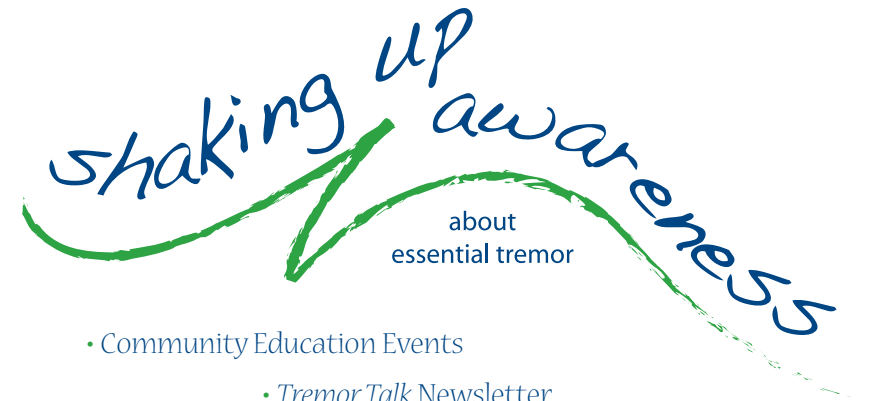




INTERNATIONAL
ESSENTIAL TREMOR
FOUNDATION



- Community Education Events
 - *Tremor Talk* Newsletter
- Support Groups
 - Free Patient Information Packets
 - IETF Website
 - Physician Referrals
- Community Outreach through Media

12 Month Annual Report

April 1, 2006 through March 31, 2007

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 • Website: www.essentialtremor.org

IETF Leadership

Board of Directors

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Peter LeWitt, MD

Vice President:

Kelly Lyons, PhD

Secretary:

Edward M. Block, PhD

Treasurer:

Dean Cavey

Past President:

Shari Finsilver

Past President:

L. William Teweles

Mark Hallett, MD

State Senator Terry Link

Elan Louis, MD

Celeste Null, MS

Russ Rosen, MS

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William Ondo, MD

A.H. Rajput, MD

Sara S. Salles, DO

Kapil D. Sethi, MD

Mark Stacy, MD

Ray L. Watts, MD

Executive Director

Catherine Rice, BBA, MNM

Know the facts about ET

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

ET community education events. The IETF will continue the successful practice of holding community education events in cities across the United States. With the collaboration of area hospitals and healthcare professionals, 25 events will be held during FY08 to provide the most up-to-date information about ET to patients, their families, and related healthcare providers.

Product development. In order to increase revenues, the IETF will develop and sell items that will also serve as marketing tools in raising awareness about essential tremor. Items under consideration include colored silicone bracelets, tote bags, window decals, polo style shirts, sun visors or caps, and coffee mugs.

Research

Two research projects will be funded during FY08. "Neural Correlates of Essential Tremor," Dr. Khalaf Bushara, has been approved for a \$25,000 grant. "Postmortem Neurochemical Alteration in Essential Tremor Patients: A Clinicopathologic Study of Essential Tremor," Dr. Frederic Calon, has been approved for a \$25,000 grant.

Tulips for Tremor. Following up on the regional success of the IETF's first fundraiser, *An Enchanted Afternoon Home and Garden Tour*, the IETF will conduct its first national fundraiser that will include national media exposure made possible through the generosity of sponsors. Tulip bulbs will be offered for purchase with the proceeds going to the IETF. It is the intention of the Foundation to make this an annual fundraising event.

IETF staff

Executive Director:
Catherine Rice

Marketing/Public Relations Specialist
(volunteers, support groups, Tremor Talk):
Debbie Lovelace

Marketing/Public Relations Specialist
(community relations, events):
Dee Ragan

Membership Coordinator:
Carol Rucker

Administrator of Patient Programs in England:
Karen Walsh

Mission

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

Again in FY07, the IETF Board members and executive director re-committed their allegiance to you, the people we serve. The ET community deserves and will receive the highest service and standards from the IETF. We promise to:

- Manage with care your donated funds.
- Value your support and 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.

From the executive director

Fiscal year 2007 (FY07) for the IETF was about the future. It marked a period of difficult but important realizations about how the organization must change in order to survive, an expansion in the ideology as well as the activity of raising awareness about ET, and a continued vested interest in ET research.

FY07 was a year of challenges and growing pains for the IETF. With these challenges came the realization that the IETF's future depends upon the organization's ability to change.

One specific challenge of FY07 was the direct effect of world events. The monetary necessities of assisting victims of natural disasters negatively affected memberships and donations during most of the year. By the close of FY07, things began to pick up once more, and donations in FY08 are currently 68 percent greater than the same period in FY07.

But the financial realities of FY07 are not lost upon us. What we learned was that the IETF might be able to exist on membership donations only – at least until the next series of major disasters – but the organization will neither grow nor expand services or awareness without other sources of funding.

