



Moebius Syndrome Foundation Grant Policies

Funding Priorities of the Moebius Syndrome Foundation:

1. To advance the diagnosis, treatment, and/or quality of life of people with Moebius syndrome and its associated conditions.
2. To promote sustainable and comprehensive programs of research focused on Moebius syndrome by providing “seed funds” for larger research programs and grant submissions to larger funding organizations.

Grants offered

Each year, the Board of Directors decides on a funding limit per grant, which will be approximately \$75,000 per year, with a maximum of two years of funding. Three types of funding will be offered.

1. Trainee Award

The Moebius Syndrome Foundation Trainee Award was created to incubate post-doctoral scholars and trainees who show potential as leaders in Moebius syndrome research. Clinicians and researchers who have received their doctoral or terminal degree and who will be in a post-doctoral or research training position are eligible. Funding limit is \$50,000 each year for one to two years. Funds may be used for salary and fringe benefits, but indirect costs are not allowed.

2. Investigator-Initiated Proposals

Proposals for scientific research are accepted for studies that address the funding priorities of the Foundation. Applications from early career scholars (who received their doctoral or terminal degree less than 10 years prior) are encouraged.

3. Requests for Proposals (RFPs)

At its discretion, the board of directors will announce RFPs to address specific emergent research priorities.

Submission Process

Applicants must complete a proposal form, biosketches for each study team member (using the current NIH form), and a budget.

Examples of allowable budget items:

- Travel
- Participant payments
- Small equipment and supplies
- Salary and fringe benefits for research team members other than the Principal investigator

Examples of non-allowable budget items:

- Principal Investigator salary
- Facilities (buildings)
- Overhead or indirect costs

These documents should be emailed to vicki@moebiusyndrome.org.

Peer Review and Evaluation

Grants are accepted on a rolling basis and will be reviewed four times per year during quarterly Board of Directors meetings. Proposals are evaluated on scientific merit, relevance to the mission of the Foundation, and feasibility. Grants will be reviewed by at least two peer reviewers, at least one of whom will be a Moebius Syndrome Foundation Scientific Advisory Board Member. Expert ad-hoc reviewers may be enlisted at the Board's discretion. The Board will make a funding decision based on these reviews, funding goals, and its own discretion based on a majority vote.

In order to avoid potential conflicts of interest within the evaluation system, members of the Moebius Syndrome Foundation Scientific Advisory Board or Board of Directors associated with an application are prohibited from review and discussion of that particular application. In addition, members of the Board of Directors associated with any application are excluded from the entire review and funding approval process for the rest of the fiscal year.

Funding Acceptance and Compliance

Once the Foundation's Board of Directors passes a research funding resolution, applicants (hereafter referred to as investigators) are notified of their proposal's acceptance or denial. The investigator must then sign a formal Funding Acceptance Agreement stipulating the terms and conditions of the grant award, including, but not limited to, the following:

- Funds received from the Foundation must be used specifically as defined in the original Grant Application; should the nature or scope of the project alter from its original intended use, the investigator must submit a written request for approval to the Foundation justifying the proposed changes.
- A written progress report must be submitted to the Foundation six months after the project's start (based on the date funding is received), and then again six months after the conclusion of funding. The progress report must also include a version written in layman's terms for dissemination through the Moebius Syndrome Newsletter and website.
- Any published material or presentations referring to the information resulting from Foundation-funded research must acknowledge the support of the Foundation.
- Investigators are required to present the project's conclusions and findings at the Biennial Moebius Syndrome Foundation Research Symposium.
- The timing of fund disbursement will be decided at the Board's discretion in consideration of the project goals. A Funding Acceptance Agreement will include this information and must be signed by the project investigator and returned to the Foundation. The funding will be disbursed to the Principal Investigator's institution.