



Care and a Cure

Myotonic Dystrophy Foundation
Director of Development
San Francisco, CA –2018

The Opportunity

The Myotonic Dystrophy Foundation announces the search for a new Director of Development. Myotonic dystrophy (DM) is the most common form of the muscular dystrophies. According to leading researchers' estimates, as many as 1 in every 3,000 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, 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 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. In 2017, the organization was awarded \$1M as the first tranche in a multi-phase initiative to develop a gene therapy for myotonic dystrophy, and the organization succeeded in efforts to have DM included in the Department of Defense Peer-Reviewed Medical Research Program (PRMPR), a \$300M funding source in 2018. 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 based in San Francisco's Presidio, a national park located on the edge of SF Bay. The Director of Development is responsible for the leadership and administration of the fundraising function, and works closely with the CEO, board, program staff and engaged volunteers. The position reports to the CEO, and will receive some staff support from the Program Associate position. 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 drug development pipeline through an initiative called MDF 4.0. In the past three 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 will launch 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 in 2018. The Foundation is also actively pursuing additional DM research-related funding through programs at the National Institutes of Health and the Department of Defense.
- Increasing clinical studies. MDF is supporting a nine-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 fellowships since 2009.
- 2nd largest patient registry in the world. MDF created and operates the Myotonic Dystrophy Family Registry (see 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 1,800 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, Faegre Baker Daniel, 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) 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, are being published in 2018.
- 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 Director of Development is responsible for the leadership and administration of fundraising for the organization's important work, and works closely with the CEO, board, program staff and a cadre of engaged and passionate volunteers. 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 current annual fundraising goal is approximately \$2 million, the majority of which is raised from committed individual donors, and the annual conference and gala fundraiser. A small amount of funds are raised from corporate and foundation sources. Key responsibilities of the role include:

- Leadership and administration. Provide strategic and creative leadership and for the development department and the organization's fundraising goals. Oversee and administer development activities for the organization, partnering closely with others.
- 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. Maintain donor services database, including processing, acknowledgement, accounting and regulatory requirements of 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.
- External ambassador. Serve as a knowledgeable and passionate external ambassador representing the organization's important work to various stakeholders.

- Knowledge about DM. Maintain knowledge about MDF's strategic priorities and accomplishments, and stay current on trends and information in MD research, advocacy and education.

Qualifications

- A bachelor's degree or equivalent.
- Substantive broad experience in development, with at least three years at a 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 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, self-confidence, diplomacy, teamwork, good judgment, and respect for confidentiality.
- Demonstrated familiarity with cultivating, soliciting and stewarding prospects and donors.
- Familiarity and comfort using fundraising software.
- Willingness to travel outside the office, occasional evening and weekend work, and to adjust to other needs of the department.

Compensation and Benefits

The Foundation offers an excellent benefits package and salaries that are commensurate with education and experience.

Application Process

Interested and qualified candidates are encouraged to apply by sending a cover letter and resume to molly.white@myotonic.org. All correspondence will remain confidential.