

THE TMA VOLUNTEER HANDBOOK

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Table of Contents

I. INTRODUCTION

- A. Who we are 2
- B. Our Mission 2
- C. What We Do 2
- D. TMA Membership 3
- E. Who's who at the TMA 3

II. ENGAGEMENT GUIDELINES

- A. Support of Individuals with Rare Neuro-immune Disorders 3
- B. Becoming A Volunteer 3

III. CONDUCT GUIDELINES

- A. Representing The TMA 4
- B. Email Policy 4
- C. Social Media Policy 5
- D. Use And Copyright of Website 6
- E. Code of Conduct 6
- F. Discrimination and Sexual Harassment Policy 7
- G. Liability 8
- H. Dispute Resolution 8
- I. Conflict of Interest 8
- J. Confidentiality 10

IV. EVENT ORGANIZING GUIDELINES

- A. Event Liability 10
- B. Managing Event Finances 11
- C. Event Sponsorships 12
- D. Event Receipts and Tax-Deductible Charitable Donations 12
- E. Support from The TMA Staff 13



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I. INTRODUCTION

A. Who we are

The Transverse Myelitis Association (TMA) is a not-for-profit international foundation dedicated to the support of children, adolescents, and adults with a spectrum of rare neuro-immune disorders including: Acute Disseminated Encephalomyelitis (ADEM), Neuromyelitis Optica Spectrum Disorder (NMOSD), Optic Neuritis (ON) and Transverse Myelitis (TM), including Acute Flaccid Myelitis (AFM).

Founded in 1994 by family members and individuals with these diagnoses, The TMA was incorporated on November 25, 1996 in the state of Washington and we became a 501(c)(3) organization on December 9, 1996.

We support individuals living with rare neuro-immune diagnoses and their families, promote awareness to empower patients, families, clinicians and scientists, build a collaborative and dedicated clinical care network and help advance scientific understanding and research.

B. Our Mission

- To support and advocate for individuals and their families diagnosed with rare neuro-immune disorders of the central nervous system
- To promote awareness and to empower patients, families, clinicians and scientists through education programs and publications
- To advance the scientific understanding of and therapy development for these rare disorders by supporting the training of clinicians-scientists dedicated to these rare diseases and by supporting basic and clinical research

Our goal is to improve the quality of life of individuals with these rare neuro-immune disorders

C. What We Do

We are an information resource on rare neuro-immune disorders for our community through our website, newsletters, blogs, Ask The Expert Podcast Series, educational events such as symposia and workshops for the exchange of current and up-to-date information regarding the diagnosis, treatment and management of these disorders. We offer a support network between persons with these disorders through local support groups located throughout the world and through our partnership with Smart Patients, while also organizing annual



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quality of life programs such as family camps for children with these disorders and their families. We support the post-residency training of clinicians committed to careers in academic medicine specializing in these disorders, provide grant support to academic Centers of Excellence and fund novel pilot research ideas.

D. TMA Membership

Membership of the TMA includes individuals with these rare disorders, their family members and caregivers, and the medical professionals who treat individuals with these disorders. The TMA currently has more than 11,000 members from more than 80 different countries and has a large number of support groups across the United States and around the world. There are no membership fees.

E. Who's who at the TMA

Learn more about our staff, members of the board and medical and scientific council members on our website <https://myelitis.org/about>.

II. ENGAGEMENT GUIDELINES

A. Support of Individuals with Rare Neuro-immune Disorders

We ask our volunteers to be confidential and sensitive to the experiences of those who seek the TMA. Volunteers agree to become familiar with education tools and materials that offer accurate information to individuals in need and the general public (brochures, support forums, website, Medical Professional Network, etc.)

Volunteers are not permitted to offer medical advice of any kind, but can direct those in need to the TMA website and to the Medical Professional Network for locating a medical professional, or to the general email of the TMA at info@myelitis.org for proper dissemination of an inquiry that may require medical expertise. All volunteers are required to sign a confidentiality agreement.

B. Becoming A Volunteer

Opportunities for volunteers will be listed on our website. The application form and process will be outlined in the job description.

We take great pride in, appreciate and depend upon our volunteers who help us to achieve our goals. Once a volunteer takes on a task or makes a commitment, the expectation is



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that the volunteer will follow through to the best of their ability in a timely manner. If for any reason the volunteer is unable to complete a task, it is their responsibility to notify the TMA as soon as possible.

To help keep the TMA running smoothly, it is important that volunteers complete their tasks on schedule. If deadlines cannot be met, it is important to let the Executive Director or volunteer leader know immediately and/or to seek out another volunteer to help with those responsibilities.

