Duchenne Ireland
Terms and Conditions of Research Grants
(2021)

Please sign this form and return to:

Research Funding Department
Duchenne Ireland
Cavan Hill
Lifford
Co. Donegal
Ireland
F93 P2XC

E-mail: duchenneireland@gmail.com

MISSION STATEMENT

The aims of Duchenne Ireland are to raise awareness of Duchenne Muscular Dystrophy at local, national and government level. Our objective is to raise funds which shall go directly to the researchers and clinicians who we believe have the best chance of developing improved therapies which will benefit this generation. We are also working towards achieving an infrastructure which is on a par with best international practice.

RESEARCH STRATEGY

We aim to fund translational research for Duchenne Muscular Dystrophy which will move towards the clinic within a defined timeline. We encourage applicants to have a clear path to the clinic in place if work is successful i.e. A plan for success.

Duchenne Ireland confirms that our organisation complies with the Governance Code for the Community, Voluntary and Charitable Sector in Ireland.

CONDITIONS OF GRANT

1. The Principal Investigator must hold a contract at an institution, which extends beyond the termination of the grant.
2. The grant must be used by the Institution only for the purposes of the project.
3. Duchenne Ireland is not the Research Sponsor. This position will be held by Institution in which the research takes place, or if necessary a third party.
4. The Institution must accept full responsibility for the management, monitoring and control of all research work funded under this Duchenne Ireland grant and all those staff (permanent, temporary and students) employed in or involved in any research funded as a result of this grant. This includes, but is not limited to, the requirements of all regulatory authorities governing the use of radioactive isotopes, animals, pathogenic organisms, genetically manipulated organisms (GMOs), toxic and hazardous substances, and research on human subjects and human embryos.
5. The Institution shall be responsible for maintaining appropriate policies of insurance covering professional indemnity, public liability and employer's liability insurance and it shall provide evidence of such cover to Duchenne Ireland upon request.
6. Before a grant may be finalised, the Institution must accept and agree to abide by the Duchenne Ireland's Terms and Conditions. The Institution must obtain the same undertakings from all individuals subsequently funded within the remit of the grant.
7. The Principal Investigator and any other lead investigators involved in clinical trials involving medicines, must be properly authorised to perform the necessary work.
8. Duchenne Ireland must be notified if the start date differs from that specified in the grant application. The project must begin within six months of the date of the award letter. Written approval from Duchenne Ireland is required for extension beyond this period.
9. Any significant deviations in research protocol from those stated in the grant application must be reported immediately to the Research Department of Duchenne Ireland.
10. The project must terminate within the time period specified in the award letter. If necessary, requests for a project extension should be submitted in writing to Duchenne Ireland.
11. If any of the applicants move to another Institution during the tenure of the grant, the grant may not move with him or her without prior approval from Duchenne Ireland. Duchenne Ireland will not be responsible for any additional costs as a result of such a move.
12. Duchenne Ireland reserves the right to change the terms and conditions in accordance with legal requirements, at which point the new terms and conditions will apply to new and existing grants.
13. Duchenne Ireland reserves the right to terminate the grant, without notice, in the event of serious misconduct, improper use of the grant, or for other material breach of these terms and conditions. In such cases, Duchenne Ireland will reimburse the Institution for expenditure properly incurred under the award up to the termination date, but will not be responsible for any administrative or overhead costs imposed by an Institution. Duchenne Ireland also reserves the right to terminate the grant, with three months notice, should financial restraints require it to do so.

FINANCE

1. Duchenne Ireland is heavily reliant on voluntary sources of funding and therefore, is subject to the continued availability of necessary funds. If the total project is approved in principle, payments will be made in accordance with mutually agreed timelines and milestones. Approval for continued funding will be subject to the provision of satisfactory interim reports by the grant holder.
2. All payments made by Duchenne Ireland are made to the Principal Investigator's Institution.
3. Grants may be for salaries (apart from Principal Investigator) of part-time or whole-time workers and if appropriate, for costs of laboratory consumable materials and equipment. It is assumed that ordinary equipment; facilities and materials are available in the laboratory in which the work is undertaken.
4. Duchenne Ireland research grant funds should not be used to meet administrative or other overheads imposed by a University or other Institution.

AUDIT

1. Duchenne Ireland reserves the right to audit the finance of a grant at any time and the Institution shall cooperate fully if such a request is made.
2. Grant recipients are required to have in place formal purchasing procedures that ensure only valid grant expenditure is charged.
3. The grant may be cancelled if such procedures are found not to be in place.

EMPLOYMENT OF STAFF

1. Duchenne Ireland does not act as an employer or accept any responsibility for staff employed as a result of the grant being awarded.
2. All liability in respect of employee insurance claims, maternity benefits, sick leave, health and safety lies with the Institution.
3. Duchenne Ireland is to be informed of each member of staff employed on the grant. Any changes to these details or changes in staff during the period of the award can only be made with the prior approval of Duchenne Ireland.
4. The *Curriculum Vitae* of each staff member must be submitted to Duchenne Ireland once his or her identity is known.
5. The Institution must ensure that all permanent and temporary staff and students employed in or involved in the research receive training appropriate to their duties.
6. Any proposed promotion or re-grading of staff with financial implications must be submitted to Duchenne Ireland for review before implementation.