With this realization, the IETF shifted a great deal of focus onto obtaining grants from various sources as well as developing a national fundraising campaign and a fundraising product line. The results of this change of focus are just now being seen in FY08 in terms of very positive financial growth as well as awareness of ET and the IETF in the media.

Though FY07 does not look like a successful year when crunching numbers, the change in focus it demanded created an atmosphere of excitement and accomplishment that is going to pay off in big ways during the coming years.

One of the most important changes during FY07 was the development of an organizational branding identity. *Shaking Up Awareness About ET* is our slogan and logo for future awareness campaigns.



Catherine Rice,
Executive Director

Looking ahead

Continuing to build on our strong foundation, IETF programs and projects for FY08 are well under way.

Community Ambassador Program. Made possible by the Medtronic Foundation, this program will enable the IETF to recruit four professional volunteers from communities across the United States to represent the IETF at health fairs and other community events, distribute literature about ET and the IETF, assist in the formation and maintenance of support groups, and perform other activities as required. Community Ambassador Program goals are to:

- Increase awareness about ET within each community by distributing educational materials to the public, institutions, businesses, and those affected by ET.
- Help develop and increase the number of support groups to meet emotional and social needs.
- Act as a local contact for quality educational information, referral to specialists, and coping mechanisms.
- Develop and increase fundraising potential assuring an ongoing program by linking available community resources with the IETF to help develop chapters in specific geographic areas.
- Partner with and provide educational information that will enhance the patient-healthcare provider relationship. The IETF will act as a support system in tandem with healthcare providers.

The Community Ambassador Program essentially ensures that support will be provided in many diverse areas at the local level to meet the needs of those with ET.

Chapter development. A grant request will be prepared and submitted to AmeriCorps for funding to plan the development of one to four chapter offices that will serve various U.S. regions. Supervised by the IETF office in Lenexa, KS, the chapter offices will assist in serving those affected by ET, increasing awareness of ET, and raising funds for research that will lead to better treatments and possibly a cure.

Matching gifts

We thank the many companies who donated to the IETF in FY07 through their matching gift programs. And we thank all our IETF members who generously made these matching gifts possible.

ALADKA TANKER COMPANY, LLC
Bruce Benn

MAYTAG CORPORATION FOUNDATION
Mr. and Mrs. Donald Siebert

EXXON MOBIL FOUNDATION
Vernon Johnson

PFIZER FOUNDATION MATCHING GIFTS PROGRAM
Robert Lester

QUEST DIAGNOSTICS
Jodi Zdinak

SEARS
Doreen Stachowski

SQUARE D FOUNDATION
Robert Fuller

VERIZON FOUNDATION
Mr. and Mrs. James Franken

Foundation and Corporate Contributors

The Broyhill Family Foundation
The Medtronic Corporation
The Medtronic Foundation
Montrose Secam, LTD

Trusts and bequests

Howard Fisher Trust, \$41,675

Along with the crafting of this branding tool, planning of future awareness campaigns to supplement current community education programs took precedence. Many activities and events that are being carried out in FY08, and that will be carried out in years to come, were born and tailored during FY07.

One major event is the IETF's first-ever national fundraising campaign Tulips for Tremor, which provides outstanding national media exposure. Other projects born of FY07 include the Community Ambassador Program as well as chapter planning and development.

But change on a grand scale does not mean all things are altered. Research is part of the IETF mission and remained a priority during FY07. The IETF renewed its mission to fund research into the cause(s) of ET by funding two projects through the generosity of our members. These projects are:

- Dr. Khalaf Bushara, Minneapolis Veteran's Administration Medical Center, "Neural Correlates of Essential Tremor," \$25,000.
- Dr. Frederic Calon, Molecular Endocrinology and Oncology Research Center at Laval University Medical Center, Quebec City, Canada, "Postmortem Neurochemical Alteration in Essential Tremor Patients: A Clinicopathologic Study of Essential Tremor," \$25,000.

Because you are a valued member of the IETF, we hope you will get excited with us and choose to participate in the many opportunities that will be available to you in the future. You are our focus!

Sincerely,



Catherine Rice
Executive Director

New Executive Board members share ET stories, goals

Celeste Null, MS

What strengths do you bring to the IETF Executive Board?

My primary strengths are strategic development, biomedical engineering, ideation, and being a learner. My secondary strengths include the ability to look systematically at challenging issues as demonstrated in my 27-year background in industry. The application of vision and implementation of the convergence of biotechnology and semiconductor technology have guided my passion.



Celeste Null, MS

What goals do you have as a board member?

I would like to see ET as well known and as well funded as Parkinson's disease through strategic collaborations with academia, research, and industry. As a learner and leading biomedical engineer at Intel Corporation's Digital Health Group who happens to have ET, I'd love to see product incubation ideas that respond to the growing Boomer population.

