



# Review of 2016/17 KPIs

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The Strategic Plan 2016/2017 Key Performance Indicators were endorsed by the FOP Australia board of directors 5<sup>th</sup> January 2017. This review has been undertaken in order to assess the progress achieved during the remainder of the 2016/17 financial year, to allow transparency to members and the community, and to inform further strategic planning and development of key performance indicators for the 2017/18 financial year. This report was endorsed by the FOP Australia board at the September 2017 board meeting. Further information on the activities described below can be provided upon request from [info@fopaustralia.org](mailto:info@fopaustralia.org).

## **1. Provide a significant proportion of our fundraising to advances in research into treatments and/or a cure for FOP.**

### **1.1. To raise \$10 000 by the end of the 2016/17 financial year to donate to the International FOP Association in order to further global research efforts.**

- a. This target was met through fundraising activities undertaken since the confirmation of the strategic plan in January 2017, before the end of the financial year. Along with individual donations this enabled a donation of \$25,000 to be pledged to IFOPA for purposes of research. Because the total target for the donation was exceeded significantly, in addition \$5000 was pledged to the University of Pennsylvania Shore Lab, in order to further the foundational science research critical to further FOP.

*Further actions arising for 2017/18:*

1. *Transfer of funds.*

### **1.2. To utilise networks beyond the board to extend fundraising capacity, and develop policies to support this.**

- a. Mycause account was set up as a mechanism to enable individuals and groups not linked with the board to be able to run fundraisers easily (including utilising tax deductible donations and receipting facilities with no burden on the fundraisers). This has been promoted in member newsletters, website and social media. It was trialled successfully for the Bay-City fundraiser by Brooke Scott. It has not yet been a utilised for someone off the board.
- b. Peninsula City Church (contacts of Talia Wilson and Tyson Stanley) initiated a fundraiser independently, raising \$970. Although two other fundraisers were coordinated by people off the board (Jamberry – Shan Carty, contact of Talia Wilson and Entertainment Books – Amy Ellingworth, contact of previous chairperson Lara Boniface) they were both initiated by board members.

*Further actions arising for 2017/18:*

1. *Expanding the fundraising capacity has been identified in board discussions (including July 2017 meeting) as a key priority for next financial year. Suggested actions to be considered include the re-establishment of a fundraising committee, focus on working for philanthropic grants (and increasing our people-power in*

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*order to do this), continuing to promote mycause using examples of individual activities.*

## **1.3. To run a minimum of four fundraising initiatives during this period, including at least one that is accessible to all members in Australia and New Zealand**

- a. The fundraisers held since the Strategic Plan was formalised are:
  - a. Jamberry fundraiser (online, thus accessible to members nationally and in NZ). Notably, participants included a member with FOP who has significant mobility restrictions that would limit travel to other events.
  - b. Bay-City fun run (SA)
  - c. FOP Trivia Night (Victoria)
  - d. Entertainment Books (online, thus accessible to members nationally and in NZ)
- b. Additional donations were received via the GiveNow page, including the first recurring monthly donation. A donation drive was also held prior to the end of the financial year, ie. posts made on social media to encourage EOFY donations

*Further actions arising for 2017/18:*

1. *Other comments arising from board meetings regarding fundraising planning include the need for the fundraising calendar to be planned as far in advance as possible, with July-December 2017 to be finalised in July 2017 board meeting, and January-June 2018 plan finalised August 2017, with outline of anticipated events for July-December 2018 to be made August 2017 (anticipating possible changes post AGM 2017 with new board).*

## **2. Build and maintain links with the medical community, including clinicians in Australia and overseas to understand new developments in medical research and its potential application to people with FOP.**

### **2.1. Maintaining our website as a source of up to date medical information, with an annual review of the content at minimum.**

- a. Website information reviewed and updated January 2017.

*Further actions arising for 2017/18:*

1. *Twice yearly review of information and links to continue.*

### **2.2. Twice yearly medical updates to clinicians**

- a. First clinician update sent February 2017. Evidence of effect with the newsletter being mentioned by clinicians during clinic appointments for two patients.

*Further actions arising for 2017/18:*

1. *Next update planned November 2017 (post IFOPA Drug Development Forum)*

### **2.3. Maintain and expand the database of treating clinicians in order to enable effective dissemination of information, with an annual review at a minimum.**

- a. List reviewed and updated January 2017.

