**

*"Bill was a pioneer in getting the movement disorder community to focus on essential tremor. In the beginning movement disorders was focused on diseases of the basal ganglia and others were neglected. Bill not only began to pay attention to essential tremor, he ran the early clinical trials, and then was instrumental in starting the IETF."*

Mark Hallett, M, Executive Board member

*"I am grateful to Dr. Koller for having taken an active interest in ET and patients by starting the IETF and advancing the diagnosis and treatment of ET."*

Shari Finsilver, past-president,  
IETF Executive Board and essential tremor patient

## Independent Auditors' Report

Board of Directors  
IETF  
Overland Park, Kansas

We have audited the accompanying statement of financial position of International Essential Tremor Foundation (a nonprofit organization) as of March 31, 2006, and the related statements of activities, functional expenses and cash flows for the year then ended. These financial statements are the responsibility of the Organization's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of International Essential Tremor Foundation as of March 31, 2006, and the changes in its net assets and its cash flows for the year then ended, in conformity with accounting principles generally accepted in the United States of America.

DANA F. COLE & COMPANY, LLP  
Overland Park, KS  
June 23, 2006

## IETF

### Statement of Financial Position

#### Year Ended March 31, 2006

ASSETS	
CURRENT ASSETS	
Cash	<u>261,581</u>
PROPERTY AND EQUIPMENT	
Office equipment	31,893
Less accumulated depreciation	<u>(23,835)</u>
Net property and equipment	<u>8,058</u>
OTHER ASSETS	
Security deposits	<u>1,100</u>
TOTAL ASSETS	<u>270,739</u>
LIABILITIES AND NET ASSETS	
LIABILITIES	
Accrued expenses	<u>7,893</u>
NET ASSETS	
Unrestricted	88,710
Unrestricted – Board designated	<u>25,000</u>
Total unrestricted net assets	<u>113,710</u>
Temporarily restricted	<u>149,136</u>
Total net assets	<u>262,846</u>
TOTAL LIABILITIES AND NET ASSETS	<u>270,739</u>

# IETF

## Statement of Activities

### Year Ended March 31, 2006

	Unrestricted	Temporarily Restricted	Total
<b>REVENUES, GAINS AND OTHER SUPPORT</b>			
Contributions	56,809	39,711	96,520
Membership dues	307,748		307,748
Memorials and bequests	17,496		17,496
Honoraria	14,549		14,549
ET Community events		5,771	5,771
Other exempt function revenues	35,461		35,461
Interest	5,555		5,555
Amounts released from restrictions	<u>90,345</u>	<u>(90,345)</u>	<u>0</u>
Total revenues, gains and other support	<u>527,963</u>	<u>(44,863)</u>	<u>483,100</u>
<b>EXPENSES</b>			
Program expenses	426,122		426,122
Management and general expenses	78,158		78,158
Fundraising expenses	<u>26,053</u>	<u>0</u>	<u>26,053</u>
Total expenses	<u>530,333</u>	<u>0</u>	<u>530,333</u>
<b>CHANGE IN NET ASSETS</b>	<b>(2,370)</b>	<b>(44,863)</b>	<b>(47,233)</b>
<b>NET ASSETS, beginning of year</b>	<b><u>116,080</u></b>	<b><u>193,999</u></b>	<b><u>310,079</u></b>
<b>NET ASSETS, end of year</b>	<b><u>113,710</u></b>	<b><u>149,136</u></b>	<b><u>262,846</u></b>