Presidents Club honors IETF member leaders

We extend a very special thank you to all our FY07 Presidents Club members. Your generosity helped bolster many educational, research, and support programs the IETF provided for the general public, for people who have been diagnosed with ET, and for people affected by someone who has ET. The Presidents Club was established by the IETF Executive Board in 2005 and is the first such group in the ET community. The group was established so the IETF could honor members who regularly contribute \$1,000 or more each year.

The IETF recognizes and thanks the members of the Presidents Club FY07. 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 ET. Thank you

Ms. Judy Atkinson
Mr. John Barkley
Mr. Paul H. Broyhill
Mr. & Mrs. John Cakebread
Ms. Lillian Courtheoux
Ms. Virginia Culver
Mr. & Mrs. Al Davis
Stan & Shari Finsilver
Ms. Anna Fischer
Ms. Juanita Froelich
Mr. & Mrs. Richard Frinier
Mr. Robert G. Grahamslow
Ms. Carol Grassel
Ms. Carol Gruen
Mrs. Diana Gustafson
Mr. & Mrs. Martin Holford
Mr. Robert Jaffe
Mr. & Mrs. Theodore Leber
Ms. Elizabeth McQuale
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 & Helen DeVos Foundation
Mrs. Joan Robbins
Mrs. L. Everett Roberts
Ms. Susan Robinson
Mr. & Mrs. Alan Spoon
Mrs. Joan Stearns
Mrs. Walter Telly
Mr. William Teweles
Ms. Margaret B Thaw
Mr. James Thomas
Ms. Nancy Uppal
Dr. & Mrs. Douglas Ward
Mrs. Leah Wickham
Ms. Leonara Zamuco

Research

Research update

Research has shown that the cerebellum, the part of the brain that uses information from the senses to control movement and coordination, plays a major role in the occurrence of ET. A problem in the process of information transfer from the senses to the cerebellum through another part of the brain called the inferior olive is one possible cause of ET.

To determine if an abnormality of the inferior olive is involved in ET, an IETF grant from the W. Carroll Beatty and Thelma D. Beatty Bequest was awarded during FY07 for "The Requirement of the T-type Calcium Channel Cav3.1 for Tremor Expression in Two Rodent Models of Essential Tremor." This research is being conducted by Arnulfo Quesada, PhD, and Adrian Handforth, MD, of the Veterans Affairs Greater Los Angeles Healthcare System, Research and Neurology departments.

Dr. Handforth has requested an extension on his research report to the IETF until March 2008, explaining, "I am not altogether comfortable describing unpublished work."

New research

During FY08, two projects will receive research funding.

Dr. Khalaf Bushara, assistant professor of neurology at the Minneapolis Veteran's Administration Medical Center, will receive \$25,000 for a project titled "Neural Correlates of Essential Tremor." The objective of this research will be to apply noninvasive magnetic resonance imaging technology (MRI) to identify neural correlates of ET and to develop a non-invasive method to diagnose and monitor treatments.

Dr. Frederic Calon, assistant professor, Molecular Endocrinology and Oncology Research Center at Laval University Medical Center, Quebec City, Canada, will receive \$25,000 for a project titled "Postmortem Neurochemical Alteration in Essential Tremor Patients: A Clinicopathologic Study of Essential Tremor." This research will focus on postmortem neurochemical investigations of the cerebellum of ET patients to identify alterations with the intent of developing new treatment strategies.

Russ Rosen, MS

What strengths do you bring to the IETF Executive Board?

I have 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. With a master's in social work administration, my career has been about helping people.



Russ Rosen, MS

Now that I am moving into my retirement stage, I want to continue to make a difference in people's lives and this is a great place to achieve my personal goals.

What goals do you have as a board member?

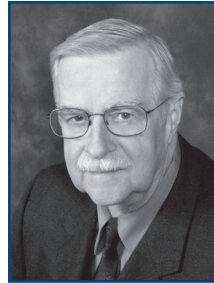
Arlene and I have been married for almost 40 years. Her mother was diagnosed with familial tremor. About nine years ago, Arlene was diagnosed with ET and began to start taking a variety of medications. I was brought up that one should take as few medications as possible and, therefore, I was not as supportive as I should have been. I was concerned, but with limited experience and knowledge, I could only be ineptly supportive.

After attending the support group meetings in Dayton, OH, I began to better understand what Arlene and other support group members were experiencing. I was especially struck by the high level of emotional support and help with coping skills. I want to strengthen the support groups with the resources to expand their efforts in reaching out and helping as many people as possible. I also want to work to help find the cure.

Doug Ward, PhD

What strengths do you bring to the IETF Executive Board?

I have served on local, national, international, and state-level boards for more than 40 years. This experience makes me very familiar with the responsibilities and expectations present in an appointment to a board such as that of the IETF.



