

The following KPIs were developed and endorsed by the FOP Australia board in July 2019 in response to review of the progress towards 2018/19 KPIs, and the results of the 2019 Community Survey. The activities of FOP Australia in 2019/20 will be reviewed at the end of the financial year against these KPIs to inform further strategic planning.

- 1. Advocate for people with FOP in Australia and New Zealand to have access to any effective FOP therapies, including subsidised funding of therapies**
 - a. Have information materials that can help spread our messages
 - i. Develop preparation notes to aide community members with awareness presentations
 - ii. Develop preparation notes with key talking points for advocates meeting politicians/policymakers
 - b. Enable opportunities for board directors and members to gain skills for effective advocacy.
 - i. Information webinar sessions to include education on drug development and regulatory approval processes, including sharing our advocacy strategy and information about the role for patients and families and advocates.
 - c. Work with Rare Voices Australia on rare disease advocacy.
 - d. Disseminate advocacy strategy in annual report
 - e. Increase awareness of FOP amongst federal politicians, with a target of linking 5 politicians into FOP Awareness Day activities.

- 2. Provide a significant proportion of our fundraising to advances in research into treatments and/or a cure for FOP.**
 - a. Funds raised in 2019/2020 will be allocated in keeping with the community priorities demonstrated in the results of the 2019 community survey:
 - i. We will offer donors (making donations via GiveNow or direct deposit) the opportunity to direct their donation within the choices of research/support activities/particular projects identified by the board (eg. patient gathering)/general funding pool.
 - ii. We will offer supporters organising fundraising activities the opportunity to choose to direct the funds raised to a choice of research/support activities/particular projects identified by the board (eg. patient gathering)/general funding pool.
 - iii. Of the undirected pool of money (general funding pool) raised in 2019/2020FY we will donate 50% to research, 10% to other support activities, 40% to go towards a patient gathering.

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- iv. Funds received from corporate/government grants would be directed in keeping with the application process and terms of reference for that grant.
 - b. Extend fundraising capacity beyond the board, including
 - i. Establishing an active fundraising committee
 - ii. Engaging our FOP families in fundraising activities, including by:
 - 1. developing of clear instructions (on website and an operational handbook) to guide those who are interested on how to help
 - 2. including the above information on how to help fundraise in two newsletters
 - iii. Exploration of grant opportunities, including:
 - 1. applying for a minimum of two grants
 - 2. exploring grant opportunities within New Zealand
 - iv. Create a process for recognition of small and large contributions, so contributors know this is valued
 - c. To run a minimum of six fundraising initiatives during this period, including:
 - i. At least two that are accessible to all members in Australia and New Zealand
 - ii. Two major fundraising events (ie. raising over \$8000 each; one per six months)
- 3. Build and maintain links with the medical community, including clinicians in Australia and New Zealand and internationally to understand new developments in medical research and its potential application to people with FOP.**
 - a. Maintaining our website as a source of up to date medical information, with minimum annual review of all content.
 - b. Twice yearly medical updates to clinicians
 - c. Maintain and expand the database of treating clinicians in order to enable effective dissemination of information, with:
 - i. an annual review at a minimum
 - ii. seeking to add New Zealand based clinicians to the database
 - d. Develop educational activities targeting clinicians who are likely to be involved in initial recognition of FOP, diagnosis and management, including:
 - i. Submitting at least one article for publication in a relevant peer reviewed journal
 - ii. At least three presentations to clinical staff
 - iii. Offer at least one webinar as an information session for clinicians
 - e. Hold at least one webinar for the community that includes a clinician presentation
- 4. Build and maintain strong links with those undertaking FOP research, including academic centres and pharmaceutical companies.**

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- a. A 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.
 - b. 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 permitted by the drug company.
 - c. 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.
 - d. Encourage maximal participation by people from Australia and New Zealand in the FOP Connection Registry.
- 5. Build and maintain strong links with the international community, specifically IFOPA, to ensure new information and developments in medical research are provided to the FOP community in Australia and New Zealand.**
- a. 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.
 - b. Include an IFOPA update in each newsletter
- 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.**
- a. Follow up on the results of the 2019 community survey, with:
 - i. Feedback to community regarding the results
 - ii. Incorporate survey results to strategic planning
 - iii. Communicating what has been done in response to the survey throughout the year
 - b. Based on the results of the 2019 community survey, to work towards an Aus/NZ patient gathering within the next five years including
 - i. assessing feasibility from a financial and logistical perspective
 - ii. identifying community priorities for the gathering
 - iii. plan a timeframe for the gathering
 - c. To build a sense of community amongst the FOP families and supporters. Measurements that will be used to gauge this include:
 - i. Membership numbers
 - ii. AGM attendance
 - iii. Tracking interactions via social media channels
 - iv. Participation in activities (information sessions, community consultation, fundraising activities) including participation of non-board members

- v. Nominations for board positions and other tasks
- vi. Subscriptions to email list (to be opened to those who have not signed on as members)
- d. Communicate regularly and effectively with members and supporters
 - i. The dissemination of quarterly updates to our members via email and website
 - ii. Maintain our website as an up to date source of information with one full review of content per year, as recorded in board minutes.
 - iii. Investigate current membership structure and potential member benefits.
- e. Continue to work towards optimal board performance and ensure the organisation maintains appropriate governance, integrity and longevity
 - i. Continue development of policies and procedures (including the addition of further necessary policies as guided by legal advice)
 - ii. Development of an operational handbook for board directors and volunteers helping in other roles
 - iii. Complete the ongoing work on developing a guide to regulatory requirements for board directors
 - iv. Develop calendar of prompts for board directors to ensure timely action on strategic and operational requirements.
 - v. Map out skill sets required to improve organisation function in order to guide future recruitment of board directors and portfolio holders
 - vi. Enable opportunities for education of board and committee directors to help them fulfil their responsibilities to members and the FOP community