

2002 ANNUAL REPORT

Awareness.

Education.

Research.

The IETF is changing lives.

IETF

INTERNATIONAL ESSENTIAL TREMOR FOUNDATION



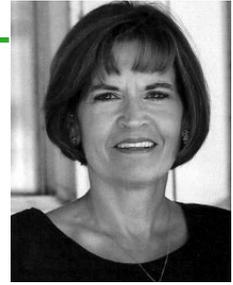
The IETF is a proud member of Community Health Charities.

 Community
Health Charities
Kansas & Missouri
WORKING FOR A HEALTHY AMERICA

FROM THE EXECUTIVE DIRECTOR

In a year when many charitable groups experienced difficulties, the IETF posted steady, significant gains in funding, membership, and services. We made great strides toward our three major goals:

- Raising awareness about essential tremor (ET),
- Providing education about ET, and
- Funding research that will result in adequate treatments and ultimately a cure.



Catherine Rice
Executive Director

In 2002, we saw:

- A 77 percent increase in the number of requests for educational packets over 2001, from 3,096 to 5,483.
- A 40 percent increase in our list of potential donors, from 17,602 in 2001 to 24,687 in 2002.
- Continued growth in the number of support groups across the country, up 59 percent from 34 to 54.
- Total revenues of \$620,452, up 62 percent from \$382,114 in 2001.
- Bequests of \$253,368, up 183 percent from \$89,393 in 2001.
- Membership and general contributions of \$357,932 as compared to \$273,285 in 2001, a 31 percent increase.
- Miscellaneous income from memorials, interest, and public research contributions of \$9,152, down 53 percent from \$19,436 in 2001.

Total expenses increased to \$419,416 in 2002, up 40 percent from \$299,697 in 2001 largely as a result of growth in services, educational materials, outreach, and funding for research. Administration and fundraising accounted for only 20 percent of the total budget.

Since 1988, the IETF has been a significant, worldwide source of information and help for people who have ET and the people who love and care for them. From educational materials to a physician-referral service to support groups to participating in health fairs and other similar events, we continued to change lives in 2002.

For that, I thank the thousands of people who support the IETF with their talents, time, and money, the many tireless, enthusiastic support group leaders throughout the country, our Board of Directors, physicians who tell their patients about us, and the IETF staff, especially Kelly Schroeder, our database manager, who created our sound, usable database. 2002 was indeed a good year for the IETF — and, thanks to thousands of people, I know it is only the beginning.

Catherine Rice
Executive Director

FINANCIAL REPORT

INDEPENDENT AUDITORS' REPORT

IETF Board of Directors Overland Park, Kansas

We have audited the accompanying statement of assets, liabilities and net assets — modified cash basis of IETF (a nonprofit organization) as of December 31, 2002, and the related statements of revenues, expenses and changes in net assets — modified cash basis, cash flows — modified cash basis, and functional expenses — modified cash basis 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.

As described in Note 1, these financial statements were prepared on the modified cash basis of accounting, which is a comprehensive basis of accounting other than accounting principles generally accepted in the United States of America.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of IETF as of December 31, 2002, and the changes in net assets and its cash flows for the year then ended, on the basis of accounting described in Note 1.

DANA F. COLE & COMPANY, LLP
Overland Park, Kansas
March 10, 2003

IETF

Statement Of Assets, Liabilities and Net Assets — Modified Cash Basis

December 31, 2002

CURRENT ASSETS

Cash	\$404,305
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PROPERTY AND EQUIPMENT

Office equipment	25,461
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Less accumulated depreciation	15,641
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Net property and equipment	9,820
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OTHER ASSETS

Security deposits	1,100
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Other	856
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Total other assets	1,956
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TOTAL ASSETS	416,081
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LIABILITIES AND NET ASSETS

NET ASSETS

Unrestricted	311,139
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Temporarily restricted	104,942
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Total net assets	416,081
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TOTAL LIABILITIES AND NET ASSETS	416,081
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IETF

