

## Executive Director Message

I am often asked what the IETF mission is. Quickly I reply, "to provide support, services and education to people with ET while funding research." Technically, that is what we do. We work to distribute literature, develop and maintain support groups, increase awareness and fundraise to benefit research. But, describing what the IETF does isn't telling the whole story. Why do we do what we do?

In thinking about this past year, I reflect upon the many programs that were developed and the advances that have been made in ET research. I think about our many friends and members whose support we could not have done without, the healthcare colleagues that made the ET Awareness events so successful, the bequest donations that supported our cause in a big way and the corporate support we received in order to accomplish so much.

I think about the IETF staff who gave so much more than time each day, cheerfully performing their duties and collaborating to find the best ways of meeting IETF goals and supporting people who have ET. I admire the commitment of volunteers, including support group leaders and ambassadors, in donating valuable time so important work can be accomplished. I appreciate the commitment of the Executive Board and Medical Advisory Board members who ensure that the IETF not only meets its financial and research commitments but also meets its ethical and moral obligations to donors.

So just what about this past year, beyond the accomplishments listed in this annual report, explains why the IETF does what it does?

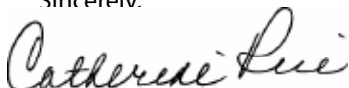
It is you! You are the reason we do what we do and why we do it. It is you who make us a strong, viable and committed organization. It is you, the 10 million and more who have ET and your families that are the reason we do what we do.

So while the mission determines the organizations activities, I want to reassure you that in performing those activities you are never far from our thoughts. The IETF is your organization. You are the fuel that drives the engine of every activity, program and research endeavor.

As we look forward to FY10, we again promise to work tirelessly on your behalf by funding research to find better treatments for ET and by reinforcing ET awareness so the public better understands your concerns and challenges.

In closing, I want to thank you for your support, commitment and loyalty. Though great strides have been made, there is still much to do.

Sincerely,



Catherine Rice  
Executive Director

## Lyons New IETF Executive Board President

During the fall of 2008 Kelly E. Lyons, PhD, who has previously served six years as the vice-president of the IETF Board of Directors, succeeded Peter A. LeWitt, MD as the president of the Board of Directors. Dr. LeWitt now serves as vice-president.

Professionally, Kelly is a research associate professor of neurology and director of research and education for the Parkinson's Disease and Movement Disorder Center at the University of Kansas Medical Center, Kansas City, KS. Her work focuses on clinical care, research and education for persons with ET, Parkinson's disease and related disorders.

"I am honored to have the opportunity to be president of the IETF, and proud to be part of an organization that has provided invaluable support and education to help improve the quality of life for so many persons with ET."



President  
Kelly E. Lyons, PhD

## IETF Staff

Four people work in the IETF office:  
Catherine Rice, executive director  
Debbie Lovelace, publications editor and public relations specialist  
Dee Ragan, coordinator for support groups and events  
Carol Rucker, membership coordinator, memorials and honorariums



Executive Director  
Catherine Rice

## Community Ambassadors

IETF Ambassadors are self-motivated leaders who serve as volunteer representatives of the IETF in their communities and surrounding areas. Each Ambassador works with the IETF to increase awareness about ET, help increase the number of support groups, provide support to support group leaders, provide educational information, increase fundraising potential and enhance the relationship between the IETF national office and their communities.

During FY09, the IETF added four new Ambassadors to the Community Ambassador program:

- Tim Beals, Prince Edward Island, Canada, the IETF's first Online Community Ambassador, maintains a presence on several social networking sites.



Tim Beals

- Patrick Farrell, Hilton Head Island, SC serves the southern, Mid-Atlantic coastal region.
- Mary J. Fitzpatrick, Manchester, MO serves the St. Louis, MO metropolitan area.
- John Gijzen, Appleton, WI serves eastern Wisconsin.

Ongoing IETF Community Ambassadors are Preston Boggess, southwest Virginia and Peter Muller, eastern Virginia, Maryland and Washington, DC.

The IETF is proud of the Ambassadors and thank them for their support, hard work and dedication to helping those with ET. The Ambassadors did a magnificent job in creating a greater unified community spirit through their efforts at establishing additional support groups, creating greater public awareness and establishing viable relationships with community healthcare providers than ever before. The Ambassador Program was funded by a generous grant from the Medtronic Foundation.

The plan for FY10 is to write a grant to extend and expand the program, design new marketing materials and provide more information resources for the media.



