

# 2011 ANNUAL REPORT

## International Essential Tremor Foundation



### Overview

What a great year of accomplishment! During fiscal year 2011, the Tulips for Tremor Campaign, the inaugural Spirit of Hope Award and the Congressional approval of the first National ET Awareness Month were high-profile initiatives that the IETF undertook to generate positive awareness and education for people affected by essential tremor. While the economy gave us some pause, we continued to keep our eye on our goals.

As you review highlights of the terrific programs that involve educational activities and materials, research funding

and support services in the annual report, I think you will agree that a great deal was achieved. We thank our donors, who gave in so many different ways, for their support. Your generosity of spirit, volunteerism and financial contributions made these accomplishments possible.

We look forward to another grand year and even greater success. Stay tuned – this is only the beginning!

Catherine Rice, Executive Director, IETF

### Financial Statement

#### Revenues

Contributions	\$107,699*
Investment	\$ 2,778
Membership Dues	\$354,547
Memorials/Bequests	\$ 47,108
Research	\$ 56,961
Function Revenues	\$ 13,327
Program Service Fees	\$ 1,560
Special Events	\$ 16,991+

Total Revenue \$600,971

#### Expenses

Program	\$462,991	79%
Management/General	\$ 84,959	14%^
Fundraising	\$ 43,840	7%

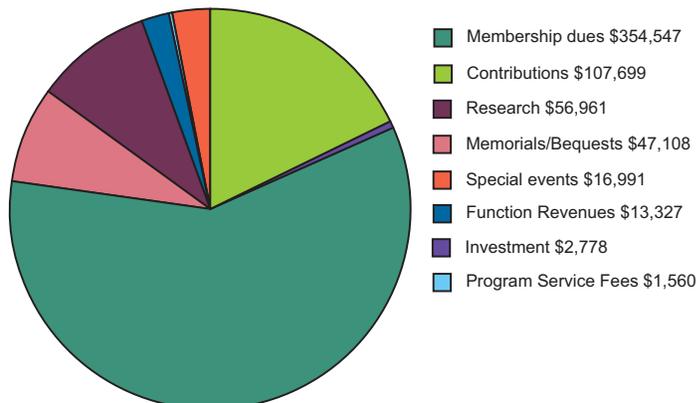
Total Expenses \$591,790

\*Contributions - Corporate contributions totaled \$105,962 with \$1,737 provided from the public for general support.

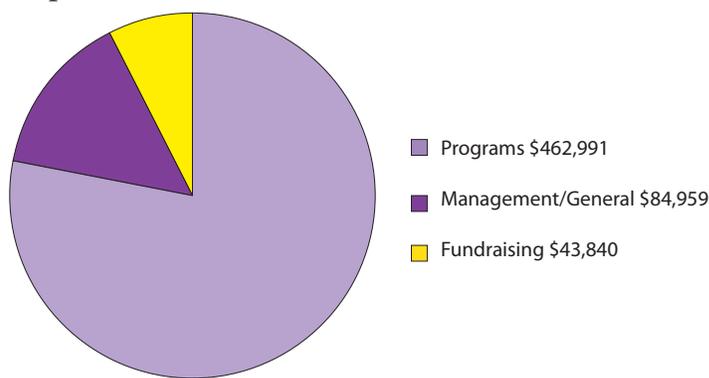
+Special Events - Revenue received from the Tulips for Tremor Campaign and National ET Awareness Month.

^Management/General - These are expenses related to office overhead such as supplies, computers, copier, salaries, rent, etc.

#### Revenues



#### Expenses



Programs - Includes awareness, education, support and research activities and initiatives.

Fundraising - Includes Tulips for Tremor Campaign, the annual appeal, membership materials, National ET Awareness month and other initiatives.

