

Scientific Advisory Board (SAB)

Terms of Reference

1 Purpose

The purpose of the Scientific Advisory Board (SAB) is to offer advice on scientific and medical matters when called upon by the IamGSD Board of Trustees.

2 Activities

The SAB's activities are to be exclusively scientific and educational, including but not limited to:

1. Recognizing the values and mission of IamGSD;
2. When called upon, reviewing any materials containing scientific information to be made available to members and the public, including scientific information disseminated online and in print;
3. Contributing to the identification of external funding sources including, but not limited to, grants and sponsorships;
4. Advising on the scientific merit, originality, and contribution to the area of muscle GSD of any research projects seeking funding;
5. Assisting in the identification of new areas of scientific research about muscle GSD;
6. Attending in-person or telephone conference call meetings to discuss updates and goals for the upcoming year (minimum once per year);
7. Providing recommendations for grants, events, and research in the best interest of the organization and muscle GSD patients.

3 Procedures

The SAB must adhere to the following:

- a. The SAB will be comprised of no less than three members.
- b. The Chairman of the SAB shall be appointed by the IamGSD Board.
- c. Each SAB member shall be appointed by the IamGSD Board for a three-year term of office (fiscal year January – December), with possible reappointment following the end of their term for another term, capped at three consecutive terms.
- d. Approval by the IamGSD Board for any activities performed by the SAB on behalf of the organization, prior to public dissemination.
- e. Actions performed should be in the best interest of the organization and cannot personally profit any member(s) involved in the review and approval of the activity.

4 Conflict of interest policy

No member of the IamGSD SAB shall derive any personal profit or gain, directly or indirectly, by reason of his or her participation on the SAB. Each individual shall disclose to IamGSD any personal or financial interest which he or she may have in any matter pending before IamGSD, and shall refrain from participation in any discussion and decision on such matter.

7 May 2019