**ORPHAN DISEASE CENTER**

**2021 MILLION DOLLAR BIKE RIDE**

**Pilot Grant Full Application**

**Cover Page**

PI Name:

PI Title:

PI Institution:

Project Title:

Rare Disease:

Human Subjects Research: [ ]  Yes (Please attach IRB approval letter) [ ]  No

Animal Research: [ ]  Yes (Please attach IACUC approval letter) [ ]  No

Abstract (Up to 250 words):



**Checklist**

**CONTENT to be uploaded:**

[ ]  **Cover Page/Checklist/Institutional Signature Page [PDF].**

[ ]  **NIH-style Biosketch with Other Support of PI and key personnel** (5 pages max/PI, including Other Support). **[PDF]**

The PI must include accurate and complete information regarding all other sources of grant support (current and pending), including title, abstract, annual and total amount of grant, inclusive funding period, and percent effort.

[ ]  **Detailed Budget and Justification.** **[combined into one PDF]**

Complete Excel budget sheet (to be provided). Describe justifications in a Word document. Award will be for one year. Proposed funding period: February 1, 2021 – January 31, 2022.

 Total Budget depends on disease RFA:

|  |  |  |  |
| --- | --- | --- | --- |
| **Disease** | **Total Funds** | **# of Awards** | **Award Total** |
| APBD | $99,025 | 1 or 2 | $99,025 or $49,513 |
| A-T | $70,966 | 1 | $70,966 |
| BPAN/NBIA | $66,366 | 1 | $66,366 |
| CADASIL  | $120,456 | 1 or 2 | $120,456 or $60,228 |
| Castleman | $64,205 | 1 | $64,205 |
| CHI | $73,045 | 1 | $73,045 |
| CDKL5 | $74,775 | 1 | $74,775 |
| Choroideremia | $64,360 | 1 | $64,360 |
| CF | $117,655 | 1 | $117,655 |
| CLA | $106,921 | 2 | 53,460 |
| CMD | $97,752 | 1 or 2 | $97,752 or $48,876 |
| Cohen Syndrome | $162,161 | 1 or 2 | $162,161 or $81,080 |
| FD/MAS | $161,374 | 2 ,3 or 4 | $80,687, $53,791, or $40,343 |
| FOP | $64,000 | 1 | $64,000 |
| Glut 1DS | $64,465 | 1 | $64,465 |
| LAM | $73,491 | 1 | $73,491 |
| ML4 | $64,335 | 1 | $64,335 |
| MPS | $64,015 | 1 | $64,015 |
| MPS Gene Spotlight | $64,645 | 1 | $64,645 |
| MSUD | $119,555 | 1 or 2 | $119,555 or $59,777 |
| NEHI | $82,000 | 1 or 2 | $82,000 or $41,000 |
| NPC | $50,010 | 1 | $50,010 |
| NUBPL | $50,198 | 1  | $50,198  |
| Pitt Hopkins | $78,530 | 1 | $78,530 |
| RASopathies | $75,431 | 1 | $75,431 |
| SETBP1 | $91,466 | 1 or 2 | $91,466 or $45,733 |
| Snyder-Robinson | $74,691 | 1 | $74,691 |
| STXBP1 | $160,141 | 2 | $80,070 |
| TBCK | $50,400 | 1 | $50,400 |
| Telomere | $65,445 | 1 | $65,445 |

 Institutions may opt to take up to 10% IDCs from their award totals. Awarded amounts will not exceed Award Totals listed above.

|  |  |
| --- | --- |
| **Allowable direct costs** |  **Unallowable costs** |
| * Salary for PI\*
* Salary/stipend and related benefits for graduate student/postdoctoral fellow/technical support
* Travel (up to $1500)
* Laboratory supplies and other research expenses
* IDCs of 10% are included in the total award amount
 | * Consultant costs
* Tuition
* Professional membership dues
* Equipment >$5,000
* General office supplies institutional ----administrative-charges (e.g., telephone,-- other electronic communication, IT --------network, etc.)
* Pre‐award charges
* Any other expenses not directly related --to the project
 |

**\***Beginning in May 2020, PI salary on all ODC Pilot awards will be applicable to the National Institutes of Health Executive Level II Salary Cap. The current NIH Salary Cap for the year 2020 is $197,300. For background and guidance, please refer to the following link: <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-065.html>