# IETF

## Statement of Functional Expenses

### Year Ended March 31, 2006

	Program Expenses	Management and General Expenses	Fundraising Expenses	Total
Legal and accounting	6,114	1,146	382	7,642
Bank charges	3,060	574	191	3,825
Board member development	77	14	5	96
Board travel and meeting	2,986	560	187	3,733
Contractual services	2,880	540	180	3,600
Design work	960	180	60	1,200
Dues and subscriptions	276	52	17	345
Education and public awareness	129,472	24,276	8,092	161,840
Depreciation	2,994	298	99	3,391
Equipment maintenance	1,641	308	103	2,052
Specific assistance for research and development	15,644	2,933	978	19,555
Insurance	24,951	4,679	1,560	31,190
Lease	4,694	880	293	5,867
Maintenance	5,651	1,060	353	7,064
Miscellaneous	1,054	198	66	1,318
Office supplies	4,397	825	275	5,497
Salaries	126,916	22,317	7,439	156,672
Payroll taxes	8,932	1,675	558	11,165
Pension	2,371	445	148	2,964
Postage/freight	27,700	5,194	1,731	34,625
Printing	26,346	4,940	1,647	32,933
Rent	11,440	2,145	715	14,300
Repairs	119	23	8	150
Support groups	947	177	59	1,183
Taxes, licenses and fees	1,682	315	105	2,102
Telephone	4,759	893	298	5,950
Website maintenance	<u>8,059</u>	<u>1,511</u>	<u>504</u>	<u>10,074</u>
<b>TOTAL</b>	<b><u>426,122</u></b>	<b><u>78,158</u></b>	<b><u>26,053</u></b>	<b><u>530,333</u></b>

## Financial Report

### Gross Revenue

In comparing this year to last, April 1, 2005 through March 31, 2006, revenue increased \$27,850 or 6%. Membership dues revenue increased \$35,110 or 13% and the 2nd Fundraiser (Special Events) generated additional revenue of \$27,770 which was \$22,770 greater than in 2005. Grant revenue was \$17,000 higher than the same period last year. Research revenue decreased \$15,289 or 50% and bequest revenue decreased \$16,150 or 68%. In FY06, there was a greater emphasis placed on obtaining grant and membership revenue than acquisition of research funds thus creating the decline.

### Net Revenue

The net revenue decreased \$38,876 when comparing this year to last. This decrease occurred because there were grant funds awarded for community outreach in 2005 that weren't spent until FY06. Funds were drawn from equity to cover these costs.

### Expense

In comparing this year to last, total expenses increased \$66,727 or 15%. This increase is the result of growth in services necessitating more educational materials and community outreach. Community outreach was in part funded by grants provided by the Medtronic Foundation and Corporation. Program expenses accounted for 80%, Management and General Expenses 15% and Fundraising 5%.

## FY06 Milestones

- Increased membership dues revenue \$35,110 or 13% as compared to 2004/05. Dues revenue in 2005 was \$272,638 and \$307,748 in FY06.
- Increased membership renewal by 51 percent from 4,519 in 2004/05 to 6,825.
- Increased appeal donations by 3 1/2% from \$101,543 in 2004/05 to \$105,325 in FY06.
- Increased Presidents Club contributions by 12% from \$60,500 in 2004/05 to \$67,603 in FY06.
- Mailed essential tremor information packets to more than 5,469 individuals and families.
- Provided essential tremor information to more than 14,373 physician offices in the United States.
- Continued the development of a database of physicians who specialize in essential tremor.
- Added 1,601 new members in FY06.

## Membership Enhancements Continue

Becoming a member of the IETF not only keeps a person informed about new advancements in the treatment of essential tremor, it provides member benefits. In addition, those people who become members can do so in several different ways by choosing the membership plan that fits their needs as well as their giving pattern.

- The “Add a Member” program encourages members to add-on additional family and friends for a discounted fee of \$15 per person for the first year.
- The online membership provides members with additional benefits via the IETF website for \$15. The online membership includes participation in a live chat with a physician specializing in essential tremor three times a year, and unlimited access and downloading of all resource material on the website, including online newsletters.
- The various levels provide packages of incremental benefits: \$30 Basic; \$50 Bronze; \$100 Silver; \$250 Gold; \$500 Platinum; and \$1000 Presidents Club. Each giving level is provided packets of information, videos or DVD's commensurate with their giving level.

