THE MARFAN FOUNDATION

CLINICAL RESEARCH GRANT PROGRAM

GUIDELINES

The Marfan Foundation is requesting proposals to the Clinical Research Program which supports one or two year grants for studies focusing outside the cardiovascular arena. Proposals can be retrospective or prospective and may utilize data obtained through registries/databases, observational studies, and surveys. Proposals should conduct scientifically rigorous research that produces valid new knowledge with clinical and quality of life endpoints in the absence of randomized clinical trials. Proposals may focus on patient-oriented research, including epidemiologic, behavioral, quality of life studies and outcomes research.

Grants will be reviewed by a special review committee with clinical and quality of life expertise including Jonathan Weinsaft, MD, Weill Cornell Medicine, Chair, and Craig Basson, MD, PhD, Novartis Institute for Biomedical Research.

SCHEDULE

Application Deadline:	April 20, 2018
Announcement of Awards:	October 1, 2018
Funding Available:	January 1, 2019

SPECIAL AREAS OF INTEREST

Special areas of interest include: ophthalmology, pulmonology, gastroenterology, allergy and immunology, autism, ADHD, ADD, physical therapy/exercise, pain and fatigue, mental and emotional health, behavioral studies and/or nutrition studies for Marfan syndrome, EDS, LDS, and other related disorders.

CONTACT

Please direct all questions and correspondence to:

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Chief Science Officer

The Marfan Foundation
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Port Washington, NY 11050

Tel: 800-8-MARFAN or 516-883-8712 ext. 117
Fax: 516-883-8040
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Application Forms which need to be separately downloaded:

1. Title Page Form
2. Table of Contents Form
3. Biographical Sketch Form

PROCEDURE FOR SUBMISSION, REVIEW AND AWARD OF CLINICAL RESEARCH GRANTS

A. INTRODUCTION

The Marfan Foundation provides funds to support clinical research related to Marfan syndrome, EDS, LDS, and other related disorders. The goal of this program is to advance research outside of the cardiovascular arena.

B. TYPES OF PROPOSALS SOLICITED

The Marfan Foundation is currently accepting proposals for clinical research studies focusing on fields of study outside of cardiovascular arena such as ophthalmology, pulmonology, gastroenterology, allergy and immunology, autism, ADHD, ADD, physical therapy/exercise, pain and fatigue, mental and emotional health, behavioral studies and/or nutrition studies for Marfan syndrome, EDS, LDS, and other related disorders. Proposals can be retrospective or prospective and may utilize data obtained through registries/databases, observational studies, and surveys. Proposals should conduct scientifically rigorous research that produces valid new knowledge with clinical and quality of life endpoints in the absence of randomized clinical trials. Proposals may focus on patient-oriented research, including epidemiologic, behavioral, quality of life studies and outcomes research.

C. BUDGET

Budgets can range from $25,000 to $50,000 per year for one or two years.

D. QUALIFICATIONS OF THE PRINCIPAL INVESTIGATOR (PI)

The principal investigator must hold an MD, DO, PhD, ScD, DDS, DVM or equivalent degree. The investigator must have proven ability to pursue independent research as evidenced by original research publications in peer-reviewed journals. Work can be performed in the U.S. or internationally and non U.S. appointments are acceptable.

E. REVIEW PROCESS

A special committee of the Scientific Advisory Board of The Marfan Foundation will review each application. The NIH peer review study section model will be followed. Each proposal will receive a priority score based on the evaluation of the committee. Priority scores will be forwarded to The Marfan Foundation where award decisions will be made based upon relative scientific merit ranking of the submitted grants, and on priorities of The Marfan Foundation. Grant awards are based on the approval of the Board of Directors. All applications will be held in the strictest confidence and all decisions by the Foundations are final.

F. TERMS OF THE AWARD

1. Duration
The funding period begins January 1, 2019. Requests for change in funding dates will be considered.

2. Changes of Status of Principal Investigator (PI)
If the named PI changes affiliations the award will follow only after approval of transfer from The Marfan Foundation. If the named PI ceases research in the field for which the award was made, the award will terminate and the remaining balance will be returned to The Marfan Foundation.

3. Site of Project
Awards are for studies at international or national universities, public or private universities, colleges, hospitals, and biomedical research institutions. The PI will make all arrangements for conduct of the proposed research projects.

