Established in 1988, the International Essential Tremor Foundation (IETF) is a charitable 501(c)3 not-for-profit organization headquartered in Overland Park, KS. The IETF is not funded by federal or state grants and, therefore, depends on the donations to further the mission. With a small staff of four, the IETF relies on its volunteers to help raise awareness and funds.

The IETF increases public awareness about essential tremor through:

- **Hope.** The IETF empowers individuals to regain control of their lives.
- **Awareness.** The IETF actively advocates for greater ET awareness and educates at every level.
- **Research.** The IETF funds scientific research to find more effective treatments and a cure for ET.
- **Support.** The IETF sponsors support groups around the world.

**Mission Statement**

The mission of the International Essential Tremor Foundation (IETF) is to provide global educational information, services and support to children and adults challenged by essential tremor (ET), to their families and health care providers, as well as to promote and fund ET research.

The mission of the IETF is better accomplished when many are involved, rather than a few.

**Vision Statement**

The International Essential Tremor Foundation (IETF) will be the premier source of information, support and advocacy for the essential tremor community. IETF will be a growing organization, funding its activities and new initiatives with increasing financial resources.

**The purpose of this guide**

This guide is designed to be a road map for the establishment, development and maintenance of a community-based support group. In addition, it will help you better understand the responsibilities and benefits of leading a support group.
# TABLE OF CONTENTS

## Part One
Starting an essential tremor support group

1. What is an IETF support group?
2. What skills and traits are needed to start and lead a group?
3. What are the benefits of being a support group leader?
4. How does the IETF assist support group leaders?
5. What does the IETF expect of support group leaders?
6. How does the IETF recognize support group leaders?

## Part Two
The first meeting

4. When should we meet?
5. Where should we meet?
6. How do I let people know about the meeting?
7. What do we do once we get there?

## Part Three
The meeting agenda

9. Dividing the responsibilities.
10. Working with speakers.
11. Keeping the faith when attendance is down.

## Part Four
Sample meeting plans

13.
What is an ET support group?

An informal, self-managed, self-help group. It is run by and for people who are affected by essential tremor. A support group is not a substitute for qualified medical care.

A place to be you.
Everyone is welcome and accepted at ET support group meetings. The group is a place where people talk openly about the challenges of living with ET and exchange ideas in a comfortable and safe environment. It is a place where privacy and confidentiality are respected.

A source of information.
With so much information available it’s hard to know what to believe. The IETF offers timely and accurate information about every aspect of essential tremor, from cutting-edge research to emerging medications.

A circle of friends.
It is a place to talk, laugh, and be inspired. At an IETF support group, members never have to worry someone will ask if they’re cold or nervous. They will find support and fellowship among others who are just like them.

As unique as its membership.
The interests and capabilities of support group members vary greatly, and change over time. It is not uniformity that counts or meeting a standard. Rather, it is making the most of what each group has to offer its members, at any given time.

What skills and traits are needed to start and lead a support group?

It takes a special kind of person to be a volunteer. It is important you consider the traits necessary to be successful in the role.

Time.
Most volunteers spend at least 4-6 hours each month preparing for their meetings, although more time is usually spent in the beginning, while the initial planning is taking place.

Organizational skills.
As the leader, it is important for you to prioritize tasks and keep good records.

Ability to work with others.
ET comes in all shapes and sizes. It affects people of all races and ethnicities. It is not bound by age or gender. So it is imperative that you are able to work with a diverse group of people in a positive and compassionate manner.

Basic computer skills.
In the digital age, it is important for you to communicate online with your members and the IETF online. Computer access and a valid email address are very helpful.

What are the benefits of being a support group leader?

Research shows volunteering leads to better health, greater life satisfaction and higher functional ability. In fact, these studies show those who volunteer experience greater health benefits than
those who receive support through these activities. A study of adults age 65 and older found volunteering had a positive effect on physical and mental health.

Just knowing you are not alone can be the biggest benefit of them all. Support groups strengthen social ties and protect people from the social isolation that often affects those with essential tremor.

In addition to all the health benefits, the IETF waives annual donations for all active support group leaders. As an IETF support group leader, you will receive the IETF’s donor magazine, *Tremor Talk*, in addition to any other special benefits offered.