## Community Education Events Bring Grassroots Awareness

Just as in 2005, the IETF continued collaboration with local hospitals and physicians nationwide to bring information and awareness about essential tremor and the IETF to individuals and families affected by this condition — as well as to the general public — through a series of community education events.

During FY2006, 17 essential tremor educational events were held in communities across the United States. In addition to the educational value of these meetings, people were given the opportunity to meet with local physicians and to openly discuss treatment options.

The events were held in Baltimore, MD; Ashland, KY; Louisville, KY; Jacksonville, FL; Winston-Salem, NC; Atlanta, GA; Albuquerque, NM; Salt Lake City, UT; Las Vegas, NV; Tucson, AZ; Phoenix, AZ; Palo Alto, CA; Portland OR; Austin, TX; Peoria, IL; Chicago, IL; Manhasset, NY.

Supported by grants from the Medtronic Foundation and Corporation, these events not only are designed to provide patient education, but to increase public awareness about essential tremor in each community.

However, the benefits of the events don't stop there.

- *At the organizational level*, community education events allow the IETF to form relationships with local hospitals and the physicians within the communities who specialize in the diagnosis and treatment of essential tremor.
- *On the personal level*, as executive director, they introduce me to IETF members, essential tremor patients and their family members. At each event I have the opportunity to shake hands with these people we serve, and to gain further insight into how we can help. I listen to their needs and hear their complaints. Here at the IETF, their concerns are our concerns and are taken very seriously.

- *Physicians benefit too!* Although they explain the diagnosis process as well as the medical and surgical treatments that are available at these events, they also get to know the patients as people. They too walk away with greater appreciation for the essential tremor patient, and a respect for the strength and character of those who must live each day with the affects of this condition. They participate in a question and answer session following their presentations and provide all attendees with the opportunity to seek answers to unanswered questions.

Prior to each event a considerable amount of work is done to ensure success. Newspapers, radio and TV stations are contacted. Flyers are mailed to internists and family practice physicians in each community. Flyers are also distributed to hospitals, libraries, senior centers, retirement facilities, local neurologists, and churches. The support groups in each location help with registration and want to make everyone feel comfortable.

## The ET Community Education program has far reaching benefits

1. Provides valuable information to patients, friends and family who attend the events and those people share what they learn with other family members and friends in other locations.
2. Increases the quality of life for the persons affected by enhancing their ability to continue employment while discouraging isolation due to embarrassment and humiliation caused by the condition.
3. Provides the person affected with local support mechanisms and opens effective communication pathways within the community.
4. Presents the opportunity for IETF staff to provide effective community support.
5. Enables the IETF to utilize its media resources and media tools that have already been developed for use in many communities.
6. Encourages individuals to seek the treatment that best suits their needs by introducing them to the specialist within the community.

We are proud to say that the IETF provided educational information to approximately 7,000 people affected by ET; 14,373 physician offices (combination of internists, family practice and neurology); and 8,415 senior centers, hospitals, retirement homes, assisted living homes, pharmacies, and libraries.

### Print and Broadcast News

As a result of the marketing effort to increase public awareness in the above cities, 74 newspapers, 69 Television stations and 73 radio stations ran news about essential tremor.

## Surveys reveal that community education events have a significant impact

- Average attendance per event is 74 people
- Average number of surveys returned per event is 26.8
- Average percentage of surveys versus attendees is 36.2%
- The average person attending the event is 63 years old, Female (56%) and White, non-Hispanic (88.5%)
- The average person attending has a diagnosis of essential tremor (73%), was diagnosed with essential tremor at the age of 51.4 years and first noticed signs of essential tremor at the age of 42.3 years
- The attendees learned about the event through:
  - Flyer/Brochure mailings – 20%
  - Postcard mailings – 18%
  - Tremor Talk*, IETF's quarterly newsletter – 16%
  - Newspaper advertising – 11% (Used in approximately one-half of events)
  - Website – 8%
  - Family – 8%
  - Support Group – 5%
  - Friend – 5%
  - Physician – 5%
  - Other – 4%
- The average person was aware of the IETF before the event (55.6%), would recommend the event to others (96.8%) and want to be notified of future IETF events (92.4%)

## Education essential in medical decision making!

Because knowledge is essential to making informed choices, the IETF believes that quality information about essential tremor needs to be widely available. In FY06, the IETF continued to provide a variety of educational materials to the public, healthcare providers, and the media.

