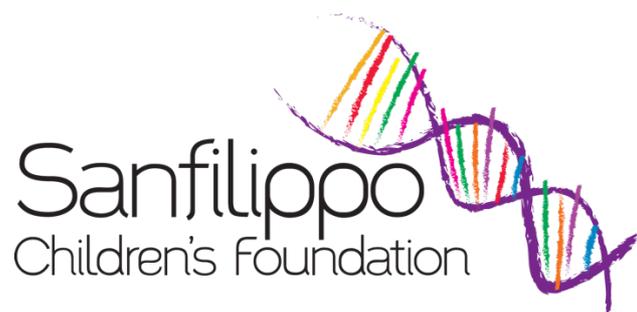


# Scientific Advisory Board Terms of Reference

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## 1 Aims & Purpose

- Work with the Sanfilippo Children's Foundation (SCF) Board of Directors to identify research and clinical trial opportunities
- Provide non-binding but informed guidance on matters specific to SCF's research and funding strategies
- Peer review applications submitted to SCF for funding and provide recommendations on projects to be funded
- Support any grant applications submitted by SCF to other funding bodies
- Contribute to any relevant SCF research media opportunities.
- Participate in periodical reviews of SCF's Research Strategy.

## 2 Duty and Values

- Members of the SAB agree to act in the best interests of the SCF, in good faith and in an open, honest, professional and courteous manner.

## 3 Membership

- The SAB will consist of a Chair, Deputy Chair and up to 9 members.
- The members of the SAB are individuals, external to SCF, who have scientific knowledge, experience and expertise relevant to Sanfilippo and/or associated research disciplines. The majority will be active in research.
- The board should include a significant number of non-beneficiaries, and beneficiaries should not be present when the decisions are made.
- SAB members will be reimbursed for all their travel expenses for each meeting attended.
- SAB members are appointed for a three-year term, after which they can offer themselves for re-election immediately for an extension term of 2 years.
- Potential new SAB members will be nominated by the SCF Board of Directors or current members of the SAB. Reliance on one person to nominate individuals should be avoided.
- Any new members wishing to join the SAB will be voted in by the current members of the SAB.
- All SAB members will be asked to complete a declaration of all potential conflicts of interest and update this before each review meeting.
- A SAB member may retire or resign his/her office at any time and is requested to provide written notice to the Board of Directors of his/her decision to do so.

## 4 Nomination of the Chair and Deputy Chair

- The Chair and Deputy Chair are appointed for a three-year term, after which they can offer themselves for re-election immediately for an extension term of 2 years.
- The Chair and Deputy Chair will be nominated by the SCF Board of Directors or current members of the SAB. All members of the SAB will be given the opportunity to nominate for these positions. Reliance on one person to nominate individuals should be avoided.
- The Chair and Deputy Chair will be voted in by the current members of the SAB.

## 5 Role of the Chair and Deputy Chair

- The chair will:
  - contribute to determining the agenda for meetings where appropriate (circulated by the secretary)
  - chair meetings of the SAB and take reasonable steps for the proper functioning of the SAB, including ensuring proper conduct of meetings, facilitating an appropriate level of discussion, ensuring that every member's views are considered, and where possible seeking consensus amongst the members
  - take reasonable steps regarding the adequate flow of relevant information to, and from, the SCF Board of Directors;
- If the Chair of the SAB is not present at a meeting of the Board, the Deputy Chair will act as Chair for that meeting. If the Chair and Deputy Chair are not present at a meeting of the Board, the members present may elect another member to act as Chair for that meeting.
- It is recommended that the Chair should not be eligible for funding during their tenure, however if this cannot be avoided then the Deputy Chair must step in at meetings where an application by the Chair is being considered.
- The chair has sole discretion on small grants of 10k or below – travel grants and co-funded scholarships. The chair's recommendation will be passed to the Board of Directors for a final decision on funding.
- It is recommended that the Chair of the SAB attends (or joins by teleconference) SCF Board of Directors meetings as necessary to maintain a line of communication between the SAB and the Directors.
- The Chair will be consulted if the SCF Research Manager or SCF Board of Directors have concerns regarding the progress of a funded research project.
- If there is a declared conflict of interest between the chair and an applicant or grant holder the deputy or another SAB member will be nominated to assess such applications and grant progress reports.