*Further actions arising for 2017/18:*

1. *Activities to expand contacts beyond clinicians actively managing FOP, to increase knowledge of FOP amongst other clinicians.*

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**3. Build and maintain strong links with academic centres and pharmaceutical companies that are planning or undertaking any drug trials that may have potential application to people with FOP.**

**3.1. The FOP Australia International Fibrodysplasia Ossificans Progressiva Association (IFOPA) International President's Council (IPC) representative to maintain contact with Professor Matt Brown and his team at the Queensland University of Technology throughout the year, including an annual invitation to address the board, and invitation to contribute to our member newsletters.**

a. Prof Brown has been invited to contribute to each newsletter, and submitted an article for the April 2017 edition.

*Further actions arising for 2017/18:*

1. *Invite Prof Brown to board meeting*

**3.2. The FOP Australia IFOPA IPC representative to meet via video link a minimum of four times per year with Clementia Pharmaceuticals, with updates tabled at board meetings after each occurrence, and information disseminated to FOP community when required.**

a. IPC representative has maintained contact with Clementia meeting x times in the x months since assuming the role, plus FOP Australia representative on the IFOPA Research Committee has also attended a VC with Clementia regarding clinical trial proposals. Information from Clementia disseminated through website and social media regarding:

a. Enrolling patients in Phase II palovarotene trial in Brisbane

b. Future plans for Phase III palovarotene trial

*Further actions arising for 2017/18:*

a. *Review relevance of setting a specific number of meetings, as email contact has been effective and is often sufficient.*

**3.3. Make contact with any other research companies who develop plans for clinical trials in the Asia Pacific region**

a. No other companies have raised the possibility of trials in the Asia Pacific region, however Regeneron are planning phase II trial internationally.

*Further actions arising for 2017/18:*

a. *Ongoing engagement through IFOPA with other research developments (eg. FOP Australia representation at the 2017 Drug Development Forum) to ensure any arising opportunities for research in the Asia Pacific region are maximised.*

**3.4. Have an FOP Australia representative at a major international research meeting each year, with updates disseminated to the community after each event. Although FOP Australia's own financial resources are not currently sufficient to support this, potential other sources of funding (such as the IFOPA IPC) will be explored and utilised where possible.**

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- a. FOP Australia representative registered to attend the 2017 IFOPA Drug Development Forum in October.

*Further actions arising for 2017/18:*

- a. *Attendance at 2017 DDF and reporting back to the Fop Australia community*

### **3.5. Maintain membership of FOP Australia representative on the IFOPA Research Committee, with updates provided to the board and community when allowable under the intellectual property agreements with IFOPA.**

- a. Membership of RC ongoing.

### **4. Build and maintain strong links with the international community, specifically IFOPA, to assure new information and developments in medical research are provided to the FOP community in Australia and New Zealand.**

#### **4.1. Have an FOP Australia representative at a major international community meeting each year, with a meeting chosen for goal 3 that will achieve this goal as well.**

- a. FOP Australia representative registered to attend the 2017 IFOPA Drug Development Forum in October.

*Further actions arising for 2017/18:*

- a. *Attendance at 2017 DDF and reporting back to the Fop Australia community*

#### **4.2. Develop strong communication pathways amongst the Australian FOP families and supporters, as part of encouraging a sense of community. This will include encouraging interaction via Facebook with response measured by interactions with our Facebook page and website. This will also include quarterly updates to our members, sent via email and posted on our website.**

- a. Engagement via social media with community members (including Likes/Comments/Shares of posts), via Facebook, Twitter and Instagram. 11 people with FOP (or their guardians) have interacted with the organisation through social media.
- b. Website posts have been made on average of once per month to keep community updated. Website structure does not allow for easy tracking of web traffic.
- c. Two quarterly updates sent in the six month period since strategic plan developed, with positive feedback received.
- d. Direct email contact by IFOPA IPC rep with FOP families with each newsletter published.
- e. Overall 13 of the people with FOP (or their parents/guardians) have engaged with FOP Australia in some way in the six month period since the development of the strategic plan.

*Further actions arising for 2017/18:*

- a. *Member newsletters scheduled for release August 2017 and November/December 2017.*
- b. *Next strategic plan to include ways to increase engagement with increased number of families, including in running the organisation.*

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**4.3. The IPC representative (or a proxy) will participate in all IFOPA IPC meetings (in person or remotely) on behalf of FOP Australia, and updates disseminated to the board and members.**

- a. FOP Australia IFOPA IPC representative attended videoconferenced IPC meeting June 2017.