### Publications

- **Children with Essential Tremor, a Guide for Parents and Other Caring Adults.** Educates adults about essential tremor in children as well as ways to help children cope with the condition.
- **Coping with Essential Tremor.** Offers suggestions, ideas, and coping tips, provided by IETF members with essential tremor, for the benefit of others with essential tremor and their families.
- **Glossary of Terms.** Lists most common terms and definitions used in the diagnosis and treatment of essential tremor.
- **IETF Marketing Brochure.** (English and Spanish). Provides information about the IETF and briefly summarizes essential tremor.
- **Matching Gift Brochure.** Provides donors with information about how to take advantage of their employer's Matching Gift Program.
- **Medical Alert Card.** Provides a simple and quick reference about essential tremor that members can carry with them. Essential tremor is often mistaken for intoxication, so these cards help law enforcement officers, driver license bureau staff members, and others to understand the condition. The front of the card explains essential tremor's symptoms, asks that officials call the cardholder's family or physician, and lists information about the IETF. The back of the card has space for the cardholder's name and specific medical information.

- **A Patient Information Handbook.** (English and Spanish). Provides information about the diagnosis and treatment of essential tremor to English- and Spanish-speaking individuals.
- **Seek the Comfort of Another.** Provides information about local support groups.
- **Support Group Leaders Guide.** Describes in detail how to start a support group with suggestions for monthly meetings.
- **Surgical Treatment of Essential Tremor.** Reviews the history and surgical procedures for the treatment of essential tremor.
- **Tremor Disorders in Children, a Clinical Discussion.** Provides information for pediatric physicians whose patients include children with essential tremor.
- **Tremor Talk.** Provides information about new research, coping tips, advice and insights from medical experts, and ideas for spreading the word about essential tremor. Quarterly publication.

## Volunteers make the difference!

When it comes to giving time, IETF volunteers set the standard. During FY06, support group volunteers gave a total of 2,520 hours, averaging 210 hours per month. A total of 235 support group meetings were held during the year for an average of approximately 20 per month. Office volunteers assisting with mailings and other projects donated a total 185 hours for an average of approximately 16 hours per month.

To think of this in another way, the total value of volunteer time donated to the IETF during FY06, based on \$10 per hour, would equal \$27,050! This is only one reason why we believe that the IETF could not carry out its mission without the tireless devotion of our volunteers.

### A Team Effort for Distribution of Information

Support group leaders and support group volunteers distributed literature and answered questions at a variety of events and health fairs. These included:

- Colorado Health Fair, Denver, CO
- Several United Way Campaign speaking engagements including Hallmark Cards, Inc., Kansas City, MO
- Alamo Area Parkinson's Disease Symposium, San Antonio, TX
- The Meadows Senior Retirement Center, Glen Ellyn, IL
- In-Service Training Session, Northwestern Parkinson's Disease and Movement Disorders Center, Chicago, IL
- ET Public Relations Push, Portland, OR
- Santa Clara, CA Health Fair, Santa Clara, CA
- Colorado Statewide Movement Disorders Symposium, Colorado Springs, CO
- Home Health Agency in Chicago, IL
- Numerous small health fairs throughout the United States

## Support groups are the backbone of the organization

IETF support groups are informal, self-managed resources for people who have essential tremor as well as the people who love and care for them. Members share information about and ideas for living with essential tremor, and they provide support and real-life wisdom. Since 1998, the number of support groups has grown from 14 to 76.

