



Strategic Plan 2016/17

Key Performance Indicators

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

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.
- 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.

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 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.
- 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.



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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.
- 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 people with FOP in our region have early and equitable access to any therapies developed.

- 5.1. Develop a strategy to position FOP Australia to lobby effectively 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.

6. To establish and 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.
 - 6.1.2. The dissemination of quarterly updates to our members via email and posted on our website.
 - 6.1.3. Membership numbers
 - 6.1.4. 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 medical information, with an annual review of the content at minimum.
- 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.
 - 6.3.2. This is to include a Code of Conduct for board directors or members acting on behalf of FOP Australia
- 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 board transitions.

Endorsed by the board of directors 5th January 2017