

## CYSTINOSIS IRELAND SEEDCORN FUNDING

### GENERAL TERMS AND CONDITIONS

#### Funding

Cystinosis Ireland pays 100% of the funding on receipt of the signed contract from the Research Body and an invoice for the stated sum of money.

The funding is to be spent on items specified in the Research Proposal that are required for the funded Research Project as approved by Cystinosis Ireland.

€10,000 is the maximum funding contribution unless otherwise agreed by Cystinosis Ireland.

If the costs incurred by the Research Body in carrying out the project amount to less than the maximum amount of €10,000, Cystinosis Ireland shall be obliged to pay only such amount as may be necessary to discharge the actual costs incurred.

If any part of the funding remains unused or uncommitted at the Research Project end date, it shall be returned to Cystinosis Ireland within sixty days of such end date or earlier termination.

Any foreign exchange loss arising on the payment of the funding or any part of it shall be borne in full by the Research Body.

**Cystinosis Ireland does not provide any contribution to the overheads of the Research Body.**

Any foreign exchange loss arising on the payment of the Award Amount or any part of it shall be borne in full by the Research Body.

#### Responsibilities of the Research Body and the Principal Investigator

The Research Body shall, without limiting the generality of the foregoing:-

- i. Comply in full with the terms and conditions of this contract.
- ii. Ensure that the Research Project activities are performed with due skill, care and diligence and by appropriately qualified personnel and are completed within the term of the contract.
- iii. Ensure that all monies claimed and paid are allowable, necessary and reasonable for the conduct of the Research Project.
- iv. Ensure that the Principal Investigator receives a copy of this contract and any subsequent binding variations and procure that the Research Project activities are carried out under the

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supervision of the Principal Investigator.

- v. Ensure that the Principal Investigator and any other members of the research team engaged in working on the Research Project fully comply with the obligations on the part of the Research Body contained in this contract.
- vi. Ensure that the Principal Investigator and any other members of the research team engaged in working on the Research Project are sufficiently qualified or will receive training appropriate for their duties including health and safety training.
- vii. Ensure that appropriate direction and supervision of the research team is provided.
- viii. Not accept or receive funding for the same Research Project activities from any other source.

### **Notification**

The Research Body shall notify the Cystinosis Ireland of any of the following matters;-

- i. Any proposed change in the objectives of the Research Project activities (which proposed change for the avoidance of doubt shall not be made without the written consent of the Cystinosis Ireland).
- ii. Any material adverse occurrence or anticipated occurrence relating to the Research Project activities.
- iii. The Principal Investigator has devoted or intends to devote substantially less effort to the Research Project activities.
- iv. The Principal Investigator severs or intends to sever her connection with the Research Body.
- v. The Principal Investigator has been absent for a continuous period of three months or more.
- vi. The Principal Investigator has relinquished or intends to relinquish active direction of the Research Project.
- vii. The Research Body terminates the Principal Investigator's employment or engagement.

### **Dissemination of results**

The Research Body and the Principal Investigator have a duty to the public to ensure that discoveries and advancements in knowledge arising from the Research Project activities are translated for public

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benefit. This includes disseminating any findings, results or products of the project in peer review publications, through the media and among the general public as far as possible or practicable.

The Research Body and the Principal Investigator shall expressly acknowledge Cystinosis Ireland as the source of funding in any publication, presentation, report or media interview/coverage in respect of the Research Project by including the following statement in the main body of any press release, website, publication or similar: *“This research was funded by Cystinosis Ireland, Charities Regulatory Authority No: 20053796.”*

The Research Body and the Principal Investigator shall notify Cystinosis Ireland one month in advance of all publications and events that are based on research or studies in connection with this Research Project. This includes full journal papers, books, reports, abstracts, presentations, press releases or policy papers etc.

### **Intellectual Property.**

Cystinosis Ireland makes no claim to any intellectual property arising from the Research Project.

### **No cost extension (NCE)**

Cystinosis Ireland may approve a once-off request to extend the duration of the Research Project for a maximum period of 6 months (“No Cost Extension”).

A request for a No-Cost Extension must be made in writing by the Principal Investigator, not less than one month before the end date of the Research Project. In making a request for a NCE, the Principal Investigator must provide justification and must assure Cystinosis Ireland that the NCE is required to ensure completion of the Research Project.

A No-Cost Extension may be granted at the absolute discretion of Cystinosis Ireland and must be conducted within the original award monies.