EQUIPMENT

1. Equipment purchased with grant funds must not be removed from the original location or modified without permission from Duchenne Ireland.
2. Any loss resulting from payments made for equipment in advance of delivery will be entirely the responsibility of the Institution.

3. The Institution is responsible for ensuring that any equipment, provided by this grant, has adequate insurance cover. If the equipment is damaged or destroyed, the Institution will be required to repair or replace it.
4. The Institution is responsible for maintenance of the equipment during its lifetime.

TRAVEL

1. When travel is an integral part of the programme supported by Duchenne Ireland it should be included in the budget as outlined in the grant application.
2. Expenses involved in attending scientific meetings should not normally be included in research grant applications but should be the subject of separate applications on the part of the workers assisted by grants from Duchenne Ireland.

RESEARCH MONITORING

1. The Principal Investigator is required to complete progress reports for Duchenne Ireland at agreed intervals.
2. A decision on subsequent funding will be made after consideration of the interim report(s).
3. On termination of the grant, the Principal Investigator is required to complete an end of project report which is to be received by Duchenne Ireland within 3 calendar months of receipt by the Principal Investigator of the relevant end of project report form as issued by Duchenne Ireland. Failure to submit will result in the final payment being withheld until submission of the report and may affect future grant applications.
4. Where volunteers are involved in research the grant holders are required within the bounds of relevant ethical framework to provide feedback to their patients or their carers at appropriate intervals during their research.

SITE VISITS

1. Site visits may be arranged with reasonable notice by Duchenne Ireland.
2. As trusts/donors may be involved in funding of grants, it may be requested that such trusts/donors visit the Institution with prior arrangement.

PUBLICATION AND PUBLICITY

1. The Institution or the Principal Investigator should contact Duchenne Ireland before contacting the media on any aspect of the project. If a publication is likely to generate media interest Duchenne Ireland require prior notification to enable materials to be disseminated to its members.
2. Any publication resulting from all or part of the work funded by Duchenne Ireland must bear due acknowledgement to Duchenne Ireland. A hard copy and electronic version (if possible) must be sent to the Research Department of Duchenne Ireland.
3. Duchenne Ireland should review and approve any Press Release, or lay interpretation of research work, prior to its distribution.
4. Duchenne Ireland wishes to be informed once a publication has been accepted.

TERMINATION

1. In the event of the applicant terminating the grant, written notification must be given to Duchenne Ireland immediately, outlining the reasons. An end of project report must be completed within three months and the final claim is to be submitted within six months of notice of discontinuation.
2. The Institution will be reimbursed for expenditure properly incurred or reasonably committed up to the termination date.

DANGEROUS PATHOGENS AND GENETIC MANIPULATION

1. Applicants whose projects involve the use of dangerous pathogens and genetic manipulation confirm that the accommodating department will conform with the recommended safeguards for this type of research.

DATA PROTECTION

1. Duchenne Ireland requires that all grants comply with current data protection regulations and any subsequent changes.

RESEARCH INVOLVING ANIMALS OR ANIMAL TISSUE (if applicable)

1. The research project must ensure the species used are most appropriate.
2. Alternatives to the use of animals should be sought.
3. The number of animals used should be the minimum required for statistical analysis.
4. The severity of the procedures should be kept to a minimum and if painful procedures are necessary, appropriate steps are taken to minimise pain and suffering.
5. Appropriate legislation concerning the use of animals for research must be followed.

USE OF FOETUSES AND FOETAL MATERIAL (if applicable)

1. Applicants whose projects involve the use of foetuses, foetal tissue and foetal material are expected to obtain ethical approval for their research proposals before submitting the application.
2. Grant holders have absolute responsibility for ensuring that no research is undertaken prior to permission being granted.
3. Any projects involving human embryos must be carried out under the appropriate regulatory guidelines.

REMOVAL OF HUMAN TISSUE

1. Applicants should note that Duchenne Ireland expects that any procedure undertaken during the course of their projects that involve the removal of human tissue at post-mortem examination will be carried out in accordance with the guidance issued by the Health Department/local Health authority.
2. It is the responsibility of the grant holder to check whether ethical approval is required.

STEM CELLS

1. Grant holders whose research involves the use of stem cells must adhere to the current Codes of Practice concerning the use of human stem cell lines.
2. Duchenne Ireland requires a written statement of compliance from the institution before funding will be released.

HUMAN VOLUNTEERS

1. Where human volunteers are to be involved in the research, grant holders must obtain relevant ethical approval before the project starts.
2. The voluntary informed consent of every volunteer must be obtained in writing.
3. Research involving individual patient data where the patient's consent will not be obtained may require compliance with additional procedures.
4. Grant holders and Institutions have absolute responsibility for ensuring that investigations being undertaken at any site do not take place without the explicit approval of the appropriate authority in advance.
5. Any serious incident arising in the course of a research project must be immediately reported both to Duchenne Ireland and appropriate ethics committees. The research must be suspended until the ethics committee has reached a conclusion as to whether this research may continue.

