



National Essential
Tremor Awareness

WALK

How to Organize an ET Walk in Your Community



International Essential
Tremor Foundation

Your Voice for Essential Tremor

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Planning & Preparation

Assemble Leadership

Once you decide you want to plan an ET Walk in your community, it's time to rally for volunteers. Successful events hinge on the recruitment and action of a strong leadership team. The first step to creating a great event is to recruit help. Ideally your team should be comprised of individuals with diverse skills and talents who share a common interest in raising awareness for ET. When recruiting, consider who you know that may possess any or all of the following characteristics:

- Enjoys managing details
- Exhibits creativity and passion for the cause
- Feels comfortable asking for sponsorships, in-kind gifts and/or donations
- Understand local laws and regulations and can work effectively with governing bodies
- Holds experience in the successful management of projects
- Knowledge of marketing, PR and social media tactics to help spread the word.

Even if you don't know individuals who have these specific characteristics, feel free to ask for help to everyone you know. They may surprise you with hidden talents.

- Support Group Members
- Friends & Family
- Neighbors
- Co-workers
- Church/Community Organization Members



Planning & Preparation

Choose a Route

Before organizing route logistics, it's important to brainstorm the type of walk you'd like to have. Is it a short walk around the park? Will it be long hike up a mountain? Or will it be a few laps around the local mall. Consider your options and be as inclusive as possible. Try to include people of all ages and physical abilities so that everyone can help raise awareness. That said, when choosing your route it is a good idea to not only look at a map, but to actually walk the route yourself. When surveying the course, keep in mind elevation, traffic, road conditions, safety, accommodations, construction, etc. Another factor to remember is visibility. Will the general public see your walk? The goal is to raise as much awareness as possible. The better the visibility, the more awareness we raise.

Once you determine the type of event you'd like to have, now you can choose a date, time and distance. There may be several legalities to consider:

- Is special permission needed to use your planned route? Contact the city and local government to obtain permits if needed.
- Are there any other events planned around your route on the same day?
- What size of event do you expect? Do you need to schedule police presence or do you need to request road closures?
- Have you contacted the IETF for waivers and liability releases?

Every city, town, or district may have their own set of regulations, how you address them will depend on local law and requirements. Contact your local council for more information.

Did you know?

Essential Tremor is often misdiagnosed as Parkinson's, although 8 times more common.

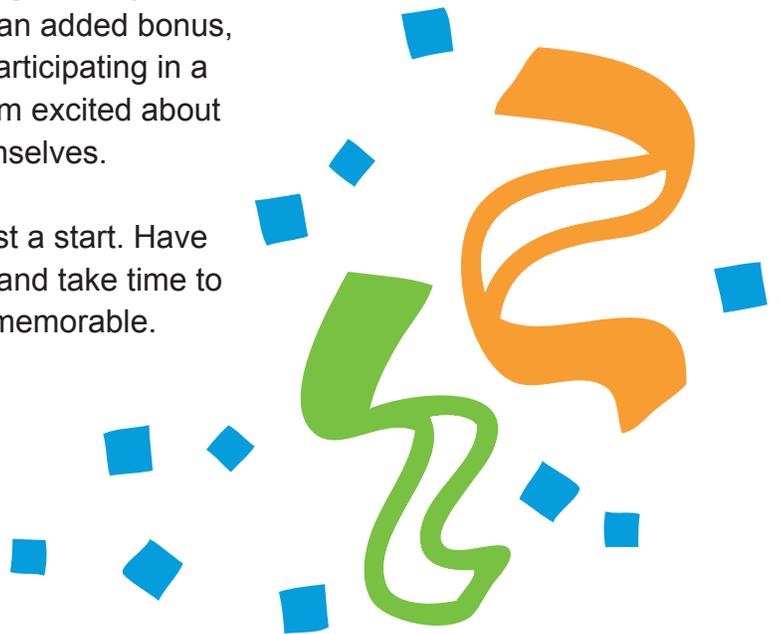
Planning & Preparation

The Fun Factor

People like fun. It's that simple. Make your walk fun and memorable and it can potentially draw loyal participants year after year. Plus it's an opportunity to channel your creative side. Plan an event YOU would want to attend. People will come for the cause, but will stay for the fun.

