



**Position Title: Executive Director**

**Reports to:** The Board of Directors

**Position:** Full-Time, Exempt

**Location:** Hybrid, Onsite, Columbia, Maryland

### **About The Myositis Association (TMA)**

---

The Myositis Association (TMA) is a nonprofit organization dedicated to providing support and resources for individuals affected by myositis, as well as promoting awareness and advancing research for this group of rare autoimmune muscle diseases.

The Myositis Association was founded in 1993 by a group of individuals affected by myositis who recognized the need for a support network and resources for patients and their families. The organization aims to provide education, raise awareness, and support scientific research to improve the understanding and treatment of myositis.

Through its advocacy efforts, TMA raises awareness about myositis among the general public, healthcare professionals, and policymakers. They strive to promote early diagnosis, access to appropriate medical care, and improved quality of life for individuals living with myositis.

### **The Opportunity**

---

TMA seeks an exceptional Executive Director to steer the organization's mission toward transforming the landscape of myositis research, patient support, and advocacy. As Executive Director, you will have the unique opportunity to shape the organization's future, impacting every aspect of its operations and driving positive change for thousands of patients worldwide.

The Executive Director offers a unique opportunity to lead a growing team and engage with committed board members to advance strategic goals and lay a course for the organization's growth. Your proven success steering an organization's growth will be instrumental in ensuring TMA's operational, programmatic, and fiscal initiatives align with the organization's mission. This role is integral to ensure TMA's work improves the lives of persons affected by myositis, funds innovative research, and increases myositis awareness and advocacy. As Executive Director, you will lead enhancements to patient resources and support programs, ensuring individuals affected by myositis receive the tools, information, and emotional support needed to navigate their journey with this rare disease.

In addition to impacting strategy, operations, staff growth, and patient advocacy, you will play a pivotal role in TMA's fundraising efforts, leveraging your established network and cultivating critical relationships with grassroots supporters, major gift donors, philanthropic organizations, and corporate partners. By advancing fundraising opportunities, campaigns, technology, and talent, you will ensure the financial sustainability of TMA, enabling the organization to invest in

groundbreaking research, expand patient support programs, and amplify advocacy efforts globally.

This Executive Director role is ideal for a strategic, conscientious, and compassionate leader who will bring a track record of executive-level experience in passionate support of TMA's mission. Your ability to inspire and engage TMA's stakeholder community—including board members, association members, staff members, myositis patients, strategic partners, and donors—will be critical in shaping the organization's mission-driven work and long-term success.

## **Impact Areas**

---

### **General Operations**

- Assist in the development and maintenance of a strategic plan and vision to serve TMA's members and those with myositis
- Provide leadership to staff and Board members in developing programmatic, operational and financial plans to achieve the goals identified in TMA's strategic plan
- Manage and promote TMA's research program through coordination and strong relationship with its Medical Advisory Board
- Ensure compliance with applicable laws and regulations
- Maintain a working knowledge of significant developments and trends in the nonprofit health sector
- Assist with the conduct of activities in support of the Board, including meetings, committees, communications, and identification and recruitment of Board members.
- Represent the best interest, professionalism, and integrity of the organization in all activities and relationships through a unified message of the mission and a commitment to organizational standards
- Provide management and support for the development of mission driven programs

### **Management / Leadership**

- Recruit, manage and evaluate full-time, part time, and contracted staff
- Provide direction and oversight of operations to ensure that staff understand duties, timelines to be met, quality of work expected, and function well as a team
- Facilitate communication between staff and Board members to allow for appropriate and timely access to information and resources
- Maintain an office environment suitable to the recruitment and retention of a highly qualified and diverse staff

### **Communications**

- Serve as principal staff spokesperson in representing TMA to the public, membership, media, policy, community, and other audiences
- Ensure accurate and timely reporting of information to the Board and its committees regarding the organization's programmatic performance, finances, and strategic direction
- Provide clear and cohesive marketing and communications strategy across all mediums including, social and digital media, print, as well as with vendors and consultants

- Maintain helpful collaborative relationships with other health organizations to share TMA's agenda and work toward achievement of its programmatic and policy objectives
- Provide to members and the public accurate and timely reports on the activities of TMA

### **Finances**

- Develop and monitor an annual operating budget—currently at \$1.4M—that will achieve TMA's organizational goals and objectives for the year
- Manage financial reserves to provide necessary funds to operate TMA
- Maintain sound financial practices to meet the public's expectations of nonprofit organizations and result in an acceptable annual financial audit
- Oversee the preparation of reports, organizational records and other documentation which present the progress and status of the organization's plan and activities
- Manage contracts, purchases, and banking activities

### **Fiscal Development**

- Establishes an annual income development plan, which represents broad opportunities for event fundraising, donor prospecting, cultivation, retention, upgrading, acknowledgement and recognition
- Directs, and is actively engaged in the cultivation and meaningful involvement of volunteers at all levels in income producing activities
- Evaluates the income growth potential of all activities and develops appropriate strategies to ensure income stability and growth
- Evaluates the resources within the organization's targeted markets to develop plans which support maximum market penetration
- Take lead, and assist the Board, in identifying and soliciting public and private support to provide funding needed to meet strategic goals and objectives
- Cultivate relationships with donors and companies to provide ongoing and long-term financial support
- Promote planned giving and fundraising among TMA membership

### **Knowledge, Skills, and Expertise**

---

- Minimum of 7 years management experience with at least 5 of those in nonprofit management
- Demonstrated ability for strong public speaking and communications skills
- Demonstrated ability in fundraising, partnerships, and member services
- Experience working with health professionals is preferred
- Hands-on experience and familiarity with areas such as managing or participating in multi-state collaborations and successful fundraising activities as well as familiarity with areas such as program planning, budgeting and implementation, health education, advocacy, and research
- Ability to multitask, delegate and disseminate information in a high-paced and quickly changing environment
- Ability to manage competing demands from constituencies
- Highly motivated, assertive, entrepreneurial, and a sense of humor

- Ability to travel nationally as needed, with an expectation of 10-15% travel outside of the local market
- Four-year college degree in a relevant field of study. Master's degree preferred

The Myositis Association has retained the exclusive services of Charity Search Group to coordinate the search for this position. To discuss your suitability for the role, please contact Pascale Hughes at [pascale@charitysearchgroup.com](mailto:pascale@charitysearchgroup.com) or visit [www.charitysearchgroup.com](http://www.charitysearchgroup.com).

*The Myositis Association is an Equal Opportunity Employer. We value a diverse workplace and strongly encourage women, people of color, LGBTQ+ individuals, people with disabilities, members of ethnic minorities, foreign-born residents, and veterans to apply. We celebrate diversity and are committed to creating an inclusive environment for all employees.*