Preston Boggess



Patrick Farrell



Mary J. Fitzpatrick



John Gijzen



Peter Muller

## Support Groups

After beginning FY09 by restructuring older support groups and eliminating inactive groups, the IETF concentrated on leadership training for new and prospective support group leaders. Since there were numerous groups started in a short period of time by ambassadors, Preston Boggess and Peter Muller, the IETF facilitated an all-day Support Group Leader Training and Support Conference in Charlottesville, VA. The meeting was attended by active and prospective support group leaders from Maryland, Virginia and West Virginia.

By the end of FY09, restructuring of the support group leader system was complete. We now have a total of 63 active support groups and more being developed each month. All new and prospective support group leaders receive a training DVD and manual to help establish and maintain their groups. Dee Ragan, IETF staff member responsible for the development of support groups, works closely with each leader in establishing their groups and marketing meetings through mailings.

The plan for FY10 is to develop several more support groups, particularly in the areas where the Community Ambassadors are located. Support group leaders and members of the support groups will be encouraged to attend more community health fairs, assist in the distribution of literature and promote the group through the various community media resources.

## Awareness Activities

### IETF Goes to Washington

While attending the Nonprofit Congress in Washington DC, in June 2008, IETF members from three states along with IETF staff members took the ET story to congressional representatives, asking for sponsorship of a proclamation calling for a National ET Awareness Month. Appointments were scheduled in the offices of Sen. Sam Brownback (KS), Rep. Samuel Graves (MO), Rep. Christopher Van Hollen, Jr. (MD), Sen. Jim Warner (VA), Sen. James Webb (VA), Rep. Frank Wolf (VA), Rep. Eric Cantor (VA), Rep. Tom Davis III (VA), and Rep. Bob Goodlatte (VA). Information packets about ET were left in the offices of Sen. Pat Roberts (KS), Sen. Robert Byrd (WV), Sen. Claire McCaskill (MO), and Rep. Rob Wittman (VA).

The plan for FY10 is to work with Senator Sam Brownback and Senator Richard Durbin to sponsor and co-sponsor the National ET Awareness proclamation so it can get approved for roll out in March, 2010.

### Tulips for Tremor™ and Shaking Up Awareness Merchandise

The IETF designed Tulips for Tremor™ and the Shaking Up Awareness About ET shirts, caps and tote bags to help raise awareness about ET and support research and related initiatives. These items were sold online and through mail order.

The Tulips for Tremor™ pin and pendant were designed and donated for the fundraiser by Janis and Harvey Eismen as a way to honor their 40 year friendship with Shari and Stanley Finsilver. Shari is a past president of the IETF. The Eismens' design celebrates this friendship through giving, and symbolizes hope and the wearer's awareness of ET and support for those who live with it every day.

The Eismens have been in the jewelry business for 18 years as owners of Southfield Gold and Diamonds, Flint, MI. Through referrals, they sell jewelry in their community and throughout the country.

### Veterans Awareness

The IETF became a member of the VA Consortium Center Network that was launched in 2006 as a means to broaden the impact of the VA Parkinsons Disease Research Education and Clinical Center (PADRECC) mission. Fifty designated Consortium Centers provide specialized movement disorders services within all Veterans Integrated Service Networks (VISN(m and with the PADRECCs creates a hub and spoke model of care that is highly innovative

and effective. The IETF provided educational materials to the healthcare providers within the centers as well as to veterans.

#### Community Awareness Events

IETF Community Education Events were held again during FY09 and ran through May, 2009 to complete the scheduled 19 events funded by an unrestricted Medtronic Corp. educational grant. Approximately 1,500 people attended to learn about the diagnosis and treatment options for ET. The events took place in Rochester, MN; Atlanta, GA; Nashville, TN; Aurora, IL; Buffalo, NY; Philadelphia, PA; Richmond, VA; Fairfax, VA; Springfield, MA; Greensboro, NC; Charlotte, NC; Columbia, SC; Charleston, WV; Los Angeles, CA; Charleston, SC; Chicago-Deerfield, IL; Seattle, WA; Oxnard, CA; Cleveland, OH.

The plan for FY10 is to continue the education and awareness program by holding 20 more community education events throughout the US.

#### Medical Conference Attendance

The IETF staff attends as many medical conferences as possible in order to distribute educational literature and gather physician names to create ongoing relationships. This year, the staff attended two medical conferences – the American Association of Neurology (AAN) and Movement Disorder Society (MDS) Conferences in Chicago, IL in April and June of 2008.