People who have essential tremor rank quality-of-life issues and emotional support at the top of their needs. Staff member Debbie Lovelace coordinates the formation of new support groups and provides support for existing groups.

### Satisfaction is the reward for being a support group leader

Admittedly, being an essential tremor support group leader requires hard work. But in return, it provides a number of rewards as testified to by the following leaders when asked what they found to be the most rewarding aspect of leading a support group:

**Diane Breslow**, Chicago, IL: "...being witness to the personal, meaningful connections that develop among the participants."

**Tim Duvall**, Appleton, WI: "...the open sharing of how each of us has coped with specific problems."

**Dorothy Lewis**, Kansas City, MO, KS: "...being with others with the same problems, and sharing useful information."

**Suzanne Reichwein**, Philadelphia, PA: "...the members who faithfully come to each group. They are such an enjoyable bunch and seem to get something out of every presentation."

**Alta Rudomin**, Los Angeles, CA: "...spreading the word about essential tremor to the ever-increasing number of people we are reaching whether through newspaper announcements or flyers."

**Jim Tremblay**, San Antonio, TX: "...knowing that we've touched more than 60 folks, and they have grown to better understand and cope with their ET. Many of us have gained a significant increase in our circle of close friends."

**Doug Ward**, Glen Ellyn, IL (Chicago area): "I always return home (from a support group meeting) with a feeling that the time was well spent, and realizing that several people have been helped, and that information has been exchanged. The participants often express their thanks for providing a meaningful time of sharing."

### Support group locations

**Alabama:** Madison

**Arizona:** Chandler, Phoenix, Sedona, Sun City, Sun Lakes, and Tucson

**California:** Calimesa, Clovis, La Jolla, Los Angeles, Northridge, Pleasanton, Sacramento, San Jose, and Santa Barbara

**Colorado:** Loveland

**Delaware:** Dagsboro and Lewes

**England**

**Florida:** Tampa, Margate, West Palm Beach Gardens

**Hawaii:** Kaawa

**Illinois:** Chicago, East Peoria, Glen Ellyn, Libertyville, Northbrook, and Rockford

**Indiana:** Schererville

**Iowa:** Burlington, Cedar Rapids

**Kansas:** Overland Park

**Kentucky:** Henderson

**Louisiana:** Baton Rouge

**Massachusetts:** Chicopee

**Mexico:** Mexico City

**Minnesota:** Minneapolis

**Michigan:** Orchard Lake and Saginaw

**Missouri:** St. Louis and Kansas City

**Nebraska:** Omaha

**New Mexico:** Albuquerque

**New York:** Mahopac

**New Zealand**

**Ohio:** Aurora, Hilliard, Newark, New Philadelphia, and Warren

**Oklahoma:** Ardmore and Oklahoma City

**Oregon:** Eugene, Portland

**Pennsylvania:** McKeesport

**South Carolina:** Aiken

**South Dakota:** Sioux Falls

**Texas:** Cleburne, San Antonio, Tomball, and Windcrest

**Virginia:** Lexington

**Washington:** Spokane

**Washington DC**

**Wisconsin:** Appleton and River Falls

## Research — IETF members contribute \$14,960 for research during FY06!

Research into the etiology, pathogenesis, and treatment of essential tremor is important to finding effective treatment and, ultimately, a cure. IETF funding supports innovative research that also has the potential for receiving substantial support from the National Institutes of Health and other sources. Research continued in FY06 with the funding of a new project and the completion of a project funded in 2005.

### Conference on essential tremor identifies research goals

*Extracted from the Executive Summary prepared by Rodger J. Elble, MD.*

Essential tremor is not a lethal condition. Because of this, few grant requests have been submitted to the National Institutes of Health for research into essential tremor. Among numerous deficiencies in essential tremor knowledge is that no consistent set of characteristics has been defined for this disorder, and no essential tremor gene has been identified. A better understanding of this condition and better treatment options are needed.