4. Budget
Budgets ranging between $25,000–$50,000 per year for one or two years are acceptable. Payments will be made to the PI's institution which will be responsible for administering the funds. Salaries for PIs, support personnel or current research post doctoral 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. The Marfan Foundation does not pay for institutional overhead, construction or renovation; purchase of major capital equipment; office equipment or furniture; travel (except as required to perform the project); tuition fees; journal subscriptions, dues or memberships; equipment service contracts; salaries for secretaries. Funds will be distributed semi-annually.

5. 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.

6. Institutional Support
The PI assumes responsibility for conducting research projects and supervising the work of co-investigators. The PI must demonstrate that access to a suitable caseload or patient population will be available for study during the funding period for clinical studies.

7. 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. Institutional review board (IRB) or its equivalent must approve research involving animal and human subjects and a copy of the approval or pending approval must be sent with this application. Copies of annual renewal of IRB 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 if the proposed project uses facilities not routinely available to or directly under the supervision of the sponsoring program.

8. 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. Two reprints of each publication must be forwarded to The Marfan Foundation.

9. 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.

10. Progress and Financial Reports
The Principal Investigator must provide a progress report and a financial report no later than 45 days after the completion of each 6-month period during the term of this grant. Failure to provide such reports will preclude the Principal Investigator from obtaining further funding. Consideration for future funding will be dependent upon completion of these progress reports.

G. CONTACT INFORMATION FOR CORRESPONDENCE

Josephine Grima, PhD
Chief Science Officer

The Marfan Foundation
22 Manhasset Avenue
Port Washington, NY 11050

Tel: 800-8-MARFAN or 516-883-8712 ext. 117
Fax: 516-883-8040
Email: research@marfan.org

H. DETAILS OF PROPOSAL

The application must be submitted electronically, including the application forms, additional pages, and appendices, as a single PDF file, via The Marfan Foundation website, marfan.org. Please name your application using the following format:

ClinicalResearchGrant_Lastname_FirstName.pdf
Example: ClinicalResearchGrant_Smith_Jane.pdf

The application forms may be completed by 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.

Additional pages should be typed single-spaced using a font size of at least a 10 points and with one inch margins. 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. Table of Contents: 1 page
Application form provided

3. Project Abstract and Lay Person 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, EDS, LDS or other related disorders and/or improving the treatment or diagnosis of Marfan syndrome or related disorders (limit 300 words).

Rewrite the abstract in abbreviated form in terms suitable for presentation to lay persons (limit 500 words).

4. Research Plan: 3 pages

a. Include Goals and Objectives; Rationale; Methodology; Evaluation. (Figures may be placed in appendix if needed).

b. Please comment upon the importance of funding:

   i. Will this funding allow you to pursue studies that would otherwise not be performed? Is funding meant to supplement other sources of support?

   ii. Do you anticipate that this funding will increase your competitiveness for other funding sources?

c. Please comment upon the significance of the work that you propose:

   i. Is it similar to or a direct extension of work that has been or is being performed elsewhere?

   ii. Does the work complement or extend other studies that are being performed at your institution?

   iii. How novel are the studies that you describe?

   iv. Would such a proposal be competitive for NIH funding in its current form, or would you require additional preliminary data?

   v. Do you anticipate that the support would lead to the generation of physical resources that might be useful to other investigators in the field?

   vi. If so, would you be willing to make them widely available?

5. Budget and Justification
List full budget with amount requested. Include:

a. Names, titles, time/percentage effort of all participants, requested salaries and fringe benefits and total amount required.

b. Statement that the institution or other funding sources will absorb indirect costs.

c. A written budget justification.

The budget justification should be suited to the proposal. It is important that the investigators match the dollar award with the actual project. If funding from other sources is being used to cover certain parts of the study, please elaborate on what parts of the budget will not be completed with Foundation funding and what the approximate costs of the full project would be. No overhead or indirect costs will be considered. List the additional sources of funding if budget exceeds proposal amount.

6. Other Support: 2 pages

List other support received by principal and co-investigators for any projects (include yearly and total budget and duration of any grants):

a. Current

b. Pending

c. Description (in a paragraph, describe each current or pending grant and whether it has scientific or budgetary overlap with the present proposal).

7. Biographical Sketches: 5 pages each

Using the supplied form, please provide biographical sketches for key personnel. Indicate the total number of publications in each of the (2) categories: referenced articles and invited works. If you prefer, you may use the NIH biosketch form instead.

8. Facilities Description: 1 page

Describe the research facilities (laboratory space, clinical population, etc) available for the project.

9. Appendix

a. Figures, tables etc.

b. Literature cited

c. Human subjects experimental approval

d. Vertebrate animal experimental approval

e. Letters of support