Statement of Revenues, Expenses and Changes in Net Assets — Modified Cash Basis

Year Ended December 31, 2002

	Unrestricted	Temporarily Restricted	Total
REVENUES, GAINS AND OTHER SUPPORT			
Contributions	401,232	53,071	454,303
Membership dues	150,068		150,068
Memorials	7,781		7,781
Other exempt function revenues	4,851		4,851
Interest	3,449		3,449
Total revenues, gains and other support	<u>567,381</u>	<u>53,071</u>	<u>620,452</u>
EXPENSES			
Program expenses	336,307		336,307
Management and general expenses	37,702		37,702
Fundraising expenses	45,407		45,407
Total expenses	<u>419,416</u>		<u>419,416</u>
CHANGE IN NET ASSETS	147,956	53,071	201,036
NET ASSETS, beginning of year	<u>163,174</u>	<u>51,871</u>	<u>215,045</u>
NET ASSETS, end of year	<u><u>311,139</u></u>	<u><u>104,942</u></u>	<u><u>416,081</u></u>

IETF

Statement Of Cash Flows — Modified Cash Basis

Year Ended December 31, 2002

CASH FLOWS FROM OPERATING ACTIVITIES

Increase in net assets	<u>\$201,036</u>
Adjustments to reconcile change in net assets to net cash provided by operating activities:	
Depreciation	4,122
Increase in other assets	<u>(1,234)</u>
Net cash provided by operating activities	<u>203,924</u>

CASH FLOWS FROM INVESTING ACTIVITIES

Purchase of fixed assets	<u>(4,150)</u>
Net cash used in operating activities	<u>(4,150)</u>

INCREASE IN CASH 199,774

CASH, beginning of the year 204,531

CASH, end of the year 404,305

FAST FACTS

- Tremor refers to the rhythmic shaking of a body part. Of the more than 20 different kinds 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 1.5 million people in the United States.
- Tremor is not confined to the elderly. Children and the middle-aged 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 tremor 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 a few effective treatments available for ET, including medications and surgery. Unfortunately, many experts believe that only a small percentage of people who have ET seek medical assistance.



MISSION

Founded in 1988, the IETF is a 501(c)(3) corporation and is the only foundation of its kind in the world. The IETF’s purpose is to provide funding for ET research as well as to provide information, services, and support to people who have ET and to their families and healthcare providers.

AWARENESS

Although up to 10 million people in the United States — and millions more around the world — have ET, public awareness of the incurable condition is low. Increasing that awareness has always been one of the IETF's primary goals, and we made great strides in 2002. A carefully crafted and executed public relations program launched late in the year garnered substantial media coverage about ET, people who have ET, and the IETF. Information appeared in the following.



- *Prevention Magazine*
- *Raleigh (North Carolina) News and Observer*
- *AARP's My Generation magazine*
- *Rochester (New York) Post Bulletin*
- *Paul Donohue's syndicated column*
- *Sacramento (California) Bee*
- *The (Albany, New York) Times-Union*
- *Toledo (Ohio) Blade*
- *The Chicago Daily Tribune*
- *The Times-Picayune (New Orleans)*
- *Greensburg (North Carolina) Daily News*
- *Tulsa (Oklahoma) World*
- *Harvard (Medical School) Health Letter*
- *U.S. Pharmacist magazine*
- *The (Minneapolis) Star Tribune*
- *Watertown (Ohio) Daily*
- *Palm Beach (Florida) Post*

We are especially grateful to the following donors for their contributions to fund public awareness projects and ensure our ongoing campaign.

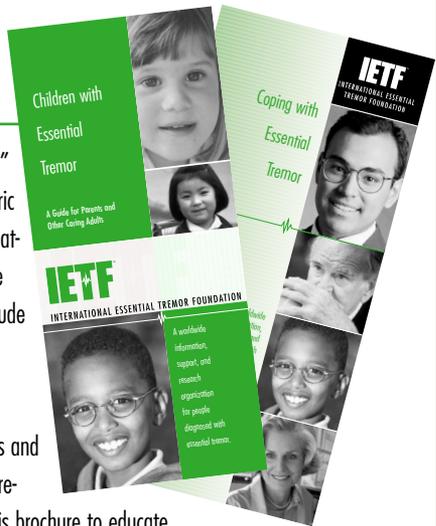
- Mrs. Shari Finsilver, \$10,000 to support statewide ET conferences
- Rose Kleiner Trust, \$48,948
- Barbara Kurtz Trust, \$111,087
- William and Mary Shelley Trust, \$33,333
- Mr. Kenneth W. Sidwell, \$16,000

EDUCATION

Knowledge is indeed power. With that thought firmly in mind, the IETF created a variety of educational materials in 2002 and took advantage of opportunities to provide face-to-face education across the country.

