



Thank you for your interest and commitment to lead a TMA Walk-Run-N-Roll awareness campaign in your city. We know you want to help support and raise awareness about these devastating diseases that turn lives upside down. But where do you start?

We have developed this Campaign Guide and Volunteer Expectations to help you get started with the planning of the event. Please note that this is a Guide to help plan the event, we welcome new ideas and suggestions and look forward to discussing them with you.

What's the goal?

The goals of the TMA's Walk-Run-N-Roll campaign are to increase awareness, develop and strengthen the TMA community, and raise funds for research and programs that the TMA offers, such as our James T. Lubin Fellowship, Ask the Expert podcast series, support groups, TMA annual family camps for children and families with these rare neuro-immune diseases, other education, and awareness research efforts. The Board of Directors and Medical and Scientific Council of the TMA will determine how the funds raised to benefit TMA programs will be used. To learn more about the TMA, please visit <http://myelitis.org>.

Does the event title have to be "Walk-Run-N-Roll? Can it be named for my loved one such as "Walk-Run-N-Roll for Mary"?

What started as a local, community initiative in NJ by one of our members has now grown into a larger nationwide effort where more communities want to join this campaign, and we would like to build an identity for the TMA that we can leverage to help raise awareness and funds to achieve our goals. The "Walk-Run-N-Roll" name is key to extending our "brand" from community to community. We ask that the event incorporate the name of your state, city or community with the title, "Walk-Run-N-Roll for TMA." For example, the Illinois Walk-Run-N-Roll for TMA. The name was chosen to be inclusive of all patients and their families and should be used. We encourage you to acknowledge all individuals diagnosed with this spectrum of rare neuro-immune diseases and celebrate their resilience and journey. The best way to honor your loved one is to form a team under his or her name.

How Do I Get Started?

It seems a bit unconventional that someone who is not a member of the TMA is leading an awareness event to raise funds for the TMA. We ask that all volunteer leaders be members of the TMA. If you have not already, please join to become a member of the TMA through this link <https://myelitis.org/registration-step-2>. There is no cost associated with being a member of the TMA.

To get started, so we can learn a little bit about you, please complete the volunteer form and sign the Confidentiality Agreement and return to Chitra Krishnan at ckrishnan@myelitis.org or by mail to 1787 Sutter Parkway, Powell, OH 43065. Because you may have access to health information of others in your area as you are planning this event, to protect privacy we have drafted the confidentiality agreement.

What happens next?

We will call you once we receive your forms and speak with you about the time and commitment requirements of a volunteer leader. If you will be handling money or working on an event that includes minors, we will need to perform a **background check**. This is to ensure the safety of our participants and maintain the integrity of the TMA and its volunteers. When these steps are completed, we will call you to discuss the next steps.

Does one person lead the Walk-Run-N-Roll event or is a team approach better?

In our experience, as you start thinking about this event, it is better to plan and execute the event as a Planning Committee. If you know of other TMA members in your area who would be willing to form a Planning Committee with you, please let us know. It is not essential to work as a committee, as some of you may want to work with friends and family members to plan the event. Regardless, we have learnt that it not only helps to share the responsibilities, but also builds the local TMA community by providing contact with others who are suffering from these diseases!

If you would like us to find other members to volunteer with you, we will be glad to help! We ask that you write a letter of invitation to other members to join you, which we will email to the members in your area and connect you so you can form a Planning Committee. We can give you examples of letters that have been written by other volunteers, if you wish. We also suggest writing a blog about your story, or your interest so we can share with members in your area and identify people who would be interested to form the Planning Committee with you.

How many members do we need to form the Planning Committee or the team?

Based on our experience, we recommend a minimum of 5 people on a committee – Chairperson, Sponsorships Leader, Marketing and Communications Leader, Family Teams Leader and Events Leader. In addition, we suggest that a minimum of 3 members for each sub-committee to help achieve the goals set. Often multiple people take on multiple roles, so it all depends on how many volunteers and the capacity every city has.

What are the different roles and responsibilities of the Planning Committee members?