If for any reason a volunteer is unable or unwilling to carry out their commitment of service, she or he should notify the Executive Director or volunteer leader as soon as possible.

If for any reason the TMA feels it necessary to terminate relations with a volunteer for the protection of the organization, it can do so at its sole discretion.

III. CONDUCT GUIDELINES

A. Representing The TMA

All actions (i.e., speaking publicly, posting online, raising funds, spreading awareness) performed on behalf of the TMA must be carried out with a positive and professional approach. It is the responsibility of volunteers to regularly visit the website, read informational emails and newsletters, and stay current and knowledgeable about TMA activities and accomplishments.

The TMA does not keep track of volunteer hours. If you need documentation of hours, please advise the Executive Director in advance of volunteering.

Professional, respectful and timely communication is expected of anybody representing the TMA whether in person, by email, phone or other form of communication.

B. Email Policy

The TMA will provide volunteers a TMA email account for all correspondence related to the TMA activities. All email accounts are the property of the TMA and as such we expect the following:

- Please respond to emails received in a timely manner, usually within 48 hours. An out-of-office message should be set for emails that will be unmonitored for greater lengths of time.



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- Although less formal than other written communication, email is a business communication tool and users are obliged to use it in a responsible, effective, polite and lawful manner, recognizing that all representatives of the TMA can be held liable for unlawful, libelous or defamatory emails;
- Email should NOT be used for personal matters
- All TMA business should be conducted on your TMA email account;
- Passwords should not be shared with others;
- Accounts not used for 60 days will be deactivated.

C. Social Media Policy

The TMA considers social media sites (including, but not limited to, Facebook, Twitter, Smart Patients, Instagram, Snapchat) to be an important extension of our communications strategy. Volunteer leaders of specific Walk-Run-N-Roll sites or other TMA-sanctioned events may seek approval to set up and maintain social media accounts specific for their event, or one may be created for them. All accounts must adhere to the following:

1. All TMA Walk-Run-N-Roll or other TMA-brands belong to the TMA and are considered an extension of the official methods of communication. Volunteers must adhere to all conduct guidelines of Use of Logo Policy.
2. All TMA Walk-Run-N-Roll or other TMA-branded communication channels should only be used to:
 - a. Fundraise for the TMA,
 - b. Raise awareness for the TMA,
 - c. Advertise and raise support for officially-sanctioned TMA events,
 - d. Share information relevant to the mission of the TMA.
3. Volunteers cannot advertise fundraising events for organizations outside the TMA on the TMA sites.
4. A member of the TMA staff must have administrative access on Facebook pages that contain any TMA-branded events or images.
5. Volunteers can share links from other organizations meant for educational value in the field of spinal cord injury and research, neuro-immunology, physical therapy and rehabilitation, rare neuro-immune disorders such as that shared by the staff communication team on The TMA's Official Facebook page. We encourage collaborations that drive greater awareness and education for our cause and that align with our goals and mission. When unsure of an outside article's relevance, volunteers should consult with the Executive Director or TMA staff.
6. Volunteers operating TMA social media accounts can (and should) advertise fundraisers that directly benefit the TMA. This includes Walk coordinators advertising supporting



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fundraisers of their own or a fellow Walk coordinator's local Walk-Run-N-Roll, i.e., a restaurant night or bake sale, the proceeds of which are donated to the Walk-Run-N-Roll.

7. If or when a volunteer leader of a TMA-sanctioned event ceases to serve in that role, the volunteer should immediately remove him or herself from administrative rights of the page, or the TMA will remove the volunteer upon learning of their intent to not continue with the event. At their discretion, TMA staff will maintain the account until a new volunteer leader is placed in the role, or delete the account. At all times the account remains the property of the TMA and under no circumstances shall it be used for any purpose other than those set forth in this section.
8. The TMA staff reserves the right to remove any content found objectionable on TMA-branded social media sites.
9. Volunteers can be removed from their position on social media pages should they violate any of the communications policies outlined in this Volunteer Handbook.

D. Use And Copyright of Website

Volunteers should become familiar with the TMA website. Using the TMA website for personal business promotion or other advertising is not permitted. The TMA reserves all rights and privileges to its logo, graphics, endorsement, and property, which cannot be used without consent of proper TMA authorities.

E. Code of Conduct

A Code of Conduct agreement must be signed by all volunteers working with the TMA. As a volunteer you are the face of the TMA and are expected to act professionally and responsibly at all times.