Publications

- “Tremor Disorders in Children, a Clinical Discussion.” Partnering with Michael Pranzatelli, M.D., a pediatric neurologist at the University of Illinois, the IETF created and published this landmark brochure to provide information for physicians whose patients may include children with ET. We distributed the brochure to 19,700 pediatric neurologists at no charge.
- “Children with Essential Tremor, a Guide for Parents and Other Caring Adults.” Working with parents and caregivers of children who have ET, the IETF created this brochure to educate adults about ET in children as well as ways to help children cope with the condition. We distributed 250 copies at no charge.
- “Coping with Essential Tremor.” Drawing on suggestions, ideas, and coping tips from hundreds of people who have ET, the IETF re-issued this brochure filled with ideas for ways to cope with ET. Originally available at \$5 per copy, the new brochure fits into a business envelope and is free to members.
- “A Patient Information Handbook” (Spanish). In 2002 the IETF made information about ET accessible to thousands more people with the publication of this brochure in Spanish. We distributed 7,500 copies.
- *Tremor Talk*. This quarterly publication provides information about new research, coping tips, advice and insights from medical experts, and ideas for spreading the word about ET.
- Medical Alert Card. Because ET can often be mistaken for intoxication, the IETF created the Medical Alert Card to 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. The card is free to members.



Meetings and conferences

- 2nd Annual Support Group Leader Conference. Three dozen support group leaders spent 1 1/2 days in Chicago learning more about ET from a variety of healthcare professionals and learning ways to improve their support groups from experts in fundraising, public relations, speakers, and topics, to name only a few. Keynote speaker Sen. Terry Link (R-IL) talked about his life with ET. *The Chicago Tribune* and Chicago TV channel 9 covered the conference. Stories also appeared in 22 smaller newspapers across the country as a result of newswire pick-up. The conference was funded by a Medtronic Corporation grant.
- General educational conferences. The IETF, support group leaders, and Medtronic Corporation sponsored a variety of conferences to educate local community residents about ET diagnosis and treatment options. In 2002, we held conferences in Akron, Oh.; Aurora, Colo.; Baltimore, Md.; Bloomington, Minn.; Casper, Wyo.; Glendale, Mesa, and Phoenix, Ariz.; LaJolla and Orange County, Calif.; and New York, N.Y.
- Health fairs. Support group leaders distributed literature and answered questions at health fairs in Albuquerque, N.M.; Glen Ellyn, Ill.; Oakland, Sacramento, and Sunnyvale, Calif.; and Phoenix, Ariz.

Community events

- National Geriatric Nursing Association meeting, Denver, Colo. IETF volunteers distributed more than 250 informational packets.
- “Caring for the Elderly,” Broward County, Fla. IETF volunteers distributed more than 700 informational packets.
- International Congress of Parkinson’s Disease and Movement Disorders sponsored by the Movement Disorder Society. IETF staff members distributed information to more than 200 physicians from around the world.
- Chicago Chamber of Commerce. Sandy Wisniewski made a presentation to increase employers’ awareness of ET in the workplace.
- Independence Center, Independence, Mo., fundraiser. The IETF received a percentage of all tickets purchased for a special shopping event at the center. It was the first such fundraiser for the IETF in the Kansas City, Mo., area.
- ET posters. Lexi-Comp Corporation created 26”x40” posters for display in physician office waiting areas and examination rooms to help educate both physicians and patients about the diagnosis and treatment of ET.

Special initiatives

The National Education Association Initiative. Children who have ET often have low self-esteem and difficulty functioning with others as well as feelings of sadness, anger, and isolation. The IETF is working to educate teachers to help them understand ET, identify and help solve problems with students, educate others, and become advocates for children who have ET.



Support groups

People who have ET rank quality of life issues and emotional support at the top of their needs. Because support groups are so important, the IETF hired a support group development staff member in 2002 to coordinate formation of new support groups, especially in areas that had no groups.