In general, the Chairperson is responsible for the overall planning and execution of the event, manages the time line, calls and chairs the meetings and also serves as the Finance head.

- The **sponsorships subcommittee** focuses on community and local business sponsorships to help support the costs of the event and raise funds. Although all volunteers focus on this task, the sponsorships team leads this. Sponsorships can even be in kind – like donations of food and water, a screen-printer may donate X amount of T-shirts for their name to be included on the shirts, donation of auction items, etc.

- The **marketing subcommittee** focuses on communication about the event through social media, radio, and print media to spread the word and help raise awareness by developing materials to do the same. We suggest that the marketing subcommittee start an event Facebook page to promote the event and share progress. Creating awareness- The goal of the campaign is to share stories from our community to increase awareness about these rare neuro-immunologic disorders through various social media strategies, publications and podcasts. We ask that our volunteers share their story so we may share through our blogs and other social media avenues.
- **Family subcommittee** helps recruit families or groups of friends or coworkers to join the walk campaign, form a team, and sets goals to raise funds and awareness.
- Lastly, the **event subcommittee** focuses on any planned events for the day such as determining the walk-run-n-roll course, DJ, music, sound system, program, refreshments, silent auction, raffles, face painting, wheelchair basketball, etc. The event subcommittee also generally takes on the responsibility for photo and video releases, which the TMA will provide. This is necessary to accompany all photos and videos from the event so we can share the celebration on the TMA website and through other social media.

How Are Committee Meetings Conducted?

It all depends on the location of the volunteers and whether there is a planning committee. The meetings can be held in person or by phone. In-person meetings can be held at a volunteer's home or at a fast-food restaurant. TMA will be able to help with conference call-in numbers in case you need the help. This first meeting is crucial in getting to know one another, setting team goals, sharing ideas from each subcommittee for the event.

How is the Venue Chosen?

The choosing of a venue for the event is at the discretion of the local volunteer and the team. Where public parks are used, specific application forms need to be completed that require the TMA's EIN number, 501(c) 3 status, etc. as the main hosting/charity organization. We ask that the volunteers contact us before submitting the application or signing a contract on behalf of the TMA. Per our non-profit status, only a few individuals are able to sign on behalf of the organization.

Other ideas of venues that have been used in the past include local schools and community colleges. A few things to make note of while determining the venue - the course must be paved for wheelchairs and have an adequate number of accessible restrooms. Ideally, a shelter or indoor area large enough for all participants should be available. It might also be helpful to ask for a map of the venue, inquire about parking, overflow parking and if there are other events planned for the same day in the venue.

How do we pay for the venue and other costs?

In order to keep the costs of such an event at a bare minimum, we encourage that emphasis be placed on sponsorships and donations to cover the costs of the event which include but are not limited to the venue, food and beverage, communications printing and mailing, tee-shirts, and other give-aways including raffles and silent auctions if they are being considered for the event. The TMA may be able to help cover the cost of venue, on a case-by-case basis, which will be counted against the funds raised from the event. We will work with you to pay vendors directly for expenses, but we ask that these expenses be discussed with TMA in advance so we can budget appropriately, and find alternative ways to keep costs at a minimum and maximize funds raised for research and programs.

If I donated an expense related to event (the park fees, for example), will I get a tax receipt?

We will provide tax receipts to sponsors and donors for their non-monetary/in-kind donations made to the TMA, however we cannot assign a value to these donations.

How do I handle liability insurance for the venue?

Liability insurance for parks and other venues may be covered under the TMA Master Liability Policy and a certificate of insurance will be issued, where applicable. To obtain this certificate, we ask that you provide us a copy of the insurance requirements from the contract or agreement so we may determine if the coverage written for the TMA is adequate for the event in your city. Currently the General Liability coverage written in our policy is at limits of \$1,000,000 per occurrence/\$2,000,000 aggregate.

Do I need to find sponsors?

Community and local business sponsorships are a great way to spread the word about the event, about the rare neuro-immune diseases and also a way for businesses to get recognized on communication material developed for the event. Although not necessary, in our experience, identifying one or two sponsors in your community who will be willing to work with you for the benefit event prior to embarking on this event is very beneficial.

