



# Scientific Advisory Board Terms of Reference

## 1. INTRODUCTION

In 2016 the Brittle Bone Society ("**the Charity**") established a Research Committee, to provide expert 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 SAB advises the Trustees of the Charity ("**the Trustees**") on the Charity's research strategy and makes recommendations to the Trustees as to which research grant applications the Charity should support.

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 selected by the Trustees to ensure a broad range of inputs from clinicians and researchers (who may be active or retired) in areas relating to OI. Lay members of the Charity may also be appointed. Trustees may also be appointed to serve on 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 provide external peer review feedback to the process by which the Charity makes decisions on which applications to fund.
- (F) To help develop and maintain a research strategy for the Charity, taking into account global research efforts and scientific advice.
- (G) To provide advice on the Charity's research strategy, to keep under review the achievements by the Charity of its agreed research strategy and to recommend changes as appropriate.
- (H) At the request of the Trustees, to communicate to the donors and supporters of the Charity in a 'user friendly' manner.
- (I) 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.
- (J) 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) Carry out external and internal reviews of the scientific quality of research applications.
- (B) Assess applications through a minimum of two members of the SAB or other external experts with appropriate experience and expertise. Once external reviewers have provided a written report on the research application, their feedback will be passed to the SAB to assist in assessment of the applications.

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 Trustees shall appoint members of the SAB, subject to the maximum number set out in paragraph (A)<sup>1</sup>.
- (C) Members of the SAB are appointed for an initial three-year term, following which they are eligible to be reappointed by the Trustees for additional three-year terms. The Trustees may remove any member from the SAB by notice in writing.
- (D) 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, subject to approval by the Charity. Such member will hold that position until the member wishes to resign or is replaced or such member's term of office comes to an end. The quorum for meetings of SAB will be three members present in person or by tele/videoconference.
- (E) The SAB will meet at least once a year and more often at the request of the Trustees or the Chair. Meetings may be held in person and/or via tele/video conference. Members may need to be contacted in-between meetings to ask for specific advice.
- (F) Meetings may be held to discuss projects funded by the Charity and any other items relating to the Charity's research strategy.
- (G) Representatives of the Charity who are not members of the SAB may be in attendance at meetings of the SAB but will not be involved in the SAB's decision process on research applications.
- (H) All members of the SAB will be reimbursed for any reasonable travel costs and any other preauthorised expenses.

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<sup>1</sup> 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) appropriate networks of the Health Professionals 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.

## **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.

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.

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 such member must be absent from the meeting room whilst the application is being discussed and is not to be given access to the external review reports.

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. Such SAB member may subsequently be asked by the Chair to be absent from discussion of the application concerned.

## **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.

(4<sup>th</sup> April 2024)