



THE **MARFAN**
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EVEREST GRANT AWARD: LETTER OF INTENT GUIDELINES

The Marfan Foundation and its divisions are requesting Letters of Intent to the Everest Grant Award Program to support four-year grants in the amount of \$200,000 per year for a total of \$800,000 to researchers studying Marfan syndrome, Vascular Ehlers-Danlos syndrome, Ehlers-Danlos syndrome, Loeys-Dietz syndrome, and other aortic and vascular related conditions. Grant awards and yearly renewals will be based on full proposal evaluation and annual milestone reviews by The Marfan Foundation Scientific Advisory Board with the approval of the Board of Directors. The Marfan Foundation plans to award one Everest Grant in 2023.

SCHEDULE

Letter of Intent:	January 31, 2023
Request for Full Proposals:	February 24, 2023
Full Application Deadline:	March 27, 2023
Announcement of Awards:	May 19, 2023
Funding Available:	July 1, 2023

SPECIAL AREAS OF INTEREST

The goal of the Everest Grant Award is to inspire outstanding, collaborative and transformational research designed to “reach the summit” on a critical path to a breakthrough in basic or translational science that has direct relevance to human health. Proposals should be transformational, highly relevant and easily transitioned to human research and result in new knowledge that will make a significant impact on the lives of patients and families affected by Marfan syndrome and/or related conditions.

CONTACT

Please direct all questions and correspondence to:

Lauren May, MPH
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The Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050
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A. INTRODUCTION

The Marfan Foundation and its divisions are requesting Letters of Intent to the Everest Award Grant Program to support four-year grants in the amount of \$200,000 per year for a total of \$800,000 to researchers studying Marfan syndrome, Vascular Ehlers-Danlos syndrome, Loeys-Dietz Syndrome, and other aortic and vascular related conditions. Grant awards and yearly renewals will be based on proposal evaluation and annual milestone reviews by The Marfan Foundation Scientific Advisory Board with the approval of the Board of Directors. The Marfan Foundation plans to award one Everest Grant this cycle.

B. TYPES OF PROPOSALS SOLICITED

The goal of the Everest Grant Award is to inspire outstanding, collaborative and transformational research designed to “reach the summit” on a critical path to a breakthrough in basic, translational, or clinical science that has direct relevance to human health. Proposals should be transformational, highly relevant and easily transitioned to human research, if not clinical stage already, and result in new knowledge that will make a significant impact on the lives of patients and families affected by Marfan syndrome and/or related disorders. All proposals should include a description of an extended strategy that would lead to improved patient care. Proposals must include one or more institutionally funded graduate students or fellows. Funding can be used for teams of researchers, consisting of independent research groups, to work together on the big research questions that remain unsolved. Collaborations across organizations, national borders, scientific disciplines and with partners outside of academia are all encouraged.

Examples of these research questions might include but are not limited to:

- DNA/RNA or cell-based technologies directed at developing therapies to modify the effects of the mutations responsible for life-threatening vascular fragility in aortopathies, vascular conditions, pulmonary, orthopedic and ocular issues.
- Novel diagnostic modalities to assess aortopathies, vascular conditions, pulmonary, orthopedic and ocular issues.
- Biomarkers that identify and predict processes that lead to dissection and/or aneurysm; risk stratification strategies and predictive model building that incorporates circulating or genomic biomarkers and/or imaging to eventual enable precision medicine strategies; validation of short-term predictors of aortic health improvement.
- Understanding phenotypic switching or modifiers; promoting repair responses to abnormal matrix; identification of factors that lead to severe disease versus mild disease in all disciplines.
- Understanding modifiable mechanisms underlying elongated bone growth, muscle function and pain.





- Strategies to improve quality of life.

C. QUALIFICATIONS OF THE INVESTIGATOR(S)

The principal investigator(s) must hold an MD, DO, PhD, ScD, DDS, DVM or equivalent degree. Investigators can come from academia, private foundations or private/public companies. The investigator(s) must have proven ability to pursue independent research as evidenced by an established track record of original, independent research publications in high impact peer-reviewed journals. Work can be performed in the U.S. or internationally and non-U.S. investigators are acceptable.

D. LETTER OF INTENT (LOI)

A letter of intent is required to ensure responsiveness to the transformational, breakthrough science and collaborative nature of this program. The Marfan Foundation will contact the applicants with permission to submit the full application. Only invited applicants can submit a full application.