No volunteer should:

- Authorize or use the name, emblem, logo, endorsement, services, or property of the TMA for the benefit or advantage of any person or organization, except in conformance with TMA policy.
- Accept or seek any financial advantage or gain other than nominal value offered as a result of the volunteer's affiliation with the TMA, or knowingly take any action or make any statement intended to influence the conduct of the TMA in such a way as to confer any financial benefit on any person, corporation, or entity in which the individual has a significant interest or affiliation (see Conflict of Interest section for more detail).
- Disclose or use any confidential TMA information that is available as a result of the



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volunteer's affiliation with the TMA to any person not authorized to receive such information.

- Act in a manner that creates a conflict with the interests of the TMA and any organization in which the individual has a personal, business, or financial interest. The individual shall disclose such conflict of interest to the Executive Director, or a member of the Board of Directors, as applicable, upon becoming aware of it.
- Commit a theft or inappropriate removal or possession of the TMA's property or that of any volunteer, staff, agent or visitor, including failing to cooperate fully in any investigation of improper usage of TMA property.
- Volunteer under the influence of alcohol or illegal drugs.
- Creating a disturbance at sponsored activities or in areas which could jeopardize the safety of others, including any violation of any federal, state, or local safety or health law.

F. Discrimination and Sexual Harassment Policy

The TMA does not discriminate against any applicant, employee, volunteer, member or client with respect to hiring, retention, promotion, benefits or compensation because of race, national origin, ethnicity, citizenship, gender, gender expression, age, marital status, creed, sexual orientation, disability or any characteristic protected by law. The TMA is committed to the promotion of diversity and we expect that our volunteers adhere to this policy.

The TMA is committed to providing volunteers with a safe and productive environment and will not tolerate any form of sexual harassment. It is unlawful to harass a person because of that person's sex. Harassment can include "sexual harassment" or unwelcome sexual advances, requests for sexual favors, and other verbal or physical harassment of a sexual nature. Harassment includes offensive remarks about a person's sex. For example, it is illegal to harass a woman by making offensive comments about women in general. Both victim and the harasser can be either a woman or a man, and the victim and harasser can be the same sex. Although the law doesn't prohibit simple teasing, offhand comments, or isolated incidents, harassment is illegal when it is so frequent or severe that it creates a hostile or offensive work environment or when it results in an adverse employment decision (such as the victim being fired or demoted).

Any complaint or knowledge of sexual harassment should be brought to the attention of the Executive Director, or the Board of Directors ombudsmen at ombudsman@myelitis.org.

G. Liability



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The TMA is not financially or otherwise liable for injury or casualties that occur to anyone while serving as a volunteer for the TMA. Accordingly, volunteers agree to waive any claims against, indemnify, and hold harmless the TMA, its respective officers, directors, employees, sponsors, representatives and volunteers from any and all liability, including attorney fees, that may accrue on account of, or in any way growing out of, any and all property damage, personal injury, and/or economic loss as a result of or in any way related to or arising out of the volunteer's involvement with the TMA.

H. Dispute Resolution

If an issue or dispute should arise between volunteers, or between a volunteer or volunteers and staff, the parties involved should first communicate directly with one another in a respectful attempt to reach a mutual understanding. If the parties cannot reach a reasonable resolution, then a volunteer must contact the Executive Director of the TMA, or a staff member to help mediate a resolution.

If a resolution cannot be reached, or if such mediation is unreasonable or impracticable (i.e., because a volunteer has a concern, complaint, or other issue the volunteer feels cannot be resolved by working with a staff member), then the volunteer is invited to contact the Board of Directors ombudsman at ombudsman@myelitis.org, an appointed member of the TMA Board of Directors. The ombudsman serves as a public advocate charged with representing the interests of the volunteer by investigating and addressing complaints of maladministration or violation of rights. A volunteer wishing to utilize this process should send an email to ombudsman@myelitis.org, which will be received directly by the Board member serving this role.

The TMA website forums and social media are public and may not be used as a medium for airing conflicts or grievances, including message boards that are protected from public view.

I. Conflict of Interest

The TMA wants all volunteers to fully recognize the importance of their duty to the TMA's constituents and supporters and the necessity to act in a manner that merits public trust and confidence. It is therefore necessary for volunteers to refrain from engaging in any transaction in which personal interests conflict, potentially conflict or appear to conflict with those of the TMA.

An actual or potential conflict of interest occurs when a volunteer is in a position to



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influence a decision that may result in a personal gain for the volunteer or for a relative of that volunteer as a result of the TMA's business dealings. For the purposes of this policy, a relative is a person who is related by blood or marriage, or whose relationship with the volunteer is similar to that of persons who are related by blood or marriage. Participation in any activity prohibited by this Policy can result in the termination of volunteer service.

