



Medical Research Grant Application Guidelines

Thank you for your interest in medical research grants from the Progeria Research Foundation (PRF). The attached guidelines will provide you with a brief introduction to the goals and policies of PRF, and lists the specific information required when submitting a proposal.

I. Statement of Research Grant Policy and Procedures

The Progeria Research Foundation awards grants to applicants who seek to conduct research to find the cause, treatment, or cure for Hutchinson-Gilford Progeria Syndrome (HGPS).

II. Application Guidelines

The following general guidelines apply to PRF research grants:

- a. Principal investigators must hold post-doctoral positions or beyond.
- b. Awards will be granted only to applicants affiliated with institutions with 501(c)3 status, or the equivalent for foreign institutions.
- c. Proposed projects must have specific relevance to HGPS, and show promise for contributing to the scientific advancement in this field of study.

III. Funding Guidelines and Limitations

- a. Projects will ordinarily be funded for a period of one to two years. Under exceptional circumstances, funding will be continued for a third or fourth year of the project.
- b. Grant awards will be provided in amounts up to \$50,000 per year.
- c. Payment will be made on a quarterly basis at the beginning of each quarter, with the exception of the final quarter of each year of the grant, which will be paid within thirty days receipt and approval of the year-end report as specified in Section VI below.
- d. PRF reserves the right to withhold payment at any time pending resolution of any discrepancies in the use of funds, and/or if the specific aims are not met, all as set forth in the grant proposal and any revisions required thereto by PRF prior to acceptance and approval.
- e. Awards may not be contributed to a unified or pooled fund that will be used to award grants or support other projects.
- f. Grants are awarded on the basis of the content of the proposal, as well as the specified Principal Investigator and sponsoring institution. If the principal investigator(s) terminates his/her affiliation with the institution identified in the grant award, and wishes to continue the project at another qualified sponsoring institution, the principal investigator must notify PRF in writing. PRF reserves the right to require resubmission of the grant with the appropriate changes in staff and/or venue, and PRF reserves the right to reject such a change.
- g. If the principal investigator(s) wishes to discontinue the project prior to completion, he/she must notify PRF in writing within sixty days of termination of work on the

project. The original institution identified in the grant award shall have the opportunity to identify another principal investigator(s) within sixty days of notification. PRF reserves the right to require resubmission of the grant with the appropriate changes in staff and PRF reserves the right to reject such a change. If the original institution does not wish to continue the project, the remaining funds from the grant award as of the date of termination of work on the project must be returned to PRF.

f. The following will not be funded:

- Overhead or indirect costs
- Collaborator salaries
- Salaries or stipends for students, except for summer research positions
- General institutional expenses
- General fundraising campaign expenses such as dinners and mass mailings
- Religious, political, or other research that does not fall within PRF's areas of interest, as described above
- Journal subscriptions, advertisements, tuition fees, professional society dues, meals, receptions, or parking fees

IV. Processing of Grant Applications

Grant applications will be accepted and considered two times per year. The PRF Medical Research Committee will review each proposal and present its recommendations to the Board of Directors, whose decisions on awards are final. The Board of Directors will consider proposals at their second and fourth quarterly meeting of the calendar year, typically held in May/June and November/December. The deadline for applications to be considered at a specific Board meeting is six weeks prior to the meeting date. Please email us or check our web site at <http://www.progeriaresearch.org/committees.shtml> for the most up to date meeting schedule.

Notification of accepted and denied proposals will be made within two weeks of the Board of Directors meeting. For approved awards, the grant period will begin within four months thereafter, at the discretion of the principal investigator.

