Myotonic Dystrophy Data Project Internship

Oakland, CA – January 2024

The Opportunity

The Myotonic Dystrophy Foundation (MDF) announces its search for college-level and graduate student interns to help advance MDF's mission.

Vision: We envision a world with treatments and a cure for myotonic dystrophy (DM).

Mission: The MDF mission is 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, multisystem, 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 120 countries around the world. 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

MDF has a small, passionate staff based in Oakland, CA's Preservation Park, and seeks to add several college-level and graduate student academics to its team as interns focused on strategic projects. Interns will report to the Myotonic Dystrophy Family Registry (MDFR) Coordinator and will work collaboratively with all departments. The position is available a minimum of eight hours/week, beginning March/April 2024. Multiple Part-to-Fulltime positions are available during summer 2024.

Family Registry Intern Projects

- Database analysis: The Data Projects intern will help compile, clean, organize, and analyze de-identified data.

- Assess database activity along the years: Conduct environmental scan of past and present datasets. Identify level of responsiveness within different surveys.

- Review of outcome data: MDF is committed to data-driven decision-making. The Data Projects intern will help conduct data analysis and comparison between different databases to determine accuracy and strategize outreach initiatives.

- Help identify low participation geographic areas in database: map and compare past and existing community programs and events (support groups, conferences, etc.) to support the planning of future MDF strategic initiatives.

- Prepares reports, graphs and figures on performance and metrics.

- Other projects as identified. Flexibility as new opportunities emerge!

Qualifications

- A minimum 3 years of experience and proven success in similar positions with similar responsibilities, preferably in the nonprofit sector.

- College degree or current student enrollment required (preferably in the field of biomedical sciences, public health, or a related discipline). Community College and University students and graduates are encouraged to apply.

- Strong research skills and ability to work with databases.

- General knowledge of statistical analysis techniques.

- Familiarity with literature search, preferred.

- General computer skills. MS Office experience required especially Excel, Word, PowerPoint, and Outlook.

- Consistent high attention to detail with the ability to self-monitor for accuracy.

- Empathetic self-starter, with a natural curiosity and ability to quickly join new projects while leveraging the expertise of others.

- Ability to work with diverse groups and tailor communication to reach diverse populations.

- Knowledge of rare diseases, including myotonic dystrophy, preferred.

Compensation and Benefits

The Foundation offers interns $20/hour for the duration of the internship.

Application Process

Interested and qualified candidates are encouraged to apply by sending a cover letter and resume to Myotonic Dystrophy Family Registry Coordinator, Sofia Olmos sofia.olmos@myotonic.org. All correspondence will remain confidential. Submissions without cover letters will not be considered.