

These 2018/2019 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 2017/18 KPIs undertaken from July to August 2018. These KPIs were endorsed by the FOP Australia board of directors on the 28th August 2018.

Activities undertaken during the 2018/19 year, as recorded in FOP Australia records (board meeting minutes and financial records), will be reviewed against the KPIs by the board in July 2019. Input from members is welcome. Further information 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 sufficient funds by the end of the 2018/19 financial year to enable to following contributions to research
 - 1.1.1. \$31 000 to the IFOPA to be used for research
 - 1.1.2. \$5000 to the University of Pennsylvania Shore Lab to be used for FOP researchIncluding the amount we hope to allocate for support activities (\$5000), our total fundraising goal will therefore be \$40,000.
 - 1.2. Extend fundraising capacity beyond the board, including:
 - 1.2.1. An active fundraising subcommittee
 - 1.2.2. Exploration of grant opportunities
 - 1.2.3. Engaging our FOP families in fundraising activities
 - 1.3. To run a minimum of six fundraising initiatives during this period, including:
 - 1.3.1. At least two that are accessible to all members in Australia and New Zealand
 - 1.3.2. Two major fundraising events (ie. raising over \$8000 each; one per six months)
- 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 a 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:
 - 2.4.1. Submitting at least one article for publication in a relevant peer reviewed journal
 - 2.4.2. At least three presentations to clinical staff

- 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 invitation to address the 2018/19 AGM and invitation to contribute to our member newsletters.
 - 3.2. A representative to maintain contact with any pharmaceutical/biotechnology companies undertaking/planning FOP research in the Asia-Pacific region, with updates tabled at board meetings after each occurrence, and information disseminated to FOP community when required.
 - 3.3. 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 all IFOPA IPC meetings (either in person or by videoconference) with information subsequently reported to the board and disseminated amongst the community.

- 5. Advocate for people with FOP in Australia and New Zealand to have access to any effective FOP therapies, including subsidised funding of therapies;**
 - 5.1. Work with Rare Voices Australia on rare disease advocacy.
 - 5.2. Increase awareness of FOP amongst federal politicians, with a target of contacting and informing five local members about FOP within this financial year.
 - 5.3. Development of information package targeted at policy makers to communicate key messages.
 - 5.4. Enable opportunities for board directors and members to gain skills for effective advocacy.

- 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 plan and undertake a survey of people with FOP in Australia and New Zealand, and their families, in order to improve consultation with the community and guide future strategic planning for the organisation.
 - 6.2. To build a sense of community amongst the FOP families and supporters. Measures to reflect this include:
 - 6.2.1. Membership numbers
 - 6.2.2. AGM attendance

- 6.2.3. Tracking the number of interactions with social media channels
- 6.2.4. Participation in fundraising activities
- 6.2.5. Nominations for roles on board or committees
- 6.3. Communicate regularly and effectively with members and supporters;
 - 6.3.1. The dissemination of quarterly updates to our members via email and website
 - 6.3.2. Maintain our website as an up to date source of information with two formal reviews of content.
- 6.4. Allocate funds towards activities to support those living with FOP in Australia and New Zealand.
 - 6.4.1. Include and maintain record of funds allocated to support activities in financial reporting
 - 6.4.2. If the fundraising target of \$40 000 is achieved in the 2018/19 financial year, to allocate \$5000 towards support activities
 - 6.4.3. Complete consultation for the establishment of a support grant program and launch the program
- 6.5. Continue to work towards optimal board performance and ensure the organisation maintains appropriate governance, integrity and longevity
 - 6.5.1. Finalise endorse and enact policies and procedures manual
 - 6.5.2. Development of an operational handbook for board directors
 - 6.5.3. Clarify and consolidate board reporting processes to ensure appropriate records are kept efficiently
 - 6.5.4. Review audit and regulatory processes after completion of 2017/18 audit to consider how we can more efficiently comply with requirements
 - 6.5.5. Enable opportunities for education of board and committee directors to help them fulfil their responsibilities to members and the FOP community