- Support groups. IETF support groups are informal, self-managed resources for people who have ET as well as the people who love and care for them. Members share information about and ideas for living with ET, and they provide support and real-life wisdom. Since 1998, the number of support groups has grown from 14 to more than 60.
- Support group leaders. These volunteers have ET or they care for or love someone who has ET. Collectively, they donate thousands of hours every year planning and organizing meetings and special events and raising awareness about ET.
- Support group locations. Madison, Ala.; Chandler, Phoenix, and Tucson, Ariz.; Clovis, Los Angeles, Sacramento, San Diego, San Jose, and Santa Barbara, Calif.; Littleton, Colo.; Dagsboro and Lewes, Del.; Boca Raton, Pinellas Park, Pompano Beach, and West Palm Beach, Fla.; Kaawa, Hawaii; Burlington, Iowa; East Peoria, Glen Ellyn, Libertyville, Northbrook, and Rockford, Ill.; Schererville and Valparaiso, Ind.; Baton Rouge, La.; Chicopee, Mass.; Kansas City and St. Louis, Mo.; Orchard Lake, Mich.; Omaha, Neb.; Oak Island, N.C.; Mahopac, N.Y.; Aurora and Newark, Oh.; Ardmore and Oklahoma City, Okla.; Eugene, Portland, and Rainier, Ore.; McKeesport, Pa.; Aiken, S.C.; Dallas and San Antonio, Texas; Lynchburg, Va.; Spokane, Wash.; Appleton and River Falls, Wis.; England; New Zealand.

RESEARCH

Research into the etiology, pathogenesis, and treatment of ET is important to finding effective treatment and, ultimately, a cure. IETF funding supports innovative research that also has the potential for receiving substantial support from the National Institutes of Health and other sources. Research continued as a primary goal for the IETF in 2002 with the funding of two projects.

Research projects

- “Pathology of Essential Tremor.” Led by Elan Louis, M.D., M.S., this study seeks to lay the foundation for developing better therapeutic strategies. The study addresses two questions: What is the pathological basis for ET? What is the neuro-chemical basis for ET? The research is particularly important because, even though ET is common, researchers have studied few brains and even fewer in detail. Dr. Louis plans to study the brains of 10 deceased ET cases and compare findings to the brains of 10 deceased control subjects — people who do not have tremor. Dr. Louis will look at specific parts of the brain to help determine a starting point for ET. This is extremely important research in helping the IETF move forward in the crusade to find the cause that will lead the way to effective treatment and cure.
- “Quality of Life in Essential Tremor.” This study addresses measuring disabilities and quality of life issues associated with ET. The study is being conducted by Kelly Lyons, PhD, and Rajesh Pahwa, M.D. (University of Kansas Medical Center) with Alexander Troster (University of Washington in Seattle). Quality of Life in Essential Tremor (QUEST) assesses day-to-day difficulties in the lives of ET patients. In the initial phase, more than 200 people who have ET tested the 65-question QUEST assessment. Their responses resulted in the next version of the assessment, which contains 35 questions about everyday life — physical activities, emotional issues, communication, hobbies, and work-related issues. Further tests will help ensure the final QUEST version is valid and reliable for measuring disabilities associated with ET as well as understanding and assessing quality of life for people who have essential tremor.

Research funding

- Thelma D. Beatty Trust. This trust contributed \$60,000 in research funding in 2002 with additional funding scheduled for 2003.
- Beverly Myers Research Fund. Beverly Myers donated her original artwork and note cards, which resulted in \$5,900.
- Member donations. Members contributed \$8,060 for research in 2002.

MAJOR DONORS

The following IETF members gave \$1,000 or more in 2002.

- Mr. and Mrs. William Chester
- Mrs. Margaret S. Edwards
- Mrs. Shari Finsilver
- Mrs. Heather Holford
- Mr. and Mrs. Edward L. Hughes
- Mr. and Mrs. John C. Kielhorn
- Mrs. Lois Kreider
- Ms. Roberta M. Langtry
- Ms. Ruth S. Lippitt
- Mr. John F. Miller, III
- Mr. and Mrs. Herbert J. Myers
- Mrs. Rosemary W. Nothwanger
- Mr. and Mrs. John F. Papach
- Mrs. Jill G. Pelisek
- Mr. Eli Robinson
- Ms. Beth Schild
- Mr. Kenneth W. Sidwell
- Mr. L. William Teweles
- Mrs. Margaret B. Thaw
- Mr. John B. Vermynen

Memorials

Memorial donations honored the following people.

