



Chief Science Officer
Oakland, CA – January 2023

The Opportunity

The Chief Science Officer will play a pivotal role in helping to define the research strategy for the Myotonic Dystrophy Foundation (MDF) and will be responsible for the implementation of the research-related objectives of MDF's new Strategic Plan (2021-2024). The position reports to the MDF CEO and works closely with the CEO, Research Coordinator, Family Registry Coordinator, and the Scientific Advisory Committee (SAC) in developing research strategies and interfacing with industry, academic, and government agencies working on myotonic dystrophy (DM).

The Foundation is strongly positioned to make multi-million dollar research investments over the next three years and will utilize the Chief Science Officer's (CSO) insight and guidance to manage that project. The CSO will also provide scientific oversight to MDF's research grant and fellowship programs throughout the pre-award, application review, and post-award process. They will also work with staff to develop strategies to continually improve the grant administration process.

The position is a full-time exempt position and offers a competitive salary and benefits package. Part-time may be considered.

Organization Background

Launched in 2007 by a deeply committed Board of Directors, the [Myotonic Dystrophy Foundation](#) 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 adult form of the muscular dystrophies. According to leading researchers' estimates, as many as 1 in every 2,100 people globally are living with DM, most undiagnosed. Myotonic dystrophy is

a rare, genetic, inherited, 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 and DM community are 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.

Key Responsibilities

- Strategy development. Work closely with the CEO, Research Coordinator, Registry Coordinator, and the Scientific Advisory Committee (SAC) to shape the vision of the MDF's research program strategy and guide the development of a grantmaking services portfolio that aligns with the program aimed at accelerating drug discovery and development for myotonic dystrophy.
- Strategy implementation. Serve as the technical lead on MDF's research grantmaking projects, including project planning, implementation, evaluation, and other related responsibilities, including identifying and implementing research goals and objectives in collaboration with the Research Coordinator and SAC grantmaking team. Work with grantmaking team to develop, manage, and track grant program budgets.
- MDF Annual Conference. Collaborate with the CEO, SAC, and the Program Director to plan and organize a professional/research track at the MDF Annual Conference that would meet MDF's and the clinical/research community's goals and objectives.
- Internal collaboration. Collaborate with staff to implement strategies to advance the organization's priorities related to the research program. Contribute subject matter and/or technical expertise to internal teams. Responsibilities include helping identify new members for the Scientific Advisory Committee and translating technical research reports into lay language.
- External collaboration. Coordinate, support, and/or lead relevant meetings/workshops with federal agencies, industry, and other stakeholders. Liaise and coordinate activities with MDF's key stakeholders. Represent MDF at conferences. Update and maintain the DM Drug Development Pipeline.

- Thought leadership. Be a trusted, informed resource for staff, grantees, and the broader DM community. Submit and/or contribute to publications (e.g. journal manuscripts, practice beliefs, etc.) and/or conference abstracts, presentations, and workshops. Develop and provide content for the website, Dispatch, and/or other methods of marketing MDF's work and impact.
- Data management. Manage and analyze MDF's internal data for distribution and publication. Develop reports, abstracts, posters, papers, and presentations for multiple stakeholders.
- Business development. Write proposals and lead proposal development processes for relevant opportunities and contribute to other writing teams where appropriate.
- 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.
- Advocacy. Work with MDF's Advocacy lead to accomplish goals associated with increasing federal funding for DM, including engagement with congress, NIH, FDA, CDC, DoD, and others.
- Travel. As needed for MDF and DM-related events and activities. Participation in IDMC and other domestic and international events.
- Additional duties assigned as needed to help meet the goals and objectives of MDF.

Qualifications

- Doctoral-level degree, such as a Doctor of Philosophy (Ph.D.) or Doctor of Medicine (M.D.) in a relevant scientific or biomedical field.
- A minimum of 2 years of relevant post-doctoral work experience in positions of leadership in health-related fields and/or research.
- Demonstrated ability to establish priorities, manage shifting priorities, and handle numerous time-sensitive projects with multiple deadlines.
- Excellent verbal and written skills; including strong presentation skills and the ability to translate complex technical language to the lay public as well as for

publication.

- Experience in developing, managing, and evaluating grant programs and grantmaking practices a plus.
- Demonstrated success in developing, leading, and supervising complex projects and high performing teams.
- Knowledge of emerging trends, challenges, and best practices in DM research, including clinical trials.
- Knowledge of health philanthropy or health non-profits a plus.
- Demonstrated experience writing, reviewing, and editing grants, journal manuscripts, practice briefs, and/or conference abstracts and presentations.
- 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.
- Excellent attention to detail.

Compensation and Benefits

Annual 100% FTE salary of \$150,000 - \$200,000, dependent upon years of experience and connection to the field of myotonic dystrophy. Part time work may be considered for the right candidate. Medical, dental, vision, and life insurance. Generous vacation and sick leave. Partial 401k matching opportunity. Opportunity to work with incredibly dedicated, fun, and collaborative colleagues.

Application Process

Interested and qualified candidates are encouraged to apply by sending: 1) a cover letter and 2) resume/CV to MDF's CEO, Dr. Tanya Stevenson at tanya.stevenson@myotonic.org. All correspondence will remain confidential.