In addressing this crisis in research, the IETF, along with The National Institute of Neurological Disorders and Stroke, the United States Army Medical Research and Material Command and four other organizations, funded the 2005 "Consensus Conference on Essential Tremor." Held in Washington, DC, October 21 – 22, 2005, researchers attending the conference identified six objectives as being most important for future research in essential tremor. These include:

- Creating a collaborative network of research centers sharing research data, findings and ideas.
- Forming an international committee to standardize assessment criteria for essential tremor, and creating tremor scales that are suitable for research studies as well as routine office assessments. These scales would acknowledge the severity of impact on motor function, activities of daily living and quality of life concerns.
- Identifying one or more genes for essential tremor, which is the primary piece of the puzzle in understanding the abnormalities in brain function caused by essential tremor, and in finding a cure.

- Creating a centralized repository of reproducing human cell lines containing DNA from families with well-defined essential tremor.
- Creating a centralized repository of brain cell samples well-defined essential tremor patients after death.
- Developing animal models of essential tremor so that pharmaceutical companies can screen for promising drugs.

In addition, a further recommendation was made to utilize the skills of a movement disorder neurologist in research studies to diagnose persons with essential tremor and to identify persons without essential tremor to use as controls.

The diagnostic definition of ET was set as being the same as recommended at the International Tremor Conference in Kiel, Germany in 1997.

According to the Kiel criteria, definite essential tremor is abnormal action tremor of one or both arms, or isolated head tremor with no abnormal head positioning, dystonia or other neurologic signs. Conference participants did recognize that some researchers believe that isolated head tremor is only “possibly” essential tremor, but for the purpose of standardizing research criteria, isolated head tremor, without the above noted conditions, will be classified as essential tremor.

A problem for genetic research in essential tremor was acknowledged in that no reliable method of distinguishing mild essential tremor from enhanced physiologic tremor exists. Due to the limited value of electrophysiologic tests, many individuals with mild essential tremor will remain undiagnosed, creating inaccurate prevalence estimates.

Additional areas suggested for future research include: Healthcare costs produced by essential tremor, the natural history of essential tremor and environmental risk factors and their interaction with genetic factors.

The conference was attended by more than 70 researchers representing academic neurology departments from throughout the United States, and from the National Institutes of Health. Dr. Leslie Findley represented The National Tremor Foundation of London, UK.

## **Centralized Brain Repository — Study finds essential tremor diagnoses to be valid**

A recent study conducted by The Essential Tremor Centralized Brain Repository found that 94 of 100 participants, who were previously diagnosed with essential tremor, had correct diagnoses. Most of the remaining subjects were found to have Parkinson’s disease.

In addition to confirming the validity of essential tremor diagnoses, researchers wanted to characterize the clinical signs of essential tremor in a highly selected group of subjects in order to represent an extreme population suited for specialized research such as genetics.

## **Two rare gene mutations possibly linked with familial essential tremor**

Two rare HS1BP3 gene variants have been found more frequently in Americans with familial essential tremor than in persons with non-familial essential tremor or without essential tremor.

This is the finding of the 2005 IETF W. Carroll Beatty and Thelma D. Beatty Bequest research grant funded study “Analysis of Candidate Genes for Familial Essential Tremor.” This project was conducted by a team of researchers, lead by Dr. Joseph J. Higgins, at the Center for Human Genetics and Child Neurology at the Mid-Hudson Family Health Institute in New Paltz, NY.

According to Dr. Higgins, it is possible that essential tremor is not caused by a single genetic variant, as is currently believed, but is a “complex disorder that involves several genes.” He also points out that “it is unclear if these genetic variants actually cause essential tremor, or, as in many other common human disorders, it is an interaction between these variants and other genes and the environment that is the cause.”

HS1BP3 variations are believed to affect dopamine metabolism, according to Dr. Higgins.