The plan for FY 10 is to continue this practice and attend the AAN Meeting in Seattle, WA as well as the Neuroscience Meeting in Chicago, IL to increase awareness about the IETF research program and interest in ET research.

## Fundraising

#### Tulips for Tremor™

The second annual Tulips for Tremor™ fundraiser was held between February 1 and September 1, 2008. The fundraiser was developed to increase awareness about ET and raise funding for research initiatives. The fundraiser was once again successful with tulip sales revenue of \$12,758 and member sponsorships of \$26,590. Sponsorship money was used to place awareness advertisements in AARP Bulletin, Grand and Mature Living Magazines. Tulip jewelry sales revenue totaled \$1,893.

#### Shaking Up Awareness

The second fundraising campaign focused on increasing awareness for ET. Polo shirts, button front shirts, caps and tote bags carrying the slogan Shaking Up Awareness about ET were offered. Gross sales revenue totaled \$3,888. While disappointing, it should be noted that the economy had just turned downward at the beginning of this campaign. While revenue from sales was slow it was also steady. The hope is that the revenue from sales will increase in FY10.

#### Goulden Touch Foundation

Chicago Bears placekicker Robbie Gould joined the fight against ET by partnering with the IETF to raise funds to support ET research. Gould understands the daily activity and financial challenges people with ET face as he maintains a close relationship with a family friend who is bravely facing the disorder. The IETF was proud to be a signature sponsor of the first annual “Kick Off for a Cause” to benefit those with ET. The fundraising gala — hosted by Gould and held at the Hard Rock Hotel in Chicago, IL on Friday, October 10, 2008 — raised \$102,085. After expenses, \$50,000 will be designated for research funding and the remainder will provide financial assistance to those with ET.



Robbie Gould

FY10 fundraising plans include the third annual Tulips for Tremor™ campaign, which will include the sale of Tulips, merchandise, pins and pendants. The IETF will continue to sell books and work with the Goulden Touch Foundation on the second annual ET research fundraiser in Chicago, IL during the fall of 2009. Also, planning is underway for a walk-a-thon to coincide with the March 2010 ET Awareness month in Illinois.

## Publications

- In the fall of 2008, Tremor Talk became a 4-color member magazine with full-length feature articles. Published twice a year, this change was initiated because of increasing postage and print costs. Adding a few extra pages to a publication is considerably cheaper and only costs a few cents more to mail than publishing a third newsletter and incurring separate postage fees. Reactions to the new format have been very favorable.
- Spanish versions of the Patient Handbook, the general brochure, the ET Fact Sheet, Medications Sheet and Coping Tips Sheet were produced and offered.
- Previously published essays, abstracts and articles written for the IETF by movement disorder specialists and specialized health care providers was bound in a 137-page Anniversary Edition of Essays. The content spans 20 years, 1998-2008 of what is known about ET. The spiral bound book will be offered for a limited time only.
- The FY09 Annual Report was reformatted as an eight-page insert to the Fall 2008 edition of Tremor Talk in order to save on postage and print costs. A stand-alone version was also created for distribution and available on the IETF website.



## Memorials

April 1, 2008 through  
March 31, 2009. Memorialized in capitals and donors in lower-case italics.

MARIE V. ALLMENDINGER  
Doris M. Danekind  
ILLENE ANDERSON  
Thomas Anderson  
Judy Dunbar  
Nancy Stockert  
RINNA ATKINS  
William Smoot  
Kathy Rial  
SYLVIA BARAK  
Shelly Guggenheim  
James Wishart  
EDWARD S. BENTZ  
Mary Jane Bentz  
Robin Wolgast  
ANNA BERNER  
Morton Ozur  
THOMAS E. BURDICK  
Darlene Merchant  
FRANCES CARLINE  
Gerald Barker  
Stephen Barkin  
Dennis Brophy  
Gary Mellema  
Thomas Miller  
Ole Paugh  
RMC Research Corp.  
Richard Quindt  
Robert Quindt  
Isabel Wilson  
AL CONE, JR.  
Charles H. Damsel  
HUBERT COX, JR.  
Toni Silverman  
JOSEPHINE K. DEWING  
Eugene R. Armstrong  
Bill Hulltquist  
Brenda Miller  
Gary Schanz  
HARRY D'ORSI  
Mike Cassettari  
Robert Flohr  
Michael Gerstein  
Edward L. Longo  
Patrick Theberge  
Joseph's Industrial Catering Corp.  
FREDA DIGNEAN  
Madelyn H. Pruski  
MARTHA DUMLER  
D. Edward Elliott  
RAYMOND EESLEY  
Delphi Electronics & Safety  
Richard Griffin  
Ike Stage  
DAVID EHRICK  
N. Romelle Ehrick  
H. LEON ENSIGN  
Helen Ensign  
DARREL FENTON  
Gerald Barnes  
Jeanne Benson  
Robert O'Brien  
Barbara Gary  
Susan L. Haley  
Haley Herriott  
George W. Howe