**How does the IETF assist support group leaders?**

- Offers additional training opportunities throughout the year.
- Markets the group to people in the IETF database.
- Provides free literature on essential tremor for each group’s use.
- Lists support groups on the IETF website, along with your contact information.
- Lists meeting dates and locations on the IETF events calendar.
- Distributes an email newsletter for support group leaders.
- A dedicated staff person at the IETF office to provide guidance and support.
- Provides regular updates on research and treatments.
- Refers new members, and others, to support groups.

**Research shows that volunteering leads to better health, greater life satisfaction and higher functional ability.**

**What does the IETF expect of support group leaders?**

Many people become overwhelmed imagining too much will be expected of them if they take on this type of volunteer role. In reality, the IETF has very few expectations:

- Complete a volunteer application and brief phone interview.
- Maintain an active support group.
- Ensure meetings are open to everyone, affected and unaffected.
- Have a working email address.
How does the IETF recognize support group leaders?

The IETF is committed to the support group leader program and recognizes the important role support group leaders play in their communities and in the mission of the IETF.

Support group leaders are recognized for their commitment to the mission and their passion for service.

*Here are some of the ways we recognize our support group leaders:*

- Celebrates and shares your special achievements and extra efforts with the other IETF support group leaders.
- Shares your unique support group stories on a special IETF webpage and in social media.
- Offers award certificates to top-performing volunteers (Volunteer of the Year and Funding the Mission).
- Provides professional development opportunities, special projects, or tasks for those who desire additional responsibilities.
- Applauds achievements, both big and small, with a heartfelt “thank you”.
- Sends notes and cards to show our appreciation for your efforts and to acknowledge your birthday and holidays.
PART TWO
THE FIRST MEETING

Now that you understand the basics of what a support group is and what your responsibilities are, it’s time to get down to business and start planning your first essential tremor support group meeting!

When should we meet? Where should we meet? How do I let people know about this meeting? What do we do once we get there? These are important questions for you to consider when planning your first meeting. Let’s take a look at these one-by-one:

**When should we meet?**

When planning your first meeting, or any future meetings, consider your availability as well as the availability of others. Consider if you or your members are in school or still working, as this may dictate the time of day and day of the week the group can meet. When looking at weekend meetings, however, don’t forget to consider the religious differences within the group. Some groups find it is best to alternate times according to the season.

If possible, schedule your meetings for the same day and time each month. This will help people get into the habit of attending and make it easier for them to remember. Most meetings last between 1-2 hours.

**Where should we meet?**

The meeting location can often determine when the group meets because some facilities are available only at certain times. Find a meeting place that offers physical comfort, as well as a positive environment conducive to friendship, laughter, and conversation. The meeting facility must be able to accommodate members with a variety of disabilities, so be sure wheelchair access and elevators are available.

Some common meeting locations include:

- Public libraries
- Community centers
- Hospitals/Neurological centers
- YMCA or YWCA
- Senior centers
- Churches and synagogues
- Rehabilitation centers
- Senior housing communities
- Community rooms at local malls
- Apartment complex clubhouses
- Colleges

When you are researching possible locations for your meetings, there are some important factors to consider:

- **Is there a cost?** Most facilities offer free space to non-profit groups, and because you are affiliated with the IETF, you can take part in this benefit. If the facility requires specific information about your affiliation or the IETF, such as a tax ID number, just let the IETF Volunteer Manager know and we’ll provide you with what you need to move forward.

- **When is the room available?** Plan ahead. If you know you will need the space at a specific day and time each month, go ahead and book it in advance. Don’t wait until the meeting date approaches as you might find the
space already reserved by someone else.

- **Are tables and chairs provided?** Just ask the facility manager how this works and what their expectations are of you. It’s good to know in advance if they expect you to do the set-up before the meeting starts or if they expect you to stack all the chairs up in a corner at the end of the meeting.

- **How many people will the room hold?** You might also ask if there is other space available if your group should grow beyond the space.

- **Is the building and the room ADA compliant?** Don’t forget to check the location and ease of access to the restrooms as well.

- **Is parking safe and convenient?** Check to see if there is a good drop-off place at the door nearest to the meeting room.

- **Who is the contact person?** Find out the best way to secure the room. It may be a personal contact or just an online sign-up form.

