

## Guidelines for the 2022 MWS Research Grant Cycle

MWSF seeks to fund research that will in some way enhance the lives of individuals with MWS and increase their lifespan. MWSF also supports efforts to educate families and healthcare providers about MWS. As funds become available, MWSF will solicit proposals for research grants from interested scientific and medical researchers. The Board of Directors, Medical Advisory Board and Community Advisory Board are primarily concerned with achieving a better understanding of MWS and treatments for the associated conditions with the goal of improving the quality of life for people with MWS and their families.

MWS is caused by heterozygous variants in the ZEB2 gene. Its symptoms and severity can be quite variable and ongoing research is needed to better inform families and health providers. For this reason, MWSF awards grants to applicants who seek to conduct basic, pre-clinical, natural history, translational, and clinical research projects that investigate all aspects of MWS. The MWSF is particularly interested in funding research projects that may contribute to the scientific advancement of this rare disease by:

- Identifying novel interventions and therapies that may significantly improve the quality of life of individuals with MWS
- Investigating an aspect of MWS that is less well researched or is a promising new area for research and could make a significant contribution to the understanding of MWS or its treatment
- Producing preliminary data that would facilitate broader or more substantial long-term funding from the NIH, research centers, foundations, or pharmaceutical companies in the future

MWSF strongly encourages interdisciplinary collaboration and the sharing of resources for MWS research. We are committed to sharing biospecimens, cell lines, animal models and de-identified data. Any content resulting from research funded by MWSF must be made available to the public and when possible used to promote further discovery. MWSF endorses the principles of the Association of American Medical Colleges (AAMC) report, “The Maintenance of High Ethical Standards in the Conduct of Research.” All research funded by MWSF must follow U.S. National Institutes of Health (NIH) Guidelines (or equivalent national guidelines in other countries) for the humane care and use of animals in research and for the use of human subjects in research. All funded research must comply with all local government regulations regarding the participation of human subjects and the use of animals in research.

The Maci Whisner Research Grant was established in memory of Maci Whisner, a child with Mowat-Wilson Syndrome who passed away in 2021. Although Maci suffered from many conditions and her medical needs were very complex – she was such a sweet girl, the purest soul. Her story has inspired hundreds of other MWS families to embrace life and live it to the fullest, despite any challenges they may face. You can learn more at [Maci's Mended Heart](#) on Facebook.



Key Dates
January 15, 2022 grant webpage goes live with all accompanying documents
January 27 2021 Inaugural MWS Researcher Coalition Meeting
Applications will be accepted from February 1, - March 31, 2022
Applications will be reviewed from April 1 – May 30, 2022
Announcement of Successful Applications: June 15, 2022
Financial awards will be made by June 30, 2022

All applicants must follow the instructions below

To be considered for funding, an LOI must be submitted via email to [MarciaSmith@Mowat-Wilson.org](mailto:MarciaSmith@Mowat-Wilson.org). A confirmation email will be sent for every application received. All applications must include 3 separate PDF documents:

**1. The Cover Page (limited to 2 pages) must include the following information:**

Corresponding Applicant

- First name
- Last name
- Credentials
- Affiliations
- Email address
- Phone number
- Mailing address
- 3 most recent or ongoing research projects
- up to 3 prior publications

Co-applicants

- First name
- Last name
- Credentials
- Affiliations
- 3 most recent or ongoing research projects
- up to 3 prior publications

Organizations collaborating in the research project – This list should include all universities, private and public labs but not funders.

- Name of organization
- Address
- Role in research

IRB information

- Institution overseeing the IRB process
- A statement indicating if the study has IRB approval (Please attach approval letter) or if the study does not yet have IRB approval and an explanation of the IRB process.

- 2. The Main Body of the Application (limited to 3 pages) must present the Abstract. Please note that this PDF must not include the researchers' names**
  - The Abstract must include the following: Short introduction, method, population and sample, research questions or hypotheses, purpose of research, and a timeline for the research
- 3. The Budget Appendix (limited to 3 pages) must include the following information**
  - List of other funding for proposed research
    - This list should include both public and private funding
  - Amount needed for research
    - Please provide a condensed budget (for the entire research project) with a short explanation for each item
  - Amount of request
    - Please provide the amount requested from the Mowat-Wilson Syndrome Foundation

Letters of support are welcome but not required.

