

## Muscular Dystrophy Ireland Research Committee

### *Terms of reference*

July 2021



### **Purpose of the Research Committee**

The purpose of the Research Committee is to advise the Muscular Dystrophy Ireland (MDI) Board on all matters relating to research and to support the organisation in its work on behalf of people living with Muscular Dystrophy, in areas relating to neuromuscular research.

### **Committee Member Roles**

Committee members will undertake the role of MDI Research Committee Member and are requested to assist the organisation in one or more of the following ways:

- Provide support and guidance on continual development of research committee policy and procedures.
- Assist MDI in the formulation of a research strategy towards the development of treatments, cures, and improved patient outcomes.
- Offer advice and guidance on development of research partnerships.
- Assuring the responsible allocation of MDI's research funds.
- To consider the implications for MDI of emerging national and international initiatives, which have an impact on research activity, and developing appropriate responses.
- To encourage appropriate and relevant coordination of research strategies within and between organisations, including the development of interdisciplinary research.
- To advise the Board on the quality and the relevance of projects submitted to MDI for funding.
- Where possible, to advise on sources of funding for MD research.
- To bring a variety of unique and important perspectives to neuromuscular research.
- By undertaking an occasional task that will support the work of MDI in the area of research.

### **Frequency and Timing of Meetings**

The Research Committee will meet, as a minimum, 4 times per year.

### **Committee Composition**

- Chair
- Secretary
- General committee member

**Appointment:** Membership of the Committee will be determined or confirmed by the Board of Muscular Dystrophy Ireland.

The Chairperson of the Research Committee shall be selected by the Board of Muscular Dystrophy Ireland.

There shall be at least one member of the Board of Muscular Dystrophy Ireland represented on the Research Committee

The Research Committee consists of members of MDI and key experts drawn from the neuromuscular research community.

Membership of the research committee shall be drawn from a variety of expertise; scientific research, social research, family perspectives, member perspective, etc.

A staff member of Muscular Dystrophy Ireland shall provide administrative support to the Research Committee. No remuneration shall be afforded to members of the research committee without approval by the Board of Muscular Dystrophy Ireland.

**Membership time-period:** Committee members will serve for a maximum of 3 years. After this time period positions will be rotated or re-affirmed. – To be decided by MDI Board

### **Research Funding Procedure**

- When MDI has funds available for research, a meeting of the Research Committee is called. The CEO and Research and Information Officer may attend meetings of the Research Committee but do not have voting rights.
- All decisions about funding research projects are made by the members of the Research Committee.
- All funding award decisions shall be presented to the Board of Muscular Dystrophy Ireland for final approval.
- The Research Committee may, as needs arise, issue a call for proposals for funding. Applications for funding are open to any researcher, scientist or clinician who wishes to research any issue relating muscular dystrophy, including medical and social research.
- An application for funding must include details on what the research is, what the objectives are, where it will take place, what is the time scale, how much money is being sought and a breakdown of the costs.
- When the Research Committee receives applications for funding, it will send these applications to be confidentially peer reviewed. This means that other scientists and / or clinicians will assess the proposal and give their views on the methodology, costs and aim of the research.
- The Research Committee will take the views of the peer reviewers into account, along with the funds that are available for research, and will make a recommendation to MDI's Board at this stage about whether to fund the proposal or not.
- If a proposal is accepted for funding, a contract will be drawn up between MDI and the researcher / institution, setting out the terms of funding.
- Funds are paid in instalments. Awarded Researchers must submit updates in a timely manner to MDI on the status of the research in order to receive their next instalment of funding. Researchers must also agree to present to the MDI Board, Council or wider membership at least once per year while they are receiving funding to up-date the members on their research progress.
- Members of MDI who are fundraising for research purposes can make suggestions to the Research Committee around what area of research they would like the funds raised to be spent. The Committee will then request a submission for funding. The Committee will then decide whether to fund this research or not, as per the procedure outlined above.

**All decisions on research funding awards will be approved by the MDI Board who's decision is final.**