- **How will we gain access to the building, especially on nights and weekends?** Find out when the staff is available and make note of any important contacts, such as audio-visual technicians, security, and maintenance.

- **What technology is available?** Does the facility have WiFi, a video projector, screen or other audio-visual equipment you can use, if needed?

- **Can refreshments and beverages be brought into the meeting room?** Some facilities will allow you to bring in whatever you like; others require that you use only their approved catering. Find out what is allowed and plan accordingly. We do not recommend spending money on refreshments, as many groups have a committee that manages this for the group (see “Dividing the responsibilities” for more information on committees).

**How do I let people know about the meeting?**

You’ve found a great space that will work
for your group. Now, you just have to find the group!

Getting people to your first meeting is not as difficult as you think, if you plan ahead. Some people will respond to a personal invitation from you. Some will respond to local newspaper advertisements. Some will see your name on the IETF website or receive an email invitation. It’s important not to rely solely on one method of publicizing your meeting.

Most groups start out with a small number, five or six people, and gradually add members as time goes on and the group receives more publicity. It takes some work in the beginning, but over time marketing your group and your meetings will become second nature.

Most newspapers, radio stations, and community cable stations accept public service announcements (PSA’s) about community events and meetings, free of charge. Look for community calendars in your local publications. Your local newspaper may also be interested in doing an article about essential tremor and/or your support group, once the group is established. However, you need to submit a press release at least four weeks in advance of your meeting in order to give them time to develop their story.

A sample release is available in the support group leader section of the IETF website, www.essentialtremor.org/sglonly. Follow the step-by-step instructions on how to write your release and submit it to your local outlets via email. Most media outlets no longer accept releases by fax or postal mail. Send it to the community editor or calendar editor. Unless you have a personal relationship with a specific anchor or reporter, it is always best to send releases to the editors. They make the decisions on what will and will not be covered. Be sure to search their website in advance for information on their policies about publicity and articles.

And if they don’t pick it up the first time, try again. And again. And again. They may be waiting for the right time or angle or availability. The key is not to give up. Eventually, your efforts will pay off.

Physicians’ offices, libraries, colleges, community centers, places of worship and senior centers usually allow meeting flyers to be posted on their community bulletin boards. But many require permission before posting. Check with the office manager to see if your meeting flyer can be posted. To get an IETF-branded flyer created specifically for you and your meeting, complete the “meeting request form” found in the support group leader section of the website (www.essentialtremor.org/sglonly).

You can also contact the public relations department of your local hospital or movement disorder clinic. This is particularly important if you meet in their facility. However, even if your meetings are held elsewhere, public relations staff members are usually more than willing to assist in advertising community health-related events.
What do we do once we get there?

You have done lots of work to get to this point; you have found a good location and marketed your meeting. You’ve had invitations emailed from the IETF and are well stocked with educational materials. Now several people have arrived for the first meeting, what do you do?

Everyone in the group is going to be a little nervous and apprehensive. This is a new group, a new experience for everyone, and it is up to you to make them all feel welcome and at ease. Here are some suggestions on how to start your very first support group meeting:

- Arrange the chairs in the room, preferably in a circle, so that people can make eye contact with each other.
- Have name tags. Most of us have trouble remembering names. Name tags will lessen the embarrassment of having to ask someone’s name several times. If writing their name or address is too difficult for them, remember to offer assistance. Remind them everyone in the room is shaky; it’s expected and accepted.
- Pass around a roster sheet to gather everyone’s name, mailing address, phone number, and email.
- Introduce yourself and welcome everyone. Tell the group why you thought it was important to start the support group and what you hope to accomplish.
- Ask everyone to introduce themselves. Some leaders like to start with an “ice breaker” activity. Go around the room and state what everyone had for breakfast, the most disgusting food they’ve ever eaten, or what their favorite cartoon character was as a child. These activities are usually quick, lighthearted, and non-ET related. They help people relax and start the meeting with a smile. Encourage everyone to share, but remember not everyone opens up at first. Some people need more time to feel comfortable.
- Go around the room or ask for volunteers to share why they decided to attend the meeting. Allow plenty of time for this activity. Once people get started, it’s hard to get them to stop. People with voice tremor often find it difficult to speak, so be sure to give these individuals plenty of time. But be sure not to linger on one individual too long, as you want to give everyone the chance to share. It’s your job as the leader to keep the conversation moving.
- As the meeting draws to a close, set future meeting times and locations. Discuss preferences and options with your members. If the specifics have not or cannot be determined, the group
If you were deserted on a desert island, what three books would you take with you?