Dorothy J. Jacobson  
Glenn Markham  
Michael Schmid  
Joseph W. Turner  
ALEXANDER FORBES  
Dorothea V. Forbes  
EDWARD FRANK  
Laura Frank  
RUTH ERICH GALE  
Douglas Armstrong  
Jeanne M. Black  
Dick Coombs  
Gary JCoon  
Mike Drusbacky  
Robert Gulas  
Robert Hartung  
Terry Hetrick  
Carl Koebel  
Stephen C. Miely  
John Papcun  
Charles Rainger  
Marilyn Russell  
John Seiler  
Paul Stark  
Evelyn M. Sweet  
Wayne Warden  
Herman Weibel  
Jeff Williams  
Rodney R Zerkle  
JAMES GALLAGHER  
Charles H. Damsel  
DEAN GARRETT  
B. Jane Garrett  
MARY GRABOSKI  
Byron Scott  
HARRY GUTKOWSKI  
Pamela Eder  
RUSSELL HAGEN  
Ella Hagen  
VERNA HAKUCHA  
Charles H. Damsel  
ROBERT HARTZELL  
Margaret M. Ackerman  
Julie Garvin  
Nancy Mowrey  
Thomas Neith  
Janice E. Rossetti  
Donald Wieand  
Saucon Valley High School  
Moravian College Softball Team  
DOLTON H. HERMELING  
Charles H. Damsel  
RICHARD J. HILLMAN  
SEA Retired Teachers Group  
MARILYN HUFFMAN  
Lee R. Huffman  
MOLLIE ISAACSON  
Sharon Ritt  
LUCILLE IVICH  
Nancy Kuntz  
Tony Moon  
Shriners Hospital for Children - St. Louis, MO  
BETTY P. JACOBSON  
West Suburban ET Support Group  
RICHARD LAWSON JOHNSON  
Hollis Armstrong  
Carl Carver  
Leslie Usher  
MARY PAT KIEHM  
Jan Krembs  
VESTAL KING  
Naomi King  
Verna Lippke  
Werner Schmidt  
MAXINE KORT

Shawn Burk  
Michael Cohen  
Lori Davidson-Mertz  
Steven & Nancy Epstein  
Arnie Fellman  
Richard Fink  
Shari & Stanley Finsilver  
Nate & Cathy Forbes  
Stefany Freeman  
Robert Gaberman  
Sheila Hecht  
Bruce Israel  
Mark Jacobs  
Mitzi Jacobs  
Stan Jacobson  
Dennis Kay  
Jerry Kohen  
Alger P. LaHood  
Hy Levine  
Walter Marshall  
Jodi Millman  
Allan Rein  
Debbie Robbins  
Todd Sachse  
Valerie Schanes  
David Schlanger  
William Seppala  
Bernadene Strager  
Truman D. Timmis  
Jocelyn Tink  
Julie Zalla  
JEAN T. KRAMPERT  
Alice Jean Kaufman  
Craig Flinn  
ALVIN KRUPICKA  
Sidney Buchanan  
John Christian  
Larry Curd  
Edward J. Kastanek  
Kenneth Krupicka  
Alan Krupicka  
Alan Krupicka  
Dolores Krupicka  
Emil Odvody  
Stella Turowski  
J.R. LATHAM  
Martha L. Bass  
HELEN LEDERMAN  
Bruce Marger  
FREDERICK LEVERSUCH  
Jim Battle  
Sandra Berman  
Michael Champagne  
David Dalsin  
Harriett E. Fox  
Patrice Flower  
Irene Freeborough  
June M. Israel  
Michael Grysiewicz  
Elsie Johnson  
Margaret Kiernan  
Martha Leversuch  
Jean Middlekauff  
Toby Sirota  
Don Theisen  
Jan Wildman  
IBM Corp.  
ECHO LONG  
Nancy Willison  
NANCY MCLAIN  
Marianne Yeagley  
MAXINE MARCUS  
Estelle Salzman  
ROBERT MAYNARD  
Red Rock Crossing Village, Inc.  
HELEN MCRAE  
Roy L. Dudley

