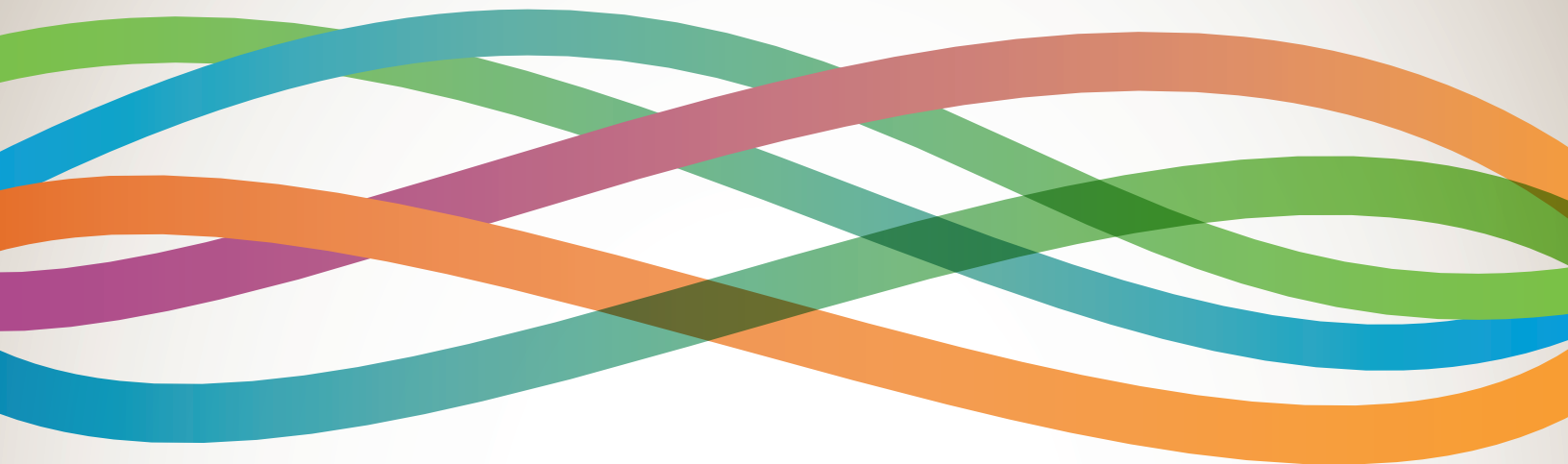




International Essential
Tremor Foundation



APRIL 2016 - MARCH 2017

ANNUAL International Essential Tremor Foundation REPORT

MESSAGE FROM THE EXECUTIVE DIRECTOR



As we look back on the past year, I am very excited about the progress we have made raising awareness for essential tremor and our continuing efforts to increase educational opportunities for patients, family members, and doctors. These programs and projects would not be possible without the help of many people.

First, I would like to thank our loyal donors, support group leaders, and corporate partners for their support and generosity. We could not do what we do including raising awareness, providing educational materials and events, scholarships to students affected by ET, and awarding more than \$750,000 in research grants without your donations of time, talent, and treasure.

I also want to thank our staff. Tara Duerr and Dawanna Fangohr do great work and have taken on additional duties recently. Their hard work and dedication allow us to further our mission to provide hope to the ET community worldwide. The next time you call, e-mail, or write please thank them for all they do for the IETF and the ET community.

And of course I want to thank our Board of Directors and Medical Advisory Board who are committed to the mission of the IETF and guarantee we meet our financial and research commitments along with the ethical and moral responsibilities for everyone with ET. Recently two long time board members, Russ Rosen and Ed Block, retired from the Board. We want to thank them for their service to the IETF and helping us grow into the organization we are today.

The IETF continues to improve the way we deliver our messages. This year we hosted three teleconferences on a variety of topics with more than 600 reservations for each call. If you missed one, recordings of each call are posted on our website on the “About Essential Tremor” page. We also continue to host regional ET Education Forums. This year we had the opportunity to visit Denver, CO; Boca Raton, FL; and Detroit, MI with future events scheduled in Cleveland, OH; Sacramento, CA; and Philadelphia, PA. We hope you can attend one of these events when we come to your town.

We are also working on a project to increase awareness for ET and the IETF. The *Informed Series* with Rob Lowe is producing a documentary video for the IETF to be broadcast on over 200 public television stations in the next year. The project also includes a one minute commercial to be broadcast on various cable channels including CNN, The Discovery Channel, and MSNBC. We will also receive a video profiling ET and the IETF which we will use on our website

and social media channels to continue to increase education and awareness. You will hear more about these videos and the broadcast schedule this fall.