While some conflict of interests are easily identifiable, the TMA requests that all volunteers be aware of examples of conflict of interest to promote the best working environment for the TMA. All public statements on behalf of the TMA should be made by those dedicated to it in an official capacity by a designated TMA staff member.

The following list of "conflict of interests" is illustrative only and should not be regarded as all-inclusive:

Accepting Payment or Gifts: No volunteer shall solicit for compensation of any kind (including gifts, cash, discounts, concessions, services or other similar item or benefits) for services rendered as part of his or her volunteer service. This includes payment for speaking engagements or for participation in workshops or similar activities. NOTE: If a person or organization wishes to make a charitable donation, volunteers are encouraged to direct them to the proper donation channels, or if that is impossible, direct them to the project director so that the donation can be processed correctly. Please see the Fundraising Guidelines in Appendix B for more information.

Improper Influence: Any volunteer or relative should not, when acting on his or her own behalf or when acting on behalf of another person, business or organization, attempt to influence the TMA's position on any issue, matter or transaction nor participate in any discussions pertaining to a related organization.

Confidential Information: Inside, personal or sensitive information should not be used either for the purposes of gaining advantage for one's self, a relative, or another organization or for any other purpose not specifically approved for use by the TMA.

Political Activities: Volunteers are encouraged to participate in the political and governmental process. However, except for those authorized to act on behalf of the TMA concerning official affairs, volunteers participating do so as individuals and not as official representatives of the TMA. To avoid any inference of support or sponsorship by the TMA, a volunteer must never represent that his or her political donation, endorsement or other political activity was made or engaged in with the approval, or on behalf, of the TMA.



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J. Confidentiality

Volunteers may be exposed to confidential information that is defined as inside, personal or sensitive information, and may include contact information, health information, or personal experience stories. The Code of Conduct signed by all volunteers upon completion of their volunteer application includes a confidentiality statement barring the sharing or disclosing of this information for any unauthorized purposes, including personal benefit.

IV. EVENT ORGANIZING GUIDELINES

We gratefully welcome those who wish to organize events that raise funds and awareness on behalf of the TMA, in accordance with our mission. Please review these guidelines if you are interested in hosting a special event or doing fundraising for the TMA.

It is our goal to empower, not limit, you in your desire to help this cause. Please use this information as a tool that leads you to a successful and rewarding experience on behalf of the TMA. If at any time you have questions or need more guidance, please contact the Executive Director of the TMA by emailing info@myelitis.org.

Guides to help plan a Walk-Run-N-Roll event are available on the TMA website - <https://myelitis.org/get-involved/fundraise>. Events and promotions must fit the TMA's mission and provide a favorable, non-controversial public image. Every event is an opportunity to increase awareness about these rare neuro-immune disorders. The TMA has a variety of brochures, publications, awareness merchandise which can be provided by our staff to organizers.

The TMA name or logo can only be used with prior approval. Materials printed with the TMA name or logo, including letters, tickets, ads, banners, etc. that promote an event, or request contributions, need to be reviewed by a Board Member or Executive Director.

A. Event Liability

The volunteer organizer is responsible for filing for any permits needed to hold the local third-party fundraising event. Depending upon the event, insurance coverage may be obtained through the TMA. Please be certain to contact the Executive Director prior to the event to arrange for insurance coverage, if available. The TMA cannot promise to pay or reimburse fees for permits or coverage without prior approval from the Executive Director. The TMA cannot be held responsible in any way for casualties, thefts or accidents that



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occur at the event.

The TMA is not financially or otherwise liable for the promotion or staging of local events or projects. This includes ticket sales or other administrative aspects. The organizer must seek sponsorship, prior approval from the Executive Director for expenses, or have the means to cover up-front costs, such as ticket sales, promotion costs, or supplies. Should the volunteer incur costs or anticipate costs associated with the administration and management of the event, they must first submit a written request for approval from the Executive Director. Any costs reimbursed to the volunteer must be submitted with appropriate documentation (invoice and/or receipt, as appropriate) along with the TMA Reimbursement Form and within an acceptable timeframe of incurring or anticipation of the costs. All costs incurred relative to the event will be paid from the overall event funds raised.

Federal tax laws disallow third-party events (events where funds do not go directly to the TMA) from using the TMA sales tax-exemption number or Federal Employer Identification Numbers when purchasing any goods or services from suppliers/vendors.