Doug Ward, PhD

There is a responsibility to become knowledgeable about the policies and procedures of the board and to be an active advocate for the IETF and its various initiatives. It has been a role for me to continually seek to expand the activities of the groups I am involved with by seeking members, developing new programs, and significantly expanding revenues. I consider each of these areas of activity to be key roles for board members. I also have a network of contacts, most significantly through the osteopathic medical profession and the higher education community, which could be of assistance to the IETF Board. In addition, I currently serve in support of two international medically related boards with interests that span the entire globe.

What goals do you have as a board member?

First, I would seek to educate myself on the operations of the board itself and the existing expertise that is found within the board.

Also, I would be in a position, I believe, to assist in the development and promotion of a major fundraising activity, perhaps on a broad scale and in the greater Chicago region.

In addition, I would like to explore the current state of knowledge and activity regarding education about ET throughout the osteopathic medical colleges and postgraduate training programs and seek to distribute ET information throughout that system of 60,000 physicians and students.

New Zealand: Lower Hutt

North Carolina: Asheville, Wilmington, western North Carolina

Ohio: Aurora, Cincinnati/Dayton, Hilliard, Newark, New Philadelphia, Warren

Oklahoma: Ardmore, Oklahoma City

Oregon: Eugene, Portland

Pennsylvania: McKeesport

South Carolina: Aiken

Texas: Cleburne, San Antonio, Tomball, Windcrest

Virginia: Lexington, Roanoke

Washington: Spokane

Washington, DC: Georgetown

Wisconsin: Appleton, River Falls

Support group locations

Alabama: Madison

Arizona: Chandler, Phoenix, Prescott, Sedona, Sun City, Sun Lakes, Tucson

California: Calimesa, Clovis, La Jolla, Los Angeles, Northridge, Pleasanton, Sacramento, San Diego, San Jose, Santa Barbara, Stanford.

Colorado: Loveland

Delaware: Dagsboro, Lewes

England: Essex

Florida: Tampa, Margate, West Palm Beach Gardens

Idaho: Boise

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

Indiana: Schererville

Iowa: Burlington, Cedar Rapids

Kansas: Overland Park

Kentucky: Henderson

Louisiana: Baton Rouge

Maryland: Baltimore

Massachusetts: Chicopee

Mexico: Mexico City

Michigan: Orchard Lake, Saginaw, Detroit

Missouri: St. Louis, Kansas City

Nebraska: Omaha

New Mexico: Albuquerque

New York: Mahopac

Meet new IETF Medical Advisory Board members

Four new members recently joined the IETF Medical Advisory Board. They are Sara S. Sales, DO; Kapil D. Sethi, MD; Mark A. Stacy, MD; and Ray L. Watts, MD.

Sara S. Salles, DO

Dr. Sales received her medical training at the University of Health Sciences-College of Osteopathic Medicine in Kansas City, MO, and completed her residency in physical medicine and rehabilitation at the University of Kentucky in Lexington. Since then, she has devoted her career to caring for individuals with impairments and disabilities as a result of neurological disorders. Dr. Salles is especially interested in persons with movement disorders and is actively involved in the multi-disciplinary care of patients with ET.



Sara S. Salles, DO

As a Medical Advisory Board member, Dr. Salles describes her goal as helping to “expand general public awareness of ET and all treatment options available.” She would also like to increase awareness about rehabilitation options that can help simplify daily living for people who have ET.

Mark Stacy, MD

Dr. Stacy completed his medical education at the University of Missouri, his neurology residency at Hahnemann University, and movement disorders fellowship at Baylor College of Medicine. He has served as a faculty member for the University of Missouri; Barrow Neurological Institute, Phoenix, AZ; and Duke University Medical Center. Dr. Stacy is currently director of The Duke University Movement Disorders Center and is an associate professor in The Division of Neurology. He also serves as director of The Neuroscience Clinical Research Center and supervises all clinical research activity for neurology. He is a member of the Movement Disorders Society and the American Neurological Association.



Mark Stacy, MD

"I am honored to be part of the IETF Medical Advisory Board," Dr. Stacy says. "My goal is to participate fully as a reviewer and to increase the number of submissions from our movement disorders and bench science colleagues."

Kapil Dev Sethi, MD

Dr. Sethi earned his medical degree at the Christian Medical College, Ludhiana, India. He served his residency in internal medicine at the Post Graduate Institute of Medical Education and Research, Chandigarh, India, where he also underwent fellowship training in neurology. Dr. Sethi continued his medical education by completing a research fellowship in neurology at the Charing Cross Group of Hospitals and Medical School, London, UK. Dr. Sethi is professor of Neurology at the Medical College of Georgia, Augusta, Georgia, where he is also director of the Movement Disorders Clinic and the National Parkinson Foundation Center of Excellence.