- **Keep it festive** - You don't have to spend a fortune to make an event more fun. Incorporate additional fun and games after your walk. Consider having a local band provide live music, host a bingo game, or have a clown paint faces.
- **Provide food** - Don't send them away hungry! Host an ice cream social, picnic or community potluck after the walk. Or host a bake sale to raise even more funds after the walk.
- **Make it a dog walk** - What's more fun than walking with friends and family? Walking with a pet! Have participants bring their dogs to join them along the walk. Don't forget to enforce leash laws and safety precautions.
- **Come up with a gimmick** - Participants in the Leukemia & Lymphoma Society's Light the Night Walk carry illuminated balloons to show their connection to leukemia and lymphoma. Come up with something original for your own event that will make it memorable for those who participate.
- **Get the kids involved** - A school walk is a great way to raise money and awareness about ET. As an added bonus, you'll introduce kids to the experience of participating in a non-profit walk at an early age and get them excited about being a part of something bigger than themselves.

Use your imagination. The ideas above are just a start. Have a meeting with everyone involved in planning and take time to brainstorm ways to make your event fun and memorable.



Recruitment

Get the Word Out

Now that you picked an event location and have all of the necessary approvals and permits, its time to start spreading the word! Traditional marketing consists of mail, tv, radio, newspaper advertisements and signs posted up about town. These methods can be effective, reach large audiences, and should be looked into but they can come at a high cost. Don't let that get you down though. The IETF provides many templates available for you to download for free at www.essentialtremor.org to make marketing your event easier. Templates available include:

- Customizable Poster
- Letter to the Editor
- Press Release
- Sponsorship Proposal
- Digital Downloads – Facebook/Twitter cover photo, email signature and a desktop wallpaper.

Use these templates to reach out to your local media. Submit your press release to radio stations, TV stations, newspapers and magazines. Write a letter to the editor sharing your story on why you are organizing an ET walk. Paint your town with walk posters and flyers. You can become the face of ET in your community to help educate others about the condition while recruiting for your walk.

The Internet has also spawned many highly targeted, low-cost, and sometimes free marketing channels that are ideal for creating a buzz about your walk. Here is a list of some web marketing options that you may want to consider:

- **Facebook, Twitter, Social Media** – There are countless online communities and fan pages out there that are filled with people passionate about the same cause you are raising money for. Get involved with these people and immerse yourself in the online conversation. Promote your walk on your Facebook, LinkedIn or Twitter page, invite your online friends and encourage them to recruit to get involved. Post news and updates about your involvement.
- **Submit Your Walk to an Online Events Calendar** – There are many websites that will give you a free event listing on their online calendar. Submit your walk profile to as many of these as possible and make sure to include a link back to the website in the description.
- **Email** - Reach out to the IETF for a targeted email sent to people with a connection to ET in your community. The staff will be happy to send out an email in your town to help promote your walk.

Recruitment

Recruitment Tips

When it comes to recruiting participants and volunteers, nothing will be more important than your existing network. It's easiest to start with the people you know. **Ask everyone** you know to participate. Then have them ask their friends and family members to reach out to their networks to register for your walk. The word will eventually spread making your network even bigger. Think about people who are serving in leadership capacities that are well established in the community. The relationships these people have in your community are not only important for recruiting sponsors, but also for recruiting participants. Often, companies value opportunities to engage their workforce in community activities, which is known to boost employee moral and team attitude. Therefore, it's important to ask companies not only for sponsorship, but also for their participation.