[ ]  **Research Plan** (5 pages max) and **Bibliography** (1 page max). **[combined into one PDF]**

 Include the following sections: Specific Aims, Background and Significance, Preliminary Studies/Data, Research Design and Methods. Research plan should address the following questions: 1) Do you require access to reagents, cell lines, animal models, IRB/ethical board approvals, and/or equipment necessary to complete work? If so, please describe your plan to gain access within the time-frame of this grant period. 2) Have you identified qualified personnel to complete this project within the grant period? If not, please provide your plan to do so. Text citations should use a numbered format. Include all author names in the reference list.

All previous MDBR grant awardees must include a statement of outcomes including publications, patents and additional funding granted as a result of data generated from those grants. Specific aims must be different from those in previous applications.

[ ]  **Appendix** **[combined into one PDF]**

Limited to 5 pages of supplemental information pertaining to proposal or preliminary data only; a maximum of 3 relevant reprints are also acceptable. Include IRB and/or IACUC approval letters if relevant.

**Project Disclosures and No Cost Extensions (NCE):**

* NCEs will be granted at the discretion of the ODC.
* Awardees will be limited to 1 NCE request for their award.
* Maximum NCE time awarded will be 6 months.
* NCEs will be granted after a formal request through [this form](https://upenn.co1.qualtrics.com/jfe/form/SV_5pCr7v7vjyNPKAu) found on the ODC website prior to the NCE deadline with adequate justification.
* If granted a NCE, you are still required to submit an interim scientific report 6 months into the duration of the original award period, regardless of your new project end date.
* In your letter of interest, you will be required to certify that you have identified qualified personnel to complete this project within the grant period **PRIOR** to the start date of the award. If you have not, you will be required to provide your plan to engage said personnel. Only under extenuating circumstances will personnel issues be considered for NCE requests.
* In your letter of interest, you will also be required to state whether or not you require access to reagents, cell lines, animal models, IRB/ethical board approvals, and/or equipment necessary to complete your work. If so, you will be required to describe your plan to gain access within the time-frame of this grant period.

**ORPHAN DISEASE CENTER**

**2021 MILLION DOLLAR BIKE RIDE PILOT GRANT PROGRAM**

**INSTITUTIONAL SIGNATURE PAGE**

**Certification and Acceptance:**

We, the undersigned, certify that the statements contained in the attached grant application are true and complete to the best of our knowledge. We agree to conform to the policies and rules governing this award. We agree to openly share final data sets and observations with the full scientific community, and all reagents and/or research tools developed under support by this mechanism will be made accessible upon request. We understand that the University of Pennsylvania makes no claim to rights on these items or intellectual property other than for those faculty employed by the University of Pennsylvania. We understand that indirect costs are limited to 10% of direct costs.

**Principal Investigator:**

 **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

Name (typed) Signature

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**Institutional Official:**

 **\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

Name (typed) Signature

Title:

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**ORPHAN DISEASE CENTER**

**2021 MILLION DOLLAR BIKE RIDE**

**Grant Program Award Terms**

1. Indirect Costs are limited to up to 10% of direct costs.
2. Awardees are required to provide updates concerning other support, resulting publications, and research activities, as requested.
3. An interim programmatic report is due ~August 1, 2022. A final report is due one month after the close of the project. Each two-page report must contain a synopsis of scientific progress, a list of resulting collaborations, publications and grants, a description of the relationship of the project to the goals of the related-disease research, a financial report, and a statement regarding unspent funds.
4. Awardees will receive payment on a quarterly cost reimbursement basis. Awardees must submit invoices with a breakdown of incurred costs to the grant over the previous three-month period. A template and invoicing details will be provided in the award agreement.
5. The following citation must be included in all publications: This work was supported in part by a research grant from the University of Pennsylvania Orphan Disease Center.
6. Appropriate citation of all collaborations must be included in all publications.
7. All final data sets and observations must be shared openly with the full scientific community, and all reagents and/or research tools developed under support by this mechanism must be made accessible upon request. The University of Pennsylvania makes no claim to rights on these items or intellectual property other than for those faculty employed by the University of Pennsylvania.

NOTE: Award terms are subject to change. If awarded, please refer to the grant award contract for actual project terms.

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