If you were deserted on a desert island, what three books would you take with you?

should decide how everyone will be informed of the next meeting. For instance, if you have a small group, a round robin email or calling system could be established with each person contacting the next person on the contact list.

- You may also want to use this time to discuss possible topics and guest speakers for future meetings. For instance, the topic “The Diagnosis Process for ET” is usually presented by a movement disorder neurologist, neurologist, or nurse specialist. Encourage members to volunteer to contact possible speakers, and obtain a commitment for the time and day of the meeting. This volunteer can then report back to you, so you can arrange for appropriate marketing and publicity. It is best to schedule speakers six weeks in advance. But speakers are not always necessary. Consider a variety of topics for discussion.

- Discuss the feasibility of serving refreshments at meetings. The decision is usually based on the members’ interest and the facilities available. If the group decides in favor of serving refreshments, the job can be rotated among the members. A small donation can be taken each meeting to cover the cost of refreshments, although such donations are not tax deductible.

- Be sure the roster is complete before everyone leaves. This list should include everyone’s first and last name, mailing address, email, and telephone number. Once the list is developed, it is up to each individual to decide if the list should be shared with other group members and the IETF. Due to privacy concerns, the list cannot be shared with any other third party, regardless of circumstances.

- Consider how the first meeting went. What went well? What did not? Don’t be hard on yourself about the things that do not go exactly as planned, but use the experience to do things differently next time. Take pride in all the things that did work and look forward to more success in the future.

- Feel free to reach out to the IETF to discuss how it went and get advice, if you need it.
PART THREE
THE MEETING AGENDA

Dividing the responsibilities
It might seem easier to do everything yourself, but this can soon lead to burn-out. It is easy to forget you experience the same challenges as your group members. But as the leader of the group, you must conserve energy by delegating responsibilities. This needs to happen by the second or third meeting, otherwise an unstated expectation will develop -- you will do it all while other members only have to attend meetings. Establishing expectations and responsibilities for other group members in the beginning will help keep your members engaged for the long-term.

Some members may hesitate to take on a task because of the severity of their tremor or other circumstances. No one should be pressured into taking on additional responsibilities. However, those who hesitate might accept if each task or job has a term-limit or a back-up person assigned. Be encouraging to your members and remind them it’s a group effort. When you work together, everything is easier.

Below, we have listed some suggested job titles with their associated responsibilities. We highly recommend that you implement these roles as soon as possible.

Small groups (2-25 members)
• Co-leader(s): Plans and leads meetings during leader absence and sometimes assists in leading the group.
• Correspondence Secretary: Maintains membership roster, including updating addresses, phone numbers, e-mail addresses; mails meeting notices, writes guest speaker thank-you notes and other correspondence; and keeps name tags.
• Notes Secretary: Takes meeting notes and shares those notes with people who miss the meeting. These notes can also be used to begin a small newsletter for the group. It is suggested there be a backup person for this position.
• Reception Committee: Select a group of two or three individuals who will arrange for refreshments and beverages during the meeting, including coffee, tea, and water, as well as cups, straws, lids, and plates. This committee would also be responsible for managing the refreshment sign-up sheet and refreshment donations.
• Welcoming Committee: Welcomes new members and current members
who have missed a meeting or two. It's nice to know you have been missed. These individuals can also help ensure everyone is signed in on the roster and is provided with a name tag.

- **Telephone Contact(s):** Serves as contact person(s) for meeting notices and public announcements. This person would develop a telephone tree or round robin calling system for members who can only be contacted by phone.

- **Marketing Committee:** Sends meeting announcements to the local newspapers and ensures it is posted on local community calendars. This committee also explores ways to market the group through physician's offices, hospitals, places of worship, community centers, senior centers, etc. Also, the chairperson of this committee maintains a complete list of media contacts.

**Large groups (26 or more members)**
The following additional or modified roles can be added as your group grows.

- **Welcome/Outreach Committee:** Distributes meeting materials. Aligns with newcomers so they feel more comfortable at meetings.

- **Treasurer:** Keeps member contributions and memorials. Manages treasury to pay for group expenses.