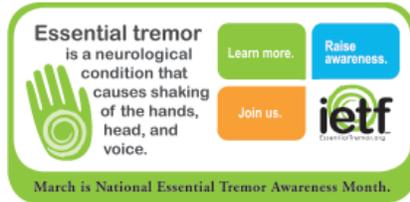
# IETF Highlights

**Tremor Talk Magazine** - Distributed 22,200 copies to members.

**The Scoop** - Distributed 24,800 copies of the newsletter.

## National ET Awareness Month (NETA)

- December 2010 - The IETF culminated a successful three-year effort by getting Congress to pass a House resolution that officially designates March as "National Essential Tremor Awareness Month."



- Promoted NETA to national press through multiple press releases.

- First official National ET Awareness Month campaign was launched nationally, resulting in numerous press releases, press mentions, stories of those living with ET and a newspaper column by Dr. Donohue that focused on essential tremor. The media exposure resulted in thousands of individuals learning more about essential tremor.

- Received donations from 120 people during National ET Awareness Month totaling \$3,503.

- 367 NETA posters distributed to the public. 546 NETA posters distributed to movement disorder neurology offices. 244 NETA T-shirts sold in first year offered.

- The IETF hosted a reception in Washington, D.C., sponsored by the IETF Board of Directors, where 546 congressional representatives were invited to attend. The IETF Executive

Director and four people from the Board met with legislative staff to distribute literature about ET, raise ET awareness and thank them personally for their support and approval of the National ET Awareness Month congressional resolution.

## Spirit of Hope Award

Inaugural award presented to Shari Finsilver in recognition of her extraordinary effort to bring hope to those suffering from essential tremor (ET) and their families. She supports the IETF's mission and the ET community by raising awareness, leading fundraising efforts, launching a Michigan support group, serving on the IETF board and donating time, money, and resources generously on behalf of the IETF.



## IETF Partners

To find better ET treatments and a cure, the IETF has partnered with organizations such as the National Institutes of Neurological Disorders and Stroke, American Brain Coalition, Columbia University Brain Repository for the Study of ET, Society for Neuroscience, Movement Disorders Society, Genetic Alliance and Nonprofit Congress.

## DC Connection

The IETF enlisted Washington D.C. liaison Tom Bruderle to help get the congressional resolution for National ET Awareness Month passed. He also increased ET awareness and support among congressional lawmakers and developed relationships through the Congressional Neuroscience Caucus (CNC). Bruderle attended the first-ever CNC in summer 2011.

# 2011 Research Highlights

> **The IETF announced several research studies** on its website and through print publications, including a call for Columbia University Genetics of ET research study participants; a Non-invasive Thalatomy Study Related to Essential Tremor at the University of Virginia Health System; and a ST101 Essential Tremor Research Study at West Los Angeles VA Medical Center.

> **A new study by the Banner Sun Health Research Institute** examines Neuropathological and Biochemical Substrates for Essential Tremor. Dr. Holly Shill, Director, Cleo Roberts Center for Clinical Research, Christopher Center for Parkinson Research, leads the study which is **funded by the IETF**. The cause of essential tremor (ET) is unknown but recent findings have shown genetic links to the genes LINGO-1 and LINGO-2.

> **A study by Dr. Adrian Handforth and Dr. Arnulfo Quesada** has yielded notable results with a potential focus for essential tremor (ET) drug treatment. **Funded by a grant from the IETF**, the study concerns the impact of five drugs in blocking T-type

calcium channels and suppressing tremor in two different models when tested on mice. Drawing from their IETF-supported work, the scientists produced three papers, one of which was published in 2008 in *Drug Metabolism and Disposition* and another published in 2010 in *Neuropharmacology*. The third paper has been accepted for publication in the *European Journal of Pharmacology*.

# \$450,000+

The funding that the IETF has provided for essential tremor research.

## Donations

The IETF relies on member donations to fund research, host education events, fund support groups and ambassador activities, provide educational materials, support awareness initiatives and fund general operating expenses. Donations come from different sources including memorials given in honor of a deceased loved one, honorariums given to honor an individual(s), general donations, membership dues, research, bequests, Tulips for Tremor, ET Awareness month and other ET campaigns.