These research findings, he adds, are “an exciting advance toward designing treatments for essential tremor. In the future the hope is to implement therapeutic interventions before the appearance of symptoms to partly or completely prevent essential tremor.”

Dr. Higgins is a Fellow of the American Academy of Neurology and board certified in neurology with special qualifications in child neurology. He is a Diplomate of the American Board of Pediatrics and board certified in general pediatrics. In addition to his position at Mid-Hudson, Dr. Higgins is an associate clinical professor of neurology and pediatrics at Albany Medical Center, Albany, NY.

## **Presidents Club honors IETF member leaders**

We extend a very special thank you to all our FY06 Presidents Club members. Your generosity helped bolster many educational, research, and support programs the IETF provided for the general public, and for people affected by essential tremor. The Presidents Club was established by the IETF Executive Board in 2005 and it is the first such group in the essential tremor community. The group was established so the IETF could honor members who regularly contributed \$1,000 or more each year.

### **Presidents Club**

The IETF would like to recognize and thank the members of the Presidents Club FY06. Without their valuable support and leadership, the IETF would not be moving forward in the mission of providing global educational information, services and support to people with essential tremor. Thank you!

*Ms. Judy Atkinson*

*Mr. John Barkley*

*Mr. Paul Broyhill &  
Mr. Paul H. Broyhill*

*Mr. & Mrs. John Cakebread*

*Ms. Lillian Courtheoux*

*Mr. & Mrs. Al Davis*

*Mr. and Mrs. Stan &  
Shari Finsilver*

*Ms. Anna Fischer*

*Mr. & Mrs. Richard Frinier*

*Ms. Carol Grassel*

*Ms. Carol Gruen*

*Mrs. Diana Gustafson*

*Mr. & Mrs. Martin Holford*

*Mr. Robert Jaffe*

*Mr. & Mrs. Theodore Leber*

*Philippe Loustaunau, Ph.D.*

*Dr. Robert Maddox*

*Mr. John Mancino*

*Ms. Stephanie Mendel*

*Ms. Donna Miller*

*Mr. & Mrs. Herbert J. Myers*

*Mrs. Consuelo G. Nichols*

*Mrs. Rosemary W. Nothwanger*

*Ms. Dorothy Ott*

*Mr. & Mrs. Roland Pohlman*

*Richard and Helen  
DeVos Foundation*

*Mr. and Mrs. John &  
Joan Robbins*

*Ms. Lynda Robinson*

*Mr. & Mrs. Alan Spoon*

*Mrs. Joan Stearns*

*Mr. William Teweles*

*Ms. Margaret B Thaw*

*Mrs. Leah Wickham*

*Ms. Leonara Zamuco*

## Matching gifts

We thank the many companies who donated to the IETF in FY06 through their Matching Gift programs. And we thank all our IETF members who generously made these matching gifts possible.

ABBOTT LABS  
*Ms. Jacqueline Knue*

BP AMOCO FOUNDATION, INC  
*Mr. & Mrs. Bob Wagner*

ITW FOUNDATION  
*Ms. Linda Curcio*

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*Ms. Donna Miller*

## Foundation and Corporate Contributors

The Broyhill Family Foundation  
The Medtronic Corporation  
The Medtronic Foundation

## Trusts and Bequests

Barbara Kurtz - \$2,978  
Howard Fisher Trust - \$3,505

## Looking ahead

IETF programs and projects for FY07 are well under way.

### Essential tremor community education events

The IETF will hold 21 events in FY07, with the collaboration of area hospitals and healthcare professionals to provide the most up-to-date information about essential tremor to patients, their families, and related healthcare providers.

### Volunteer program

IETF staff is scheduled to begin another round of volunteer management training sessions. Because the volunteer program continues as a priority for FY07, the IETF will continue to work on the development of a volunteer handbook and in recruiting community volunteers.

