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## 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 fulfill FOP Australia'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 and perception of bias, utilising a selection panel of people who are not from or directly linked to the family of a person currently living with FOP in Australia or New Zealand.
- A FOP Australia volunteer 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 be a 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 the FOP Australia board 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)
- 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.



### **Amount:**

Each application can be for up to a total of \$1500.

### **Decision to open for applications:**

- When the board decides that sufficient funds have been allocated to support activities to be open to applications (ie. when no less than \$1500 is available for grants) the board will announce that applications are open to members via the website, email and social media.
- When applications are closed (due to insufficient funds, or insufficient volunteer resources to administrate the grants) this will be stated on the FOP Australia website.

### **Summary of grant application and approval process:**

1. Board determines sufficient funds are available to open for applications.
2. Board informs returning officer and selection panel members, and checks that sufficient volunteer resources exist to administrate the grants.
3. Call for applications published on website and by email.
4. When an application is received, the returning officer confirms that the application:
  - a. is complete
  - b. meets eligibility of applications criteria (including checking with the organisation's membership register, which includes lifetime free membership to people with FOP in Australia and New Zealand).before sending on to selection panel.
5. The selection panel members review applications and send feedback to returning officer with two weeks of receipt; This can include questions from the selection panel for further information (for the returning officer to obtain from the applicants and provide back to the selection panel).
6. After the returning officer has collated feedback from each selection panel member, they send the collated information to all selection panel members, allowing a week for members to voice any concerns about the outcome.
7. If successful, the returning officer then informs the board of names and account details of successful applicant, so that the board can approve and arrange release of funds
8. The returning officer then informs the applicants of the outcome, and confirms receipt of purchase of items in keeping with the terms of the application.

### **Maintaining confidentiality of application details:**

- **Returning officer:** The returning officer will be selected by the board as the FOP Australia representative to receive and process applications. They will not be from or directly linked to the family of a person currently living with FOP in Australia or New Zealand. The identity of the returning officer will be confirmed by the board prior to the opening for applications 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.



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- **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 email accounts ([info@fopaaustralia.org](mailto:info@fopaaustralia.org), [fopaaustralia@gmail.com](mailto:fopaaustralia@gmail.com), and [fopgrantprogram@gmail.com](mailto:fopgrantprogram@gmail.com)) and will be removed from the email accounts 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 according as such according the organisational policies. 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.
- The selection panel members 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 based in Australia or New Zealand, as the FOP representative will have to be sourced internationally.
  - **An allied health representative:** Someone with experience of disability services in a professional capacity. Preferable to be based in Australia or New Zealand, as the FOP representative will have to be sourced internationally, and as knowledge of available services is required.
  - **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 often 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 the meet the other criteria above.
- 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



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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.
- 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 reasonably otherwise be fully met through other means. This will include consideration of utilizing NDIS funding and/or IFOPA Quality of LIFE grants.
- 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

**Review process:**

- As above, members of the selection panel, will be asked to complete the assessment form and return to the receiving officer within two weeks.
- 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 sufficient 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. This will enable concurrent successful grant applications to be funded in order from highest to lowest score until funds allocated to the grants 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. A selection panel member may also choose to advise the board to consider allocating further funds to the support grant program in this instance.
- 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



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will initially be by email. However any panel member may request the selection panel hold a video/teleconference meeting to discuss an application. In that instance the returning officer will arrange the meeting and record minutes for the selection panel's records.

- 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 until further funds become available.

#### **Transfer of funds:**

- The returning officer will ask successful applicants to send an invoice or receipt from the vendor. In the event that this method is impractical, the successful applicant will liaise directly with the returning officer regarding an alternative method for confirming proof that funds will be, and then have been, used in keeping with the terms of the application (the returning officer may choose to refer this matter to the board if there is doubt regarding the proposed process). After confirmation of this, funds may be transferred directly the successful applicant or direct to the vendor.
- 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. However this is not mandatory, and the applicant's decision about whether or not provide information for this purpose will be respected.

#### **Future revision:**

- The terms of reference will subsequently be reviewed by the board at least every five years.

#### **Versions:**

- Version 1: July 2019.
- Version 2: December 2022. Summary of main changes: Adjusted from round structure to continuously receiving applications. Increased maximum grant amount from \$1000 to \$1500. Specifying that checking the membership register as part of confirming eligibility.