Request for Applications:
2024 DM Small Grants Program

Myotonic Dystrophy Foundation
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Contracting Officer: Tanya Stevenson, Chief Executive Officer, MDF
Location: United States, Canada, and eligible international sites
Date Issued: April 12, 2024
Proposals Due: Rolling basis, subject to fund availability
Selection Notification: 4-6 weeks post-submission
Period of Award: Varied
Anticipated Award: $5,000 for open-access fees/ $2,500 for conference travel
Number of Awards: To be determined based on applicant mix and available funds

Synopsis

In response to a need to expand access and boost research efforts in myotonic dystrophy (DM), the Myotonic Dystrophy Foundation (MDF) is launching the DM Small Grants Program in 2024. This initiative aims to enhance engagement in and access to DM research by easing access to funding for open-access publication fees and conference travel costs. Researchers can apply for grants of up to $5,000 for open-access fees and $2,500 for travel and conference expenses on a rolling basis.

Goal

The Myotonic Dystrophy Foundation seeks to foster collaboration among researchers and clinicians in the field of myotonic dystrophy by removing barriers such as open-access publication fees and conference travel costs.

Background

Understanding the complex pathophysiology of DM requires interdisciplinary collaboration, advanced techniques, and dedicated research efforts. However, expanding engagement in DM research faces obstacles due to limited funding and resources concentrated on more prevalent diseases. To address this, MDF seeks to facilitate interdisciplinary collaboration and advance access to knowledge relevant to improving the quality of life for individuals with DM. The Small

Grants Program targets open-access publication fees and conference travel costs to increase accessibility to DM research.

Open-Access Publications. Publishing in open-access journals ensures global access to DM research findings for researchers, healthcare professionals, patients, caregivers, and the public. It enhances visibility, promotes patient engagement, and fosters collaboration among researchers, driving scientific progress toward the understanding of myotonic dystrophy and the development of effective therapies.

Conferences. Researchers presenting at DM-focused conferences contribute to the collective understanding of the disease and its underlying mechanisms. These presentations can spark collaborations, inspire new research directions, and facilitate the dissemination of novel findings to a diverse audience of scientists, clinicians, patients, advocates, and policymakers. Conferences provide networking opportunities and insights into the latest developments, enhancing researchers' contributions to the scientific discourse on myotonic dystrophy.

We hope that this initiative expedites the translation of scientific findings into clinical applications. We hope to foster the development of therapies, diagnostic tools, and management strategies that benefit individuals living with DM by providing resources, open-access materials, and support.

Grant Focus Areas

Myotonic dystrophy is a chronic disease with multiple dimensions that affects the lives of DM patients and their families every day. There are two major types of myotonic dystrophy: type 1 (DM1) and type 2 (DM2). Both types of myotonic dystrophy are inherited autosomal dominant disorders affecting all areas of the body. The primary clinical physical manifestation is characterized by progressive muscle wasting and weakness affecting the lower legs, hips, hands, shoulders, neck, and face in DM1 and progressive muscle wasting and weakness affecting the proximal leg muscles, hips, shoulders, and neck in DM2. Research indicates that as many as 1 in 2,100 individuals in the United States are affected by myotonic dystrophy or at risk of passing the disease to the next generation.[i]

People with this disorder may have prolonged muscle contractions (myotonia) and may not be able to relax certain muscles after use, affecting grip and speech, for example. They may also develop cataracts, cardiac conduction defects, and infertility. Many patients demonstrate CNS effects, including white matter abnormalities that are associated with central fatigue, excessive daytime sleepiness, and difficulties in executive function. A variation of DM1 called congenital myotonic dystrophy includes weak muscle tone (hypotonia), breathing and swallowing problems, delayed development, and CNS involvement that results in intellectual disability at birth.

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Opportunity for DM Research

Recognizing that the symptoms and the severity of DM vary widely among affected people and often severely impact activities of daily living, mobility, and independence, **the MDF is soliciting proposals for small grants to publish DM-related research in open-access journals or to present DM-related research at scientific conferences.** The grants provide opportunities for researchers to share their work, enhance collaboration, and contribute to advancements in DM understanding and treatment.

Duration of the Award

Awarded grants are for a one-time amount to cover either publication or travel costs. Applicants may apply for only one Small Grant for travel each calendar year.

Payment

Awards are made to the applicant organization on behalf of the grantee. These grants available are up to $5,000 for open-access fees and $2,500 for travel and funding grants. The MDF awards may not be used to fund institutional capital cost recovery, overhead, or other indirect costs. A progress report satisfactory to the MDF is required four weeks after the end of the award.

Applications

Eligibility Requirements

Applications are limited to those from academic institutions and/or non-profit research institutes. For-profit organizations are not eligible for this RFA. Applications from non-U.S. academic institutions or non-profit organizations are permitted, as long as they are accredited academic medical centers or research institutes.

1. *Principal Investigator requirements*. The submitting principal investigator must:

    - Be employed or enrolled at an appropriate educational, medical, or other non-profit research institution and be qualified to participate in, conduct, and/or supervise a program of original research.
    - Have both administrative and financial responsibility for the grant.
    - Have access to organizational resources necessary to conduct the proposed research project.