V. Detailed Application Instructions

Guidelines for completing proposals are described below. Submission of an incomplete application will result in a delay in review or non-consideration. Due to administrative resources, only proposals written in the English language will be considered.

a. Format:

- Maximum length is ten one-sided pages, single-spaced, using a standard 12-point font (information page, documentation, budget information, project personnel, funding history, references, diagrams and drawings are not included in the 10-page limit)
- Number each page consecutively
- Include principal investigator's name on each page as a header

- Abbreviate only after complete wording has been provided
- Use standard black type that can be photocopied
- Black and white diagrams and drawings are recommended

b. Content:

The proposal should describe the rationale and potential importance of the project, and should include the specific aims and research design and methodology. Summarize previous relevant work with progress to date. Include sufficient detail in a concise manner to facilitate evaluation of the proposed work. Reviewers will consider brevity and clarity of the proposal to be indicative of a focused approach to a research objective and the ability to achieve the specific aims of the project.

The application should include the following items:

I. Principal Investigator Information Page

- Name of organization:** Provide the name of the affiliated non-profit organization
- Title of project:** Choose a title that is descriptive and specific, not general
- Principal Investigator:** Provide name and relevant title(s)
- Contact information:** Provide mailing address, telephone number, fax number, and e-mail address
- Specific amount requested:** Indicate the total dollar amount requested from PRF for the first year of the application.

II. Project Description

- Abstract:** Provide a project summary that addresses the following: What problem does the project address? Why is the work important to children with HGPS? How will the project be accomplished? Signify up to eight key words in bold lettering.
- Specific aims:** List the project's objectives and describe concisely the specific goals of the research, including any hypotheses to be tested. One page is recommended.
- Background and significance:** Briefly outline the background of the proposed project. Include a critical evaluation of previous research and existing knowledge, and specifically identify the gaps that the project is intended to fill. State explicitly the importance of the proposed research by relating the project's specific aims to the medical issues of HGPS patients. Two to three pages are recommended.
- Preliminary studies:** For new applications, a report of the principal investigator's preliminary studies is recommended.

- E. **Research design and methods:** Describe the research design and methodology that will be used to accomplish the project's specific aims. Include the means by which data will be collected, analyzed, and interpreted. Describe facilities, laboratory space, and major equipment that are pertinent to the project. Describe any new methodology and its advantage over existing techniques. Discuss the potential difficulties and limitations of the proposed procedures and alternative approaches to achieve the project's aims. Provide a tentative sequence or timetable for the project. Describe any procedures, materials, or situations that may be hazardous to personnel and the planned precautions to be exercised.
- F. **Human subjects:** Regulations require that all affiliated institutions establish and maintain appropriate policies and procedures for the protection of human subjects. If applicable, briefly describe the population of subjects involved in the project, the process for informed consent, and the means by which protection will be ensured. Provide proof of current or pending project approval by an Institutional Review Board or similar oversight committee.
- G. **Animal studies:** All proposals must conform to regulations for the safe and humane treatment of animals. If applicable, briefly describe the animals to be studied, and measures to minimize pain and discomfort. Provide proof of current or pending project approval by the institution's Animal Use and Protection Committee or similar oversight group.
- H. **Budget:** Provide a detailed budget for Year One and, if applicable, Year Two of the project. See attached budget form.
- I. **Budget justification:** In narrative form, provide justification for the following budget items: salary and benefits for the principal investigator and other project personnel; travel, printing/publications, consultant costs, patient care costs; and equipment and supplies. Travel to professional meetings for the purpose of presenting grant-funded work will be limited to Year Two of any proposal.
- J. **Project personnel:** Provide the name, title, and role of any individual who will be involved in the project, including the principal investigator. Indicate the percent effort that each person is expected to devote to the project. Provide the curriculum vitae (CV) of the principal investigator and any collaborator(s). The CVs are not included in the ten-page limit for the proposal, and the CV of the collaborator(s) may be abbreviated to include relevant work and publications.
- K. **IRS 501 c (3) determination letter, or its equivalent for international institutions.**
- L. **Funding history:** If applicable, indicate the amount and granting organization for any other sources of funding for the proposed project. For the principal

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principal investigator, provide a list of current funding support as well as awards received in the past five years.

