

Research Review Committee Terms of Reference

Members of the Research Review Board have volunteered their time to help Reverse Rett (RR) by making a rational, independent evaluation of the merits of proposals for Single Institute Funding designed to make progress in developing new clinical treatment options for Rett Syndrome patients. Their brief is to assess whether the proposed investment is likely to lead to significant developments and improvements in care for patients with Rett Syndrome and whether the research lies within the mission and objectives of Reverse Rett.

In addition, they will be a key part of the regular monitoring and evaluation of the progress being made by the Institute.

Single institute funding supports research programs which typically run for several years. The AMRC insists on a thorough review of progress every five years, with interim reviews annually. Setting up a new project involves higher levels of uncertainty and in our case, we intend to have a major review after three years. A minimum of three years is needed to allow the project to be set up, start the clinical treatments and to evaluate the quality of work in, and the output from, the project.

Members of the Research Review Board will represent a range of experience which is relevant to the issues surrounding the treatment of Rett patients and the nature of the research which will be conducted. We aim to have medical doctors, data analysis specialists, and nonmedical specialists working in the field of Rett syndrome and lay people on the Board. They will generally not be active in the field of research into Rett Syndrome or have any relationship to the institute which is being considered for funding.

They will be asked to use their judgement on research proposals, supported by input from external reviewers, and to make a recommendation to the Board of Trustees of Reverse Rett as to whether the research should be funded by the charity.

When appropriate, they should also feel free to make suggestions on how research proposals could be improved in order to meet the required value standard.

Add to the Research Review Committee ToR that their remit includes the review of 3rs when necessary.

Role of Members

Evaluation of project

1. To evaluate proposals and make recommendations to the Board of Trustees as outlined above.
2. To review the 3Rs regarding use of animals in research throughout all application processes and refer to NC3Rs where appropriate.
3. To participate in the process of ongoing evaluation of progress of projects.

Research Strategy

4. To provide in putto the periodic review of the RR Research Strategy; keep under review the achievement by the charity of the goals of the Research Strategy and to recommend changes as appropriate.

Policies and Briefing

To adhere to the Confidentiality Policy and the Conflict-of-Interest policy, bringing attention to the Board of any concerns in these areas.

5. To support the AMRC's position statement on the use of animals in research and to endorse the AMRC position statement supporting research in universities.

6. Members of the research Review committee will be briefed on the AMRC Principles of Peer Review including Single Institute funding.

Meetings

7. We hope to occasionally hold in person meetings of the Reverse Rett Research Review Committee. Usually, however and for the foreseeable future, the meetings will be online via Zoom or Teams.

Members are required to declare at the beginning of every meeting if they have a conflict of interest with any agenda item.

Members may need to be contacted between meetings to ask for specific advice.

Membership

8. Membership of the Committee will normally be for three years. This is to allow rotation of members. Members who are on the first Committee may have to serve longer in order to establish rotation. Members are co-opted by the Board of Trustees.

The term can be renewed for a second three years.

Reimbursement

9. Members of the committee will be reimbursed for any reasonable travel costs and any other pre-authorised expenses incurred in the role.

