



Community Engagement Manager
Oakland, CA - September 2023

The Opportunity

The Myotonic Dystrophy Foundation (MDF) announces the search for a Community Engagement Manager, to help advance MDF's Community and Care mission priorities.

About the Foundation

Vision: We envision a world with treatments and a cure for DM.

Mission: Community, Care, and a Cure.

- We support and connect the myotonic dystrophy community.
- We provide resources and advocate for care.
- We accelerate research toward treatments and a cure.

Founded in 2007, MDF is the leading global advocacy organization helping families and professionals understand DM, a rare, genetic, multisystem, highly variable neuromuscular disease. MDF helps constituents identify resources and support, improve quality care, and advance research for management and cures. MDF has a global reach, assisting families and championing other advocacy organizations in more than 139 countries around the world. As many as 150,000 individuals may be at risk for the most common form of adult muscular dystrophy in the United States alone. Tens of thousands of affected families as well as providers, industry partners, researchers, and donors together form the MDF.

Position Overview

The Community Engagement Manager is a key member of the Community and Care Programs team, responsible for major aspects of the development, marketing, evaluation, and success of programs for a mission-driven, nimble, and entrepreneurial non-profit located in Preservation Park in Oakland, CA. Key responsibilities include community outreach, project management, volunteer program development and management, volunteer training coordination and logistics, and evaluation of MDF's related Care and Community Programs. The position reports to the Director of Programs and is fulltime exempt. Candidates must:

1. Thrive in mission-driven, non-profit work environments

2. Demonstrate exceptional customer service, especially for disabled, rare disease, or other under-served communities
3. Have experience, familiarity, and comfort with Salesforce, MS Office and Outlook, and program management best practices.

Key Responsibilities

- Community Outreach. MDF offers a professionally staffed Warmline for people living with myotonic dystrophy, their caregivers, medical professionals and others to ask questions, find support and guidance and, when appropriate, be connected to additional resources and services. The Community Engagement Manager will offer critical information and resources through the Warmline program to individuals and families living with DM. They are responsible for answering calls at the office during working hours and directing them to the right staff member. The Community Engagement Manager will also provide active outreach to community members who have placed toolkit orders and signed up for emails. The Community Engagement Manager is additionally responsible for logging all outreach activities on Salesforce.
- Program Management: Research, design and implement MDF programs/projects focused on meeting the needs of people and families living with myotonic dystrophy while managing the resources required timeframe for building, planning of the launch and metrics and evaluation components.
- Volunteer Program Development and Management: MDF relies on numerous facilitators, writers, social media moderators, and other volunteers to carry out its support, resource, and education programs. The Community Engagement Manager serves as the primary contact and resource for MDF's Support Group Facilitator volunteers. The Community Engagement Manager is responsible for recruiting, onboarding, training, and managing all MDF volunteers. Working with the Director of Programs, they will develop and lead the yearly volunteer training program, including the coordination of timing, attendance, logistics, evaluation, and other aspects of training. The Community Engagement Manager will develop communication and timelines for regular volunteer drives, and work with the Director of Programs to improve volunteer retention practices. They are responsible for facilitating monthly meetings, annual/biennial check-ins with Support Group Facilitators, and supporting MDF volunteers with information and resources.
- MDF Support Program Management: MDF offers a variety of support programs including virtual/in-person support groups, Facebook groups, phone buddies, and happy hours which are facilitated by trained volunteers. The Community

Engagement Manager will lead the implementation of these support programs by working closely with the volunteers. In addition, with the Director of Programs, the Community Engagement Manager will develop a robust evaluation and volunteer reporting system to better understand the impact of MDF volunteer activities.

- MDF Regional DM and Annual Conferences: The Community Engagement Manager will work closely with the Care and Community Programs team, event contractor, other staff, and volunteers to ensure the smooth planning, logistics, operation, and implementation of MDF's regional DM and annual family conference. They will serve as the primary resource for volunteer coordination, supporting the identification of community speakers/panelists, as well as coordination of local volunteer event host activities for all MDF regional DM and annual family conferences.
- Resource Development & Dissemination: The Community Engagement Manager will work closely with the Special Projects Manager to identify community reviewers for all new and updated community resources and education materials. They will additionally work with the Special Projects Manager, Communications team, and other MDF staff to ensure dissemination and accessibility of MDF resources to community members and their families.
- Record Keeping: MDF is committed to data-driven decision-making. The Community Engagement Manager will conduct regular data entry to ensure MDF's database of record, Salesforce, accurately reflects information from community outreach, programs, and other program-related inputs. For example, the Community Engagement Manager will enter warmline records, publication orders, and volunteer engagement/activities into Salesforce.
- Evaluation: The Community Engagement Manager is responsible for evaluating the community outreach, volunteer, and support programs.
- Intern Management: MDF is proud to offer paid internships to graduate and some uniquely qualified undergraduate students. The Community Engagement Manager will play an integral role in recruiting, training, coordinating, and assessing interns.
- Other Duties as Assigned: 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

- Highschool education required. Associate or bachelor's degree strongly preferred.
- Master's degree appreciated.
- Minimum of 3 years of project management experience required.
- Minimum of 3 years volunteer management experience preferred.
- Experience in development of volunteer program training preferred.
- Experience providing support and resources for vulnerable communities and/or rare disease communities strongly preferred.
- Extraordinary customer service skills required.
- Ability to handle multiple projects simultaneously and determine priorities.
- Strong communications/writing skills with both internal and external constituencies, especially with teams or supervisor to determine and understand priorities.
- MS Office experience required, especially Excel and Outlook.
- Ability to work well under pressure and adapt easily to changing situations and priorities. Good judgement and consensus building skills.
- Salesforce experience preferred.
- Evaluation tools experience (Survey Monkey, Qualtrics, or similar) strongly preferred.
- Desire to serve underserved, rare disease, disability, or other related communities.
- Consistent high attention to detail with the ability to self-monitor for accuracy.
- Empathy and self-starter mentality required.

Compensation and Benefits

The Foundation offers a salary range of \$75,000 - \$85,000 for this exempt position, plus benefits. MDF prioritizes candidates who live in the Bay Area and prefers, to the extent safety and health considerations allow, that staff report daily to the MDF office.

Application Process

Interested and qualified candidates are encouraged to apply by sending a cover letter and resume to mindy.buchanan@myotonic.org. All Correspondence will remain confidential. Submissions without cover letters will not be considered.