Kapil Dev Sethi,
MD

"My goal as IETF medical Advisory Board member will be to encourage more bright young minds to investigate the basic mechanisms underlying essential tremor that will lead to better treatments in the future," says Dr. Sethi.

Shari Finsilver, Detroit, MI area. Shari's group is large, perhaps the IETF's largest support group. The group has funds to market the group aggressively through traditional media and the Internet and to pay for certain services. Shari has a professional approach to running the group and depends on volunteers to assist with day-to-day functions. Very few support groups will ever reach this size or level of sophistication, but if it is your goal to create such an organization, you will find a true mentor in Shari! She is always willing to help new members get started.

Linda Hope, Loveland, CO. Linda has grown a medium-sized, group in Colorado that is very active in getting word about ET out to the general public while still offering intimate support for members. Linda markets the group at health fairs and medical conferences and has a very approachable style that makes everyone feel welcome and cared about as individuals. Most essential tremor support groups are like this one.

Diane Breslow, Chicago, IL. Diane has a small niche group among several groups within the Chicago area. It is supported partially by Northwestern University's movement disorders clinic, an arrangement approximately one-fourth of support groups have with medical entities. Diane combines the personal character of the medium-sized group with the professionalism and resources of the largest type of group and adds a dash of academic savvy to boot!

Support group, office volunteers serve with pride

When it comes to giving time, IETF volunteers set the standard. During FY07, support group volunteers gave a total of 1,371 hours, averaging 114 hours a month! A total of 101 support group meetings were reported to the IETF office during the year for an average of approximately nine per month. Office volunteers assisting with mailings and other projects donated a total of 305 hours for an average of approximately 26 hours per month.

To think of this in another way, the total value of volunteer time donated to the IETF during FY07 based on \$15 an hour equaled \$20,565! This is proof positive that the IETF would find it difficult to carry out its mission without the tremendous effort of our volunteers.

Support group leaders start and lead support groups, but what is an ET support group?

Since 1998, the number of support groups has grown from 14 to 81. People who have ET 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.

IETF develops “IETF Support Group Leaders Training Guide” and DVD as a formal training tool for new and established support group leaders.

With the intention of providing a road map for the establishment, development, and long-range maintenance of support groups, the IETF developed the “IETF Support Group Leaders Training Guide” and companion DVD. Created with a limited budget provided by The Medtronic Foundation. The DVD is hosted by IETF Executive Director Catherine Rice.

The DVD, as well as the guide, facilitates the understanding of the values and benefits of support groups by presenting the experiences and opinions of three very different types of successful support group leaders in an informal interview setting.

Ray L. Watts, M.D.

Dr. Watts is Professor and Chairman of Neurology and Director of Clinical Research, Parkinson's Disease and Movement Disorder Research Program at The University of Alabama (UAB), Birmingham, AL. He was valedictorian of his medical school class at Washington University School of Medicine in St. Louis in 1980, and completed his internship, residency and fellowship training at Harvard Medical School and Massachusetts General Hospital. Prior to going to UAB, Dr. Watts also served a two-year fellowship at the National Institutes of Health before joining the faculty at Emory University where he and his colleagues built an internationally renowned Parkinson Disease and Movement Disorders Research and Clinical Center.

Dr. Watts was unavailable for comment regarding his appointment to the IETF Medical Advisory Board at press time. No photograph of Dr. Watts was available at press time.

In memory of H. Michael Dwan

H. Michael Dwan, former IETF Executive Board member and support group leader, died of cancer on June 2, 2007, at his home in Bay City, MI.

Michael joined the IETF in 2001 and shortly thereafter formed an essential tremor support group that met in his law office in Saginaw, MI. In March 2004, Michael joined the IETF Executive Board and served two years.



H. Michael Dwan

"Michael had a real passion for the IETF and wanted to do everything he could to help people with ET," said IETF Executive Director Catherine Rice. "He was always wonderful to work with, very generous in every way."

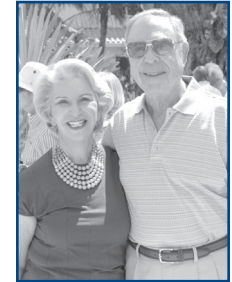
Former IETF President Shari Finsilver shared her memories. "Mike was a very special person. He was so involved and committed with different organizations, one of which was the IETF. He worked so hard to create a support group in the Bay City/Saginaw area. In doing so, he helped many people with tremor learn more about ET and better cope with their situations.

"I first met Mike and his wife Carol at the initial meeting of this group," Shari continued. "Mike was looking for a speaker for this get-acquainted meeting and I happily agreed to drive up to speak to the group about ET and the IETF. Mike always spoke about his family, which was growing by leaps and bounds. He was very committed to them."