### Support Group Leader Training

It is recognized that not everyone learns using the same media resources. Some would prefer to read manuals while others prefer to listen to audio tapes or learn through DVD's. In order to accommodate everyone's preferred learning method and to enhance the support group leader training materials, the IETF will begin work on the development of a support group leader training DVD. Once completed, the DVD will be mailed to each prospective leader as well as the current leaders. A revised written support group leader guide will accompany the video.

### Board Member Recruitment

Recruiting volunteers for board membership can be challenging. Especially with the fast paced, multi-tasking lives we live. There never seems to be enough time for ourselves let alone time to volunteer. The IETF understands the time constraints and will be working to include e-mailing and conference calling as a way to get board members together beyond the two meetings a year. In FY07 the IETF will be seeking out additional persons who are interested in board service with recruitment utilizing the newly created orientation policies and board training methods that were set forth in FY06.

## Research

Another research proposal will be funded in FY07. As in FY06, the IETF will give \$50,000 to another researcher to help find a cause for ET. In FY06 not only did the IETF fund a genetic study in the amount of \$50,000, it funded an additional \$20,000 toward the Research Consortium meeting in collaboration with the National Institutes of Health as was discussed previously.

## Tremor Facts

- Essential tremor is a neurological disorder that causes the hands, head, voice, legs, or trunk to shake rhythmically.
- Although there are many possible causes of tremor, essential tremor is the most common.
- People who have essential tremor become disabled at worst and feel frustrated or embarrassed at best.
- Experts estimate that up to 10 million Americans have essential tremor — more than double the estimated 4.6 million people who have Alzheimer's disease.
- Essential tremor is often misdiagnosed as Parkinson's disease, which affects approximately 1 million people in the United States.
- Essential tremor is not gender, age or race specific. It is false to assume that essential tremor is confined to the elderly. Children and the middle-aged can also develop essential tremor. In fact, newborns and infants have been diagnosed with the condition.
- Essential tremor is caused by abnormal communication between certain areas of the brain. While the cause is unknown, there is evidence that essential tremor is genetic. That means each child of a parent who has essential tremor has a 50 percent chance of inheriting a gene that causes essential tremor. Sometimes, however, people with no family history of tremor develop essential tremor.
- There are a few effective medical treatments available for essential tremor. Unfortunately, it is estimated that less than 60% of people with essential tremor are helped by these medications. In addition, many experts believe that only a small percentage of people who have essential tremor seek medical assistance.
- Researchers estimate that 4 to 5.6 percent of people aged 40 to 60 have essential tremor. The incidence rate for people age 60 and older is estimated at 6.3 to 9 percent.

## Current IETF Leadership

### Board of Directors

President: Shari Finsilver

Vice President: Kelly Lyons, PhD

Secretary: Edward M. Block, PhD

Treasurer: Dean Cavey

Past President: L. William Teweles

H. Michael Dwan

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Joseph Jankovic, MD

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Anthony E. Lang, MD

Peter Lewitt, MD

Elan D. Louis, MD

A.H. Rajput, MD

## **IETF staff**

Executive Director:  
*Catherine Rice*

Database Manager:  
*Kelly Schroeder*

Marketing/Public Relations: Volunteers, support groups and newsletter  
*Debbie Lovelace*

Marketing/Public Relations: Community relations and events  
*Judy Blankenship*

Administrator of Patient Programs in England:  
*Karen Walsh*

## **Mission**

Founded in 1988, the IETF is a 501(c) (3) corporation. The purpose of the IETF is to provide global educational information, services, and support to those affected by essential tremor (ET), and to healthcare providers, while promoting and funding ET research.

Once again in FY07, The IETF board and executive director re-commit our allegiance to you, the people we serve. The ET community deserves and will receive the highest standards from the IETF. We promise to:

- Manage with care your donated funds.
- Value your support and to honor your requests.
- Guard the trust you have placed in us.
- Remain loyal to you.
- Act ethically, and in good faith without regard to personal interests.
- Assure that laws are followed.