- M. **Letters of reference:** For principal investigators who are at the assistant professor level or below, provide two sealed, confidential letters of reference on behalf of the principal investigator.
- N. **Institutional support:** Provide a letter of institutional endorsement of the project, signed by an appropriate official and the institution's business manager or fiscal officer. Provide contact information for each.

c. Submission

Submit the original of the completed application, 9 copies and a PDF of the proposal on a CD (preferably in PC, not in MAC, format). Please include all documents, including institutional letters, publications, etc. in PDF format if possible (sealed letters excluded). Mail materials to:

The Progeria Research Foundation
Grants Division
PO Box 3453
Peabody, MA 01961-3453

Fed Ex or other delivery service address: 532 Lowell Street, 2nd floor, Peabody MA 01960
Please do not submit applications via fax or e-mail.

Application materials and further information can be obtained from The Progeria Research Foundation at the above address, via the website (www.progeriaresearch.org) or by contacting the organization at one of the following:

The Progeria Research Foundation
Phone: 978-535-2594
Fax: 978-535-5849
Email: agordon@progeriaresearch.org

d. Acknowledgement of Receipt

PRF will acknowledge receipt of proposals within fourteen days. Applications will be reviewed for completeness within thirty days of receipt, and then will be forwarded to the Medical Research Committee. Applicants submitting incomplete proposals will be notified and applications will be held on file pending receipt of all required documents.

VI. Responsibility of Recipient



The Progeria Research Foundation

Grant Agreement Form

(To be signed along with the PRF Patent, Intellectual Property and Technology Transfer Policy after a grant is awarded)

In accepting a Grant from The Progeria Research Foundation, Inc. (PRF), the principal investigator and the grantee institution assume an obligation to expend grant funds for the research purposes set forth in the application and to affirm that there is no duplicate funding for these purposes. The principal investigator and grantee institution will promptly notify PRF of activation or funding of any application for support to which PRF support is alternative.

Grant Period: The initial date of the grant period is the earliest that funds may be obligated or expended. Termination date of the award will be the date indicated in the original notification letter or the date provided by an authorized extension. Termination date of the award is the latest that funds may be expended except to liquidate authorized obligations.

The grantee institution is obligated to administer the grant in accordance with the regulations and the policies governing the Grant programs of PRF or, where not specified, consistent with the policies and practices of the grantee institution.

The fiscal officer of the grantee institution will provide an Expenditures Report co-signed by the principal investigator within 60 days after termination of the award. The fiscal officer of the institution will agree to make available to representatives of PRF, following due notice, accounting records of disbursements made from PRF's grant funds.

Every twelve months during the grant period, the Principal Investigator shall submit a Progress Report of his/her technical accomplishments and a financial report, or more frequently at the discretion of PRF with thirty days notice. In the final year, the PI shall submit a list of articles published or accepted for publication plus a summary of the research results.

The final quarterly payment for each grant year will be withheld pending receipt and approval of all required reports. This sum will revert to PRF in the event the reports are not received and approved within 6 months following the report due date.

Results of research will be made freely available to the public through appropriate scientific channels and all publications will bear the statement: "THIS WORK WAS SUPPORTED BY A GRANT FROM THE PROGERIA RESEARCH FOUNDATION" The investigator will not permit release of any publicity regarding the award or the research without advance clearance from PRF.

Permission for a transfer must be authorized by PRF in advance or the grant will terminate on the date the principal investigator leaves or ceases to work at the institution at which the grant was awarded.

Discoveries or inventions resulting from the Principal Investigator's research, or to which the investigator is a party, and carried out during the tenure of the PRF Grant, will be subject to the current Patent, Intellectual Property and Technology Transfer Policy of PRF in effect at the time 1) an application for a patent is submitted, and/or 2) the execution is initiated of a licensing or other agreement that will have an application of value such that its use, licensing, lease or sale can generate revenue; as well as being subject to the corresponding policies of the institution where the work was performed. The principal investigator shall notify PRF in advance of intent to participate in any contractual arrangement or to submit a patent application.

PRF endorses the principles of the Association of American Medical Colleges (AAMC) report, "The Maintenance of High Ethical Standards In The Conduct of Research."