We continue to strengthen our current partnerships and build new ones with a variety of companies and other non-profits who focus their efforts on promoting ET education and awareness. One of the biggest concerns we hear is the lack of progress in ET specific treatments. Several of our partners are working to create new treatment options or to improve their existing treatments. Working together we can combine our efforts for a unified voice for the ET community.

So as we start the new fiscal year we continue our commitment to work for you on raising ET awareness, providing the most up to date information through Tremor Gram, Tremor Talk, and our social media channels, and fund research to find the cause and hopefully someday a cure for ET.

Thank you again for your support of the IETF. Feel free to contact our office if you need any materials to share via personal meetings, phone calls, or social media. You are our best advocates and we hope you continue to spread the word about essential tremor and the IETF.

Sincerely,

A handwritten signature in black ink that reads "Patrick McCartney". The signature is fluid and cursive, with a long, sweeping underline that extends to the right.

Patrick McCartney
Executive Director, IETF

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INTERNATIONAL ESSENTIAL TREMOR FOUNDATION

OUR MISSION

The IETF provides hope to the ET community worldwide through awareness, education, support and research.



THE YEAR



*WHAT
YOU'VE
MADE
POSSIBLE*

SUPPORT

RESEARCH

AWARENESS

EDUCATION

IN

NUMBERS

2016-2017

Number of participants attending education programs across the nation

1,857



Including two education forums, one webinar and two teleconferences.



\$75,0000

Funded to three IETF research projects to further better treatment options for ET.



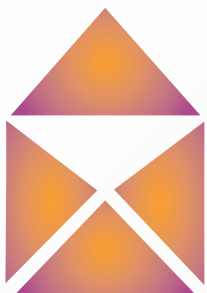
EIGHT SCHOLARSHIPS



Awarded to lessen the burden of higher education for students with ET.

1,318

INFORMATION PACKETS SENT



To educate and increase awareness for ET and the IETF to patients and healthcare providers



48,806

Media deliveries sent through press release distribution to nearly 6,000 media contacts.

In hopes of raising awareness to a potential global audience of 5.3 billion.

COMMUNICATIONS

ELECTRONIC COMMUNICATIONS

The IETF touches many people worldwide thanks to the advancements in technology and communications. Through an interactive and user-friendly website, informative and frequent e-mails, and a strong social media presence, the IETF reaches thousands across the globe.

Electronic communications not only allow us to reach more people than ever before, they allow us to make meaningful connections at a fraction of the cost of postal mailings. The IETF connects people together on several social media sites to help raise awareness among the general public and to provide additional communication avenues and support for those affected by ET. Follow the IETF's latest information at the following sites.



Website
www.EssentialTremor.org



YouTube
YouTube.com/essentialtremorIETF



Facebook Page
[Facebook.com/InternationalEssentialTremor Foundation](https://Facebook.com/InternationalEssentialTremorFoundation)



