

Scientific Advisory Committee

Terms of Reference

To provide independent scientific advice to Ataxia UK's Trustees on:

- Research priorities for Ataxia UK
- Whether to fund specific research proposals
- The significance of research developments in related fields for ataxia and the development of novel research approaches
- The quality and progress of research projects funded by the Charity
- The best practice to review grant proposals
- The most appropriate mechanisms for attracting high quality research proposals
- Promoting research in the field of ataxia

How the Scientific Advisory Committee operates

The Scientific Advisory Committee meets three times a year to discuss grant applications (generally in February, June and October on mutually convenient dates). Occasionally Committee members are contacted in-between meetings to ask for specific advice. In addition, interim and final reports of projects funded by Ataxia UK are reviewed by one member and comments are circulated to the Committee by email for further comments and discussion. The quorum needed for committee meetings is 5 members, with at least 3 scientific members. To allow for unexpected absences or conflicts of interest, we aim to have at least 6 members at each meeting, with at least 4 scientific members. If a quorum is not reached, the meeting will be rescheduled.

Panel members are rotated. There is a three-year fixed term followed by a two to three year extension period. Panel members can be reinstated if they have not been on the Committee for at least three years.

Ataxia UK staff members and an Ataxia UK Trustee are in attendance at meetings of the Scientific Advisory Committee to provide information when relevant and relay discussions to Board of Trustees. They will not be involved in making funding decisions made by the Scientific Advisory Committee on research proposals.

Committee members also agree to comply by Ataxia UK's conflicts of interest and confidentiality policies (see Annex 1 and 2). After the meeting or review over email, Committee members agree to delete all emails and attachments, and destroy any hard copies of papers distributed to the Committee.

Composition of Scientific Advisory Committee

The Committee comprises independent scientists and clinicians specialising in a range of research areas of relevance to Ataxia UK including Molecular Biology, Biochemistry, Clinical Pharmacology, Physiology, Neuroscience, Genetics and Neurology. Ataxia UK has a specific policy to select individuals who are not active researchers in the ataxia field in order to minimise bias and maximise impartiality.

The Committee also includes lay representatives. These lay members are Friends of Ataxia UK who either have ataxia themselves or are close to someone who has ataxia and provide input from a patient and lay perspective. See Annex 3 for a list of current members.

Annex 1 – Ataxia UK’s confidentiality policy in research

Scientific Advisory Committee

Members of Ataxia UK’s Scientific Advisory Committee have agreed to follow principles of confidentiality during Committee meetings and in any correspondence relating to Committee meeting business. Committee members agree to not disclose any confidential information with any third parties. Confidential information would include information included in research grant applications and progress reports, recommendations made to Ataxia UK on research to fund, information provided by peer reviewers etc.

External referees

Maintaining confidentiality in the peer review process is important to Ataxia UK. We believe, in line with good practice, that the best quality peer review is obtained when the referees can comment candidly, in the knowledge that their identity will only be disclosed to those directly involved in the decision-making process and not to the applicants. Applicants will be sent comments received from peer reviewers, as this is particularly useful to applicants who have not been successful to help them understand why they have not been recommended for funding and to improve future applications and research. However, the only information passed on is that provided by reviewers in a section specifically marked as information to be passed to applicants. Any additional confidential information provided by reviewers will not be disclosed to applicants.

Annex 2 - Ataxia UK’s conflicts of interest policy in research

Scientific Advisory Committee

Ataxia UK believes that its Scientific Advisory Committee should have a significant number of non-beneficiaries in order to avoid potential bias (i.e. researchers who are not in receipt of a grant from Ataxia UK). To achieve this, it actively recruits members of its Committee from areas of research that are relevant but are not generally directly related to the ataxias.

Members of Ataxia UK’s Scientific Advisory Committee have agreed to follow these Guidelines to manage potential conflicts of interest:

1. The Chairman of the Committee cannot apply for funds for research grants during his/her tenure.
2. Members of the Committee, other than the Chairman, are eligible for funding from Ataxia UK. However, when an application from a Committee member is received, either as an applicant, co-applicant or collaborator he/she would need to be absent from the meeting room while his/her application is being discussed. He/she would also not be shown the reviewers’ reports on his/her application in advance of a decision for funding. In cases

where the decision regarding funding is not clear-cut the individual must not be in a position to influence the decision on competing applications and will therefore take no part in the discussion about prioritising applications for funding.

3. Committee members are required to declare at the beginning of a meeting if they have a conflict of interest with any agenda item. If there is a conflict of interest the same criteria as described in point 2 would apply.

Examples of conflicts of interest to declare:

- If there is an application for discussion that is similar to one prepared or in preparation by a Committee member
- If the Committee member is closely related to the applicants (e.g., spouse, sibling, parent, etc.)
- If the Committee member is a member of the same department/research group as one of the applicants
- If the Committee member has a potential commercial interest

Procedure when a conflict of interest is declared:

- Strong conflict of interest (Committee member is the applicant or co-applicant, close relationship to an applicant): the person should leave the room and not assist in the discussion of this project or ranking of projects
- Less strong conflict of interest (e.g., committee member is in the same department as applicant): not taking part of the discussion and ranking but can stay in the room

External referees

When selecting external referees Ataxia UK will make all attempts to avoid asking someone who may have a conflict of interest to review a grant. Two or three referees are selected for each grant.

Thus referees will not be:

- From the same department/research group as the applicants
- From the same Institution
- A collaborator of the applicants
- A close relative of any of the applicants
- Have co-authored work with the applicants in the last five years
- Have a potential commercial interest

It is preferable if they do not have a grant being reviewed at the same meeting, but in the event that they do, a minimum of two other referees will be sought.

In addition, all referees are asked whether they have a conflict of interest in reviewing the grant. If they do and it is considered still useful to consider their views the reason for conflict of interest is made known to the Scientific Advisory Committee when discussing the application.

Annex 3 Current members of Scientific Advisory Committee

A Chair will be selected from the scientific members of this Committee and will be rotated.

This is likely to be circulated at each meeting. Any individual member will not be a chair for more than two years.

Scientific members:

Dr Javier Alegre Abarategui

Clinical Senior Lecturer in Neuropathology
Department of Brain Sciences, Imperial College London

Professor Helen Dawes

Professor of Clinical Rehabilitation
Medical School, University of Exeter

Dr Gregory Weir

Senior Research Fellow
Centre for Neuroscience, University of Glasgow

Dr Nicola Hamilton-Whitaker

Senior Lecturer
School of Neuroscience, King's College London

Dr Richard Eva

Lecturer
School of Neuroscience, King's College London

Lay members:

Yanita Oparlakova

Dominic Jack

Anna King

In attendance:

Professor Barry Hunt (Ataxia UK Trustee Scientific Advisor)

Dr Julie Greenfield (Ataxia UK Head of Research)

Dr Emily Cutting (Ataxia UK Research Manager)

Scarlett Parr-Reid (Ataxia UK Research Communications Officer)

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