GENEVIEVE MEINHOLZ  
Stephen Borgwardt  
Dorothy Haines  
Michael Lutz  
Vern Meinholz  
Roseanne Wilhelm  
KATHERINE HULTZEN MENDEL  
Carl Hultzen  
GEORGE E. MITCHELL  
Robert E. Mitchell  
DR. HENRY MURRAY  
Nell Younger  
KATHERINE B. NEIRINCKX  
Joe Thayer  
HUGH CHANDLER NICHOLS  
Steve Fairbanks  
Campbell R. King  
MR. & MRS. KENNETH OGILVIE  
Margaret Ogilvie Ellis  
AMANDA & GLADYS OREFICE  
Maryann Steinfeld  
LOUIS OTTO  
Chris Moody  
Dorothy E. Otto  
ROY PIERCE  
Norma Doherty  
NETTIE FENLONG POLLARD  
Madge B. Campbell  
JOSEPH POUNCEY  
James T. Green  
REVIE RADER  
JoAnne M. Tremper  
RICHARD RELLO  
James Franzosa  
WINIFRED REILLY  
Carol Brownlee  
DONNA RICKER  
Robert L. Capone  
Virginia Coppola  
Maryann Corsini  
Dorothy Curtis  
John Haddigan  
Priscilla Jane Huston  
Dorothy B. Kelso  
David K. Maynard  
Joseph Mier  
Fran Morrison  
Julie, Bob, Tess & Jack Pritchard  
Arnie & Richard Owens  
Helmut Reinhardt  
Richard Roby  
Forrest Glenn Sawyer  
Lawrence A. Zonshine  
BILL RINGLEY  
Florence W. Ringley  
LOLA ROBIN  
Barry Roberts  
SYLVIA ROUFF'S  
Husband  
Shari & Stanley Finsilver  
MURIEL RUBIN  
Rosalind Schulkin  
MURIEL RUDACK  
Shari & Stanley Finsilver  
THEODORE RUDNER  
Shari & Stanley Finsilver  
EDGAR SEATON  
Gloria Oertle  
Elaine Textor  
LEONARD SEECH  
Alamo Wood Products, Inc.  
Enterprise Engineering Consultants, LTD  
Stephen F. Ferris  
James F. Gayton

Robert J. Hartsock  
 Alice S. Herald  
 Evano Lenzi  
 James D. Miller & Sons  
 Loretta F. Terrick  
 Thomas Wright  
 PAUL SELEGMAN  
 Miriam S. Lewis  
 CURTIS SEICHTER  
 Merrill & Pete Peterson  
 EVELYN SHELLEDY  
 Adrunne Morrison  
 Randall Morrison  
 Patricia Vigna  
 JOAN SPIELHOLTZ  
 Gerald I. Spielholtz  
 BYRON STEITZ  
 Edna M. Steitz  
 SHIRLEY STETSON  
 Norma Doherty  
 Dale C. Stapleton  
 BERTHA STONE  
 Roslyn M. Meyer  
 ROSALIE THIES  
 Gordon S. Bowie  
 Eleanor Carpenter  
 Lillian Childress  
 William Jenkins  
 Saundra R. Maulson  
 Darrell Sutherland  
 Douglas Thies  
 DuPont HF Mechanical Shop  
 SIDNEY THOMSON  
 James Thomson  
 Paul Resnick  
 Rita Semel  
 RUTH TRAEGER  
 Norman L. Traeger  
 LOIS TRUEBLOOD  
 Harvey A. Wilson  
 LOIS IRENE TUCK  
 Bruce C. Tuck  
 VERA VOLK  
 Vanna Jane  
 Alice J. Volk  
 MARY JANE WALKER  
 Toni Grimm  
 ROBERT WATT  
 Arlene Watt  
 HELEN WILLIAMS  
 Amy Casai  
 BILLY & TAMMY WOOD  
 Doris G. Wood  
 OSCAR WORD  
 Edith Word  
 LOUISE YOUNGER  
 Alfred Jenkins  
 AVNNER ZAFARYAR  
 Blake Froehlich  
 EILEEN G. DAVIS ZERN  
 Charles H. Damsel  
 MARY DONNELLY ZEPP  
 Alan Frisher  
 Dianne Zabel

## Honorariums

April 1, 2008 through  
 March 31, 2009. Those  
 honored listed in uppercase,  
 donors listed in italics.