GOOD SCIENTIFIC PRACTICE

1. Duchenne Ireland expects that the researchers it funds maintain the highest standards of integrity. The Institution must have formal written procedures for the investigation of allegations of scientific misconduct.
2. It is a condition of funding that, if requested, the Institution can produce evidence of a procedure for dealing with scientific fraud. In the rare event of scientific fraud or other scientific irregularities occurring, they will not be the responsibility of Duchenne Ireland.
3. The Institution must ensure that funded work is adequately supervised, monitored and evaluated at all times.

INTELLECTUAL PROPERTY (IP) AND OTHER RIGHTS

1. Duchenne Ireland requires the Institution to develop and implement strategies and procedures for the identification, protection, management and exploitation of Duchenne Ireland funded intellectual property. The Institution is required to ensure that all those associated with the research process are aware of, and accept, the procedures for the notification of any device, material, product or process, computer software or other result

which it is considered might have commercial significance, whether patentable or not in good time before publication.

2. Duchenne Ireland will ensure that any results of funded research are applied for the benefit of the public. Therefore, Duchenne Ireland requires that all grant holders, Duchenne Ireland funded personnel and the Institution play an active role in ensuring the protection and exploitation of the intellectual property arising from this research.
3. The attention of Duchenne Ireland must, in good time before publication, or any other disclosure, be drawn to any results (as specified above) which might appear to be suitable for commercial exploitation.
4. The grant holder must advise Duchenne Ireland of the nature of any proposed exploitation, identifying partners and proposed sharing of royalties. If a third party is used in this process then the Institution/grant holder must provide details of the proposed third party to Duchenne Ireland and obtain Duchenne Ireland's prior written approval.
5. All intellectual property created or acquired out of the project belongs to the Institution. However, no intellectual property, created or acquired, as a direct result of Duchenne Ireland funding may be exploited commercially without the prior written consent of Duchenne Ireland. Exploitation includes the use for any commercial purpose or any license, sales, assignment, materials transfer or any transfer of rights. As a condition of granting consent Duchenne Ireland may require the Institution to agree to terms of exploitation including the sharing of benefits such as revenues and equity arising from the exploitation.
6. If the Institution does not exploit or protect any intellectual property, Duchenne Ireland shall have the right, but not a duty, to protect and exploit such intellectual property. If Duchenne Ireland decides to exercise these rights, the Institution/grant holder/grant personnel agrees to co-operate fully and to carry out all acts required to assist Duchenne Ireland in such protection and exploitation. Any commercial benefit will be shared between the Institution and Duchenne Ireland in such proportion as may be equitable, taking into account their respective contribution to the Intellectual Property.
7. The grant holder and staff employed on this grant will not accept appointment, enter into confidentiality agreements, or use material or compounds (not obtained commercially) , where any other party would place restrictions on the publication of, or obtain prior knowledge of, research findings excluding those relating specifically to the material or compounds supplied.
8. The Institution will provide detailed accounts of Royalty Income and relative costs as required from time to time by Duchenne Ireland, and in any case not less than once a year.
9. Duchenne Ireland expects that no obligations to other bodies have been entered into which are inconsistent with the terms of this agreement. In addition, the Principal Investigator undertakes not to enter into any such obligations without the consent of Duchenne Ireland.

EQUAL OPPORTUNITIES STATEMENT

1. Duchenne Ireland aims to be an equal opportunities employer. The Charity treats all people with whom it comes into contact with the same respect regardless of age, disability, political belief, race, religion, sex or sexual orientation. It endeavours to provide its services to all that need them and strives to ensure its services meet their individual needs.
2. The Institution must have an Equal Opportunities statement or policy and provide a copy to Duchenne Ireland upon request. If one does not exist, the Institution must abide by Duchenne Ireland's Equal Opportunity Statement.

ACCEPTANCE OF TERMS AND CONDITIONS

The Head of Department, Principal Applicant and Administrative Authority are required to sign this form to confirm acceptance of the Terms and Conditions as published by Duchenne Ireland.

Head of Department
I confirm that I have read and agree to abide by the Research Grant Terms and Conditions of Duchenne Ireland. I understand that, should the terms and conditions change throughout the duration of the grant, I would be required to sign my agreement to the new Terms and Conditions. Failure to do so could lead to termination of the grant.

Name: …….. Signed: ……. Date: ……
Please Print)

Principal Applicant
I confirm that I have read and agree to abide by the Research Grant Terms and Conditions of Duchenne Ireland. I understand that, should the terms and conditions change throughout the duration of the grant, I would be required to sign my agreement to the new Terms and Conditions. Failure to do so could lead to termination of the grant.

Name: …….. Signed: ……. Date: ……
Please Print)

Administrative Authority *e.g. Finance Officer, Bursar, Registrar*

The Institution accepts the Research Grant Terms and Conditions of Duchenne Ireland and agrees to abide by them. The Institution understands that the terms and conditions may change throughout the duration of the grant and the Institution would be required to sign agreement to the new Terms and Conditions. Failure to do so could lead to termination of the grant.

Name: …….. Signed: ……. Date: ……
Please Print)

Position within the Institution: ……..