



Review of 2017/18 Activity by 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 by the board 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 were endorsed by the FOP Australia board of directors on the 21st September 2017.

For this review, activities undertaken during the 2017/18 year, as recorded in FOP Australia records (board meeting minutes and financial records), were compared against the KPIs by the board in July-August 2018. Information can be provided upon request from info@fopaustalia.org.

KEY:

Not met	Some work done	Partially met	Aims met
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SUMMARY BY STRATEGIC GOAL:

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

			Aims met
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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.

		Partially met	
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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.

			Aims met
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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.

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

	Some work done		
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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.

		Partially met	
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SUPPORT. RESEARCH. CURE



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DETAILED REVIEW OF KPIs FOR EACH STRATEGIC GOAL

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.

- \$41,968.35 was raised during fundraising activities during the 2017/18 financial year, as outlined in the table below.

<i>Fundraiser</i>	<i>Funds raised</i>	<i>Month of event/launch</i>	<i>Description</i>	<i>Online platforms used</i>
CharityBuy (online)	\$138.48	November 2017	Perpetual online fundraiser established. Zero set-up costs.	CharityBuy platform
HOT Fitness classes	\$70	November 2017	Local gym members donated \$1 per class to one of three chosen charities	
EcoCups/Coffee Club (online)	\$1103.32	January 2018	First merchandise item for sale; combined with launch of monthly giving program	Stripe forms
Somerville Family Day (Vic)	\$115.55 (plus cup sales)	February 2018	Involved development of educational/promotional banner and flyers.	Square Reader
Entertainment Books (online)	\$336	March 2018	Included hard copy sales in Brisbane (Qld)	Entertainment Book platform
Brooke Scott's Birthday Crowdraiser (SA)	\$383	March 2018	First fundraiser using the GiveNow Crowdraiser function.	GiveNow
Waverley Gardens FOP Awareness Day stall (Vic)	\$30 (plus cup sales)	April 2018	Utilised banner, flyers and eco-cups.	Square Reader
Broome Courthouse markets stall (WA)	\$160 (plus cup sales)	June 2018	Utilised banner, flyers and eco-cups.	
Trivia Night (Morningside)	\$10 646	June 2018	Utilised banner, flyers and eco-cups. Cash donations received on the night.	Square Reader
Kate and Yvonne's Wedding Crowdraiser (NT)	\$530	June 2018	Tyson Stanley's aunties asked wedding guests to donate in lieu of presents.	GiveNow
Kununurra Half Marathon (WA)	\$901	June 2018	First fundraiser using the GiveNow Crowdraiser function.	GiveNow
Individual donations not linked to event	\$27 555 Comprising of: GiveNow \$1630 Mycause \$120 With online memberships \$580 Direct deposits \$25 225	Full year	Included EOFY online donation drive June 2018 offering donation matching.	GiveNow MyCause Stripe Caldera Forms
Total	\$41 968.35			

- Using the funds raised in 2017/18, the board approved the following donations at the August 2018 board meeting:
 - \$40,000 to IFOPA for research, including an offer to again sponsor an ACT for FOP Grant for research into potential therapies
 - \$5000 to the Shore Lab at the University of Pennsylvania to support their ongoing foundational research into understanding FOP

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- This follows the donation of \$25,000 to IFOPA confirmed in August 2017, with funds raised in the 2016/17 year being used to sponsor a Competitive Research Grant. The CRG sponsored by IFOPA with FOP Australia was awarded to A/Prof Ed Hsiao at UCSF and Prof Pam Yelick at Tufts University for establishing new models of in vivo models to test potential FOP drugs. Also in August 2017, \$5000 of the funds raised in the 2016/17 year was donated to the Shore Lab at the University of Pennsylvania for their ongoing in understanding the pathophysiology of FOP.

			Aims met
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1.2. Extend fundraising capacity beyond the board, including development of fundraising subcommittee and exploration of grant opportunities.

- A Fundraising Co-ordinator was appointed in December 2017, including the task of establishing a fundraising team.
- Advertisement for people to join a fundraising team was undertaken through the member newsletter and social media channels. Two people (including one board member) nominated to join the team.
- Social media platforms have been used by several members of FOP families not represented on the board to share promotions about fundraising activities.
- Sales of Entertainment Books within Queensland has included input by an individual member.
- Sales of Eco-cups within Queensland and Northern Territory has included input from individual supporters.
- Crowdraiser option established on GiveNow platform to enable supporters to set up independent fundraisers. The mycause platform also allows for supporters to set up independent fundraisers and buy donation gift card, and as it still more appropriate for some event types (eg. it will again be utilised for City to Bay fundraiser in September 2018).
- Board established criteria and process to develop shared fundraisers with other organisations, following work by board members to consider opportunities to pair with other charities in fundraisers to expand fundraising opportunities.
- Apart from the family groups currently represented on the board, two families have begun planning to coordinate fundraising activities in the 2018/19 year.
- Board discussed the potential for corporate sponsorship in the future. Support from businesses enabled design and production of flyers and banner to raise awareness about FOP at no cost to FOP Australia. Donation of stall space for FOP Awareness Day obtained at Waverley Gardens Shopping Centre. Sponsorship obtained from local business for Trivia Night in Somerville Victoria. Potential for corporate sponsorship of Zoom videoconference facility discussed by board.
- Directors have sourced information about grant opportunities but have not yet applied for any grant applications.
- Chair has discussed with FOP Friends (UK) chair regarding how they have utilised grant programs.