### **Important Information**

No single application will be awarded more than \$50,000

Most grant awards will likely be from \$5000 – \$35,000

We do not expect to be able to provide feedback on unsuccessful applications

### **Eligibility**

To be eligible to apply for research grant funding from MWSF, individuals or teams of applicants must demonstrate the following:

- The applicant(s) must have a Ph.D., M.D., or equivalent degree;
- The applicant(s) must currently hold a full-time position at any level (post-doctoral, research scientist, assistant/associate/full professor, etc.) at a qualified non-profit academic institution.

Must be submitted in English

### **The following will not be considered for funding**

- Proposals that have little or no relevance to MWS;
- General fundraising campaign expenses such as dinners and mass mailings;
- Religious, political, or other research that does not fall within the research priorities of MWSF
- Unrelated miscellaneous expenses including but not limited to journal subscriptions, conference attendance, and advertisements.

### **How grant applications are reviewed**

- Only applications that comply with the submission requirements will be reviewed for funding; however, the Board of Directors of the Mowat-Wilson Syndrome Foundation can allow incomplete applications to be considered by a unanimous vote.
- The applications will be reviewed for completeness and any applications that do not provide all the required information will be eliminated.
- The applications will be scored and ranked based on the criteria below.

See the Scoring Criteria for MWS Research Grants, which is attached to this guidance.

Letters of support can be provided but are not required – and these can be considered in the application review process.

The Mowat-Wilson Syndrome Foundation promotes patient-led research, where patients are involved and lead research. People who have a rare syndrome know what needs to be investigated and what questions remain unanswered; effective solutions can be designed based on their experiences. Patients with MWS have a voice through their families and caregivers. The MWSF Community Advisory Board has identified several issues that affect people with MWS that are under-researched:

- Defecation issues
- Medications – effects and implications due to the large number of medications
- CBD options and seizures
- Behavior and puberty – relationship and trends
- Aggression
- How aggression is affected by seizure medicines
- Feeding and Swallowing issues
- Digestive System issues
- Communication
- Immunology
- Augmented communication
- Sleep patterns
- Seizure medications
- How ADHD, ADD, and anxiety are affected by seizure medicines
- Aphasia
- Medicines used to treat different types of seizures
- Relationship between puberty and seizure activity
- Unique situations where an individual with MWS presents small but has advanced bone age and early puberty

#### **Have questions?**

If you have questions, please reach out to us at 844-697-7273 or email Marcia Smith, the Executive Director, at [MarciaSmith@Mowat-Wilson.org](mailto:MarciaSmith@Mowat-Wilson.org)

**Scoring Criteria for MWS Research Grants**  
2022 Grant Cycle

The following are items to be scored for each application that passes the first round of review ensuring that all required information is provided, and the application meets all stated criteria:

- **The introduction provides a short, clear and concise overview of the research:** **1** the overview is comprehensive **2** the overview is good **3** the overview is mediocre **4** the overview is lacking **5** the overview is severely lacking
- **The method is clearly explained and is appropriate for the research:** **1** the method is very clear and appropriate **2** the method is somewhat clear and appropriate **3** the method is presented but more information could have been presented **4** the method is not very clear and/or appropriate **5** the method is not presented
- **The population and sample are clearly explained and are appropriate for the research:** **1** the population and sample are very clear and appropriate **2** the population and sample are somewhat clear and appropriate **3** the population and sample are presented but more information could have been presented **4** the population and sample are not very clear and/or appropriate **5** the population and sample are not presented
- **An appropriate and valid research question(s) or hypothesis provides the basis for the study and is clearly provided in the abstract:** **1** the research question(s) or hypothesis is very appropriate and valid **2** the research question(s) or hypothesis is somewhat appropriate and valid **3** the research question(s) or hypothesis is presented but more information could have been presented **4** the research question(s) or hypothesis is not very appropriate and/or valid **5** the research question(s) or hypothesis is not presented
- **The purpose of research is clearly explained:** **1** the purpose is very clear and appropriate **2** the purpose is somewhat clear and appropriate **3** the purpose is presented but more information could have been presented **4** the purpose is not very clear and/or appropriate **5** the purpose is not presented
- **The LOI presents a clear and appropriate timeline for the research project:** **1** the timeline is very clear and appropriate **2** the timeline is somewhat clear and appropriate **3** the timeline is presented but more information could have been presented **4** the timeline is not very clear and/or appropriate **5** the timeline is not presented
- **The LOI presents a clear and appropriate budget for the research project:** **1** the budget is very clear and appropriate **2** the budget is somewhat clear and appropriate **3** the budget is presented but more information could have been presented **4** the budget is not very clear and/or appropriate **5** the budget is not presented
- **The request aligns very well with the research priorities of MWSF:** **1** Strongly agree; **2** agree; **3** Neither agree nor disagree; **4** Disagree; **5** Strongly disagree