Identifying sponsor levels and the benefits that come with each level is also a good practice, so sponsors know what kind of publicity they get for their contribution. For example, sponsors over \$5,000 get their names on the tee shirts or are allowed a display table at the event. Larger communities should consider higher sponsorship amounts.

Are there any marketing and logo guidelines?

As stated above, in order to create and maintain a sense of identity, we ask that all walks be held under the same logo and motto. Please share any taglines, event specific changes to the logo and motto with the TMA for approval prior to being used in any print or online material. We will provide you with the logos and templates from other walks to help get you started.

All print, video and web-based communication, marketing materials, sponsor packages that use our name, indicate us as a beneficiary of the event, use our logo in part or whole must be approved by the Executive Committee of the TMA prior to being used. We will be able to help you with the design of such materials as well. You may wish to recruit a volunteer graphic designer to help with materials but be sure the designer understands that he/she must work within the guidelines established by TMA and subject to the Executive Director's approval.

Are there any special rules for hosting a silent auction or raffle?

If you plan on hosting a silent auction or a raffle, there may be state specific requirements. We ask that the volunteer or team determine the legality of these fundraising methods and any state specific requirements for raffles and silent auctions and bring it to our attention prior to advertising and planning the activities so we have sufficient time for the required governmental approvals and permits. All fundraising activities to benefit the TMA must be conducted with the appropriate governmental approvals and permits.

How can donations be made?

Donations can be made by check (payable to The Transverse Myelitis Association or TMA) and online (<http://myelitis.org/donate>) prior to the event. Volunteers who receive checks from donors should thank the donor and send the check to TMA – Attn: Sandy Siegel, President, 1787 Sutter Parkway, Powell, OH 43065. TMA will generate a receipt and a thank you letter to the donor. Once the TMA receives the check, the volunteer will be notified and can enter the donation as an offline donation on the team page created on Crowdrise. We will help with walk specific web-based registration through www.crowdrise.com/thetma and donations can also be made through Crowdrise (see below for details on Crowdrise).

Day of event donations will be processed in accordance with TMA's financial procedures for fundraising events, which will be made available to the Chairperson shortly before the event.

The Transverse Myelitis Association is a registered nonprofit organization and is recognized by the U.S. Internal Revenue Service as a 501(c)(3) organization. Donations are tax deductible to the extent provided by U.S. law. Our Tax ID number (EIN) is 91-1780467.

We will provide you with a list of all donors for personal thank you notes and cards that you may like to send and also a total of the amount raised by your event. In keeping with our policy, we are not able to provide you with a list with specific donation amounts so we may maintain the privacy of the individual giving, but donors may choose to have their name be listed on Crowdrise. We value all donations from \$1 to \$1,000,000 and will send a thank you note to everyone.

How Can Participants Register to Walk-Run-N-Roll?

Event registration takes place on Crowdrise. Crowdrise is a sophisticated, all-inclusive event fund-raising product that TMA uses to support all Walk-Run-N-Roll events. It allows supporters to: (1) create their own teams; (2) accept donations by credit card; (3) accept event registrations; (4) provide running totals of donations, including offline donations and registrations; (5) simplifies bookkeeping for TMA.

A guide to setting up teams and registering on Crowdrise is included on the TMA website - <http://myelitis.org/get-involved/walk-run-n-roll-campaign>.

The TMA will help promote and advertise the event through our website, print and online journals and newsletters and social media presence in addition to inviting all members in your city and state.

The success of such an event depends on you, your family and friends and sharing about these rare diseases with people outside our community to expand their consciousness.

For all information and questions, please contact...

The Executive Committee of the TMA which includes the President, Secretary, Treasurer, Director of IT and Executive Director will be available to you to answer any and all questions and support you in your endeavor as best as we can to help make the event a success. Our main email is info@myelitis.org

You may also contact Chitra Krishnan, Executive Director of the TMA @T: 855.380.3330 or by email ckrishnan@myelitis.org