- **Librarian:** Maintains library of ET books, videos, newsletters, and other educational materials to bring to meetings for members’ use. Maintains a sign-out list for items that are borrowed.

- **Historian:** Keeps scrapbook of the group’s activities, including photographs, clippings, and other souvenirs. It helps if this person is good with a camera.

- **Planning Committee:** Meets two or three times a year to plan the year’s agenda. Key members of this committee are Co-leaders, Secretary, Treasurer, Marketing committee chair, and of course, any other interested individuals.

**Working with speakers**
All speakers have something to offer, and many will be willing to come to speak to a group of interested individuals at no charge. However, the difference between a well-prepared presentation and a presentation that misses the mark is often due to the communication between the speaker and the person who invited the speaker. The following checklist has been developed to assist you in communicating your expectations to a speaker.

**First contact**
Confirm the time, date, location, and topic in writing as soon as the speaker agrees to make the presentation. Also confirm the spelling of the speaker’s name, as well as their professional title, certifications, and affiliations.

**Two weeks before the meeting**
- Send the speaker a reminder.
- Reconfirm the time, location address, and meeting format (e.g., a 30-minute talk with 15 minutes for questions and answers).
- Provide information about your group - size, age range, etc.
The difference between a well-prepared presentation and a presentation that misses the mark is often due to the communication between the speaker and the person who invited the speaker.

- Ask the speaker if they will need a projector, flip chart, WiFi or other technology or equipment.
- Provide a list of five to ten questions the group would like addressed.
- If you plan on taking photos and/or recording the presentation, be sure to have everyone sign a waiver and photo release. You can find this document on the SGL section of the IETF website.
- Make sure the speaker has good driving directions and a telephone number to call, in case of any last minute problems.
- Request some background information or a bio from your speaker to use for marketing purposes and for your introduction.

At the meeting

If a whiteboard or flip chart is available, it is helpful to write the speaker’s name and contact information on it in large letters. Encourage the speaker to use the microphone, if available, so everyone can hear.

Keep track of the time and provide a warm thank you on behalf of the group at the end of the presentation. If the speaker needs to leave at a certain time, someone should escort him or her to the door promptly. And don’t forget to send the speaker a personal “thank you” either via postal mail or email within a week of their visit. After all, you may want that speaker to come back again!

If time has been allotted for a question and answer period, let everyone know what the time limit is and stick to it. Ensure each person gets a chance to ask a question.

Finally, it is customary to place your speakers on your mailing list, thus keeping them informed of your activities. They could know persons with ET to refer to your group or they may want to attend a future meeting for their own benefit.

Suggested speakers

Here are a list of potential speakers:

- Neurologist, Nurse Specialist, Social Worker, Psychologist, Physical Therapist, Occupational Therapist, Speech Therapist, Pharmacist, Dietician/Nutritionist, Physiologist, Recreation Therapist, Health Educator, medical equipment company, or pharmaceutical representative.
Even if they are unable to participate, do not be afraid to ask these individuals to recommend other professionals within their profession that could be potential future speakers.

**Keeping the faith when attendance is down**

Even the most upbeat and lively support groups can have its down times.

_The following ideas may help rejuvenate your group:_

- Ask each member to volunteer to call a missing member and invite him or her back. Sometimes people just need to feel wanted.
- Renew your publicity efforts via the local newspapers, radio, and TV. You may have gotten lost among all the other news, so let them know you are still around.
- Perhaps the group needs some additional social time. Organize a lunch or a holiday party. Ask for a large, quiet table or private room where you can enjoy one another’s company and hear each other talk. Spend some time discussing topics other than ET.
- Visit a neighboring ET support group or contact another IETF support group leader. You will probably find they have had similar difficulties and challenges, and you may get a few good ideas. It can even be helpful to visit other types of support groups, to get new ideas and perspectives that may be workable in your group.

Of course, none of these suggestions can make everything right. Change is a reality in the life of every support group. Allow your group to change, along with the changing energies and experiences of its members.

Acknowledge the “down” times and encourage the group to talk about them. Out of these challenges your group can find new opportunities and ways to expand and strengthen.
Don’t have a speaker lined up for the next meeting? Not to worry. Most groups have speakers only half the time or less. It is important to have a meeting plan or topic for discussion the rest of the time.