People love opportunities to compete. Taking the time to plan fun and rewardable accomplishments can add significant value to your walk by motivating participation. Consider different incentive points that can be incorporated into your walk. For example, start a friendly competition between companies on who can recruit the largest team. Or have participants challenge other participants on who can raise the most money. Competition can be fun and rewarding. Other ways to spread the word include:

- Turn every casual conversation into a recruitment opportunity.
- Send an e-mail to everyone in your address book asking them to join with a link to the walk registration page. Ask them to e-mail everyone in their address book as well.
- Wear your official ET Walk T-shirt to start a conversation about your walk.
- Display posters at your favorite local hot spots and at work. Leave your card or information for people to contact if they want to join.
- Build a pyramid. Ask each person who registers to recruit at least three other members. If you start with only three participants, and they each recruit three more and so on - you'll soon have a large walk!
- Schedule informational sessions about ET at an organization where you are a member. You will raise awareness about ET and recruit walk participants at the same time.
- Share your story. Tell people why you are participating in the walk. Make it personal, speak about the effects of ET and share why crusading for a cure is so important.
- Even if people say no to participation, odds are they may at least give you a donation.

Fundraising

Set Your Goal

Raising awareness through your ET walk can propel your fundraising efforts to new heights! Keep in mind that the money you raise directly helps people affected by ET. People give to people. It really is that simple. The main reason people will give is because you have asked them to and how you have asked. Invite everyone you know to share the experience with you.

- **Determine what amount is best for you.** Aim high. Don't underestimate donors' willingness to give.
- **Identify your prospects.** Create an ABC list. The 'A' list includes the shoe-ins (family/friends). The 'B' list includes those you are less sure about (coworkers/acquaintances). The 'C' list includes those you do not have a personal contact with but who may be interested in supporting the cause (local businesses/churches/etc.).
- **Determine your approach.** Face-to-face, social media, email/letter, phone calls, etc.
- **Make it personal.** These people are donating to support YOU. Let them know why you are fundraising.
- Share about where the money goes and how every dollar makes a difference for the millions of people living with ET.
- **Start now.** Get your fundraising done early so you can concentrate fully on the walk. It's never too soon to ask for a donation! And once you've met your goal, you can keep on going!
- **Suggest levels of pledges.** Let donors know the amount of contribution you would like for them to consider. Refer to your ABC lists. What kind of commitment do you anticipate these people to make?
- **Always keep a list** of who you have contacted including dates, addresses and phone numbers.
- **Follow up!** After two weeks, ask again. With people's busy schedules they often appreciate the reminder.
- **Set expectations!** Let donors know this will be an annual event and it will make asking easier next year.
- **Make your own contribution.** Lead the way by making your pledge first.
- **SAY THANKS!** Send a thank you note to let your donors know you appreciate the commitment they are making.



Fundraising

FUN-draise!

Fundraising doesn't have to be intimidating. You can have fun by using your imagination to come up with creative ways to fundraise for your walk. Use the available IETF online pledge sheets to track your progress. Available at www.essentialtremor.org.

- **Have a 50/50 raffle**, half of the proceeds go to the winner and the other half go towards your fundraising. Many times the winner donates their half back to the cause!
- **Sell your skills**. Provide lessons on cooking, sewing, golf, jewelry making or any other fun activity. Set a donation price and people will be happy to save some money while supporting a great cause.
- **Host a party**. Collect donations and entertain at the same time. Create a theme and have fun!
- **Ask for a birthday gift pledge**. Have your friends and family to write you a birthday check and then you can donate the amount to your pledge total.
- **Create an "Extra Change in My Pocket" Box**. At the end of the day, ask friends and family to drop their spare change in a little box.
- **Hold an Auction**. Approach local businesses to donate goods or services and hold an auction. Items can include gift certificates, gym memberships, sporting goods, concert tickets, wine and so much more.
- **Write to your local politicians**. You supported them, don't you think they should support you?
- **Remember old-fashioned fundraising**. Set up a neighborhood lemonade stand, sell greeting cards, hold a car wash, a dog wash, shovel snow or hold a bake sale.

Did you know?

Less than 60% of people with ET find the few available treatment medications helpful.

Sponsorships

Win-Win Relationship

If you can successfully recruit sponsors, each walk pledge can go further because sponsorships help immediately offset event costs. Also sponsorships often increase community exposure, which is helpful when it is time to attract the attention of the local media and recruit volunteers. For many first time organizers, soliciting sponsorships can be an intimidating task. It may be helpful to remember the following:

Companies Benefit From Sponsorship! - Everyone likes to help out a great cause; however, companies are looking for a win-win relationship. Be able to articulate exactly what your event will do for the companies that you seek sponsorship from before you speak with them. When speaking with companies, stay open to possible benefits you may have missed and look for opportunities to create more value. For example, companies located along the walk route are great prospects, especially if they sell or deal with any sort of product that correlates to walking. Beverage companies and grocery stores are great potential sponsors, especially for in-kind donations.