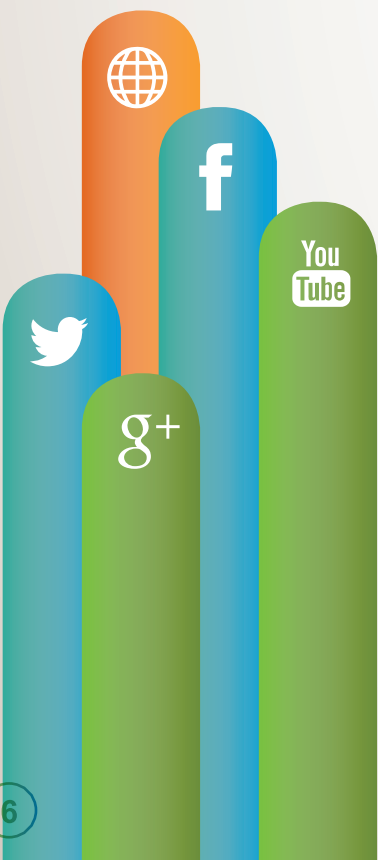
Twitter
Twitter.com/EssentialTremor



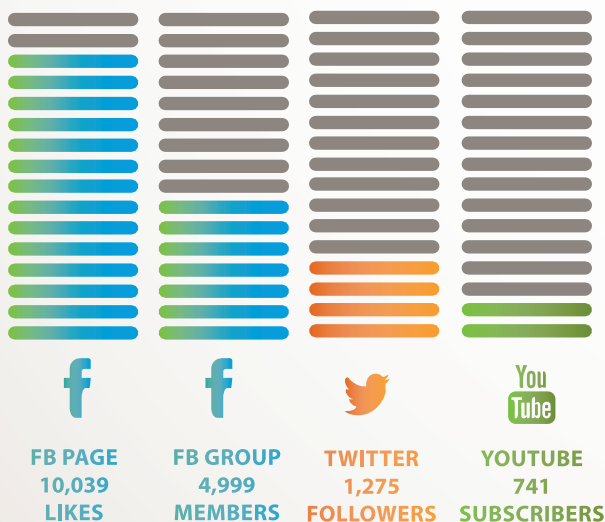
ET Awareness Facebook Group
Facebook.com/groups/5884699022/



Google+
 Search for International Essential Tremor Foundation



SOCIAL MEDIA USE



TOP COUNTRIES ON IETF SOCIAL MEDIA



TREMOR GRAM

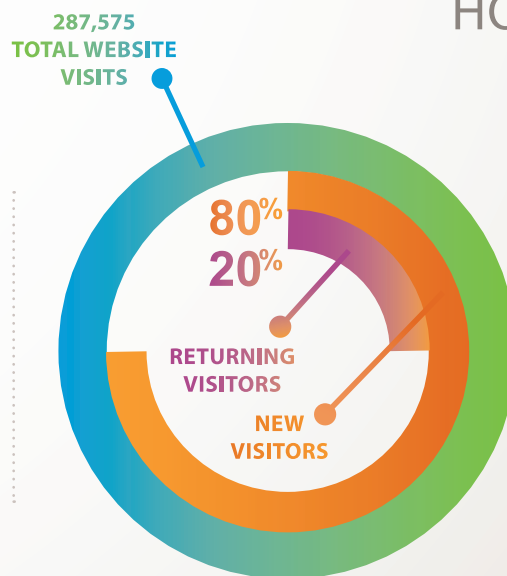
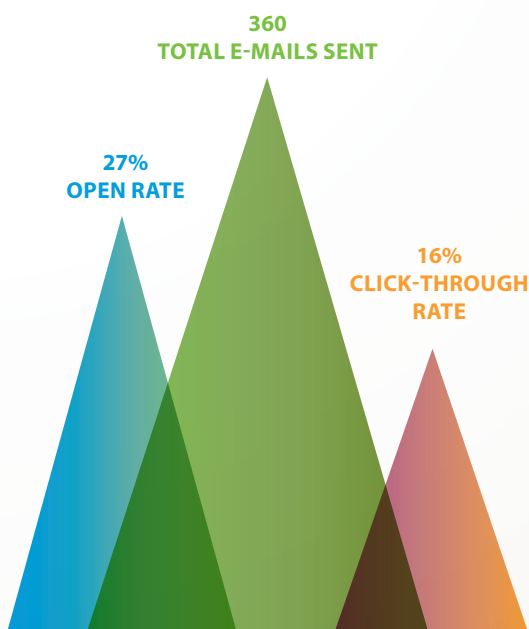
Each month the IETF sends out Tremor Gram, our free, electronic newsletter, to more than 21,000 people. Sending informative e-mails on a regular basis helps increase participation in IETF events, assists in recruiting for ET-related research studies, drives additional traffic to the website, and builds loyalty among donors. The IETF e-mails have an average open rate of 27.2%, which is higher than the industry standard. For non-profits, the average open rate is 21.9%. Click-through rates are determined by the number of people who actually click on a link within an e-mail. IETF click-through rates are consistently over 16%.

TREMOR TALK

Published three times a year, *Tremor Talk* is the IETF's 32-page, full-color, professional publication all about essential tremor. The magazine features articles written by both healthcare professionals and IETF staff on a variety of ET-related topics: personal stories about people who have ET illustrate the challenges of living with essential tremor and the unique ways real people are able to conquer those challenges; medical articles are authored by some of the top minds in the movement disorders field written so anyone can understand; and research articles offer a glimpse of what scientists are working on today and what might be obtainable in the future. *Tremor Talk* is a donor publication and is mailed only to IETF annual donors. Past issues of Tremor Talk are available at www.essentialtremor.org/about-et/publications-library.