The IETF website has numerous education materials available to you on many topics. Here are just a few ideas:

- Genetics of ET: Who in my family has ET?
- Diagnosis of ET: What are the signs and symptoms? How is it diagnosed?
- Medications: What are current and upcoming medications?
- Research Update: What research is being done? How can group members participate?
- Living and Coping with ET: How can I do more with ET? How do others cope?
- Adaptive Technology and ET: How can technology help me in my everyday activities? Are there tools or products that can help me accomplish daily tasks more easily?
- ET and Children: How can ET affect my children and grandchildren? How can I help a child with ET?

**Suggested Meeting Topics**

Next, you will find a selection of eight different topic ideas. Each topic offers a variety of discussion questions, to help facilitate the conversation among the group, and a list of suggested speakers who would be appropriate to speak on the topic. But don’t let yourself be limited by just these eight ideas. There are numerous possibilities out there. Talk to the members of your group to find out what things they are interested in and then tailor your meetings to meet their needs.

**Topic 1 — How do I feel about my ET?**

*Introduction*

One of the most important things the support group can do is try to arrive at a common understanding of what ET is, allowing for the fact each member experiences it differently.

*Discussion questions*

- How did you feel when you first learned you had ET?
- Are you embarrassed about your ET? If so, why?
- Are you depressed or feel you might be depressed?
- Do you avoid social situations or have anxiety in public?
- What can you do to feel better?
- How does ET affect your daily life and activities?
- Do you fear the future?
- What is the best way to explain ET to a friend, co-worker, family member, or even a complete stranger?

*Suggested speakers*

Neurologist, nurse, health educator, therapist, psychologist; or an information panel of patients.
Topic 2 — Diagnosis and treatment of ET

**Introduction**
Each support group member has his or her own story of how they were diagnosed. For some, the diagnosis was made almost immediately. For others, it took much longer. Those with ET may vary in their symptoms and severity, and doctors may differ in their approaches to treatment. Likewise, each person is probably on a different treatment plan.

**Discussion questions**
- What questions should I ask my doctor?
- How does a doctor diagnose ET?
- How common is the condition?
- At what age is ET most likely to develop?
- What are the symptoms of ET?
- What are some of the current theories about what causes ET?
- Can drugs, toxins, or germs cause ET-like symptoms?
- Is it important to start treating ET right away? Why do some doctors wait to start medication?
- What medications are available and what are their side effects?
- What role does physical, occupational, or speech therapy have in the treatment of ET?
- What are the surgical options for ET and who is most likely to benefit from them?
- How can I make the most of my own ET treatment and become more involved in my treatment plan?

**Suggested speakers**
Movement disorder specialist, neurologist, neurosurgeon, DBS representative, physician’s assistant, nurse, or other health professional who works with ET.

Topic 3 — Good Health and ET

**Introduction**
General good health practices play a role in every condition, including ET. A healthy, well-balanced diet, proper rest, and regular exercise support our general well-being and give us the strength and resilience to keep going.

**Discussion questions**
- What is a normal, healthy diet for adults? Is it possible to control fat, sodium and calories and still enjoy eating?
- How much protein do I need? What is the best and tastiest protein source for me?
- What are carbohydrates? Which foods are they in? Are some carbohydrates better for me than others?
- How much water should I drink during the day?
- How much sleep is needed by adults? Children? Seniors?
- Will vitamins, minerals, or other supplements help my tremor?
- How can meditation or relaxation exercises help me?
- What types of exercises are right for me?
- How will physical activity affect my tremor?
• Can good health affect mood?

**Suggested speakers**
Nurse, yoga instructor, social worker, nutritionist, holistic doctor, physical therapist, or health educator who works with ET.

**Topic 4 — You and your doctor**

**Introduction**
The doctor-patient relationship is key in the management of any chronic illness, including ET. Through changing symptoms and medication trials, the doctor-patient relationship can and should be a constant. This is not to say the doctor and patient will always agree, or it is easy to find the right doctor for you. But the search is well worth the effort.