Be creative and have fun! - For example, if a mattress store or furniture store is along the route, maybe they can create a special “rest stop” for your walkers as part of their sponsorship. This would certainly attract more eyes on their products, while at the same time helping further your fundraising mission! The possibilities are endless. Don't be afraid to think outside the box.

Don't Forget the Basics - In addition to pairing the mission of your potential sponsors and the activity or mission of your event, remember that other general benefits exist for lending sponsorship. These benefits may include, and are not limited to the following:

- Increased exposure in the community
- Tax deductions
- Opportunities for team building and employee development



Sponsorships

Utilize Your Network

Tailor Opportunities and Offer Lots of Options - The best sponsorship opportunity is one that fits the capacity of the sponsor perfectly. For this reason, it is important to remain flexible, and allow many options for sponsorship. Examples include:

- In-kind donations (such as beverages, snacks, sunscreen, and/or signage)
- Sponsorships with varied levels of financial support (such as starting line or finishing line sponsors, mile sponsors, team sponsors, and pit stop sponsors)
- Develop sponsorship levels corresponding to sponsorship size.

Utilize Your Network - You've considered your network for recruiting volunteers and participants. Have you considered your network for soliciting donations and sponsorships? A great way to build your sponsorship list is to consider who you know. Who in your team of volunteers is connected to a small business owner? Who in your team of volunteers works for a larger company or corporation that may designate funds for local community projects? Can they help connect you to the person in charge of corporate sponsorships? What employers in your area have employee-matching programs, and what are the criteria for eligibility?

The most important thing to remember about networks is that they are constantly growing and changing. Most organizations do a great job of assessing their networks when first constructing recruitment and prospecting plans. However, as your registration grows, as you recruit volunteers and participants, your network will also be growing. Schedule a second and third assessment of your network, and actively seek out connections that will aid the success of your event.

Remember that no one can do a better job of expressing the mission and importance of your event than you. Let your enthusiasm and passion be contagious and sponsorships will come. Use the sponsorship proposal template online at www.essentialtremor.org to help get you started.

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THE IETF

We're Here to Help

Organizing an ET walk can seem daunting at first, but the reward is worth it. And you're not alone. The International Essential Tremor Foundation will be with you every step of the way. If you have any questions during your planning process do not hesitate to reach out to staff. Below are a few basics to keep in mind.

- Every participant must register at www.essentialtremor.org (or send in paper registration sheets available for download on the website)
- ET Walk t-shirts are available at registration with a \$25 minimum donation. Participants may opt out of the t-shirt and just make the \$25 donation.
- Waiver and liability releases are available for download at www.essentialtremor.org.
- Keep the IETF updated with your walk details including date, time, location, etc. Staff can help promote your event if you keep them in the know.
- Take photos of your walk to document the event. The IETF may share them on the website, *Tremor Talk* and social media networks.
- HAVE FUN!

About The International Essential Tremor Foundation:

Headquartered in Lenexa, Kan., and founded in 1988, the International Essential Tremor Foundation is the leading organization in the world dedicated to those affected by essential tremor. The mission of the IETF is to fund research that will find the cause of essential tremor and lead to better treatments and a cure, increase awareness about ET, and provide educational materials, tools and support to healthcare providers, the public, and those directly affected by ET.

The IETF has distributed more than \$750,000 in research grants, to fund 30 promising studies, in the search for the cause of ET. The Foundation has hosted numerous community awareness events across the U.S. to provide those affected with the basic knowledge necessary to become their own advocate when seeking treatment. And, the IETF also provides assistance to a vast network of support groups around the world. To learn more about essential tremor and the IETF mission, visit the IETF website at www.essentialtremor.org.



International Essential
Tremor Foundation

Your Voice for Essential Tremor