PRF does not fund scientific research that involves the use of human fetal tissue. With respect to human and animal experimentation, the Executive Officer of the sponsoring institution and the principal investigator affirm: that the investigations which might involve human subjects have been endorsed by a committee on clinical investigation, or other clearly designated appropriate body, of the sponsoring institution; and that any research involving human subjects will conform ethically with the guidelines prescribed by the National Institutes of Health (NIH) including the provision of suitable explanation to human subjects or their guardians concerning the experimental design and all significant hazards, so that they may be in a position to provide appropriate informed consent prior to the investigations; and that research involving animals will conform with the current "Guide for the Care and Use of Laboratory Animals," NIH publication, DHHS/USPHS, and with federal laws and regulations, and has been approved by the Institutional Animal Care and Use Committee; and that wherever applicable, the research protocol will be reviewed and approved by the institution's biohazards committee, as well as conforming to NIH guidelines.

The nature of this arrangement is a funding agreement, and no employment or agency relationship is created.

The Progeria Research Foundation is not responsible for any claim, judgment, award, damages, settlement, negligence or malpractice arising from the research or investigation related to this award. The institution acknowledges responsibility for the conduct of research or investigations related to this award, and releases The Progeria Research Foundation from all claims or liability that may arise from the conduct of research or investigations related to this award resulting from any act or omission on the part of the institution, its employees, agents, or representatives.

PRF reserves the right to modify the terms or conditions of this contract with six months written notice to the Principal Investigator and the sponsoring institution.

SIGNATURES APPEAR ON THE NEXT PAGE

Signature of Principal Investigator	Print Name	Date
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Address

City, State, Zip Code

Telephone and FAX Numbers

Internet E-Mail Address

Award Period From, To Date: _____

Name of Fiscal Officer preparing Expenditures Report

Title

Address

City, State, Zip Code

Telephone and FAX Numbers

Internet E-Mail Address for Fiscal Officer



Patent, Intellectual Property, and Technology Transfer Policy

(To be signed along with the PRF Grant Agreement Form after a grant is awarded)

The primary purpose of PRF in funding medical research through its research grantees is to support its mission to find the cause, treatment, and cure for Hutchinson-Gilford Progeria Syndrome. PRF recognizes that such research may result in discoveries and inventions that have public health, scientific, business, or commercial value. PRF is interested in supporting and promoting science in the public interest and in making any such valuable discoveries and inventions available for public use as early as reasonably possible. Accordingly, this Patent, Intellectual Property, and Technology Transfer Policy, and any subsequent amendments hereto, are guidelines that shall apply to all discoveries or inventions created through the performance of research supported in whole or in part by a PRF Grant.

All inventions or discoveries made in the performance of research supported in whole or in part by a PRF Grant shall be reported in writing to PRF at the earliest practical time, but in no event later than when the invention or discovery is disclosed to the institution where the research was performed (“grantee institution”).

The grantee shall promptly notify PRF in writing of any decision to file a patent application or seek an application for any other type of legal protection for intellectual property rights in connection with any discoveries or inventions developed under a PRF Grant. PRF shall keep information regarding such applications confidential, except to the extent that such information is otherwise made public by someone other than PRF, or to the extent that it is necessary for PRF to obtain legal advice regarding such an application. The grantee shall notify PRF promptly and in writing of any patent subsequently issued.

PRF recognizes that the grantee may be subject to certain obligations owed to the grantee institution or others with respect to research conducted on the grantee institution’s premises. Notwithstanding such obligations, and, except as provided below, PRF shall abide by the grantee’s decision, and/or the grantee institution’s decision, if applicable, concerning whether to seek a patent or any other legal protection in connection with discoveries or inventions developed under the PRF Grant. However, to the extent that the grantee (and/or the grantee institution, if appropriate) decides not to file a patent application or otherwise seek legal protection for intellectual property rights in connection with discoveries or inventions developed under a PRF Grant, including the decision to abandon any such application, the grantee shall notify PRF in writing as soon as possible of such decision, but in any event within such reasonable time frame as would be necessary to preserve all intellectual property rights in any such discoveries or inventions. PRF, at its sole option and at its sole expense, may then decide to file a patent application or seek an application for any other type of legal protection for intellectual property in the U.S. or abroad. In the event that PRF makes such a determination, the grantee (and/or grantee institution, if appropriate) shall assign to PRF all right, title, and interest in and to any such discovery or invention and provide all reasonable cooperation and assistance necessary to assign and transfer such rights to PRF. The grantee (and/or grantee institution, if appropriate) shall further provide all reasonable cooperation and assistance to PRF in seeking to

