



THE BRITTLE BONE SOCIETY

Research Committee Terms of Reference

The Brittle Bone Society (“BBS”) Research Committee has been formed at the request of the BBS Executive Committee to provide independent scientific advice on the way in which BBS uses its research funds, so that these funds are used as wisely as possible and in line with BBS’s mission. Its members participate on a voluntary basis, and there is no stipend or employment relationship associated with participation on the Research Committee.

The Research Committee has been asked by the Executive Committee to advise the Executive Committee on BBS’s research strategy, to make recommendations as to which research grant applications BBS should support and to recommend change and develop as appropriate. The Research Committee is BBS’s internal peer review committee.

Members of the Committee are appointed by the Executive Committee and will be selected to ensure a broad range of inputs from clinicians and researchers in areas relating to Osteogenesis Imperfecta (OI) but will not generally be active researchers in the field of OI. This is to minimise bias and conflicts of interest. Lay members may also be appointed. Members of the Executive Committee may also be appointed to serve on the Research Committee. The Executive Committee will appoint the Chair of the Research Committee.

Members of the Research Committee are appointed by the Executive Committee for a three year term. This term may be renewed for a single second term.

The Research Committee will generally be constituted by [6] members, although this may change from time to time, as determined by the Executive Committee. [3] is a quorum for conduct of the Committee’s business and decisions shall be taken by the Research Committee by majority vote (the Chair voting only once). All actions by the Research Committee must be confirmed by the Executive Committee.

Introduction

Role of Committee

Research investment

- To support BBS’s commitment of ensuring the research it funds adds the greatest possible value to the overall research activity in the field of OI.
- To maintain an overview of OI research and related fields being undertaken and to identify and make recommendations to the Executive Committee on the most appropriate areas for research investment.
- To maintain an overview of research projects funded by BBS, including areas and research spend.

- To make recommendations on existing processes for calling research applications and to evaluate external peer review feedback and the process in which BBS makes decisions on which applications to fund.

Research strategy

- To develop a research strategy for BBS, taking into account global research efforts and scientific advice.
- To provide advice on BBS's research strategy, to keep under review the achievement by BBS of its agreed research strategy and to recommend changes as appropriate.

Communication

- At the request of the Executive Committee, to communicate to the donors and supporters of BBS in a 'user friendly' manner.
- To be a point of contact to provide advice on BBS's response to press articles, and to assist staff in interpreting scientific findings and research project data.

Integrity

- To assess all research investment processes undertaken by BBS and the research funded against the highest standards of ethical and research best practice.

Peer review

External and internal reviews are used for deciding the scientific quality of research applications.

Applications will be assessed by a minimum of two external experts with appropriate experience and expertise relating to the application. Once external reviewers have provided a written report on the research application, their feedback will be passed onto the Research Committee to assist in assessment of the applications.

Lay members on the Committee are not expected to judge the science of research projects. They are asked to assess the importance and impact of the project from a patient representative perspective. They look at what the potential benefit of a proposed research project is for a person affected by OI and his/her family.

Conflict of Interests

All members of the Committee must comply with BBS's Conflicts of Interest Policy. They must maintain strict confidentiality ensuring all verbal or written information shared is kept within the Research Committee and, if requested within the Board of Trustees.

Members of the Committee, other than the Chair, a member of the Executive Committee or a patient representative, are eligible to apply for funding but he/she must be absent from the meeting room whilst the application is being discussed. He/she is not to be given access to the external review reports. Members are required to declare at the beginning of every meeting if they have a conflict of interest with any agenda item.

Working Meetings

- The Research Committee will meet once a year (unless agreed otherwise).
- Teleconference meeting may be held to discuss projects funded by BBS and any other items. Members may need to be contacted in-between meetings to ask for specific advice.
- Brittle Bone Society staff may be in attendance at a meeting but will not be involved in the Committee's decision process on research applications.
- Details of applications, meeting papers and related correspondence and the names of external referees are strictly confidential and should not be discussed with persons outside the review process.
- If a Committee member is approached by an applicant for technical advice on an application, he or she may provide advice, but must report this to the Committee Chair. They may subsequently be asked by the Chair to absent themselves from discussion of the application concerned.

Reimbursement

- All members of the Committee will be reimbursed for any reasonable travel costs and any other pre-authorised expenses incurred in the role.