Kelly Lyons, PhD, IETF Executive Board Vice President, said, "It was a pleasure to have had the opportunity to meet and work with Mike Dwan. He was a kind-hearted man who did so much to help and educate persons with essential tremor. He will be greatly missed by the IETF Executive Board and the many people who were touched by his kindness and his dedication to increasing awareness and helping those with essential tremor."

Hope springs from IETF's first regional fundraiser

The power of hope was vividly demonstrated at *An Enchanted Afternoon Home and Garden Tour*, the IETF's first regional fundraiser. Raising approximately \$37,000 between January and March of FY06 from ticket sales, the event was held April 2, 2006, in Manalapan, FL, at the exquisite two-acre intracoastal and ocean home of Beverly and Herbert Myers.



Herb and Bev
Myers

Nearly 500 guests enjoyed the afternoon event that included a Japanese flower arranging demonstration, an art showing, and a plant sale.

Committee members in addition to the Myers were Estelle Berk, Stanley and Shari Finsilver, and Joan Robbins.

Sponsoring the home and garden tour were Dr. and Mrs. Gregory Adamian, Barbara Andrews and Richard Sussman, David L. Cramer and Associates, Stanley and Shari Finsilver, Robert and Ellen Jaffe, Edwin and Harriet Levine, Kenneth and Barbara Mahler, Donna Miller, Herbert and Beverly Myers, John and Joan Robbins, Steven Ryter, Ronald and Ellen Schmier, and The Wackenhut Corporation.

The IETF thanks all committee members, sponsors, donors, and other participants for making this first IETF regional fundraiser such a rousing success.

- **A Patient Information Handbook.** (English and Spanish). Provides information about the diagnosis and treatment of ET.
- **Seek the Comfort of Another.** Provides information about local support groups.
- **Surgical Treatment of Essential Tremor.** Reviews the history and surgical procedures for the treatment of ET.
- **Tremor Disorders in Children, a Clinical Discussion.** Provides information for pediatric physicians whose patients include children with ET.
- **Tremor Talk.** Quarterly publication provides information about new research, coping tips, advice and insights from medical experts, and ideas for spreading the word about ET.
- **I Can't Stop Shaking: More Than 10 Million People Suffer with Essential Tremor.** Sandy Kamen Wisniewski. Personal stories of ET and other useful information.
- **Essential Tremor: The Facts.** By Mark Plumb and Peter Bain. "Expert advice for patients, care takers and professionals."
- **Packet #1: Diagnosis, History and Genetic Factors.** Twenty-four essays covering topics such as children and ET, ET and aging, ET and Parkinson's disease, and psychosocial aspects of ET.
- **Packet #2: Diet, Alternative Therapies, Exercise & Medications.** Twenty-three essays focusing on areas such as alcohol, alcoholism and ET, exercise for relaxation, improving quality life, and medications and ET.
- **Packet #3: Other Tremor Disorders.** This 14-article packet deals with other forms of tremor such as orthostatic tremor, voice tremor, and other movement disorders.

Independent Auditors' Report

Board of Directors
International Essential Tremor Foundation
Overland Park, Kansas

We have audited the accompanying statement of financial position of International Essential Tremor Foundation (a nonprofit organization) as of March 31, 2007, 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, 2007, 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
July 7, 2007

IETF

Statement of Financial Position

Year Ended March 31, 2007

ASSETS

CURRENT ASSETS

Cash 224,129

PROPERTY AND EQUIPMENT

Office equipment 33,844
Less accumulated depreciation (27,117)
Net property and equipment 6,727

OTHER ASSETS

Security deposits 1,100

TOTAL ASSETS 231,956

LIABILITIES AND NET ASSETS

LIABILITIES

Accrued expenses 10,300

NET ASSETS

Unrestricted 120,251
Unrestricted – Board designated 25,000
Total unrestricted net assets 145,251

Temporarily restricted 76,405

Total net assets 221,656

TOTAL LIABILITIES AND NET ASSETS 231,956

IETF offers educational library

Because knowledge is essential to making informed choices, the IETF believes that quality information about ET must be widely available. In FY07, 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 ET 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 ET for the benefit of others with ET and their families.
- **The Gift of Knowledge: A Legacy of Love.** An explanation of the importance of brain tissue donation for the advancement of essential tremor research.
- **Glossary of Terms.** Lists most common terms and definitions used in the diagnosis and treatment of ET.
- **IETF Marketing Brochure.** (English and Spanish). Provides information about the IETF and briefly summarizes ET.
- **IETF Support Group Leaders Training Guide/DVD.** Describes how to start a support group with suggestions for monthly meetings.
- **Matching Gift Brochure.** Provides donors with information about how to take advantage of employers' matching gift programs.
- **Medical Alert Card.** Provides a simple, quick reference about ET that members can carry with them. ET is often mistaken for intoxication, so these cards help law enforcement officers, driver license bureau staff members, and others understand the condition. The front of the card explains ET'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.