obtain and enforcing a patent or other legal protection for intellectual property in the U.S. or abroad.

PRF shall share in any monies received from an invention or discovery developed under a PRF Grant. The grantee (and/or grantee institution, if appropriate) shall not enter into any agreement that will derogate PRF's right to share in such monies and shall notify PRF promptly and in writing of or any license, lease, sale, or other agreement concerning a discovery or invention developed under a PRF Grant that is intended to generate revenue. PRF's right to share in monies shall include the sharing of licensing fees, royalties, or any other income derived from such invention. PRF's participation shall be on a pro rata basis, based on PRF's portion of funding support for the research which led to the discovery or invention. A reasonable formula for determining PRF's participation is as follows: (1) the numerator of the sharing formula shall be an amount equal to the fees and royalties, less the grantee's expenses and disbursements of patent application costs and any other costs, taxes or expenditures as may be necessary or required by law; and (2) the denominator of the formula shall be an amount equal to the proportionate contribution of PRF and other funding organizations and grantors who choose to assert their respective rights, as well as direct and indirect support, provided to the grantee. All reasonable administrative and overhead expenses of the grantee institution, as determined in accordance with the Funding Guidelines and Limitations of the Grant programs of PRF, shall be factored into the calculation of indirect support.

In the event that the grantee (and/or grantee institution, if appropriate) grants a license to another party to commercialize an invention developed under a PRF Grant, such license shall include provisions that obligate the licensee to commercialize the invention in a commercially reasonable diligent manner, pursuant to, for example, appropriate diligence requirements and milestones, and the licensor shall monitor performance by the licensee. Unless otherwise agreed with PRF, the grantee (and/or grantee institution, if appropriate) agrees that if it, its designee or licensee has not taken effective steps to arrange for practical or commercial application (*e.g.*, through a license agreement or other reasonable terms) of the invention within three years from the date of issuance of a patent, or another clear determination of commercial value, or such other term that is commercially reasonable under the circumstances, and the institution or other titleholder cannot show commercially reasonable cause acceptable to PRF why it should retain rights in and title to the invention for any further period of time, then PRF shall have the right to require: (1) assignment of the patent or other intellectual property rights to PRF; (2) cancel any outstanding exclusive license agreement; (3) grant a license under such patent or intellectual property right on terms that are reasonable in the circumstances; and/or (4) any other reasonable disposition of rights in the invention.

If the grantee (and/or grantee institution, if appropriate) fails to commercialize any invention or discovery developed under a PRF Grant within a commercially reasonable time, including licensing such invention or discovery to another, and PRF identifies a suitable candidate interested in commercializing such an invention or discovery, the grantee (and/or grantee institution, if appropriate) shall consider such a candidate as a potential licensee and shall license the invention or discovery to such a candidate, provided that the terms of such license are reasonably acceptable to the grantee (and/or grantee institution, if appropriate).

Progeria Research Foundation Grant Application
SIGNATURES APPEAR ON THE NEXT PAGE

Signature of Principal Investigator	Print Name	Date
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Address

City, State, Zip Code

Telephone and FAX Numbers

Internet E-Mail Address	Award Period From, To Date
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Name of Fiscal Officer preparing Expenditures Report

Title

Address

City, State, Zip Code

Telephone and FAX Numbers

Internet E-Mail Address for Fiscal Officer

Grant Approved by The Progeria Research Foundation

Name: Audrey Gordon

Title: Executive Director

Signature: _____ Date: _____