## 6 Meetings

- The SAB will conduct a minimum of two meetings per year (either in person or by teleconference), plus any ad hoc teleconferences or meetings as necessary.
- All members must declare any conflicts of interest should they arise during the meeting.
- There must be a quorum of members available (50%) to schedule a meeting. There must be at least three members of the SAB with scientific/medical background and up to three lay members (including SCF Directors).
- The SAB may recommend suitable topics for specialised sub-committees and panels, or liaisons with outside organisations.
- The opinions and recommendations of the SAB are to be dealt with confidentially.
- The outcomes of research funding decisions will be publicised on the SCF website excluding any confidential information.
- Up to two members of the SCF Board of Directors may attend SAB committee meetings as observers who may give advice on the objectives and priorities of the charity but will not make comment on the scientific merit of applications.

## 7 Voting

- A consensus on any particular issue shall be reached by a:
  - (i) simple majority of votes cast in favour by members present and eligible to vote; or
  - (ii) resolution in writing signed by the majority of members eligible to vote.
- In the event of an equal number of votes being cast for or against a motion, the Chair will exercise a casting vote.
- If a member has a conflict of interest in relation to any motion, he or she must abstain from voting
- Decisions made by the SAB will be passed as recommendations to the Board of Directors for final funding decisions.

## 8 Principles of peer review

SCF requires SAB members to adhere to the [NHMRC peer review guidelines](#) that outline best practice for the conduct of peer review:

As such, it is expected that SCF peer reviewers:

- are fair, accurate and honest in their review;
- give constructive feedback
- act in confidence and do not disclose the content or outcome of any process in which they are involved;

- declare all conflicts of interest and do not permit personal prejudice to influence the peer review;
- do not agree to participate in peer review outside their area of expertise;

In particular the NHMRC guidelines go into considerable detail about conflict of interest. SAB members should consider these guidelines in relation to grants being considered, declare any conflict of interest and abstain from voting/scoring of grants.

SAB members must not discuss applications with applicants and, similarly, applicants should not approach SAB members either before or after the SAB meeting. All correspondence should be made via SCF.

## 9 Grant application review process

### 9.1 Translational Research Grants and Incubator Grants

#### 8.1.1 Expression of Interest

- Researchers will first be asked to submit an Expression of Interest (EOI) application and state in a cover letter any conflicts of interest with SAB members (listed on the SCF website).
- EOIs will be circulated to all SAB members with the exception of those with a declared conflict of interest. Only the project title and researcher name will be provided to SAB members with a conflict of interest. A speaker will be assigned to each EOI.
- The SAB will meet (may be by teleconference) to consider the EOIs and decide which applicants to invite to submit full applications. This will be decided by a simple yes/no vote.
- SAB members with a conflict of interest will be asked to leave the meeting while those applications are discussed.

#### 8.1.2 Full applications

- We will aim to have all Translational Research Grants and Incubator Grants reviewed by at least two external reviewers. More reviewers may be sought if further expert advice is required on certain methodologies for example.
- External reviewers will be chosen and invited to provide external review by a SCF staff member, or contract staff member with relevant qualifications (e.g. Research Manager) in consultation with members of the SAB. Reviewers suggested by the applicant will be considered alongside other experts in the field. Overseas reviewers may be sought and may be desirable to give a perspective on how the research fits in with international activities.
- Grant applications, along with reviewer's comments, will be forwarded to all SAB members (except those with a declared conflict of interest) within a reasonable time period prior to a planned SAB meeting.
- A scoring matrix based on the agreed assessment criteria (scientific quality, significance and/or innovation and team quality and capability) will be provided to external reviewers and SAB members
- As for the EOIs, SAB members with a conflict of interest will be asked to leave the meeting while those applications are discussed.