In fiscal year 2011, the IETF:

- Received 7,100 donations.
- Gained 1,137 new members.
- Received 342 Memorials and 102 Honorariums.
- Received donations from 21 President's Club members (\$1,000 or more).
- Received donations from 770 people for the Tulips for Tremor campaign.

## Bequests

**The IETF is thankful for the following bequests:**

Beryll Deming \$672  
Howard Fisher \$47,103  
Kathleen Wambold \$7,600  
Schmier Family Trust \$26,450  
**Total Bequests \$81,825**

Giving a gift through your will or trust is one of the best ways to leave a legacy that funds research and provides for a better future for you and your children living with ET. Consult your financial advisor for the various ways you can help and visit [www.essentialtremor.org/plannedgiving](http://www.essentialtremor.org/plannedgiving) for more information.

## Corporate Support

The IETF received corporate donations in support of its awareness and education activities from the Medtronic Corporation, \$45,962; Medtronic Foundation, \$35,000; and St. Jude Medical, \$25,000. The IETF greatly appreciates the support of its mission and goals and as a result, reductions in services are kept to a minimum.

## Other Support

The IETF receives little or no federal, state, regional or local funding. Member donations remain the key to its success.



## LOOKING AHEAD, FISCAL YEAR 2012:

In the first quarter of 2012, the IETF developed six educational webinars now available on [www.essentialtremor.org/et-webinars](http://www.essentialtremor.org/et-webinars).

18 ET education events are scheduled nationwide between July and November 2011. To view the list, visit [www.essentialtremor.org/seminars](http://www.essentialtremor.org/seminars).

## Email/Social Media Outreach

### **Tremor Gram Email Newsletter**

*Tremor Gram* email sent to 129,357 email addresses during fiscal year 2011. 64% increase in # of email subscribers from April 2010-March 2011.

### **Social Media Tracking from August 1, 2010-March 31, 2011**

#### **IETF on FaceBook**

FB Fan page - 1,803 Likes

[www.facebook.com/InternationalEssentialTremorFoundation](http://www.facebook.com/InternationalEssentialTremorFoundation)

FB Cause page: 148 members by March 31, 2011.

[www.causes.com/causes/503371-international-essential-tremor-foundation](http://www.causes.com/causes/503371-international-essential-tremor-foundation)

161,195 - # of times people viewed news feed story posted by IETF. 1,900 - # of likes and comments made on news feed stories posted by IETF.

By fiscal year-end:

- more than 1,000 active monthly users, more than 500 active weekly users and more than 300 active daily users.

#### **IETF on Twitter**

<http://twitter.com/essentialtremor>

64 followers/366 tweets by March 31, 2011.

221 followers/470 tweets by August 23, 2011.



## Volunteers

The IETF has developed an active network of support groups and volunteer leaders across the nation, providing leadership and educational materials.

[http:// www.essentialtremor.org/Volunteer](http://www.essentialtremor.org/Volunteer)

### **Ambassadors**

Ambassadors Sharon Alexander, Joe Bremhorst, Preston Boggess and Ken O'Key coordinate awareness activities with support groups, healthcare professionals and the public.

### **Support Group Leader Program**

As of April 2010 Active Groups: 46

As of March 2011 Active Groups: 58

→ **26%  
increase**

### **Volunteer hours:**

4,316 hours served nationally

\$89,989 = \$ value of hours served

### **Office Volunteer**

Sharon Whittlinger worked 44.2 hours = \$921.57 value.