THE ABERGEL FAMILY  
 Shari & Stanley Finsilver  
 DORIS & JIM AUGUST  
 August's 50th Anniversary  
 Shari & Stanley Finsilver  
 MARY BARKER  
 Mary Hockman  
 GERRY & ED BARNETT  
 Gail Burns  
 Louise Carter  
 DAVID R. BARRY JR.  
 Hannah Lee Hagen  
 JOHN BIXLER  
 Jonathan Bixler  
 Mark Bixler  
 LAUREN BEAN  
 Shari & Stanley Finsilver  
 PRESTON BOGGESE, MD  
 Bob Bayer  
 TEDDY BOLAK  
 Shari & Stanley Finsilver  
 AVIS BOLSON  
 Lin Simpson  
 SYLVIA BROCKSTEIN  
 Heidi Brockstein  
 LILLIAN A. COURTHEOUX  
 Richard Courtheoux  
 RICHARD & TERRI COURTHEOUX  
 Anniversary  
 Lillian A. Courtheoux  
 GRETCHEN ECKERIE  
 Joan L. Reiber  
 JANIS & HAVEY EISMAN  
 Shari & Stanley Finsilver  
 JULIE EISMAN  
 Shari & Stanley Finsilver  
 JOHN EVANS  
 JoAnne M. Tremper  
 DOUG & ALEXANDRA FEURRING  
 Marriage  
 Shari & Stanley Finsilver  
 SHARI FINSILVER BIRTHDAY  
 Frances J Finsilver  
 SHARI & STANLEY FINSILVER  
 Arthur Dably  
 Bernie Friedman  
 Harold S. Loss  
 Johannah Whitefield  
 Jeff Binder  
 JEANTETTE FORTUNA  
 Edward J. Fortuna  
 MAGGIE GESER  
 L. Richard Geser  
 TARA & STEVEN GREKIN  
 Shari & Stanley Finsilver  
 GINA HORWITZ  
 New Position  
 Shari & Stanley Finsilver  
 DYLAN HYMAN  
 Richard Hyman  
 LESLIE JACOB  
 Birthday  
 ROBIN KAHN  
 Eli Singer

ALAN & BARBARA KAPLAN  
 Engagement of Benji & Meg  
 Shari & Stanley Finsilver  
 THE KATZ FAMILY  
 Shari & Stanley Finsilver  
 ROBERT KEARNEY  
 Celeste Null  
 KATIE SOLOMON & MICHAEL  
 KOMORN  
 Shari & Stanley Finsilver  
 ARTHUR KORT  
 Birthday  
 Harold Kort  
 HAROLD KORT  
 70th Birthday  
 Barbara Gordon  
 THE KRAMER FAMILY  
 Shari & Stanley Finsilver  
 NATALIE KUSILEK  
 Laurie Hansen  
 ALBERT LEVINSON  
 Robert Levinson  
 STANLEY LIPSON  
 Franklin Gilbert  
 Murray Zwicker  
 Sarai Zitter  
 DALE E. MCGREGOR  
 Jim Loftis  
 MARILLA MCGREGOR  
 Jim Loftis  
 DONNA MADDIN  
 Shari & Stanley Finsilver  
 ALBY MARCUS  
 Birthday  
 Estelle Salzman  
 BEVERLY & HARB MYERS  
 Sidney Fagelman  
 Rosalyn Goldberg  
 MY ET FRIENDS  
 Mirca Liberti  
 SARAH & SY NEUMAN  
 65th Anniversary  
 JOEY FAYE OLESKY  
 Suzanne Zimmer  
 THE PAUL FAMILY  
 Shari & Stanley Finsilver  
 JACKIE POMERANTZ  
 Trish Gilbert  
 VIRGINIA PHILLIPPI  
 Thomas Phillippi  
 THE POLLACK-FIELDS FAMILY  
 Shari & Stanley Finsilver  
 MARIE QUINN  
 William Quinn  
 Patrick Quinn  
 SUSAN RAUFMAN  
 Betty Babetch  
 THE RIVERS FAMILY  
 Shari & Stanley Finsilver  
 JOAN ROBBINS  
 Doris M. White  
 LYNDA HANSEN ROBINSON  
 Joseph G. Robinson  
 RUTH  
 Harold Wiseman  
 ROBERT SCHRAWGER  
 Cathy Bennett  
 ANETTE HERRERA & RYAN SPOON  
 Engagement  
 Shari & Stanley Finsilver