Required elements for the LOI:

- Describe the proposed research objectives for an innovative, transformational, and collaborative approach to answer a compelling research question which can improve human health in the area of Marfan syndrome, Vascular Ehlers-Danlos syndrome, Ehlers-Danlos syndrome, Loeys-Dietz syndrome or other aortic and vascular related conditions. Be as specific as possible about purpose and scientific importance of the research program and the experiments planned to meet your objectives (five pages maximum).
- If investigators are from multiple disciplines and/or areas of expertise, a written summary on the collaborative relationship of the investigators and how scientific objectives will benefit from this interaction is required. An NIH format biosketch from each of the proposed investigators/collaborators outlining their qualifications should be provided in an appendix.
- The investigators must demonstrate that access to appropriate institutional resources to conduct the study will be available, including that a suitable patient population will be available for study during the funding period if clinical studies are proposed.
- Applicants can include figures in the appendix (optional).
- Bibliography of references cited in the program description (not included in the five-page research plan).
- A 300-word scientific abstract with three key words on the bottom line as well as a 500-word layperson abstract (not included in the five-page research plan).

E. LOI REVIEW PROCESS

The Scientific Advisory Board of The Marfan Foundation (a committee of experts in basic and clinical research) will review each LOI. Please note that it is the policy of The Marfan Foundation not to provide comments or feedback about unsuccessful LOI applications.





F. TERMS OF THE FULL AWARD

1. Budget and Allowable Costs:

Budgets for up to, but not exceeding \$200,000 per year of direct costs for a total of four years are acceptable. Payments will be made to a single principal investigator's (PI's) institution/foundation/company which will be responsible for administering the funds. Salaries for PIs, support personnel or current research postdoctoral fellows engaged in the project may be requested. Any unexpended funds shall be returned to The Marfan Foundation upon completion of the granting period unless extension is approved by the Foundation. Additional indirect Costs are limited to a maximum of 10% of all direct costs. The Marfan Foundation does not support direct costs for construction or renovation; purchase of major capital equipment; office equipment or furniture; travel (except as required to perform the project or present at scientific meetings/congresses); tuition fees; journal subscriptions, dues or memberships; equipment service contracts; or salaries for secretaries. Funds will be distributed semi-annually.

2. Indemnification of The Marfan Foundation:

Principal Investigator, co-investigators and his/her Affiliated Institution (AI) will be obligated to indemnify The Marfan Foundation from any and all liability that may arise from the PI's/AI's conduct and the Marfan Foundation's affiliation therewith due to the grant relationship.

3. Intellectual Property Policy

Pursuant to the Foundation's established policy, inclusion of the Foundation's IP provisions is a condition for the Foundation making a grant and entering into all research agreements. See Exhibit I.

4. Additional Support

The institution/foundation/company must commit to provide funding, in addition to the budgeted direct and indirect costs, for a full-time trainee (graduate student, postdoctoral fellow) to work on the study. The PI(s) assumes responsibility for conducting research projects and supervising the work of co-investigators and trainees.

5. Progress and Expense Reporting:

A yearly virtual or in-person progress and milestone review will be conducted 10 months into project year to obtain approval of an addition year of funds. The Principal Investigator must also provide a financial report at this time. Failure to provide such reports will preclude the Principal Investigator from obtaining further funding.





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6. Use of Animals and Humans in Biomedical Research

All PIs must certify that the research facilities, its researchers and employees adhere to the Animal Welfare Act, National Research Council Guide for the Care and Use of Laboratory Animals, and any appropriate U.S. Department of Agriculture or National Institutes of Health Regulations and Standards or similar country standards. An Institutional Review Board (IRB), Institutional Animal Care and Use Committee (IACUC) or its equivalent must approve research involving human subjects or animals, and a copy of the approval or pending approval must be sent with this application. Copies of annual renewal of IRB/IACUC protocols must be forwarded to The Marfan Foundation. IRB approval must be documented prior to dispensation of The Marfan Foundation funds. The application must include letters of support and appropriate local IRB and/or IACUC approvals if the proposed project uses facilities not routinely available to or directly under the supervision of the sponsoring program.

7. Publications

All discoveries resulting from work supported in part by The Marfan Foundation should be made available to the public and scientific community through approved scientific channels such as national meetings and peer reviewed publications. Publications will acknowledge the support of The Marfan Foundation. A PDF of each publication must be forwarded to The Marfan Foundation.