B. Managing Event Finances

Fundraising and awareness activities to achieve the mission of the TMA bring about significant tax, accounting, and liability issues and income must be documented according to state and federal requirements in order to prevent penalty to the TMA. It is crucial that our volunteers are aware of proper procedures when dealing with fundraising and for this reason we have included a few guidelines to manage event finances.

Bank accounts, line of credit, or credit card accounts cannot be opened in the name of the TMA for any reason.

As a responsible steward of public funds, the TMA expects that a reasonable percentage of the gross revenues from fundraising events be directed to the TMA programs and supported research. The total cost to produce the event should not exceed more than 10% of the total amount generated from the event.

The public should be informed of any net amounts that will actually be donated to the TMA. Potential donors must be informed that only portions of proceeds will be donated whenever less than 100% of the net income will be donated.

The organizer is responsible for accounting documentation of revenues and expenses and must work with the Executive Director and Treasurer of the TMA. TMA donation



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envelopes will be provided at events in which donations can be put in and sealed and donor information entered on the envelope. Two people should be available to accept donations at events. All donation envelopes must be mailed sealed via FedEx to the TMA at address provided by Executive Director or Treasurer. Donation tracking sheets will be provided to track all donation envelopes, silent auctions, raffles, and other transactions including credit card payments, which must be completed by the organizer, as applicable and mailed to the TMA. All proceeds must be mailed to the TMA no later than the first business day following your event.

The TMA should be informed, in advance, of any companies approached for underwriting or contributions for the event, so as to coordinate, where necessary, national and regional corporate partnerships. Based on unsuccessful experiences, The TMA discourages grant applications for local TMA events, but would appreciate notification of national grant opportunities that can be pursued by the TMA staff.

No volunteer can take a commission for hosting an event.

C. Event Sponsorships

If you plan to seek sponsorships and/or provide benefits to a business for their sponsorship, please contact the Executive Director to coordinate and discuss further by emailing info@myelitis.org.

D. Event Receipts and Tax-Deductible Charitable Donations

Receipts must be distributed by the TMA with accurate information, and income needs to be documented according to state and federal requirements and the nature of the donation in order to prevent penalty to the TMA.

All donations or event registrations are accepted by checks made payable directly to the TMA or directly through the TMA website by credit card (PayPal, Visa, MasterCard, American Express or Discover) or by cash.

Receipts for Charitable Donations

The TMA's policy is to make every effort to acknowledge all donors with an official receipt outlining the tax-deductible portion of that donation. A credit card transaction receipt is emailed directly for all donations made online to the TMA. All donations received in the mail by check or cash will be mailed a tax-deductible receipt and must have information on



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the donor and address to where the receipts can be mailed. All donations made at TMA events by cash, check or credit card will also be mailed tax-deductible receipts if the donor name and address are available.

Donation of Services & Products

If goods and/or services are received as charitable donations (i.e., auction purchases, tokens of appreciation, giveaways, meals, beverages, etc.) the fair market value of those goods and/or services must be determined by the donor, in writing, and given to the TMA office for documentation.

If the donor of cash, property or in-kind donations wishes to receive tax documentation, the organizer must provide the detailed information listed below:

- Donor's complete name and address
- Date and amount of the contribution
- Whether the contribution was cash, in-kind services or property (non-cash)
- If applicable, description of the type of property and a good faith estimate of the fair market value
- If applicable, detailed description of any goods and services provided

Please note that although the TMA will recognize property and in-kind donations with a letter, due to Federal law, we are not allowed to place a value on these donations.

Purchase of Donated Services & Products

Supporters making a purchase of an item through a silent auction, live auction, raffle, etc., should contact their tax accountant to determine what, if anything, will be deducted from the total purchase amount to determine the tax-deductible portion of the donation. (i.e., if event fee is \$100, but \$50 covers meal cost owed to hosting facility, only \$50 remains as the tax deductible donation to the charity).

E. Support from The TMA Staff

TMA staff members are available to offer general advice on event or project planning along with tips for your specific type of event, implement income documentation procedures and provide educational materials at the event, where appropriate. If you are seeking sponsors, the TMA can provide sample sponsorship letters. The TMA will also design and develop event-specific materials where appropriate.



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Announcements about your event will be emailed to the applicable members of our community, posted on the TMA website, our Facebook page, and if applicable, Twitter, and Smart Patients. Your event may possibly be included in the quarterly newsletter and/or annual report.

I understand and agree that submitting this application form does not automatically qualify me as a TMA volunteer. I must first meet various qualifications including but not limited to a background screening and verification of references.



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