NATE TARNOFF  
 Gladys Keats  
 GIACO TRAGGIO  
 Birthday  
 George Gund  
 E. Gloria Hoffenberg  
 EUGENE TRECSCOTT  
 Mary Ellen Urzetta  
 MARILYN & STEVEN VICTOR'S  
 GRANDSON  
 Shari & Stanley Finsilver  
 JEFFREY WEISS  
 Shari & Stanley Finsilver  
 SHERI WEISS  
 60th Birthday  
 Shari & Stanley Finsilver  
 THE ZIEBER FAMILY  
 Marjorie L. Zieber  
 SUSAN C. ZIMMER  
 Suzanne Zimmer



## Financial Report

### Net Assets

There was an increase in net assets of \$70,016. The \$72,845 in restricted funding released from restrictions was used to fund programs budgeted for FY09. These funds consisted of donations received in FY08 designated and restricted for the purpose of funding research, funding provided by the Medtronic Corporation for the purpose of facilitating ET Community Events and funding provided by the Medtronic Foundation for the Ambassador program.

When comparing FY09 to FY08, membership dues revenue totaled \$336,729. This was an increase of \$15,270 or 4 percent. Special events revenue of \$149,496 consisted of the Tulips for Tremor campaign, and revenue from books, mouse adapters and merchandise. This was an increase of \$31,810 over last year or 27 percent. Donations under the category of Contributions is the result of revenue from grant support, gifts and other contributions. These donations decreased \$33,301 over last year. Bequest and memorial revenue consists of revenue received from memorials, bequests and research. Memorials and bequests totaled \$100,968 with the remainder of \$18,960 received from research. This total reflects a decrease in giving of \$278,721.

The reduction in revenue is attributed to the downward trend in the economy since September 08. The IETF hopes to curb the downward trend in revenue during FY10 and seek additional funding from new sources in order to maintain the education, awareness and research programs that currently exist.

### Expenses

Total expenses increased \$71,996 compared to FY08 due to the collaboration with the Goulden Touch Foundation and the fundraising expenses associated with the first large fundraiser. This increase is not considered detrimental but a necessity in order to increase funding for research. Based on the positive outcome, additional fundraisers of this type may be on the horizon in order to tap into larger sums of funding for larger research projects.

Programs expenses were up slightly at \$2,338 and is the result of a small growth in services necessitating more educational materials, a greater number of ET Community

Events, and community outreach through the Community Ambassador program. Community outreach was in part funded by unrestricted educational grants provided by the Medtronic Foundation, Medtronic Corporation and the ANS Corporation. Program expenses accounted for 81 percent, Management and General Expenses 10 percent and Fundraising (net expenses) 9 percent.

Expenses remained consistent, with the exclusion of the Goulden Touch Foundation and IETF fundraiser. Expenses are expected to remain stable, if not lower, throughout FY10 as the organization seeks to tighten expenses to offset the possibility of lower revenue during the slower economy.

## Independent Auditors' Report

We have audited the accompanying statements of financial position of International Essential Tremor Foundation (a non-profit organization) as of March 31, 2009 and 2008, and the related statements of activities, functional expenses and cash flows for the years 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 audits.

We conducted our audits 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 audits provide 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, 2009 and 2008, and the changes in its net assets and its cash flows for the years then ended, in conformity with accounting principles generally accepted in the United States of America.

DANA F. COLE & COMPANY, LLP  
Overland Park, KS  
July 8, 2009

## International Essential Tremor Foundation

### Statements of Financial Position

March 31, 2009 and 2008

ASSETS		
	2009	2008
<b>CURRENT ASSETS</b>		
Cash	544,543	255,808
<b>PROPERTY AND EQUIPMENT</b>		
Office equipment	44,967	33,930
Less accumulated depreciation	(34,050)	(30,399)
Net property and equipment	10,917	3,531
<b>OTHER ASSETS</b>		
Certificates of deposit	152,063	378,168
Security deposits	1,100	1,100
Total other assets	153,163	379,268
<b>TOTAL ASSETS</b>	<b>708,623</b>	<b>638,607</b>
LIABILITIES AND NET ASSETS		
<b>LIABILITIES</b>		
Accounts payable	15,757	0
Accrued expenses	18,939	15,803
Total liabilities	34,696	15,803
<b>NET ASSETS</b>		
Unrestricted	309,867	221,937
Unrestricted - Board-designated - emergency reserve	25,000	25,000
Total unrestricted net assets	334,867	246,937
Temporarily restricted	339,060	375,867
Total net assets	673,927	622,804
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>708,623</b>	<b>638,607</b>