Print and broadcast news

As a result of the marketing effort to increase public awareness through community educational events, 31 newspapers, 136 television stations, and 208 radio stations ran information about ET.

Community education events have far-reaching benefits

Each event:

- Provides valuable information to patients, friends, and family who attend the events; they in turn share what they learn with family members and friends in other locations.
- Increases the quality of life for persons affected by enhancing their ability to continue employment; discourages isolation due to embarrassment and humiliation caused by the condition.
- Provides people who have ET with local support mechanisms and opens effective communication pathways within the community.
- Presents the opportunity for IETF staff members to provide effective community support.
- Enables the IETF to use media resources and media tools developed in previous years.
- Encourages individuals to seek the treatment that best suits their needs by introducing them to specialists within the community.

During FY07, the IETF provided information about ET in a very personal way through community education events to approximately 2,548 people affected by ET.

IETF

Statement of Activities

Year Ended March 31, 2007

	Unrestricted	Temporarily Restricted	Total
REVENUES, GAINS AND OTHER SUPPORT			
Contributions	76,430	5,453	81,883
Membership dues	295,170		295,170
Memorials and bequests	55,190		55,190
Honoraria	7,976		7,976
Special events, net of direct expenses	4,882		4,882
Other exempt function revenues	5,230		5,230
Interest	5,497		5,497
Amounts released from restrictions	<u>78,184</u>	<u>(78,184)</u>	<u>0</u>
Total revenues, gains and other support	<u>528,559</u>	<u>(72,731)</u>	<u>455,828</u>
EXPENSES			
Program expenses	400,154		400,154
Management and general expenses	50,038		50,038
Fundraising expenses	<u>46,826</u>	<u>0</u>	<u>48,826</u>
Total expenses	<u>497,018</u>	<u>0</u>	<u>497,018</u>
CHANGE IN NET ASSETS	31,541	(72,731)	(41,190)
NET ASSETS, beginning of year	<u>113,710</u>	<u>149,136</u>	<u>262,846</u>
NET ASSETS, end of year	<u>145,251</u>	<u>76,405</u>	<u>221,656</u>

IETF

Statement of Functional Expenses

Year Ended March 31, 2007

	Program Expenses	Management and General Expenses	Fundraising Expenses	Total
Legal and accounting	6,944	1,302	434	8,680
Bank charges	3,261	612	204	4,077
Board travel and meeting	3,016	566	189	3,771
Design work	484	91	30	605
Dues and subscriptions	137	26	9	172
Education and public awareness	90,677	0	22,669	113,346
Depreciation	2,626	492	164	3,282
Equipment maintenance	8,544	1,083	1,053	10,680
Specific assistance for research and development	52,419	0	0	52,419
Insurance	15,906	2,982	994	19,882
Lease	4,374	820	273	5,467
Marketing and public relations	0	0	7,613	7,613
Miscellaneous	2,918	548	182	3,648
Office supplies	2,837	532	177	3,546
Salaries	122,852	23,035	7,678	153,565
Payroll taxes	9,886	1,853	618	12,357
Pension	3,114	583	195	3,892
Postage/freight	22,620	4,241	1,414	28,275
Printing	25,295	4,743	1,581	31,619
Rent	12,577	2,358	786	15,721
Support groups	653	0	0	653
Taxes, licenses and fees	0	2,481	0	2,481
Telephone	4,492	842	281	5,615
Website maintenance	4,522	848	282	5,652
TOTAL	400,154	50,038	46,826	497,018

— Support group – 4.2 percent

— Friend – 5 percent

— Other – 10.5 percent

- The average person was aware of the IETF before the event (58.2 percent), would recommend the event to others (96.8 percent), and wanted to be notified of future IETF events (92.4 percent)

Representative sampling of attendee comments

“It felt good to be around people who were like me. I’m so self-conscious. I met some people who were interested in starting a support group in our area.”

“My mothers, aunt, and two uncles all had ET. With six sisters and brothers, I imagine one or most of us will have ET too.”

“It was a very professional, informative, educational event. I will gladly help with other meetings in the future.”

“Excellent presentation! Room was packed. Enjoyed the coffee. Took handout information for me and one for a friend my exact age.”

“This is the first time I have heard of the condition called ET. Thanks.”

“This was so very informative. The honesty and straightforward manner of both MDs was very refreshing and encouraging. Thank you!”

“It was very good. I felt like I learned something and will share everything with my daughter who lives in NY.”

“An exceptionally informative and helpful presentation!”

“Thank you for bringing information and publicity about ET. Most of the public assumes it is Parkinson’s. Receiving the IETF newsletter has been like a lifeline to me the past few years.”

“My 21-year-old son was recently diagnosed with mild tremor. I attended to get information for him while he is away at college.”

“Very informative. I would love to be involved and work for the IETF!”