**Discussion questions**
- Can a family doctor treat ET? Do I need to see a movement disorder specialist (a neurologist who specializes in movement disorders)?
- What can I expect from a general neurologist vs. a movement disorder neurologist?
- What questions should I ask my doctor?
- What does the doctor need from me? How can I give the most accurate picture of my symptoms?
- Should family members be present in the exam room and/or doctor’s office? Why or why not?
- What do I do if I have questions or difficulties between visits?
- How do I keep my other doctors up to date on my ET?

**Suggested speakers**
Movement disorder specialist, neurologist, family practice doctor, patient advocate, ET patient and/or family member.

**Topic 5 — Coping with ET**

**Introduction**
Coping with ET is a matter of using personal resources within the framework of your experience and style. While no two people cope the same way, there is some common wisdom to be found among all those who live and cope with ET.

**Discussion questions**
- What does coping mean to you?
- What are my strengths?
- What has changed since my diagnosis of ET and what has changed because of it?
- What do I tell myself about my condition? What do I tell others?
- What is the most difficult thing for me to cope with? What is the easiest?
- What do I worry about most? How and with whom do I share my worries?
- Who helps me to cope and how do they do it?
- What thoughts or actions help me cope?
- What practical advice would I give someone who is newly diagnosed with ET? What advice would I give to the spouse and/or family members?
Suggested speakers
ET patients, social worker, nurse, psychologist or therapist who works with ET.

Topic 6 — Occupational therapy
Introduction
Occupational therapy is invaluable for people with ET, but so few people know about it. Essentially, occupational therapy teaches people new ways of doing common tasks.

Discussion questions
• What is occupational therapy?
• How does occupational therapy benefit the ET patient?
• Where do occupational therapists work?
• What kind of training do occupational therapists receive and what are they qualified to do?
• How does one arrange to see an occupational therapist?
• What are assistive technology devices and which ones are effective when dealing with ET?
• How do I purchase the devices?
• Is there a source in the community for used devices that are donated or are sold at a discount rate?

Suggested speakers
Occupational therapists, people with ET who have experience with occupational therapy.

Topic 7— Working with your pharmacist
Introduction
Most people don’t know the neighborhood pharmacist can be a valuable source of information on medications.

Discussion questions
• What exactly is the job of a pharmacist?
• What kind of training do pharmacists receive?
• Is it important to use the same pharmacy all of the time? Why?
• Can a person develop a consultative relationship with a pharmacy?
• What is the difference between a pharmacist and a pharmacy assistant?
• What is the difference between generic and name-brand medications?
• What is a formulary?
• What are drug interactions? Do over-the-counter medications cause drug interactions?
• What can the pharmacist tell me about mixing my prescription medications with over-the-counter medications?
• Can a pharmacist answer questions about my insurance?
• Can a pharmacist answer questions about vitamins and supplements?

Suggested speakers
Pharmacist or pharmacy assistant
Topic 8 — Relaxation techniques

Introduction
Stress greatly affects ET, and while there are no ways of eliminating stress from our lives, we can minimize its effects through relaxation techniques.

Discussion questions
- How can learning relaxation techniques assist in coping with ET?
- Why does stress make tremor worse?
- How do relaxation techniques reduce stress?
- What are the different forms of relaxation?
- Is there a “best” or “better” form of relaxation?
- How do I learn these techniques?

Suggested speakers
Therapist, psychologist, yoga instructor or participant, meditation instructor or participant, Tai-Chi instructor or participant, biofeedback technician, etc. There are many options in this category.
I hereby acknowledge receipt of the IETF Training Guide. I understand it is my continuing responsibility to read and know its contents.

I consent photographs, artwork, audio, video, or writing submitted by myself, or any such work about me produced by a member of the International Essential Tremor Foundation (IETF) staff, may be used by the IETF, its assigns or successors, in whatever legitimate way they desire, including in marketing materials, publications, websites, television, radio, DVDs, and any other form of storage, retrieval, and reproduction. Furthermore, I hereby consent such information, photographs, artwork, audio, videos, and the plates from which they are made shall be property of the IETF, and the IETF shall have the right to sell, duplicate, reproduce, and make other uses of such information, photographs, videos, recordings, and plates, etc. as they may desire, free and clear of any claim whatsoever on my part, in furtherance of the organization’s purposes and objectives.

I have read, understand, and agree to all of the above.

Signature _____________________________________________

Print Name ____________________________________________

Date ________________________

Please complete this form and mail or email it to the IETF, Attn: Volunteer Program.