2. *Study Requirements.* Proposals may be submitted for published manuscripts or presentations on basic, clinical, or applied research directly related to myotonic dystrophy in: Proposals may be submitted for basic, clinical, or applied research directly related to myotonic dystrophy in:

- Pathogenesis
- Molecular basis underlying phenotype differences (Type 1, 2, congenital)
- Development of diagnostics and biomarkers
- Progression/natural history
- Identification and validation of drug treatment endpoints
- Standards of care and care integration, including nursing, social work, and psychology
- Epidemiology, economics, and support services
- Therapeutic development, particularly, but not limited to, early-stage projects where success can leverage larger investments

Submission Process and Requirements

Proposals must be submitted in 12-point font. Proposals must be submitted via the Proposal Central application system. Proposals can be submitted on a rolling basis. The proposal must include the following sections:

Applicant

- Professional Profile
- ORCID iD
- NIH-style applicant bio sketches (not to exceed 4 pages each)

Applicant Institution Information

- Applicant Institution Profile
- IRS EIN or TIN Number
- Signing Official Email
- Financial Official Email

Abstract

- Abstract of Research Plan. For a publication request, the applicant must submit the abstract as submitted to the publisher. For a travel request, the applicant must submit the abstract as submitted to the conference committee. This abstract will not be made public (one-half page).
- Lay Summary. A general, non-scientific description of the proposed work. If funded, the lay summary is to be used and published in appropriate places by the Myotonic Dystrophy Foundation (one-half page).

Budget

- Detailed budget (included costs are flexible for travel)
- Budget description and justification, including explanations of how uncovered costs will be met (1 paragraph)

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Attachments

- Applicant Statement. Including the applicant's name, contact information, name of conference or journal, and a very brief description of how this project will increase access to myotonic dystrophy research (1 paragraph).
- Proof of Acceptance. Evidence of acceptance to the proposed conference.
- Key Personnel Bio-Sketches. NIH-style bio sketches of all participating team members (not to exceed 4 pages each).
- References.

Review and Selection

The MDF Scientific Advisory Committee and reviewers will score and prioritize candidates based on the following criteria:

- The impact that access to the proposed research could have on the quality of life of people living with DM. Reviewers will rank proposals based on the case for impact made by the applicant in the "Lay Summary" component of the application (approximately 60% of the total score).
- The strength of the researcher's commitment to DM research and the likelihood that they will pursue independent research that continues to advance knowledge relevant to improving the quality of life of people living with DM. This will be assessed based on the information provided by the applicant in the "Applicant" component of the application (approximately 20% of the total score).
- The feasibility and scientific quality of the proposed research. This will be assessed by a subject matter expert selected by the Foundation based on the research description provided by the applicant. Applicants may suggest expert reviewers in their field for the Foundation to consider engaging for this evaluation (approximately 20% of the total score).

Proposals deemed to be infeasible or of poor scientific quality will be a low priority for funding regardless of the proposal's scores on the other dimensions.

Applicants are welcome to consult with the MDF Chief Executive Officer, Dr. Tanya Stevenson (tanya.stevenson@myotonic.org) for refinement of their proposals before submission. Technical issues should be directed to the MDF Research Grants Manager, Dr. Nadine Ann Skinner at nadine.skinner@myotonic.org.

Awards are made at the sole discretion of the MDF Board of Directors and are contingent upon the availability of funds. Availability of funds does not signify a commitment to award any grants.

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Reporting and Publications

Progress Reports

Each recipient must submit a **final brief report** (one-half page) submitted to the MDF no later than one month after the publication or presentation.

Expense Reports

Each recipient must submit a **final expense report** (including the original proposed budget and final expenses on the grant) submitted to the MDF no later than one month after the publication or presentation and should be submitted along with a check for any unexpended funds on the grant.

Publications and Conferences

- All papers, exhibits, and press releases directly resulting from MDF funding shall carry a credit line to the MDF.
- If the grant recipient is aware that a press release is being prepared about the work or the grant recipient has been contacted by a journalist, please let the MDF know this is taking place. Grant recipients should encourage their university press offices or outside journalists to contact the MDF so that publicity can be coordinated. Press releases regarding the study funded by the MDF shall be emailed to grants@myotonic.org.
- MDF encourages an open-access policy that enables the unrestricted access and reuse of all peer-reviewed published research funded, in whole or in part, by the MDF. MDF shall pay reasonable fees required by a publisher or repository to effect immediate, open access to the accepted article. This includes article processing charges and other publisher fees. While not needed to fulfill the open-access policy requirements, grantees are encouraged to deposit funded research consisting of their submitted manuscript, and its subsequent versions, on a preprint server.
- The title of each study funded by MDF, together with the lay language abstract of the research, the names of the grant recipient, and the institution, will be published on the MDF website, in MDF newsletters, in annual reports and wherever else MDF deems appropriate. The Grant recipient will always be clearly acknowledged. The lay summary description should not contain information the grant recipient does not wish to divulge to the general public.

[i] 5. Johnson NE, Butterfield RJ, Mayne K, et al. Population Based Prevalence of Myotonic Dystrophy Type 1 Using Genetic Analysis of State-wide Blood Screening Program. *Neurology*. Published online January 20, 2021:10.1212/WNL.0000000000011425. doi:10.1212/WNL.0000000000011425