



Strategic Plan 2017/18

Key Performance Indicators

The 2017/2018 Key Performance Indicators were developed as part of ongoing strategic planning to meet the goals of FOP Australia. The content was developed in response to a review of the 2016/17 KPIs undertaken from July to September 2017, and incorporating feedback received throughout the 2016/17 year from community members.

These KPIs have been endorsed by the FOP Australia board of directors on the 21st September 2017. Review of activity towards these targets is planned for July 2018 and will be released to community members when finalised. Further information on the activities described below can be provided upon request from 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 \$20 000 by the end of the 2017/18 financial year to donate to the International FOP Association in order to further global research efforts. See 6.5. for plans for further information on fundraising goals and plans for expenditure.
- 1.2. Extend fundraising capacity beyond the board, including development of fundraising subcommittee and exploration of grant opportunities.
- 1.3. To run a minimum of six fundraising initiatives during this period, including at least two that are accessible to all members in Australia and New Zealand, with the fundraising schedule outlined by the board annually and planned in detail six months in advance.

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 twice yearly review of the content at minimum.
- 2.2. Twice yearly medical updates to clinicians
- 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.
- 2.4. Develop educational activities targeting clinicians who are likely to be involved in initial recognition of FOP, diagnosis and management, including submitting articles for relevant publications and grand round hospital lectures.

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.
- 3.2. The FOP Australia IFOPA IPC representative to maintain contact 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.

SUPPORT. RESEARCH. CURE



Strategic Plan 2017/18

Key Performance Indicators

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

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. (NB - FOP Australia is not currently in a financial position to provide financial support for travel or expenses encountered for this purpose).
- 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.
- 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.

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 advocacy groups such as Rare Voices Australia.

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.
 - 6.1.2. Website engagement.
 - 6.1.3. The dissemination of quarterly updates to our members via email and posted on our website.
 - 6.1.4. Membership numbers.
 - 6.1.5. Participation of members through fundraising activities, subcommittee/working group participation, or nominating for future board positions.
- 6.2. Maintaining our website as a source of up to date information, with twice yearly review of the content at minimum.
- 6.3. To finalise endorse and enact the draft policies and procedures manual developed during 2016/17.

SUPPORT. RESEARCH. CURE



Strategic Plan 2017/18

Key Performance Indicators

- 6.4. Once the 2016/17 audit and reporting cycle has been completed, review to be undertaken of how this process could be simplified and streamlined for future cycles.
- 6.5. Allocate funds towards activities to support those living with FOP in Australia and New Zealand.
 - 6.5.1. \$3000 of funds raised in 2016/17 to be allocated towards support activities.
 - 6.5.2. Up to 10% of funds raised in 2017/18 to be allocated to fund support activities.
 - 6.5.3. Develop a support grant process to enable community members to apply and access funds that have been allocated for support activities.
 - 6.5.4. At the conclusion of the financial year, funds allocated for support activities that have not been used for support grants will be put towards future support activities such as a future national meeting.