**CYSTINOSIS IRELAND SEEDCORN FUNDING PROGRAMME 2024**

**APPLICATION FORM**

***Please return this form to*** [***research@cystinosis.ie***](mailto:annemarie.odowd@cystinosis.ie)

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| --- | --- | --- | --- |
| **Name of applicant** | |  | |
| **Email address & telephone number for applicant** | |  | |
| **Name and address of Host Institution** | |  | |
| **Title of project** | |  | |
| **Proposed start date of project** | |  | |
| **Proposed end date of project** | |  | |
| **Date of when report detailing results/outcomes of project will issue to Cystinosis Ireland** | |  | |
| **Lay abstract: Please describe your proposed project in *lay-person’s* terms (one paragraph)** | | |  |
| This should be aimed at the general public who may not be scientifically knowledgeable and may not have heard of the cystinosis disease.  It is strongly recommended that researchers engage with members of the public when writing the lay abstract. | | |  |
| **Scientific abstract: Please give a short scientific summary of the proposed project** | | |  |
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| **Detailed scientific description of the proposed project** | | |  |
| Please provide information on the following:   1. the aims/objectives of the proposed research and the relevant scientific background 2. please give sufficient detail to show that the aims are scientifically justified, and to show that the proposed research will add distinct value to what is already known, or in progress 3. where relevant, please state if the research proposed is proof of concept or a pilot study 4. describe the research plan for the proposed project including information on the experimental technique(s) and/or research methodologies proposed and why you believe your proposed plan should work 5. where appropriate, describe alternative approaches should the proposed research plan/techniques/methodology not work 6. describe the expected results/outcomes 7. if the proposed research involves partners, please state how these partners will contribute to the research plan 8. please describe how the expected results/outcomes will be used in future research activities 9. please describe your plans for using and disseminating the knowledge generated to ensure optimal use of the project results/outputs in future research activities and in the patient and the healthcare system (include if relevant, any plans for the management of intellectual property).   Please include scientific references where relevant. Include a gantt chart and/or scientific figures/diagrams in an appendix where appropriate. | | |  |
| **Resubmission statement (if relevant)** | | |  |
| If the application is a resubmission, please provide a statement referencing the previous application and explaining the differences between it and this current application.  The statement should make reference to previous reviewer comments where appropriate. | | |  |
| **What will be the impact of the proposed research?** | | |  |
| Please explain how the proposed research will benefit patients and/or families living with cystinosis.  Please explain how you feel the proposed research aligns with Cystinosis Ireland’s research strategy. | | |  |
| **Will the data generated from this proposal be turned into a larger grant application?** | | |  |
| Please give a brief description of likely subsequent research proposals if the work is successful.  Please provide details of the funding programme(s) to which you intend to apply. | | | |
| **Explain why the research environment chosen for this project is appropriate** | | |  |
| Please describe how the scientific or clinical environment(s) in which the research will be done will promote delivery of the proposed research.  Describe any clinical, or organisational dependencies necessary to support the research and/or to help translate it into practice | | |  |
| **Research track record of applicant (Half page maximum)** | | |  |
| Please provide a short research profile explaining why you are the right person to perform the proposed research.  Please attach a short cv (maximum 5 pages) as an appendix to the completed application. | | |  |
| **Names and Institutional affiliation of research collaborator(s) (if relevant)** | | |  |
| Please provide the names and institutions of any collaborators involved in the proposed research.  Please explain how each of the collaborators named will contribute to the proposed work and why their expertise is important. | | |  |
| **Name and details of researcher identified to carry out the work: (If relevant)** | | |  |
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| **Ethics and research governance considerations** | | |  |
| Please describe any ethical considerations and how these will be dealt with.  Where relevant, please describe the ethical review and research governance arrangements that will apply to the proposed research activity.  Where relevant, briefly describe if there is likely to be ethical issues arising from any involvement of people, human samples or personal data in the research proposal. If yes, please give details of how any specific risks will be managed. | | |  |
| **Public and Patient Involvement (PPI) in the proposed research project** | | |  |
| Please describe the public or patient involvement for the proposed research.  Please describe:   1. the nature and purpose of the public and patient involvement proposed 2. what public or patient involvement has taken place to date and how it has influenced/changed the research work that has been planned, and 3. what public or patient involvement is planned for the duration of the project if funded.   *Considerations*:   1. have you contacted the Worldwide Cystinosis Community Advisory Board (Cystinosis CAB) or any other cystinosis patient group about this project? 2. has any member(s) of the public and/or patient group provided input into the preparation of the project including the preparation of the lay abstract, design of the research plan, potential impact of and dissemination strategies for the anticipated research outputs 3. is it planned to include a member of the public and/or member of a patient group and/or member of the Cystinosis CAB as part of the research team?   *Notes*:  The PPI proposed should be appropriate to the stage of the research being proposed. However, researchers are strongly encouraged to include PPI even in very basic scientific research proposals.  Public involvement and patient involvement are different and should be considered by researchers separately. It is noted that patients (particularly those with rare diseases) are usually highly informed and educated about their condition whereas, more often than not, the general public will not be scientifically informed and will not be aware of most rare diseases especially ultrarare diseases such as cystinosis. | | |  |
| **Budget request (Euro amounts only, no contingency for currency conversion will be included)** | | |  |
| **Total cost of the Project:** | **Total amount requested from Cystinosis Ireland** | |  |
| €\_\_\_\_\_\_\_\_\_\_\_\_\_ | €\_\_\_\_\_\_\_\_\_\_\_\_\_ | |  |
| **Please provide a detailed budget for the proposal** | | |  |
| Please complete the project budget template in appendix 1. | | |  |
| **Budget Justification** | | |  |
| Please provide a justification for the funding requested from Cystinosis Ireland and provide as much detail as possible on what the funding will be spent.  If the funding being requested from Cystinosis Ireland is a part of a larger project please provide an overall budget for the project and indicate what proportion of the budget is being sought from Cystinosis Ireland (appendix 1).  Please indicate if any additional sources of funding required are in place. | | |  |
| **Please provide a name of one suggested peer reviewer to whom you are not connected** | | |  |
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| **If funded, any report produced from this research for publication must have a lay summary and prior to publication we would ask for sight of that summary so that we can provide feedback and suggestions. Please indicate below that you agree to do this.** | | | |
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**Appendix 1**

**Budget breakdown**

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| **Budget Item** | **Please specify FTEs**  **(Full Time Equivalents)** | **Amount requested from Cystinosis Ireland in €s** | **Amount from other funding sources in €s** | **Total amount in €’s** |
| **Personnel costs** – please list separately personnel at different grades | |  |  |  |
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| **Consumables** |  |  |  |  |
| **Travel** | For researchers/ staff |  |  |  |
| **Travel** | For patients/ participants |  |  |  |
| **Equipment** |  |  |  |  |
| **Other direct costs** |  |  |  |  |
| **Subtotal** |  |  |  |  |
| **Overheads** |  | Not eligible for funding by Cystinosis Ireland |  |  |
| **Total Project Budget** |  |  |  |  |

**Appendix 2**

**Applicant CV**

**(maximum 5 pages)**

**Appendix 3**

**Gantt chart outlining research plan (if relevant)**

**Scientific figures/diagrams (if relevant)**