WEBSITE

With information from webinars on diagnosis process and treatment options, to support groups and personal stories, essentialtremor.org remains one of the best tools for making essential tremor information available to people around the world. It is the community's one-stop-shop for accurate and timely information. Website traffic was up 55% in FY2016. More than 79% of visitors were new. Most visitors were looking for general information about what essential tremor is, what medications are currently available to treat it, and what assistive devices might be helpful. Because of our top-notch SEO (search engine optimization), 60% of the people who found our website found it via "search". The IETF continues to receive first-page rankings, often appearing before such organizations as NIH and Mayo Clinic.



HOW TIME WAS SPENT ON WEBSITE



FINANCIALS

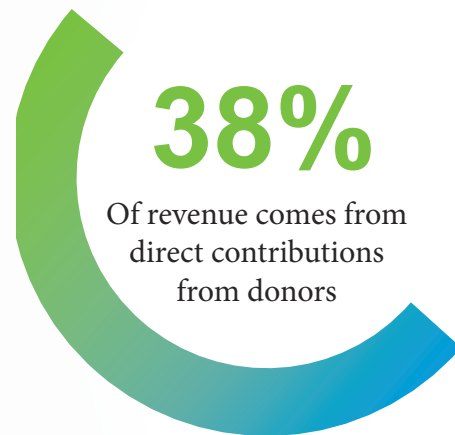
CONTRIBUTIONS

The IETF receives no federal, state or local government funding. Contributions from those affected by ET, mostly in the form of annual donations, sustain the IETF. This fiscal year, the IETF received 5,083 donations totaling \$958,274. These donations were used to fund ET research grants, provide free education and materials, offer vital support services, and fund programs that raise awareness in communities around the world.

REVENUE

Contributions	\$ 368,519
Investment income	35,213
Grants	50,000
Memorials/Bequests	368,323
Exempt function revenues	13,817
Research	53,899
Special events ¹	68,503

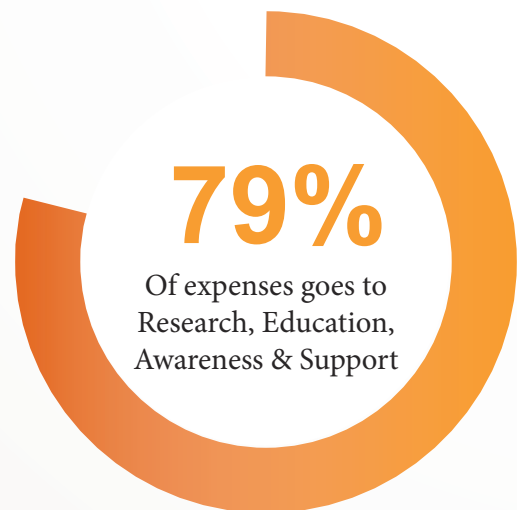
TOTAL REVENUE **\$ 958,274**



EXPENSES

Program ²	\$ 470,174
Management/General ³	86,377
Fundraising ⁴	36,535

TOTAL EXPENSES **\$ 593,086**



¹ Revenue received from National ET Awareness Month.

² Includes awareness, education, support and research activities and initiatives.

³ Includes expenses related to office overhead such as supplies, computers, copier, salaries, and rent.

⁴ Includes National Awareness Month activities, annual appeal, and annual donations.

PRESIDENT'S CLUB

DONORS

The President's Club honors individuals contributing \$1,000 or more annually to the IETF. President's Club members are everyone's heroes. Members are recognized in several IETF publications, such as *Tremor Talk* magazine, on the IETF website and in the IETF annual report. Every dollar received by the IETF is greatly appreciated, but these large donations make a significant impact on the Foundation's ability to fulfill its mission each year. Please join us in recognizing these generous donors:

Mr. & Mrs. Joseph Atkinson
Mr. Robert Barfoot
Ms. Ricki Bell
Mr. Calvin Bentsen
Mr. & Mrs. David Berryhill
Mr. Steven Beyer
Dr. & Mrs. Edward Block
Mr. & Mrs. J. Robert Booth
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The Alvin and Fern Davis Foundation
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Mr. John Watterson
Mr. & Mrs. John Williams
Mr. Michael Williamson
Mr. & Mrs. Leo Wilz
Mr. Fred Young

MEMORIALS

TRIBUTES

Giving a memorial donation is a meaningful way to pay tribute and show how those close to you continue to live on in your heart. Below you will find a list of friends and family members who have donated in memory of their loved one. Memorials are listed in ALL CAPS, and donors are listed below.