- Doug Baker
- Irene C. Beggs
- Glenda Joy Bell
- Alma Bischoff
- Erma H. Bowser
- John Branch
- Allen Congdon
- Peter Dahl
- Olga Dietzel
- Betty Dugger
- Margaret Dulin
- Eleanor Finzer
- Susan Fisher
- Edward Frank
- Frederic Franklin
- Ann Frisbee
- Richard B. Fryer
- Kennan Fuller
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- Rodney Gates
- Stuart Gottlieb
- Louis Haefele
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- Ann Hesemann
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- Mary Ann McRae
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- Margery Raikes
- Frank Scherden
- Maurice Spiegel
- Alan Stats
- Sonia Taran
- Alyce Taylor
- Ruth Traeger
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- Lydia C. Trumps
- Carl Trussell
- Lucille Turtle
- Pop-Pop and Nunny
- Doris Walski
- Hazel West
- Mary Wilcox
- Kathleen B. Windsor
- Albert Wollenberg

Foundation and corporate contributors

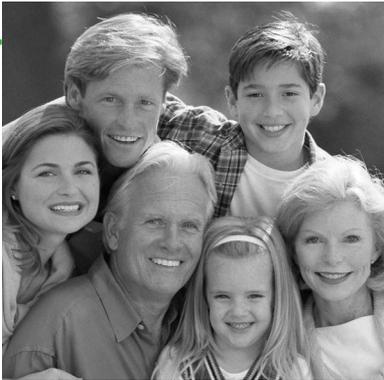
- The Berner Charitable Foundation
- The Broyhill Family Foundation
- The Henry Bull Foundation
- The Medtronic Corporation
- The Medtronic Foundation

Matching gifts

- Aid Association for Lutherans
- American Express
- Charles Schwab Corporation
- Dominion Foundation
- ExxonMobil Foundation

LOOKING AHEAD

Continuing to build on our strong foundation, IETF programs and projects for 2003 and 2004 are well under way.



- **State educational conferences.** The IETF will hold eight statewide patient conferences in major metropolitan areas that have physicians competent in the diagnosis, medical and surgical treatment of ET. States chosen have high populations of people who have ET. Conferences will be held in California (two), Florida (two), Illinois, joint Kansas and Missouri, Michigan, and Texas.
- **Video news release (VNR).** The IETF will create a VNR that describes ET and its effects, showing people who have ET performing everyday activities and the associated difficulties. We will distribute the VNR to TV stations throughout the nation with a news release encouraging health editors to air the information. The VNR means TV stations will have accurate information about ET.
- **Public service announcements (PSAs).** The IETF is taking advantage of the requirement for TV and radio stations to broadcast free PSAs. We received funding to create a professional PSA and we will be distributing it to broadcasters across the country.
- **“Seeking Solutions with Suzanne.”** Executive Director Catherine Rice has been interviewed by Suzanne Roberts, host of “Seeking Solutions with Suzanne,” a TV show geared to seniors. The show covers topics ranging from health issues to style and airs three times daily on CNN’s “Headline News” on the Comcast Cable system. The show reaches millions of people.

CURRENT IETF LEADERSHIP

Board of Directors

- President: L. William Teweles
- 1st Vice President: Kelly E. Lyons, PhD
- 2nd Vice President: Carl M. Leventhal, M.D.
- Secretary: Edward M. Block, PhD
- Treasurer: Jill G. Pelisek
- Shari Finsilver
- Howard J. Kane
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- A.H. Rajput, M.D.
- Eduardo Tolosa, M.D.
- Robert R. Young, M.D.

IETF staff

- Executive Director: Catherine Rice
- Administrator of Patient Programs in England: Karen Walsh
- Database Manager: Kelly Schroeder
- Development Specialist: Debbie Ramirez



INTERNATIONAL ESSENTIAL TREMOR FOUNDATION

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