

Muscular Dystrophy UK Strategic Programme Grant Committee Terms of Reference

1. Status

- a. The Committee for the ad hoc Strategic Programme grants in neuromuscular research 2024 scheme (referred to hereafter as the Committee) is a standing sub-committee of the Medical Research Committee of Muscular Dystrophy UK.
- b. The Committee is the body responsible for advising the Board of Trustees on funding for applications to the Strategic Programme Grant scheme.

2. Objectives

a. to advise on and monitor (where applicable) the activities relating to the Strategic Programme Grant applications to Muscular Dystrophy UK.

3. Main Responsibilities

- a. to recommend awards for research grants fitting the remit of the Strategic Programme Grant scheme within the budget set;
- b. where necessary to review the research performance against plans set out in the application, bringing to the attention of the Board of Trustees any areas of note;
- c. to adhere to MDUK's Conflict of Interest Policy;
- d. to sign and agree to abide by the confidentiality agreement for Committee members;
- e. to advise on any ethical issues relating to research that may arise;
- f. to advise on how any intellectual property rights of the charity can be protected.

4. Membership

a. The Committee consists of the Chair and nine other members.

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- b. The Chair will be the Chair of the Medical Research Committee.
- c. Up to nine members will be nominated in consultation with the Chair of the Committee, Director of Research & Innovation and other MDUK research team staff. These nominations are subject to ratification by the Chair of the Medical Research Committee.
- d. Membership of the Committee will consist of a mixture of experts and people with lived experience of a condition.

5. Term

- a. This is an ad hoc committee and members will not be asked to serve again unless the scheme is extended to future years.
- b. Ex staff may not be appointed onto this Committee until at least twelve months has lapsed from their termination of employment.

6. Meetings

- a. The Committee will be required for one meeting to review the 2024 Strategic Programme Grant applications.
- b. The Committee may invite observers to its meetings as it sees fit but they will not have the right to vote.
- c. The Chair and Vice Chair of the Board of Trustees may attend the meeting at any time but do not have the right to vote.
- d. The Chief Executive, Director of Research & Innovation and other staff as required shall be in attendance but do not have the right to vote.
- e. The quorum shall be five members not including any attendees who do not have the right to vote.
- f. The Committee may appoint one of their number to be the Chair of the meeting if the Chair is unable to attend. The Committee may also appoint one of their

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number to be the Chair of the meeting if the Chair is not present within fifteen minutes after the time appointed for the meeting.

g. The Committee will provide notes of the meetings for the Board of Trustees highlighting any actions or decisions that need ratifying. These notes will be drafted by MDUK staff and reviewed by the Committee.

7. Key skills required on the Committee:

The Committee will be made up of both people with lived experience of a neuromuscular condition and researchers with experience relevant to assessment of applications in the field of neuromuscular disease. The latter must have

- a. experience in medical research;
- b. experience in grant making or grant applications;
- c. knowledge of neuromuscular conditions or related topics that can be applied to neuromuscular conditions;
- d. experience in designing research programmes.

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