**International Essential  
Tremor Foundation**  
[www.essentialtremor.org](http://www.essentialtremor.org)

# Fun Facts - Fiscal Year 2011

- The IETF office receives over 200 emails a day from all around the world.
- The IETF printed 7,500 ET patient brochures, 10,000 Diagnosing ET physician cards and 21,200 ET informational brochures.
- You can read over 30 stories and features about people with essential tremor and photos submitted by people with essential tremor at [www.essentialtremor.org/ET-stories](http://www.essentialtremor.org/ET-stories).
- The IETF plans to host over a dozen educational seminars in cities nationwide between September 1-December 31, 2011.
- The IETF office space is 900 square feet and houses 4 full-time employees.
- 55,000 envelopes were used to send out free educational materials.
- 100,000 return envelopes were printed.
- 12,500 pieces of letterhead were used to send letters.
- 10,000 Medical Alert Cards were distributed to members.
- 2,500 “You Are Not Alone” flyers were distributed to encourage people to join support groups.
- 1,500 flyers were distributed to encourage participation in Columbia University’s Brain Repository.
- 1,760 ET Awareness Bracelets were sold.
- The average gift (donation) is \$67 per person.
- 2,784 people attended ET education events.



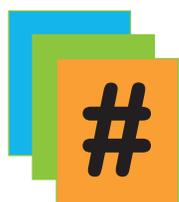
## Education, Awareness and Outreach

The IETF provides educational materials to inform and educate people newly diagnosed with ET, those already diagnosed, families and healthcare professionals. These materials not only share information but also help increase awareness among the public. In fiscal year 2011, the IETF:

- Mailed 3,841 free packets of information about ET.
- Planned and hosted 23 education events nationwide.
- Hosted booths and distributed educational materials at 7 physician conferences (nearly 50,000 professionals in

attendance) to educate physicians about ET: American Academy of Neurology, American Academy of Family Medicine National Conference, American Academy of Family Physicians Scientific Assembly, Kansas Association of Osteopathic Physicians, Kansas Association of Osteopathic Medicine, Kansas Academy of Family Physicians and Society for Neuroscience.

- Distributed over 70,000 bookmarks throughout communities.
- Answered over 1,300 phone calls and 780 personal emails, providing support to people recently diagnosed with ET or who needed educational additional materials.



**500,674** pieces  
printed for free educational  
materials



**\$24,908**  
postage cost for mailing free  
educational materials

The IETF developed and copied 170,108 free flyers that include Facts About ET, Coping Tips, Medications, Children with ET; A Guide for Parents and Other Caring Adults, Tremor Disorders in Children; A Guide for Healthcare Professionals and Information for Teachers of Children with ET and the Support Group Leader Manual and materials.

In addition, there were an additional 330,566 free brochures printed such as the Patient Handbook, information about Surgical Treatments, the anniversary edition of ET essays and the IETF General brochure.

A new and important addition to the educational materials for healthcare providers includes a Practical Guide to Diagnosing Essential Tremor for Healthcare Providers. This guide is distributed for free to all types of healthcare providers across the world. This handy card enables healthcare providers to understand the differences in Parkinson's disease and essential tremor. As a result, it helps to improve diagnosis and treatment of ET.

Educational materials are distributed for free to IETF members, the public, physicians and health care providers to increase ET education and awareness.

## Meet the Staff

**Catherine Rice, Executive Director** - Catherine has worked at the IETF for 14 years. She has worked in the nonprofit sector for over 28 years. She loves her job because every day presents a new opportunity to do more to help those with ET. She is inspired by her staff and the volunteers that do so much to increase awareness, educate and help raise funds for research. She loves to garden, take walks and train with weights.

**Carol Rucker, Member Relations & Community Events** - After a short time in the "real world," Carol was happy four years ago to return to non-profit work where she can engage the heart, not just the mind. In her spare time she attends Little League baseball and basketball games and takes yoga and cycling classes.

**Rebecca Dye, Communications and Volunteer Programming** - Rebecca is the IETF's bleeding heart in a good way. She manages the IETF's social networks and works with IETF volunteers in the U.S. and overseas; thoroughly enjoying the chance to offer compassion and support to real, everyday people. She is also the IETF's resident nerd with a passion for paleontology, ornithology, physics and medieval cooking.

### **Pete Dulin, Print and Website Editor**

Pete writes, edits and designs work for the IETF's website and printed materials. He writes freelance about food and other topics for print publications, cooks, plays sand volleyball and rarely turns down a bowl of ice cream.

### **International Essential Tremor Foundation**

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