



Support Grant Program: Terms of Reference

Aim:

- To provide a mechanism for financial support to help people in Australia and New Zealand living with Fibrodysplasia Ossificans Progressiva.
- To assist FOP Australia to fulfil the organisation's objective of providing support to people living with FOP in a transparent and unbiased way, within the small community associated with this rare disease.

Design rationale:

Supporting those living with FOP in Australia and New Zealand is a key objective of FOP Australia.

FOP Australia recognises that each support grant will only make a small contribution towards the costs associated with living with FOP.

We are grateful to our supporters and donors for making these grants possible and aim to distribute the funds available to maximise support to as many people with FOP as possible.

The selection process has been developed to avoid bias, utilising a selection panel of people who are not from or directly linked to a FOP family in Australia or New Zealand.

A FOP Australia returning officer will store and handle application details confidentially and only the name (and bank details required to transfer funds) of the applicants will be shared with the FOP Australia board.

Eligibility criteria:

To be eligible for a grant an individual must:

- Have FOP or direct caregiver for someone with FOP. Proof of the diagnosis of FOP may be required (ie. in the event where the applicant is not already known to FOP Australia as someone with FOP). A caregiver does not need to be registered with Centrelink as a carer to be eligible.
- Live in Australia or New Zealand (and must be able to confirm this with appropriate ID documents if requested)
- Be a member of FOP Australia
- Not have been awarded an FOP Australia support grant in the past two years. (NB. Note that each individual must only use one support grant for the purpose of international travel every five years)
- Only one application per family will be accepted each round
- As recommended by IFOPA, if the applicant would be eligible for an IFOPA Quality of LIFE award, the applicant will be advised to apply for an IFOPA Quality of LIFE award instead

Applicants/potential applicants or their supporters must not contact members of the selection panel directly to request funds or attempt to influence the selection process. Members of the selection panel will be required to report any such contact to the returning officer. Any applications potentially affected will be removed from selection due to the need to maintain a demonstrably unbiased process, and to ensure that the time and privacy of the members of the selection panel is respected.

No special consideration or conditions will apply for members of the board or their families. Because of the independent nature of the selection process, they will not be excluded from applying. However the family of the current returning officer is not eligible to apply for the current round.



Amount:

Each application can be for up to a total of \$1000.

Timing and number of grant rounds:

- When the board decides that sufficient funds have been allocated to support activities to open a round of grant applications (ie. when no less than \$1000 is available for grants) the board will announce a round of support grant and the date for submission of applications.
- Announcement of the grant round will be sent directly to FOP families registered with FOP Australia, along with application details and Terms of Reference.
- It is anticipated that there will be a round announced after the conclusion of each financial year (once allocation of funds raised have been finalised). Further rounds may occur throughout the year depending on the amount of funds available and allocated by the board for this purpose.

Summary of round process:

1. Board determines sufficient funds are available to have a grant round (informs selection panel members, confirms returning officer)
2. Call for applications..
3. Returning officer confirms eligibility of applications before sending on to selection panel
4. Selection panel members review applications and give feedback to returning officer, including any questions from the selection panel for further information (for the returning officer to obtain from the applicants and provide back to the selection panel).
5. Returning officer informs applicants of outcomes, and informs treasurer of names and account details of successful applicants

Receipt and de-identification of applications:

- **Returning officer:** The returning officer (to receive applications and liaise with the selection panel) will be the FOP Australia secretary or their delegated representative. The identity of the returning officer will be confirmed by the board prior to the round opens and will be available to applicants if requested. They will be bound by the FOP Australia Code of Conduct including the need to maintain confidentiality. In this instance that includes ensuring that they access only essential information about the application and ensure that information is managed securely. The returning officer must not be an applicant or the relative of an applicant in the current round of grant applications.
- **Confidentiality of applications:** Application forms will be stored confidentially for a period of ten years and then all copies will be destroyed. All emails relating to the applications will be through the official FOP Australia account and will be removed from the email account as soon as possible. Any attempt to access application information by a member/director of FOP Australia other than the returning officer will be considered a breach of the Code of Conduct and managed accordingly. The successful recipient's name and amount allocated will be known to the full board

in order to facilitate transfer of funds, but the other details of the application will not be available to the full board.

- **Incomplete forms:** The returning officer will check applications are complete and forward them to the selection panel, along with a copy of the selection criteria and assessment form. Incomplete application forms will be ineligible. The returning officer will advise the applicant of missing information and allow two weeks for that application to be included if the extra information is supplied. Beyond this, the returning officer will not be obligated to seek further information to complete the application.