- Comments and recommendations for funding will be compiled from the SAB meeting and forwarded to the Board of Directors for a final decision on funding.

## 9.2 Scholarships and Fellowships

- Scholarship and Fellowship applications will be considered by the SAB alone without external peer review. They will then make their recommendation to the SCF Board of Directors.
- References from the applicant's nominated referees must be submitted using the supplied form by the referee by the advertised due date.
- Peer review of co-funded scholarships (such as NHMRC and Adelaide University) will be handled by the co-funder and the SAB Chair will have sole discretion on recommendations made to the SCF Board of Directors on whether to go ahead with funding of the proposed candidate (unless there is a conflict of interest in which case the Deputy Chair or another SAB member will be nominated to undertake this role).

## 9.3 Travel Grants

- Travel Grant applications will not be part of the annual grant round process, but will be considered on an ad hoc basis throughout the year.
- The SAB chair will consider applications and give advice to the SCF Board of Directors (unless there is a conflict of interest in which case the Deputy Chair or another SAB member will be nominated to undertake this role).

## 10 Monitoring Grant Progress

- The SCF Research Manager will receive updates from grantees and will assess progress against agreed milestones. The SAB chair will be consulted if there are concerns regarding progress (unless there is a conflict of interest in which case the Deputy Chair or another SAB member will be nominated to undertake this role). Any concerns may be discussed with the other SAB members and fed back to the Board of Directors.
- Funding for subsequent years of the project may be withheld if progress is unsatisfactory and the Chief Investigator is unable to give a valid reason for the delay and a plan to rectify the situation.
- A recommendation to withhold funding will be voted on by the SAB, convening a special meeting/teleconference if necessary, but the final decision will lie with the Board of Directors.

## 11 Secretary

- The SAB is supported by a Secretary, which will be appointed by SCF. This will ideally be a person acting in a Research Manager role for the charity. The Secretary provides support to the SAB, prepares meeting agendas, and coordinates the preparation of documents for the meetings and prepares the meeting minutes for approval by the SAB.
- The Secretary will ensure the appropriate documents are available to the SAB in a timely manner

- As soon as reasonably practicable following a meeting of the Board, the Secretary will prepare a draft of the minutes of that meeting. The minutes are not intended to be a verbatim transcript of the meeting but rather a true and objective summary of key areas of discussion, any opposing views on an issue and key actions and recommendations.
- The Secretary will circulate the draft minutes to all Members and will accommodate all return comments in the next draft of the minutes prior to submission to the SCF Board of Directors.

## 12 Lay Members

- Up to two lay members, preferably family members of patients with Sanfilippo Syndrome, may be invited to attend SAB meetings by the Chair or Board of Directors to give their perspective on the relevance of different types of research for families and make comment on the appropriateness of any research that involves patients.
- Lay Members should be chosen for the SAB that we feel can represent the interests of the whole Sanfilippo community not just a particular subtype or age group for example.
- Lay members and scientific/medical members of the SAB must listen respectfully to the perspective of each other.
- In the same way that scientific/clinical members of the SAB must declare conflicts of interest, lay members must also declare conflicts of interest and abstain from voting. For example, if a project might directly benefit a family member through inclusion in a clinical trial.
- Lay members will not be allowed to comment on the scientific merit of applications but will have voting rights enabling them to contribute towards deciding on funding priorities.

### Authorisation

The signing of this Terms of Reference implies that the Sanfilippo Children's Foundation Scientific Advisory Board Member will strive to follow the guidelines set out here to the best of their ability to ensure a fair and equitable grant funding process.

Scientific Advisory Board Member Name:

Signature:

Date: