



**Myotonic Dystrophy Foundation**  
**Program Director – Patient Support and Education**  
*Oakland, CA – December 2020*

## **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 “Care” component of MDF’s “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 every 2,300 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](http://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 and is based in Oakland’s Preservation Park, although we are all currently working from home due to COVID-19 Shelter-in-Place restrictions. The position reports to the CEO. The position is full-time and offers a competitive salary and benefits package.

## The Organization – Strategic Priorities and Recent Accomplishments

### Research Funding and Drug Development Acceleration

MDF is committed to being the leader in the advancement of basic and translational research and the de-risking and optimization of the entire myotonic dystrophy drug development pipeline, from basic research in academic labs to the regulatory environment and the payer space.

Recent strides include:

- Increasing drug research and development. MDF is now scoping and developing the strategy to double the DM drug development pipeline. In the past five years alone, MDF has invested more than \$6M in international efforts to drive target identification, assay development and drug screening, biomarker identification and qualification, endpoint research and identification, and mouse model, cell lines and other drug development and clinical trial infrastructure and capacity initiatives. In addition, MDF was recently awarded \$1M as the first tranche in a multi-phase initiative to develop a gene therapy for myotonic dystrophy type 1, and has begun scoping and implementing the approach for this grant initiative, which began in 2018.
- New access to federal research funds. MDF worked with key congressional leadership, the organization's advocacy and public policy team in Washington, DC and key grassroots advocates, to gain DM inclusion in the Department of Defense Peer-Reviewed Medical Research Program (PRMPR), a \$300M funding source. Since then, over \$5M has been dedicated specifically to DM research. The Foundation is also actively pursuing additional DM research-related funding through programs at the National Institutes of Health.
- Increasing clinical studies. MDF is supporting a 15-site clinical research network to expand disease discovery, increase the efficiency of testing new drug candidates and increase the size and scope of sites trained, experienced and resourced to deliver clinical trials for potential therapies.
- Supporting and prioritizing DM-focused research fellowships. MDF is supporting up-and-coming pre- and postdoctoral fellows to expand the base of committed researchers. MDF has committed over \$3M in total research funding for 34 fellowships since 2009.
- 2<sup>nd</sup> largest patient registry in the world. MDF created and operates the Myotonic Dystrophy Family Registry (see [www.myotonicregistry.org](http://www.myotonicregistry.org)), which is now the second-largest patient registry in the world, leading clinical trial recruitment, patient community organization and data collection. Launched in February 2013 with the support and direction of academic and industry researchers and people living with DM, the international registry, which is still growing, includes over 2,000 records.
- Prioritizing data collection about the disease. MDF has launched several initiatives to determine the true prevalence of the DM mutation in the population worldwide and documenting the socio-economic burden of the disease.

## Advocacy

MDF considers advocacy a key tactic in realizing the organization's "Care and a Cure" mission. MDF advocates for legislation, research and infrastructure initiatives to improve the quality of life of people living with DM, accelerate disease discovery and drug development, increase the funding available for research efforts and improve prospects for therapy reimbursement and patient access.

- "Care and a Cure" advocacy campaign. MDF has worked with a leading Washington, DC public policy team, to execute an aggressive advocacy platform since 2015. A key result was convincing the Social Security Administration to list congenital myotonic dystrophy in the Blue Book of diseases qualifying for Compassionate Allowance, thereby making the application for SSA disability coverage much quicker, more streamlined and successful.
- DM inclusion in health related health legislation. MDF regularly monitors and issues position statements on health and research related legislation. The organization was active in recent efforts to repeal and replace the Affordable Care Act. MDF also recently convinced the Social Security Administration to qualify congenital myotonic dystrophy for Compassionate Allowance listing, making those with CDM immediately eligible for accelerated and priority review for disability coverage through SSA.
- Strategic partnerships. MDF also partners with other organizations focused on neuromuscular disorders to leverage resources and amplify impact.

## Support and Education

MDF is committed to making information about DM accessible and available through:

- A robust website ([www.myotonic.org](http://www.myotonic.org)) which provides information, access to support group services, patient care guidelines and toolkits, disease management resources and a digital academy with educational videos, podcasts and webinars. The website also provides care guidelines, grant information and other resources for research and clinical professionals.
- The MDF Toolkit provides a user-friendly overview of the disease and a physician primer for newly-diagnosed patients and families, along with PT, OT, anesthesia and other guidelines and additional resources.
- First-ever, comprehensive clinical care guidelines have been developed by an international group of clinical experts, and are being translated into multiple languages. These recommendations, which include specific versions for adults with DM1, DM2, children affected by congenital and childhood-onset DM, and specialist-focused recommendations for cardiologists, gastroenterologists, pulmonologists, have been published.
- Support groups and forums where patients and family members can meet, share information and communicate with and encourage each other. Patient support programs are offered through monthly webinars, peer-to-peer phone support and other venues.
- Annual conference focuses on providing the latest in research and drug development updates and symptom management strategies for the patient community, and a drug development roundtable, professional meetings and regulatory workshops for the professional community.

## Key Responsibilities

The Program Director provides leadership and oversight for the organization's patient support and education initiatives – the "Care" component of MDF's "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.
- Program development. 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, industry partners, 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, including Chief Science/Medical Officer, Development Director, communications team, and public policy consultants 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.
- MD expert collaboration. Coordinate with the Scientific Advisory Committee of MDF and other expert resources to ensure current content for Care programs. Serve as programmatic liaison on MDF Care-related issues, opportunities with external partners.
- 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.
- 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.

## 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.
- 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 and Benefits

The Foundation offers an excellent benefits package and salaries that are commensurate with education and experience. **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](mailto:tanya.stevenson@myotonic.org). All correspondence will remain confidential.