



Brittle Bone Society Scientific Advisory Board Terms of Reference 6th March 2021

1. INTRODUCTION

In 2016, the Brittle Bone Society ("the Charity") established a Research Committee separate from and independent of the Charity, to provide independent scientific advice on the way in which the Charity uses its research funds, so that these funds are used as effectively as possible and in accordance with the Charity's objects, which include advancing research into the causes, inheritance and management of the bone condition Osteogenesis Imperfecta ("OI"). The Research Committee was subsequently renamed the "Scientific Advisory Board" ("SAB"). The members of the SAB participate on a voluntary basis and there is no stipend or employment relationship associated with such participation.

Members of the SAB are appointed by the trustees of the Charity ("the Trustees") for a three-year term, which may be renewed for a single second term.

The SAB has been asked by the Trustees to advise the Charity on its research strategy and to make recommendations as to which research grant applications the Charity should support.

Members of the SAB are appointed by the Trustees and will be selected to ensure a broad range of inputs from clinicians and researchers in areas relating to OI. Lay members may also be appointed. Trustees may also be appointed to serve on the SAB. The Trustees will appoint the Chair of the SAB.

2. ROLE

The SAB's role is:

- (A) To support the Charity's commitment to ensure that the research it funds adds the greatest possible value to the overall research activity in the field of OI.
- (B) To maintain an overview of OI research and related fields being undertaken and to identify and make recommendations to the Trustees on the most appropriate areas for research investment.
- (C) To maintain an overview of research projects funded by the Charity, including areas of research and research spend.
- (D) To make recommendations on the Charity's processes for considering and prioritising research applications for funding.
- (E) To help develop and maintain a research strategy for the Charity, taking into account global research efforts and scientific advice.



(F) At the request of the Trustees, to communicate to the donors and supporters of the Charity in a 'user friendly' manner.

(G) To be a point of contact to provide advice on the Charity's response to press articles, and to assist staff in interpreting scientific findings and research project data.

(H) To assess all research investment processes undertaken by the Charity and the research funded against the highest standards of ethical and research best practice.

3. PEER REVIEW

The SAB is the Charity's internal peer review committee and will:

(A) Work with the Charity to send out applications for research funding made to the Charity, either ad hoc or in response to a funding call, to independent peer reviewers.

(B) Once at least two external reviewers have provided a written report on the research application, their feedback will be passed onto the SAB in order to undertake a prioritisation exercise in concert with the Charity.

Lay members on the SAB 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.

4. OPERATION

The SAB shall operate as follows:

(A) The SAB will comprise up to ten members including clinicians, researchers, members of the Charity and Trustees.

(B) The term of office of each member of the SAB will be three years from the date of his or her appointment. Such appointment may be renewed on one occasion only for a further three years by agreement between the Trustees and the member in question. The maximum term of office any one can serve is therefore 6 years.

(C) The Trustees shall appoint members of the SAB, subject to the maximum number set out in paragraph (A)1. The Trustees may remove any member of the SAB from his or her position, by notice in writing. The members of the SAB will select, by majority vote, one of their member to be proposed to the Charity as the Chair of the SAB and, after approval by the Charity.

Such member will hold that position until he or she is replaced as such or his or her appointment to the SAB comes to an end.



(D) The quorum for meetings of SAB will be three members present in person or by telephone.

(E) The SAB will meet once a year by tele/videoconference.

(F) Tele/videoconference meetings 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.

(G) Representatives of the Charity may be in attendance at meetings of the SAB but will not be involved in the SAB's decision process on research applications.

(H) If a SAB member is approached by an applicant for technical advice on an application, he or she may provide advice, but must report this to the SAB Chair. They may subsequently be asked by the Chair to absent themselves from discussion of the application concerned.

(I) All members of the SAB will be reimbursed for any reasonable travel costs and any other pre authorised expenses.

1 Committee vacancies will usually be advertised in the Charity's Members' Newsletter and through (1) relevant medical journals and charitable periodicals; (2) the Charity's website; and (3) through the appropriate networks of the Health Professional's involved in the SAB. Candidates will submit applications and these applications will be assessed by the Chair and the Trustees, and where necessary they may be interviewed by the Committee Chair. Recommendations will then be made to the Appointments Committee which will include the Trustee Board.

5. CONFLICTS

All members of the SAB must comply with Charity's Conflicts of Interest Policy. They must maintain strict confidentiality, ensuring all verbal or written information shared is, unless requested by the Trustees, kept within the SAB.

Apart from the Chair and any member who is a Trustee or a patient representative, members of the SAB, 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 of the SAB are required to declare at the beginning of every meeting if they have a conflict of interest with any agenda item.

6. REVIEW AND AMENDMENT

The Trustees will review these Terms of Reference on a regular basis and may amend these Terms of Reference as they shall think fit and shall give notice of any such amendment to the members of the SAB.

(6th March 2021)