### **Reporting and Audits**

Cystinosis Ireland requires the submission of a written report detailing the outcome of the Research Project. This report should be submitted to [research@cystinosis.ie](mailto:research@cystinosis.ie) within one month of the end date of the Research Project (31 July 2020).

The Principal Investigator shall also furnish updates to Cystinosis Ireland at other times as it may reasonably request for the purpose of internal reporting to the Cystinosis Ireland Executive

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Committee and/or for fundraising purposes including, if requested, a lay-person summary of progress/final report.

Cystinosis Ireland shall be entitled to have any such report audited at its expense by its nominated auditors and the Research Body and the Principal Investigator shall fully co-operate with such auditors and shall allow them full access to all Financial Records and other records referred to above and all statistical, administrative, scientific and other relevant supporting papers and records in both paper and electronic form.

### **Warranties**

The Research Body warrants that:-

- i. It has full power and authority and all necessary resources to carry out the Research Project and to comply with the provisions of and perform all of its obligations under this contract.
- ii. The acceptance of this contract has been executed by its duly authorised representative with full power and authority to bind it.
- iii. It has obtained or will obtain all necessary consents, approvals, authorisations, licences and permissions including, but not limited to, relevant ethical approvals, animal experimentation licences, which are required to enable it comply with its obligations under this contract.
- iv. It shall throughout the contract term maintain all such consents, approvals, authorisations, licences and permissions and shall not commit any act or omission which might invalidate, breach or otherwise impair the effect of any of them.

### **Limitation of Liability and Indemnity**

The Research Body shall be wholly responsible for the conduct of the Research Project, and Cystinosis Ireland shall have no obligation, responsibility, or any liability financial or otherwise of any kind to the Principal Investigator or The Research Body or any other researcher appointed to work on the Research Project, or any representation or other act or omission connected with the Research Project, save and except to pay the Award Amount in accordance with these Award Terms and Conditions.

The Research Body shall fully indemnify and hold Cystinosis Ireland, and its officers, members, servants or agents, harmless against all liabilities, loss, damages, costs (including legal and/or professional costs) and claims of any kind arising from any act or omission of The Research Body, Principal Investigator or any member of the research team in connection with the Research Project

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or the use of the Award Amount or from the provision of any funds, advices, or assistance of any kind given by Cystinosis Ireland in connection with the Research Project.

## Termination

Cystinosis Ireland will be entitled to reduce, suspend, terminate or revoke the award in whole or in part by written notice to the Research Body if:

1. any of the information in the Research Proposal is inaccurate in any material respect or any other information supplied for the purpose of drawing down the award or any use the award monies solely and entirely for the project purpose described and for no other purpose whatsoever.
2. The Research Body commits a material breach of the terms and conditions of the award and in the case of a breach capable of remedy fails to remedy the breach within thirty days of the date of written notice thereof containing reasonable details of the breach
3. any warranty or representation by the Research Body is untrue or inaccurate;
4. The Research Body is unable to obtain any relevant permits, approvals, permissions or consents necessary for the carrying out of the Research Project or any part of them;
5. If the Principal Investigator:-
  - commits an act of bankruptcy;
  - is convicted of any criminal offence;
  - has devoted or intends to devote substantially less effort to the Research Project;
  - severs or intends to sever his/her connection with the Host Institution;
  - has been absent for a continuous period of three months or more;
  - has relinquished or intends to relinquish active direction of the Grant Funded Activities;
  - The Research Body terminates the Principal Investigator's employment or engagement;
  - has committed an act of serious research misconduct or fraud
  - has committed an act or omission that brings, or is likely to bring, the charity Cystinosis Ireland into disrepute.

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The Research Body acknowledges that Cystinosis Ireland is a charity and is wholly dependent on charitable donations from the public for the funding of its research activities and that, if sufficient funding is not forthcoming from these donations, Cystinosis Ireland may not be in a position to fund all of its research funding commitments including in respect of this contract.

Accordingly, the Research Body agrees that if Cystinosis Ireland does not have sufficient funding to cover all of its research funding commitments, Cystinosis Ireland shall be entitled in its sole discretion to determine which grant commitments it will continue and which commitments it will reduce, suspend, terminate or revoke; and it shall be entitled in its sole discretion to forthwith reduce, suspend, terminate or revoke this contract by written notice to the Research Body.

#### **Law / Jurisdiction**

This contract shall be governed by and construed in accordance with the laws of Ireland and the parties expressly and irrevocably submit to the jurisdiction of the Irish Courts.

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