**The request clearly involves interdisciplinary collaboration and the sharing of resources:** **1** Strongly agree; **2** agree; **3** Neither agree nor disagree; **4** Disagree; **5** Strongly disagree



Subject: Intellectual Property from Funded Research Policy

Effective Date: 1/23/2022

Revision Date: N/A

Approved By: Board of Directors

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## **POLICY**

All awardees and their respective institutions must comply with this policy. Acceptance of a grant award from MWSF constitutes acceptance of the terms and conditions of this Policy.

## **PROCEDURE:**

All awardees and their respective institutions must notify MWSF no later than one week after filing a patent application or upon entering into negotiations with a potential licensee of all potentially patentable or other intellectual properties that result from support in whole or in part from grant awards from MWSF. In addition, all awardees and their respective institutions must notify MWSF in writing at the time of filing an application for a patent and after the receipt of any patent.

MWSF agrees to keep all information provided by the Grantee and/or Grantee institution confidential and not to release any information relating to any inventions, intellectual property or applications for protection to any third party. All expenses or costs associated with the protection of other intellectual property are the sole responsibility of the awardees and their respective institutions.



Subject: Open Science Policy  
Effective Date: 1/23/2022  
Revision Date: N/A  
Approved By: Board of Directors

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**POLICY:**

MWSF supports research on Mowat-Wilson Syndrome. MWSF is committed to being good stewards of funds received from donors, grantors, sponsors, partners and the MWS community.

The purpose of this policy is to ensure transparency of and broad access to the research we fund.

The Open Science Policy applies to all research funded in 2022 and beyond.

**PROCEDURE:**

**Open Access to Articles**

Twelve months following the date of publication, all peer-reviewed journal articles resulting from any research funded by MWSF must be made available on PubMed Central, in an open access journal or via the paid open access option for a paywalled journal.

**Monitoring and Compliance**

Grantees and their institutions are responsible for meeting all award conditions, including this policy. All progress reports for grants must include proof of compliance for all published peer-reviewed research articles. MWSF staff will monitor compliance. The MWSF Board of Directors reserves the right to deny or delay the distribution of funds or any other resource to applicants or grantees who do not comply with this policy

**Fees Related to Open Access Publication**

Budgets included in grant applications may include fees for open access publication.



Subject: Research Using Human or Animal Subjects Policy

Effective Date: 1/23/2022

Revision Date: N/A

Approved By: Board of Directors

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**POLICY:**

**Human Subjects**

Research funded by MWSF involving human subjects must be approved by an Institutional Review Board or other appropriate body.

All research funded by MWSF involving human subjects must conform with the ethical guidelines prescribed by the National Institutes of Health (NIH) or equivalent national guidelines in other countries, including the provision of a suitable explanation to all human subjects or their guardians in terms of the experimental design and all significant hazards and an appropriate informed consent procedure.

**Animal Subjects**

Research funded by MWSF involving animal subjects must be approved by an Institutional Review Board or other appropriate body.

Research funded by MWSF involving animals must conform with the current “Guide for the Care and Use of Laboratory Animals”, NIH publication, DHHS/USPHS; and all federal laws and regulations or equivalent national guidelines in other countries. In addition, all research funded by MWSF involving animals must be approved by the institutional Animal Care and Use Committee or other appropriate body.

**PROCEDURE:**

Proof of IRB oversight and/or approval must be provided by grantees.