*Further actions arising for 2017/18:*

- a. *Proxy will attend IPC rep if meeting held at IFOPA DDF October 2017*

**5. Ensure any therapies for FOP early in order to ensure Federal Government funding for the maximum number of FOP Patients.**

**5.1. Develop a strategy to position FOP Australia to lobby for access to therapies in Australia when they become available internationally. This will include meeting with other groups including Rare Voices Australia and organisations for individual rare diseases.**

- a. FOP Australia registered as a member organisation with Rare Voices Australia
- b. Ongoing liason with researchers as documented above, to enable prompt access to information about developments.
- c. Development of introductory presentation to explain FOP Australia's roles and functions.

*Further actions arising for 2017/18:*

- a. *Advocacy strategy to be developed*

**6. To establish improve the function of FOP Australia as a representative and supportive organisation for the FOP community of Australia and New Zealand.**

**6.1. To build a sense of community amongst the FOP families and supporters. Measures to reflect this include:**

**6.1.1. Tracking the number of interactions with Facebook page and website.**

- a. The FOP Australia Facebook page has 554 page likes compared with 422 in July 2016.
- b. Facebook interactions reaching up 5,900 people, with highest performing posts being in regards to the 2016 IFOPA Drug Development Forum and 2017 Rare Disease Day (reach of over 5000 people each).
- c. Website doesn't allow collection of detailed traffic information.

**6.1.2. The dissemination of quarterly updates to our members via email and posted on our website.**

See comments above under 4.2

**6.1.3. Membership numbers**

- a. 35 paying members renewed for 2017/18, plus free memberships maintained by people with FOP and FOP clinicians. The membership database has been updated to enable more accurate tracking of membership data for reporting purposes. Electronic form has been developed so people can join online to maximise renewals.

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*Further actions arising for 2017/18:*

a. *Explore possibility of setting up automated annual renewal.*

**6.1.4. Participation of members through fundraising activities, subcommittee/working group participation, or nominating for future board positions.**

a. Increased participation in fundraising activities in South Australia and Western Australia in 2016/17. Former director Lara Boniface helped coordinate Entertainment books. No subcommittees formed.

*Further actions arising for 2017/18:*

a. *Board nominations will be called for prior to AGM (date to be announced after completion of audit, anticipated September 2017)*

b. *Review how we can achieve this goal as part of next strategic plan*

c. *Board discussions have included plan to identify skills required for boards.subcommittess to enable targeted requests for assistance*

**6.2. Maintaining our website as a source of up to date medical information, with an annual review of the content at minimum.**

See comments on 2.1.

**6.3. To develop and endorse a policy and procedures manual clarifying processes that may cause difficulty for FOP Australia.**

**6.3.1. This is to include descriptions of roles and responsibilities of each board position.**

a. Included in draft.

**6.3.2. This is to include a Code of Conduct for board directors or members acting on behalf of FOP Australia**

**6.3.3. This is to be designed to be circulated to any new board or subcommittee members, with any breaches be reviewed by the board.**

a. First draft completed February 2017, with additional board meetings held specifically to work through draft. Second draft being completed July 2017.

b. No new board or subcommittee members appointed during the period covered by this Strategic Plan.

*Further actions arising for 2017/18:*

1. *Second draft to be completed and circulated to board*

2. *Legal opinion to be sought regarding final draft before board endorsement*

3. *Plan to finalise this prior to AGM*

4. *Circulate to any new board members or subcommittee members.*

**6.4. To clarify and streamline tasks required to meet financial and legislative responsibilities, so that all such requirements are met consistently, use minimal volunteer time and can be handed over smoothly during future board transitions.**

a. Policy and procedure manual draft includes:

a. Clarification of responsibilities for regulatory reporting.



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- b. Clarification of responsibilities and limitations of board members regarding financial decisions and handling of resources.
- c. Clarification of board meeting and general meeting procedures.
- d. Handover protocol for all board members to enable transfer of relevant information at change of board.
- b. Shared drive developed for storage and sharing of FOP Australia documents amongst board (except for documents containing contact details for members or clinicians, which are kept separately by secretary)
- c. Information on board director responsibilities and board function sourced from X. Compiled on FOP Australia shared drive for reference.

Became a member organisation of 'Our Community' group for ongoing educational information regarding management of not-for-profit organisations.

*Further actions arising for 2017/18:*

1. *Finalise policies and procedures as noted in 6.3.*
2. *Seek opportunities for ongoing board development through 'Our Community'*
3. *Once 2016/17 audit and reporting cycle completed, review by board of how the process could be streamlined and simplified for future years (including consideration of utilising bookkeeping software and cost-effectiveness of doing so).*