CARL L. ANGERMAN
Ms. Sandra Jameson
Mr. Wayne Rickman
Ms. Sherry Hajec

EDGAR BARNETT
Ms. Gail Sterling

GERRY BARNETT
Ms. Gail Sterling

JACOB BERGER
Ms. Georgine Spisak
Ms. Mariangela Dipietri

ELAINE BESSIER
Tallgrass Creek
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Mr. & Mrs. Douglas Williams
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Ms. Mailee Van Wye
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Mr. & Mrs. William Holston
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Ms. Marilyn Heley
Mr. & Mrs. Mark McDonald
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Ms. Jacqueline Lehatto
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ALLEN ENGELHARDT
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Ms. Marjorie Wulff
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Mr. & Mrs. Bob Abrams
Mr. & Mrs. John Malpiedi
Mr. & Mrs. Boyd Atteberry
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Mr. Michael Johnson
Mr. & Mrs. Peter Geer
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Ms. Janis Murphy
Mr. & Mrs. Todd Schnuck

ESTELLE SALZMAN
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Mrs. Faith Shaw-Holmes

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Mrs. Myrna Brown
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Mr. Kenneth Williams
Ms. Mary Claire Phelan
Dr. & Mrs. Frank Navratil
Mrs. Linda Catanzaro

MARGARET WATKINS
Ms. Susie Moore
Mr. & Mrs. Jeff & Suellyn
Johnson

LILLIAN WECHSLER
Mrs. Elaine Cohen
Ms. Ruth Katz

EDYTHE WEISS
Mrs. Barbara Shulman

HONORARIUMS

TRIBUTES

Honorarium donations are great ways to recognize important achievements and successes like: getting a new job, celebrating a birthday or anniversary, graduation, Bar Mitzvah and Bat Mitzvah events, or just to say “I was thinking about you”. Below you will find a list of people who have donated in honor of a special occasion in a friend or family member’s life.

JERRY BLASINGAME
Ms. Katy Blasingame

OBED CRAMER
Charles & Mary Jo Arndt

LILLIAN COURTHEUX
Mr. & Mrs. Richard Courtheoux

DAYTONA BEACH ET COMMUNITY
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PHIL DELAND
Ms. Linda Van Pelt

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Mr. & Mrs. J. Robert Booth

JOE DRISCOLL
Col. & Mrs. Barry Pencek

SHARI FINSILVER
Mr. & Mrs. Robert Hakim
Joyce Keller & Michael Walch

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Ms. Karen Hemmerling
Ms. Vicki Fishfader

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AMY GRIFFIN
Mr. & Mrs. Robert Booth

KYLE GRIFFIN
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Ms. Dawn Chiantello

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Ms. Jane Standish

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Thomas and Sabrina Pilarski

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Louis Wellan Community Fund
Mr. Dan Cohn

PHILLIP TUCKER
Mr. Philip R Tucker

LILLIAN WECHSLER
Ms. Ruth Solomon

LEGACY SOCIETY

PLANNED GIVING

Members of our Legacy Society have expressed their commitment to IETF through a very special and important form of financial support. These donors have named the IETF as the ultimate beneficiary of a planned gift. Such gifts might include a bequest and/or gifts of life insurance. These gifts contribute to the stability and long-term growth of the organization. It is a great way to have your support live on for years to come. If you would like to learn more about the Legacy Society or how to leave a bequest or gift of insurance to the IETF, please call our IETF Executive Director, toll free at 888.387.3667. The following individuals and families have generously named the IETF as beneficiaries in their wills or life insurance policies:

Deceased Donors

Warren Conklin Apgar Bequest
Robert Barfoot
Thelma Beatty Trust
Bernier Charitable and Scholarship Foundation
Butler Family Trust
Shirley A. Cavanagh Bequest
Willima B. Cole Trust
Nancy M. Craig Trust
E. Ruth Crum Trust
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Howard Fisher Trust
Albert Gendron Living Trust
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Edmond Jamieson
Laurita Hall Johnson Trust
Dorothy Helen King Bequest
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Barbara Kurtz Trust
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William & Mary Shelley Trust

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Martin Stinar Trust
Delbert D. Utgaard Trust
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Carol Post
Byron Scott
Jacqueline Sydow
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SUPPORT GROUPS

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Are you looking for a support group but don't see one listed in your area?

Consider volunteering as an IETF Support Group Leader, and help bring greater support and awareness to your community. Learn how to start a support group and keep it going for years to come at www.essentialtremor.org/volunteer.

Support groups are not intended to provide medical advice or be a substitute for qualified medical care. The IETF does not assume any liability resulting from participation in a support group. The opinions held by the support group leaders, attendees or presenters are not necessarily those of the IETF.



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