## Statement of Activities

March 31, 2009 and 2008

	2009			2008		
	Unrestricted	Temporarily Restricted	Total	Unrestricted	Temporarily Restricted	Total
<b>REVENUES, GAINS AND OTHER SUPPORT</b>						
Contributions	57,770	36,038	93,808	94,407	32,702	127,109
Honoraria				7,738		7,738
Interest and dividend	15,207		15,207	21,873		21,873
Membership dues	336,729		336,729	321,459		321,459
Memorials and bequests	119,928		119,928	114,649	284,000	398,649
Other exempt function revenues	34,255		34,255	13,878		13,878
Program service fees	1,925		1,925	21,015		21,015
Special events	149,496		149,496	92,917	24,769	117,686
715,310	36,038	751,348	687,936	341,471	1,029,407	
Amounts released from restrictions	72,845	(72,845)		42,009	(42,009)	
Total revenues, gains and other support	788,155	(36,807)	751,348	729,945	299,462	1,029,407
<b>EXPENSES</b>						
Program expenses	451,969		451,969	449,631		449,631
Management and general expenses	58,888		58,888	58,929		58,929
Fundraising expenses	189,369		189,369	119,699		119,699
Total expenses	700,225		700,225	628,259		628,259
<b>CHANGE IN NET ASSETS</b>	87,930	(36,807)	51,123	101,686	299,462	401,148
<b>NET ASSETS, beginning of year</b>	246,937	375,867	622,804	145,251	76,405	221,656
<b>NET ASSETS, end of year</b>	<b>334,867</b>	<b>339,060</b>	<b>673,927</b>	<b>246,937</b>	<b>375,867</b>	<b>622,804</b>

Continued from page 3

FY10 Publications plan includes updating all literature with a new IETF logo and design format, beginning in May, 2009. The publications that currently exist will be reviewed to determine if a better format can help save paper and printing costs.

FY10 Website plan includes a complete overhaul of the IETF website. The current site has become too industrial due to its content and is not easy for people to navigate. Content will be rewritten, the new site will provide easier access to educational materials for the newly diagnosed and for those people already diagnosed who want quick access to treatment options. Work will begin in June, 2009.

## Research

The IETF awarded \$66,000 in research funding to two exceptional researchers in the field of ET in FY09. Final project completion is the fall of 2009.

Holly Shill, MD, Director, Thomas H. Christopher Center for Parkinson's Research, Sun City, AZ, has been awarded \$36,000 for the study, "Brain Catecholamine System in Essential Tremor." The objects of this study are to determine and compare levels of three proteins in the brains of ET subjects, confirmed Lewy Body disease subjects and a control group.

Fatta Nahab, MD, assistant professor of neurology, Department of Neurology, University of Miami, Miami, FL was awarded \$25,000 for the study, "Identification of the Neural Generator(s) in Essential Tremor using Functional Magnetic Resonance Imaging." The objectives of this research are to locate, through the use of MRI, a region of the brain with similar oscillatory features (tremor) as the subject's observed symptomatic tremor; compare and contrast how tremor changes during various activities and at rest; and, assess the impact of alcohol on these selected areas of the brain and on the subject's tremor.

## Bequests

The IETF received two bequests totaling \$100,968. The IETF is very grateful to the families of those persons listed below for the support received through bequests and memorials.

- Howard Fisher Charitable Trusts, Chico, CA, \$46,968. This bequest is restricted and will continue for a total of 16 more years.
- Paul T. Perney Trust, \$54,000, Fayette, MO. This bequest is restricted for research.

Again, the IETF thanks the Fisher and Perney families for their commitment and support to our mission and dedication in funding ET research, continuing the struggle to raise awareness and educate the 10 million people and families who are effected by ET.

## Presidents Club

The IETF would like to recognize and thank the members of the Presidents Club FY09 for their valuable support and leadership. For more information about the Presidents Club, call IETF Executive Director, Catherine Rice, at 888-387-3667.

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## Matching Gift Contributions FY09

- AK Steel Foundation
- Aetna Foundation, Inc.
- Bank of America Matching Gift Program
- Blue Cross Blue Shield of Minnesota
- ExxonMobile Foundation
- FM Global Foundation
- GE Foundation
- GlaxoSmithKline Foundation
- ITW Foundation
- Johnson & Johnson Family of Companies
- Microsoft Giving Campaign
- Schneider Electro/Square D Foundation
- The Home Depot Foundation
- Verizon Foundation
- WellPoint Associate Giving



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