



Myotonic Dystrophy Foundation
Program Director – Patient Support and Education
Oakland, CA – August 2022

The Opportunity

The Myotonic Dystrophy Foundation announces the search for a new Program Director to lead and oversee the organization’s patient support and education initiatives – the “Community” and “Care” components of MDF’s “Community, Care, and a Cure” mission.

Myotonic dystrophy (DM) is the most common form of the muscular dystrophies. According to leading researchers’ estimates, as many as 1 in 2,100 people globally are living with DM, most undiagnosed. Myotonic dystrophy is a highly variable, multi-systemic genetic disorder for which no therapy or cure currently exists.

Launched in 2007 by a deeply committed Board of Directors, the Myotonic Dystrophy Foundation (MDF; www.myotonic.org) is a small, nimble and entrepreneurial organization devoted to accelerating research efforts focused on the search for treatments and a cure for DM and enhancing the quality of life of people living with the disease. The organization has a track record of incredible success in growing the drug development pipeline, research, advocacy, patient care, and fundraising.

In the last decade, dramatic and exciting changes in the research, treatment and drug approval pipeline for rare diseases, including DM, have occurred. The Foundation’s work is now at a “tipping point” with respect to therapy development, visibility, and global reach. The MDF Board and leadership believe the organization is poised to benefit tremendously from growing industry interest, additional federal and private research funding, medical advances, and an enormous dedicated international community of patients, families and friends, donors, researchers and advocates.

MDF has a passionate staff with a central office based in Oakland, CA’s beautiful Preservation Park. The position reports to the CEO, is full-time, and offers a competitive salary and benefits package.

Key Responsibilities

The Program Director provides leadership and oversight for the organization’s patient support and education initiatives – the “Community” and “Care” components of MDF’s “Community, Care, and a Cure” mission. Care initiatives range from the development of high-level strategic programs such as peer-reviewed consensus-based recommendations for clinicians treating people living with DM to more focused toolkits, support groups, webinars, conference programs, regional outreach and

education, and other programs serving the community at large as well as targeted constituents. You do not need to be an expert in or have significant knowledge about myotonic dystrophy - you will learn that in the position.

- Leadership. Lead assessment, strategy development and definition of a comprehensive Care platform that includes community infrastructure, education, resources and support.
- Supervision. Responsible for the supervision of the Community Programs Coordinator & Interns.
- Program Development and Administration. Research, design and implement MDF programs focused on meeting the needs of people and families living with myotonic dystrophy (DM) while managing the resources required, timeframe for building, planning of the launch and the metrics and evaluation components.
- Stakeholder Engagement. Identify and build relationships with key stakeholders in the DM care space, including community members (those living with DM and their families/caregivers), domestic and international clinicians, researchers, nurse practitioners, and other support professionals.
- Strategic Partnerships. Establish relationships and partnerships with related patient advocacy, rare disease, governmental and other stakeholder groups.
- Internal Collaboration. Coordinate with other MDF staff and consultants, leadership, and communications teams to influence key cross-platform programs, including advocacy, communications, fundraising and community volunteer programs.
- Evaluation. Develop tracking metrics and systems that ensure the efficacy of Care programs and projects and provide quarterly reports to the CEO and Board.
- Annual Conference. Lead development and execution of MDF Annual Conference with support of event manager and MDF team. This may be virtual or in person or a hybrid. Responsible for designing and implementing every facet of conference, including all educational sessions/tracks, working with the Scientific Advisory Committee (SAC) to develop professional sessions tracks, corralling speakers, working with/supervising events planner, working with/supervising graphic designer, soliciting ongoing input from community, etc.
- Administration. Work comprehensively with MDF internal programs, software (Salesforce, Mailchimp, etc.) and cloud infrastructure to track projects, contacts and communication, ensuring that timelines and other project parameters are on track.
- Patient Interface. Communicate with and engage community members through the MDF Warmline and other communications channels, and help build and maintain an empathic and knowledgeable face and voice for MDF in the DM community.
- Communications. Identify and/or create Care-related content for MDF communications opportunities, including website, Facebook page, Twitter feed, newsletters, PowerPoint presentations and other communication. As needed provide content for newsletters, grant

requests, board and other related communications effort.

- Other Duties as Needed. Having established a three-year strategic plan at the outset of 2022, MDF is prepared to undertake new initiatives, partnerships, and activities to achieve its mission. This requires not only deep commitment but also flexibility by all team members as new opportunities emerge.

Qualifications

- Bachelor's degree required. LCSW/MSW or RN or MPH degrees preferred.
- Minimum of 5 years of broad experience in managing and developing patient support and education programs.
- Experience in working with scientific advisory and/or medical advisory Boards preferred.
- Strong communications/writing skills with both internal and external constituencies.
- Ability to persuade and motivate others, command the respect and attention of the leadership and influential volunteers.
- Experience organizing small and large events, both in-person and remote.
- Experience developing and/or editing patient-facing documents, guidelines, and toolkits.
- Is both proactive and operational; can initiate new ideas/relationships while keeping pace with a fast moving organization.
- Ability to work well under pressure and adapt easily to changing situations and priorities. Good judgment and consensus building skills.
- Salesforce experience preferred.
- Ability to work with diverse groups and tailor communication to reach diverse populations.
- Empathy and self-starter mentality required.

Compensation & Benefits

The Foundation offers an excellent benefits package and salaries that are commensurate with education and experience. **Salary range for this position is \$100,000 - \$120,000. Benefits include medical, dental, vision, partial 401k match, and more!**

Application Process

Interested and qualified candidates are encouraged to apply by sending a **cover letter and resume** to tanya.stevenson@myotonic.org. All correspondence will remain confidential. Candidates without a cover letter will not be considered.