

Muscular Dystrophy UK Medical Research Committee Terms of Reference

1. Status

- a. The Medical Research Committee is a standing sub-committee of the Board of Trustees of Muscular Dystrophy UK.
- b. The Medical Research Committee is the strategic body responsible for advising and monitoring activities relating to basic and medical research.
- c. These Terms of Reference are subject to review by the Board of Trustees from time to time and subject to amendment as necessary.

2. Objectives

- a. to advise and monitor the activities relating to basic and medical research of Muscular Dystrophy UK;
- b. to review the Medical Research Strategy in line with the charity's objectives.

3. Main Responsibilities

- a. to recommend awards for scientific and clinical research grants within the budget set;
- b. to regularly review the research performance against plans, including but not limited to assessing annual progress reports for live grants, 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 avoid any conflict of interest in case a member of the Medical Research Committee applies for a scientific, clinical or studentship grant;
- e. to sign and agree to abide by the confidentiality agreement for Medical Research Committee members;
- f. to take responsibility on behalf of the Board of Trustees for overseeing the research programme to ensure quality and value for money;

- g. to recommend plans and policies to the Board of Trustees and MDUK research staff on all areas relating to medical research in order to achieve the set strategic objectives of the research strategy;
- h. to identify priorities for additional expenditure or for savings as actual income dictates and to make recommendations to the Board of Trustees if outside delegated authority;
- i. to advise on any ethical issues relating to research that may arise;
- j. to advise on how any intellectual property rights of the charity can be protected;
- k. to exercise such other powers and duties as may be delegated to the Committee by the Board of Trustees from time to time.

4. Membership

- a. The Committee consists of the Chair, Vice Chair and up to fourteen other members.
- b. The Chair will be nominated by the Director of Research & Innovation and MDUK research staff and will be subject to ratification by the Chief Executive and the Chair of the Board of Trustees or the Appointments and Remuneration Sub-committee at its next meeting or by email as necessary.
- c. Up to 14 members will be nominated in consultation with the Chair of the Medical Research Committee, Director of Research & Innovation and other MDUK research team staff. These nominations are subject to ratification by the Chief Executive and the Chair of the Board of Trustees or Appointments and Remuneration Sub-committee.
- d. At certain times it might be necessary to co-opt individuals with specific expertise to attend a meeting. These individuals will have the same voting rights as full members for the specific applications that they are asked to review. However, these individuals will not vote on other applications.
- e. The Chair and Vice Chair of the Board of ex-officio members.

5. Term

- a. The Chair and Vice Chair of the Medical Research Committee will each serve a three-year term on appointment. This is renewable once for a period of up to three years. The Chair and Vice Chair can be existing members of the Committee and the time they have served as the Chair or Vice Chair will not count towards their term on the Committee.
- b. Other than the Chair, each member of the Committee will serve a three-year term on appointment. This is renewable once for the same period.
- c. Members (including the Chair and Vice Chair) may not be reappointed onto this Committee until at least three years has lapsed from the end of their previous term of membership.
- d. Ex staff may not be appointed onto this Committee until at least twelve months has lapsed from their termination of employment.
- e. No member (including the Chair or Vice Chair) will serve on the committee for more than nine years

6. Meetings

- a. The Committee will meet a minimum of once per year.
- 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 meetings 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 six 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 a meeting if the Chair or Vice Chair is unable or unwilling to chair a meeting. The Committee

may also appoint one of their number to be the Chair of a meeting if the Chair is not present within fifteen minutes after the time appointed for the meeting.

- g. The Medical Research 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. Sub-committees

- a. The Medical Research Committee can set up sub-committees as and when appropriate and delegate authority to them. Each sub-committee being on an ad hoc basis or re-formed annually.
- b. If a sub-committee is constituted to make a funding recommendation to the Board, to be quorate, it must consist of a minimum of four voting members and should ideally include equal numbers of members from the Medical Research Committee and the Lay Research Panel.

8. Key skills required on the Committee:

- 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.