



Research Review Committee Terms of Reference

Members of the Research Review Committee 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 patients with Rett Syndrome. 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 Committee 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 laypeople 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.

Role of Members

Evaluation of projects

1. To evaluate proposals for single institute funding and make recommendations to the Board of Trustees as outlined above.
2. To participate in the process of ongoing evaluation of progress of the institute.

Research Strategy

3. To provide input to 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

4. To adhere to the Confidentiality Policy and the Conflict of Interest policy, bringing attention to the Board of any concerns in these areas (*Should they sign any other RR policies*)
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 be able to hold a face to face meeting for the inaugural meeting of the Research Review committee. Usually however the meeting will be video conferences due to the wide geographical spread of the members.
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.