



Myotonic Dystrophy FOUNDATION

Myotonic Dystrophy Family Registry Coordinator
Oakland, CA – July 2022

The Opportunity

The Myotonic Dystrophy Foundation (MDF) announces a new role, Myotonic Dystrophy Family Registry Coordinator, to support MDF's strategic plan and work to engage the myotonic dystrophy community (DM) in registry participation and clinical trials and study education and opportunities.

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, multi-systemic, 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. It is an exciting time for the DM community, with three clinical trials launched in 2021 with several more expected to begin in the coming two years! 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 MDFR Coordinator is responsible for the growth and maintenance of the [largest myotonic dystrophy-only registry in the world](#). The Coordinator will work with the DM community to encourage registry participation, provide education on clinical trials and studies, and is responsible for the quality and continued improvement of data collection and entry. As a mission-driven, nimble, and entrepreneurial rare disease non-profit located in Preservation Park in Oakland, CA, this role is essential to helping eliminate barriers to the development of the first disease modifying treatments and a cure for myotonic dystrophy. The position is fulltime and reports to the CEO and works closely with the Research Coordinator and Communications Manager.

Key Responsibilities

- Registry Program Coordination. MDF offers numerous educational and informational programs across print, in-person, and digital formats. The Coordinator will work closely with the MDF team and clinical research network sites to coordinate registry recruitment, outreach and educational programs.
- The Coordinator will play a key role in program evolution, assessing past and present registry data, conducting environmental scans, interviewing key opinion leaders, and gathering other data and insights for planning and registry growth purposes.
- Consistently and positively communicates and collaborates with affected family members via email and phone, following up on incomplete or problematic Registry records and assisting family members who have trouble completing the survey.
- Professionally and rapidly responds to researchers, supervisors and other external stakeholders, serving as a resource for institutional partners.
- Acts as the primary point-of-contact for all tasks relating to the registry website, including updating information, content, and pictures, and ensuring that the site profile is always up-to-date.
- The Coordinator will work closely with the MDF team to help plan and implement the annual conference, ensuring registry recruitment and trial and study education is prioritized.
- Maintain confidentiality and security of patient data in accordance with legal and regulatory requirements.
- MDF is committed to data-driven decision-making. The Coordinator will regularly conduct data entry and cleaning to ensure the MDF and registry databases accurately reflect information from community member outreach.
- The Coordinator will create a strategy to target low participation areas in the MDF database.
- Work with clinical research sites to drive recruitment for ongoing clinical trials.
- Maintain IRB certification and clinicaltrials.gov listing.
- Facilitate follow-up surveys and updates demographic information on participants in the registry and answers requests for registry data; extract data from database and generate reports as assigned.
- Demonstrate behavior consistent with our Core Values: Community, Collaboration, Urgency, Knowledge, Empathy, and Hope.
- 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

- Knowledge of patient registries.
- Experience working with data sets of different sizes and sensitivity levels.
- Extensive project management experience required.
- High school education required. Bachelor's and advanced degrees preferred.
- Ability to prioritize and handle multiple projects simultaneously.
- Strong communications/writing skills with both internal and external constituencies, especially working with teams or supervisor to determine and understand priorities.
- Experience and proven success in interacting with patient communities; ability to be personable and professional on the phone.
- Experience organizing small and large events or activities for different size groups, especially working in virtual platforms such as Zoom and GoToWebinar, preferred.
- Extraordinary customer service skills required.
- MS Office experience required, especially Excel, Word, PowerPoint, and Outlook.
- Ability to work well under pressure and adapt easily to changing situations and priorities.
- 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.
- HIPPA certification (may be achieved at start of employment).

Compensation and Benefits

The Foundation offers an annual salary of \$70,000 plus medical, dental, optical, and life insurance benefits, as well as a partial matching 401(k). 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. Remote position may be considered with qualified candidates.

Application Process

Interested and qualified candidates are encouraged to apply by sending a cover letter and resume to Tanya.Stevenson@mytonic.org. All correspondence will remain confidential. Submissions without cover letters will not be considered.