“At last! I am not alone.”

Community education events grow awareness for three years

Just as in FY05 and FY06, the IETF continued to collaborate with local hospitals and physicians nationwide to bring information and awareness about ET 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.

The IETF conducted 54 community education events by the end of FY07. Thirty-one events were held across the United States in San Diego and Newport Beach, CA; Ft. Lauderdale, Ft. Myers, Miami, Naples, Ocala, Orlando, St. Petersburg, and Tampa, FL; Des Moines, IA; Boise, ID; Rockford and Springfield, IL; Ft. Wayne, Indianapolis (2), and Munster/Gary, IN; Lexington, KY; Ashville and Charlotte, NC; Rochester, Syracuse, and Westchester County, NY; Philadelphia and Pittsburgh, PA; Cincinnati and Cleveland, OH; Portland, OR; and Chattanooga and Nashville, TN.

Supported by grants from Medtronic Foundation and Corporation, these events are not only designed to provide patient education, but also to increase public awareness about ET.

Surveys reveal community education events have significant effect

- Average attendance per event is 72 people
- Average person attending is 65 years old, female (50 percent), and white/non-Hispanic (84.7 percent)
- Average person attending has a diagnosis of ET (69 percent), was diagnosed with ET at age 53.9, and first noticed signs of ET at age 45
- Attendees learned about the event through:
 - Postcard/brochure mailings – 38.5 percent
 - *Tremor Talk*, IETF's quarterly newsletter – 16.8 percent
 - Newspaper advertising – 14.8 percent
 - Website – 3.2 percent
 - Family – 7 percent

IETF

Statement of Cash Flows

Year Ended March 31, 2007

CASH FLOWS FROM OPERATING ACTIVITIES	
Decrease in net assets	(41,190)
Adjustments to reconcile change in net assets to net cash provided by operating activities:	
Depreciation	3,282
Increase (decrease) in operating liabilities:	
Accrued expenses	2,407
Net cash used in operating activities	(35,501)
CASH FLOWS FROM INVESTING ACTIVITIES	
Investment in property and equipment	(1,951)
Net cash used in investing activities	(1,951)
DECREASE IN CASH	(37,452)
CASH, beginning of the year	261,581
CASH, end of the year	224,129

Financial Report

Net Assets

There was a decrease in net assets of \$41,190. The \$78,184 in restricted funding released from restrictions was used to fund projects budgeted in FY07. These funds consisted of donations received in FY06 designated and restricted for the purpose of funding research and funding provided by the Medtronic Foundation for the purpose of facilitating ET Community Events. The IETF awarded \$50,000 to ET researchers in FY07 and used the \$28,184 remaining in FY06 to fund ET Community Education Events in FY07.

When comparing FY07 to FY06, membership dues revenue decreased \$32,007 or 9%. The majority of revenue generated from the Myers Home and Garden Fundraiser appeared in FY06 because the fundraiser was held the first of April, splitting revenue and expenses between two fiscal years. The revenue was paid in FY06 but expenses were paid in FY07. In FY08 fundraising will not be split between fiscal years because it distorts revenue and expense reports. Grant revenue remained the same when comparing this year to last. Research revenue decreased \$9,506 or 175%. However, bequest revenue increased \$34,894 or 83%.

Expenses

Total expenses increased only \$12,075 or 2% as compared to FY06. 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 81%, Management and General Expenses 10% and Fundraising 9%.

FY07 Milestones

- There were 1,118 new members added to the database.
- There were 3,838 membership renewals.
- There were 4,762 information packets mailed to individuals and families. This is an increase over FY06 of 5% or 283.
- The total number of membership gifts increased 506 or 5%. The average donations were smaller but there were more in number. It seems donors were torn about where to donate. The decrease in the dollar amount versus increase in the numbers is reflective of the numerous national appeals for donations that donors received from national relief services.
- The number and amount of the end of the year appeal donations decreased less than 1%.
- There was a 2% increase of persons joining the Presidents Club, 1% in the category of \$500-\$1,000, 6% in the category of less than \$25 memberships and the basic membership donation decreased by 26%.

Even though revenue was not as expected, work continued in the field. ET Community Events which are discussed in a separate section, added a voice to communities, development of support groups and educational materials kept us in touch with those who are trying to help other people affected by ET. Recruitment for the IETF funded New York Brain Repository helped us gain a better perspective on what is needed to find the cause and the first regional fundraiser gave us valuable experience about future fundraisers.

It was the staff in the office that gave the most. They gave their heart and time to keep this organization together. Without them, the organization may have stagnated, but the staff ignored the negative and kept on going knowing that the hard work would pay off in the future. If FY08 is any indication, IETF revenue is 68% greater than last year. Thank heavens for the dedication of the staff and the donors who gave generously, worked diligently to increase awareness, provide support and bring in funding to support research.