



The Opportunity

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 myotonic dystrophy (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.

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.

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 is growing! We have a passionate staff and are based in Oakland's Preservation Park, although we are all currently working from home due to COVID-19 Shelter-in-Place restrictions. The Development Manager position reports to the CEO. The position is full-time and offers a competitive salary and benefits package.

The Organization- Strategic Priorities & 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.



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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.
- 2nd largest patient registry in the world. MDF created and operates the Myotonic Dystrophy Family Registry (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



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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 and research related 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) 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



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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

MDF has a ten-year track record of successfully raising its annual strategic operating budget to support the organization's ambitious and critical work. The Development Manager is responsible for fundraising leadership and administration. The current annual fundraising goal is approximately \$2 million, the majority of which is raised from committed individual donors, and the annual conference, and gala. Some funds are raised from corporate and foundation sources who seek to partner to eradicate this disease. Key responsibilities of the role include but not limited to:

- Leadership and administration. Provide strategic and creative leadership for the development department and the organization's fundraising goals. Design and implement annual fundraising plan, and administer development activities for the organization, while partnering closely with staff and Board.
- Donor identification and cultivation. Seek new individual donors and maintain/build relationships with current and past donors both personally and as part of an organizational effort.
- Internal collaboration. Work collaboratively across the organization on joint fundraising efforts. Collaborate with the CEO on individual donor solicitations. Work with the Board to maximize their ability to support development efforts.
- Administration. Oversee and administer all development operations and staff. Maintain donor services database, including processing, acknowledging, accounting, and administering regulatory requirements for all contributions. Explore and utilize opportunities to use technology and innovative fundraising tools to increase revenue and enhance the overall donor experience.
- Gala fundraiser. Plan and oversee the organization's gala fundraiser, in collaboration with the Gala committee chairs.



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- External ambassador. Serve as a knowledgeable and passionate external ambassador representing the organization's important work to various stakeholders.
- Knowledge about DM. Gain and maintain knowledge about MDF's strategic priorities and accomplishments, and stay current on trends and information in DM research, advocacy, and education. No prior knowledge of DM is necessary.

Qualifications

- Substantive broad experience in fundraising/development, with at least three years at a management or senior level in a non-profit setting.
- Proven track record of fundraising success with individual donors. Familiarity with seeking funds from corporations and foundations.
- Demonstrated successful experience in partnering and working closely with senior leadership, influential volunteers and a board of directors.
- Ability to represent the Foundation to external audiences through the use of strong verbal and written communication skills.
- Is both proactive and operational; can initiate new ideas/relationships while keeping pace with a fast moving organization.
- Strong interpersonal skills, compassion, empathy, self-confidence, diplomacy, teamwork, good judgment, and respect for confidentiality.
- Demonstrated familiarity with cultivating, soliciting and stewarding prospects and donors.
- Excellent attention to detail.
- Self starter, able to work independently.
- Familiarity and comfort processing gifts and using fundraising software, especially Salesforce and Network for Good.
- Proficient in Microsoft Office products, especially Word, Excel, and Powerpoint. Apsona experience a plus.



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- Willingness to travel outside the office (once it is safe to do so, of course), occasional evening and weekend work, and willingness to adjust to other needs of the department.
- Preferred experience with health non-profits or rare diseases.
- Grant writing and social media experience preferred.

Compensation and Benefits

The Foundation offers a salary range of \$75,000-\$90,000 annually and an excellent benefits package that includes PTO, medical, dental, vision, and a 401(k) partial matching program.

Application Process

Interested and qualified candidates are encouraged to apply by sending: 1) a cover letter and 2) resume to Tanya.Stevenson@myotonic.org. All correspondence will remain confidential.