



**Special Projects Manager**  
*Oakland, CA – May 2023*

## **The Opportunity**

The Myotonic Dystrophy Foundation (MDF) announces the search for a Special Projects 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 DM 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 Special Projects Manager provides leadership and oversight for multiple projects and initiatives throughout the year for a mission-driven, nimble, and entrepreneurial non-profit located in Preservation Park in Oakland, CA. Key responsibilities include project management, development of Community resources such as the DM Toolkit, volunteer management, event coordination and logistics including the MDF Annual Conference, and evaluation for MDF's Care and Community Programs. Candidates must 1) thrive in mission-driven, non-profit work environments 2) demonstrate exceptional customer service, especially for disabled, rare disease, or other high-touch communities 3) have experience, familiarity, and comfort with Salesforce, MS Office and Outlook, and program management best practices. This fulltime position reports to the Director of Programs.

## Key Responsibilities

- Program Management. Research, design and implement MDF programs\projects 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.
- Volunteer Management. MDF relies on numerous community and professional speakers, facilitators, writers, social media moderators, and other volunteers to carry out its support, resource, and education programs. The Manager works closely with the Director to develop and maintain volunteer best practice tools and resources.
- MDF Annual Conference. The Manager will work closely with the Program Director, event contractor, other staff, and volunteers to ensure the smooth planning, logistics, operation, and implementation of MDF's annual family conference, a one-of-a-kind event that brings individuals living with DM, their families, and providers together once a year. The Manager will develop programming, suggest speakers, and coordinate outreach to speakers and other volunteers.
- MDF DM Days and Medical School Roadshow. MDF provides localized one-day events (DM Days) bringing together MDF, clinicians, researchers to support DM patient and family community. Medical School Roadshow helps address the critical need to better educate the medical community about DM by partnering with medical schools to educate students about DM before the graduate and begin clinical work. These two programs run in tandem across the country, with Medical School Roadshows on Friday and DM Day on Saturday, allowing students to join the community for the DM Day. The Manager will work closely with the Program Director, other staff, and volunteers to ensure the smooth planning, logistics, operation, and implementation of MDF's DM Days and Medical School Roadshows.
- Resource Development & Dissemination. MDF provides educational and support resources for those affected by DM and their families. The Manager will coordinate/lead the final phase of review, revision, and DM focus separation (DM1, DM2, JOA, CDM) of the MDF Toolkit from one to four resources. The MDF Toolkit provides a comprehensive understanding of DM, symptom management, daily life optimization, care coordination, and much more. Ideal for the newly diagnosed individual, the Toolkit offers perspectives from neurology, anesthesiology, PT, OT and other care perspectives in lay-friendly, accessible way. Other DM resource development and dissemination projects as assigned.
- Record keeping. MDF is committed to data-driven decision-making. The Manager will conduct regular data entry to ensure MDF's database of record, Salesforce, accurately reflects information from community member outreach, programs,

conferences and events, and other program-related inputs. For example, the Manager will enter Warm Line call records, publication orders, and event attendance data into Salesforce.

- Internship Coordination. MDF is proud to offer paid internships to graduate and some uniquely qualified undergraduate students. The 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 2021, 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. Associates' or bachelor's degree preferred.
- Master's degree appreciated for Manager position.
- Minimum of 3 years of project management experience required.
- Ability to handle multiple projects simultaneously and determine priorities.
- Strong communications/writing skills with both internal and external constituencies, especially working with teams or supervisor to understand organizational priorities.
- Experience organizing small and large events or activities for different size groups, especially working in virtual platforms such as Zoom and GoToWebinar.
- Extraordinary customer service skills required.
- Ability to work with diverse groups and tailor communication to reach diverse populations.
- MS Office experience required, especially Excel and Outlook.
- Ability to work well under pressure and adapt easily to changing situations and priorities. Good judgment and consensus building skills.
- Salesforce experience 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 of \$80,000/year 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 during the COVID-19 pandemic, 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](mailto:mindy.buchanan@myotonic.org). All correspondence will remain confidential. Submissions without cover letters will not be considered.