8. Publicity

The Marfan Foundation shall be permitted to use the Principal Investigator's name, image and likeness, as well as the name of the Affiliated Institution, in connection with all statements, printed materials or electronic media related to the Grant Award or related to The Marfan Foundation Research Program. At the Foundation's request, the Principal Investigator will provide The Marfan Foundation with appropriate photographs and biographical information to be used in connection with this grant.

G. CONTACT INFORMATION FOR CORRESPONDENCE

Lauren May
Research Director
The Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050
Email: lmay@marfan.org





H. DETAILS OF LETTER OF INTENT

The full Letter of Intent (appendices, biographies, etc.) must be submitted electronically, as a single PDF file, via The Marfan Foundation website, marfan.org. Please name your application using the following format:

EverestLOI_LastName_FirstName.pdf

Example: EverestLOI_Smith_Jane.pdf

The application forms may be completed using the free Adobe Reader program. If you do not already have it, you can download it at <http://www.adobe.com/products/reader.html>. The Title Page form requires dated signatures; you may either insert a digital signature and date or print the form and then scan it to include in your application PDF.

Pages should be numbered at the bottom. Appendices should not be used to subvert the page limitation on the grant, however, figures, tables, diagrams and photographs can be placed in the appendices. Please present the proposal in the order that follows:

1. Title Page: 1 page

Application form provided

2. Scientific Abstract and Layperson Summary: 1 page each

On a single page, describe precisely and clearly the nature, objective, methods of procedure and significance of the proposed research project, and how it relates to the goal of providing a better understanding of Marfan syndrome, VEDS, EDS, LDS, and other related conditions and/or improving the treatment or diagnosis of Marfan syndrome, VEDS, EDS, LDS, and other related conditions (limit 300 words). Include an abstract in terms suitable for presentation to laypersons (limit 500 words).

3. Letter of Intent and Research Plan as described above: 5 pages maximum, 12-point font

4. Appendices:

- a. NIH Biographical Sketches
- b. Bibliography
- c. Figures





I. EXHIBIT I to Research Grant Recipient Agreement

Patent, Intellectual Property and Technology Licensing Policy of The Marfan Foundation (this “Policy”)

Effective Date: March 15, 2021

Although one of the primary purposes of The Marfan Foundation (the “**Foundation**”) in funding scientifically meritorious research is to advance its mission, the Foundation recognizes that inventions having public health, scientific, business or commercial application or value may be made in the course of research supported by the Foundation. It is the desire of the Foundation that such inventions be administered in a manner that they are brought into public use at the earliest possible time. The Foundation recognizes that this may be best accomplished through patenting, copyrighting, and/or licensing of such inventions.

Certain capitalized terms used in this Policy that are not otherwise defined herein shall have the meanings set forth below:

“**Invention**” is any discovery, composition of matter, method, process, product, program, software or know-how, whether or not patented or patentable or copyrighted or copyrightable, that is conceived or reduced to practice in the performance of a Foundation award and has an application of value such that its use, licensing, lease or sale can generate revenue.

“**Award**” is the Foundation funding mechanism and accompanying financial support given to a specific institution to support the work and/or training of a specific Investigator and any Co-Investigators (as defined below).

“**Institution**” is the entity (university, medical center, hospital, research institute or any other organization) in which the work and/or training supported by the Foundation funding will be conducted.

“**Principal Investigator**” (and/or “**Co-Investigator(s)**” if applicable) is the individual(s) receiving the award and responsible for the conduct of the research supported by a Foundation Award.

“**Collaborating Investigator**” is an individual who contributes in a substantive way to the scientific development or execution of the project.

“**Inventor(s)**” is the Investigator, Co-Investigator(s) and/or Collaborating Investigator(s) (if applicable) who made an Invention.

Inventions are subject to the Foundation’s Patent, Intellectual Property, and Technology Licensing Policy as set forth below:

1. All Inventions shall be reported in writing to the Foundation within sixty (60) days of the date when the Invention is disclosed to the Institution where the work was done, and prior to any





public disclosure. The report to the Foundation should be the initial copy of the Institution's Invention disclosure form and any subsequent versions that have substantive changes or additional information.

