



Terms of Reference

Action Duchenne Scientific Advisory Board

IT'S TIME TO STOP WASTING!

Action Duchenne Epicentre 41 West Street London E11 4LJ
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Patron: Helena Bonham Carter Registered Charity No: 1101971



Aims and Purpose

- Work with the Action Duchenne (AD) Board of Trustees to identify research and clinical trial opportunities that focus on translational research.
- Provide non-binding but informed guidance on matters specific to AD's research and funding strategies.
- Peer review applications submitted to AD for funding.
- Support any grant applications submitted by AD.
- Ensure that AD is responding to Government policies and initiatives.
- Review, edit and contribute to any relevant AD press releases.
- Support the requirements of the Duchenne muscular dystrophy community by identifying relevant areas of scientific interest that are appropriate for AD to become involved with.
- Help ensure that AD activities remain relevant to the research community where appropriate.
- Advise AD on their involvement with industry and the research community with the particular aim of improving the quality of life for the DMD community.
- Provide advice to AD on appropriate resources to support research.
- Advise other sub-committees as appropriate.
- Provide advice to AD, and any appropriate sub-committees, on issues relating to AD activities, which are either fully or partly funded by AD.
- Liaise with other relevant organisations, in particular research councils, where necessary.
- Review AD's Research Strategy annually.
- The opinions and recommendations of the SAB are to be dealt with confidentially.

Membership

- The board will consist of a Chair, Vice-Chair and up to 6 members.
- The members of the board are individuals, external to Action Duchenne, who have scientific knowledge, experience and expertise relevant to DMD.
- All board members will be asked to complete a declaration of all potential conflicts of interest, which will be a public document that will be published on the Action Duchenne website along with members' photographs. All board members will be asked to update their conflict of interest before each review meeting.
- Board members will be reimbursed for all their travel expenses for each meeting attended.

- Board members, including the Chair and Vice-Chair are appointed for a three-year term, after which they can offer themselves for re-election immediately for an extension term of 2 years.



- Any new members wishing to join the SAB will be voted in by the current members of the SAB.

Meetings

- The SAB shall conduct its business in accordance with these Terms of Reference.
- The SAB will conduct a minimum of one in person meetings a year, plus any ad hoc teleconferences or meetings.
- There must be a quorum of members available (50%) to schedule a meeting.
- The SAB may recommend suitable topics for specialised sub-committees and panels, or liaisons with outside organisations.
- Following each meeting, the SAB provides a written report, which summarises the meeting and outlines its confidential advice. Separate meeting summaries will be made available to the public on the AD website. The report will be made available to the SAB members within 2 weeks of having the meeting.

Voting

- There must be a quorum decision for any vote to stand.

Secretariat

- The SAB is supported by a Secretariat, which will be appointed by AD. The Secretariat provides support to the SAB, prepares meeting agendas, and coordinates the preparation of documents for the meetings and prepares the meeting summaries and reports for approval by the SAB.
- The Secretariat will ensure the appropriate documents are posted on the AD website in a timely manner, providing members with access to meeting documentation, etc.
- The Secretariat prepares an annual report, maintains the budget and arranges travel for members.

Revisions of the Terms of Reference

- The Secretariat will ensure that the Terms of Reference are revised every year.