Selection panel composition:

- The selection panel will comprise either 3 or 5 members.
- To maintain objectivity and transparency of the selection panel, members must not have a current direct personal or professional link with a FOP family in Australia or New Zealand. This includes being in the same family, sharing an employer, or being involved in an individual's clinical care. Where an IFOPA staff member is on the selection panel, it is anticipated that they will have had contact with FOP families globally, and therefore the FOP Australia board will determine whether they have sufficient interaction with any individual Australian/New Zealand FOP family to cause bias or perceived bias in the selection process. Members of the selection panel must inform the board if they develop personal or professional links with a FOP family in Australia/New Zealand whilst serving on the panel, and will be expected to resign as soon as a replacement can be identified.
- The majority of the panel should be from Australia and/or New Zealand, in order to have sufficient knowledge of the other sources of funding available through existing services or organisations.
- The selection panel will be appointed by the board of FOP Australia and named on the FOP Australia website. When a selection panel member resigns the board will source a replacement. Suggestions for replacements from the FOP community will be welcomed for consideration, with respect to the eligibility criteria.
- The panel will ideally include:
 - A medical representative:** Someone with a medical perspective of caring for those with functional impairments and disability services, preferably with experience with rare diseases and patient organisations, and FOP in particular if possible. Preferable to be Australian based given FOP representative will have to be sourced internationally.
 - An allied health representative:** Someone with experience of disability services in a professional capacity.
 - An FOP advocacy representative:** Someone with understanding of FOP. Due to the small FOP population within Australia/New Zealand and the need for objectivity and transparency, this person will almost certainly need to be sourced internationally. Would be suitable for person living with FOP, community advocate or IFOPA representative, where they meet the other eligibility criteria.
- Where the above representatives cannot be identified, or if those positions have already been filled, the panel may also include individuals judged by the board to have sufficient knowledge and skill can also be appointed to the board as long as they meet the other criteria above.
- Members of the selection panel will receive honorary lifetime membership of FOP Australia.

- Members of the selection panel will be required to report any direct requests for funding that they receive to the applications returning officer so that applications from those potential applicants are excluded from the selection process for that round.

Selection criteria:

- The grant must be used to improve the life of a person with FOP. This can include indirect methods such as supporting their carer, as long as it results in improving the life of the person with FOP.
- The grant must meet a financial need that could not otherwise be fully met, including through an IFOPA Quality of LIFE award or NDIS funding.
- The selection panel are guided that the organisation's preferences for allocation of funding are for:
First tier: To directly assist a person with FOP in accessing medical care or with activities of daily living.
Second tier: To assist a person with FOP in improving quality of life by other means
Third tier: Assistance for carer or items not directly used by person with FOP- Reviewers (members of the selection panel) will be asked to complete the assessment form and return to the receiving officer within four weeks.

Review process:

- Reviewers can choose to support, not support, or object based on whether they judge that it meets selection criteria.
- If a majority of reviewers support, and no reviewer objects, and funds are available, the grant will be funded.
- If a majority of reviewers choose not to support the application the grant will not be funded
- If a reviewer does not support or objects to the application they will be encouraged to give feedback to the returning officer. That information will be sent to the other members of the selection panel so they can reconsider their judgment of that application.
- Reviewers will also be asked to score each application out of ten in regards to how well they meet the selection criteria. In this scenario, the total score for each application will be calculated by the returning officer and grants will be funded in order from highest to lowest score until funds allocated to the grant round are exhausted.
- If multiple applications eligible for the last amount of allocated funding have an equal score, the returning officer will inform the selection panel and ask each panel member to indicate which of these applications should be funded, or whether each applicant should receive a proportion of the requested funds each.
- Out of respect for their time contribution, and for pragmatic purposes, the selection process will be designed to include minimum possible time from the reviewers. Involvement by the reviewers in each round will initially be by email. However any panel member may request the selection panel hold a video/teleconference meeting to discuss the applications during a round. In that instance the returning officer will arrange the meeting and record minutes for the selection panel's records.



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- The returning officer will report back to the selection panel the consensus score and results from the panel members' assessments, and give one week for selection panel members to raise concerns or questions by email before the applications are notified of the outcome.
 - The selection panel's decision is final, no correspondence will be entered in to, and there is no obligation on the reviewer to provide feedback to applicants. However if the reviewers do wish to give feedback to applicants, they can send it to the returning officer who must then pass it on to the relevant applicants as feedback from the de-identified selection panel member

Notification of application outcome:

- The returning officer will notify grant applicants by email of the outcome of their application.
- Unsuccessful applicants may choose to reapply in future rounds
- Where applications were supported by the reviewers but not funded due to exhaustion of funds, applicants will be informed of this outcome and given the options to have their application held for the next round, or to re-apply in the next round.

Transfer of funds:

- The returning officer will ask successful applicants to send an invoice from the vendor, and FOP Australia will transfer the money direct to the vendor, notifying the applicant when this is done. In the event that this method is impractical, the successful applicant will liaise directly with the returning officer regarding an alternative method of confirming that the funds will be used for the intended purpose (the returning officer may choose to refer this matter to the board if there is doubt regarding the proposed process).
- Successful applicants will be encouraged by the returning officer to share the story of how the grant improved their life on FOP Australia publications (including the website, newsletter and social media) to encourage others to apply and to encourage potential donors to support this program.

Future revision:

- These terms of reference will be reviewed after completion of the first round of grants
- If the program continue, the terms of reference will subsequently be reviewed at least every five years.