2. If the Institution receiving or disbursing the Foundation funds that support the Invention has an established and applicable patent, intellectual property or technology transfer policy and procedure for administering Inventions, the Foundation will defer to that policy with the following exceptions and requirements which shall control in the event of a conflict:
 - a. Title to any Invention shall reside in the Institution; and title may be permitted to reside in the Inventor(s) or any other person or institution with the prior written approval of the Foundation, upon advice of the Foundation's legal counsel and science advisors, except that no Foundation approval is required for title to reside in the United States Government.
 - b. Institution and Investigator(s), if appropriate, shall promptly determine whether they desire to seek patent or other statutory protection for an Invention and shall notify the Foundation in writing within sixty (60) days of the decision to seek (or not seek) such protection. The Foundation also will be notified in writing within sixty (60) days of a patent application being filed, and any patent subsequently being issued, and/or of a license, lease, sale or revenue generating agreement concerning the Invention prior to their execution. No patent or patent application shall be abandoned without prior notification by the Institution or Inventor(s) to the Foundation and offering to assign to Foundation all right, title and interest to the Invention to the extent permitted by law.
 - c. Notwithstanding any other provision of this Policy, the Foundation shall participate in the income derived from the Invention. The Foundation's participation shall be determined, within one year or a reasonable period of time after reporting of the Invention to the Foundation, by mutual agreement between the Institution or other titleholder and the Foundation, with the Foundation's rights hereunder not being affected if such determination is not made within said time period. The amount of the Foundation's participation shall be guided by the principle that the Foundation's sharing of income shall be in proportion to the Foundation's portion of support for the work or research giving rise to the Invention. The Foundation waives receipt of income until the cumulative net income (i.e., net of any direct out-of-pocket patenting costs) from an Invention conceived or reduced to practice from the performance of any Foundation Award exceeds \$500,000.
 - d. The Institution or other titleholder, when it licenses an Invention to another party for commercialization, shall include provisions in the license obligating the licensee to commercialize the Invention in a diligent manner and meet appropriate diligence requirements and concrete development milestones to avoid the license terminating, and the Institution or other titleholder shall monitor performance of the licensee relative to these requirements and milestones. The Institution or other titleholder, or its designee or





licensee shall take commercially reasonable steps to bring the invention to practical or commercial application in a reasonable time period (based on type of Invention) after issuance of a patent or other clear determination of commercial value. If the Institution or other titleholder, or its designee or licensee, has not taken commercially reasonable steps and cannot show reasonable cause why it should retain title to and all rights in the administration of the Invention for a further period of time, then, if no other parties have superior legal rights, the Institution or other titleholder and the Foundation shall determine a course of action including but not limited to

- i. the Institution or other titleholder's renegotiation of milestones with the current licensee or termination of the current license and licensing of the Invention to another licensee;
 - ii. a non-exclusive right to the Institution or other titleholder to practice the Invention for any non-commercial purpose;
 - iii. a global, exclusive or non-exclusive, non-revertible, royalty-free license to the Foundation;
 - iv. the provision to the Foundation of any additional materials necessary for regulatory filing and the technology's enablement that might be in the possession or control of the Institution or other titleholder, except for intellectual property that was not generated as a result of the Foundation's assistance; or
 - v. any other action appropriate in the circumstances.
4. If the Institution has no established and applicable patent, intellectual property or technology transfer policy or procedure for administering Inventions, title to any invention shall reside in the Institution or Inventor(s) as agreed by them and the Institution and Inventor(s) shall comply with all requirements in Sections 2.b and 2.d and the Foundation shall have all rights set out in Sections 2.c and 2.d.
5. The right of the Foundation to participate in revenue derived from an Invention pursuant to section 2.c is not waived in these situations:
- a. **Multiple funders.** If any Invention is conceived or reduced to practice from the performance of research funded by the Foundation and by independent funding from another health agency or funding organization, not an agency or department of the United States Government, the Inventors and the Institution will work with the Foundation to negotiate with the other agency/organization in good faith for a mutually satisfactory determination of rights to administer the Invention and determination of the fair share of the royalty or other income to be paid to the Institution, Inventor(s), the Foundation and other parties who independently funded such research.
 - b. **Federal funders.** Notwithstanding any other provisions of this Policy, if an Invention is conceived or reduced to practice from the performance of research funded by the joint





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support of the Foundation and an agency or department of the United States Government, the Foundation may defer to the patent, intellectual property or technology transfer policy of the United States Government.