		Partially met	
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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.

- Six fundraising initiatives were run during this period
 - Eco-cups/Coffee club
 - Charity Buy

- FOP Awareness stalls in Somerville and Waverley Gardens (Victoria), Broome and Fitzroy Crossing (Western Australia)
- Entertainment Book
- Somerville Quiz Night
- Kununurra Half Marathon
- Three of the above initiatives were accessible online (Eco-cups/Coffee club, CharityBuy, Entertainment Books)
- The board have reflected that it would be more time-effective and productive to hold more larger scale, high-yield events. Limited board capacity has seen a predominance of smaller scale activities this year. These (predominantly online) smaller scale activities have a role - especially for those who can not access events in person. However, having met our KPI for broadly accessible (online) events, we hope to hold more high yield larger scale events in the future. We recognise there are inherent challenges in this for a charity focussing on an ultra-rare disease.
- Board meetings following the December 2017 AGM included setting a schedule for events throughout 2018, resulting in further advance planning than in 2017, but further advanced planning would be beneficial. Planned fundraisers were entered into the online calendar (located in the Upcoming Events section of the website) with an outline of the 2018 calendar year present from the start of the year, and updated throughout. Increased number of events planned for second half of 2018 (4-6) as of 30th June compared to number planned for the second half of 2017 (1) at the same time last year.

		Partially met	
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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.

- 19 news posts added
- Newsletters and clinician updates loaded to website upon release
- Upcoming Events calendar maintained with revision after each board meeting.
- Several new functions have been added to the website including online membership form, and independent online fundraisers (Eco-cup sales and Coffee Club subscriptions).
- Separate pages have been updated as new information is released but a formal review of each page has not been documented by the board this financial year.

		Partially met	
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2.2. Twice yearly medical updates to clinicians

- Clinician Update published and emailed to clinician database December 2017. Subsequent Clinician Update planned for release July 2018.

		Partially met	
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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.

- Clinician database maintained and reviewed May 2018

		Aims met	
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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.

- Presentation to hospital staff at Monash Health (Victoria) including development of a Powerpoint presentation providing introductory information on FOP for clinicians,
- Flyers and banner developed to promote awareness of FOP for utilisation at future events with the public and the medical community.
- Flyers disseminated to clinicians at two general practice clinics.
- Initial planning discussion with Prof Matt Brown regarding journal article submission and developing grand round style presentation

		Partially met	
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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.

- Several posts/articles written or approved by QUT team in regards to phase II and phase III clinical trial information, including announcement of the opening of the first Australian phase III trial site.
- Chairperson and Prof Brown met to discuss FOP Australia progress and activities October 2017. There was no formal invitation to address the board sent during this financial year; Prof Brown will instead be invited to address the AGM.

		Partially met	
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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.

- Ongoing email interactions with Clementia, greater than four, most recent June 2018. IPC meeting with Clementia July 2017. Multiple in-person interactions with chairperson and Clementia representatives at IFOPA Drug Development Forum (DDF) 2017.

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

- Chairperson met informally with Regeneron staff at IFOPA DDF. No Regeneron site planned for their current trial. Email contact established with Regeneron representative.
- No other drug companies planning clinical trials in Australia/New Zealand currently
- Chairperson attend information session on engagement with pharmaceutical companies as proxy at IPC meeting, October 2017. Information session (videoconference) planned for board directors on engagement with pharmaceutical companies, with IFOPA Research Director Adam Sherman.

			Aims met
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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.

- [Chair attended IFOPA Drug Development Forum 2017, with report published online after the event and social media posts during the event. Summary of event in member newsletter](#)

			Aims met
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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.

- [Chair remains a member of the IFOPA Research committee. Information that was cleared for public release included in Drug Development Forum report \(ie. biobank planned for tissue samples, registry progressing towards opening the Medical Portal\)](#)
- [As part of being represented on the RC, FOP Australia will maintain engagement with the development of the IFOPA Biobank, in order to ensure tissue samples from Australia can be utilised for maximum benefit to the global research effort, Whilst this is still under development, chairperson liaised with UCSF laboratory to arrange the transport of teeth samples from Australia for use in stem cell models of FOP \(following discussion of options with University of Pennsylvania, where transport issues have limited utility of samples from Australia in the past\).](#)

			Aims met
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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. (NB - FOP Australia is not currently in a financial position to provide financial support for travel or expenses encountered for this purpose). [See 3.4.](#)
- 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.
 - [Four member newsletters released in this financial year](#)
 - [FOP Australia Patient and Families Facebook group remains active](#)
 - [See 6.1.](#)

		Partially met	
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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.

- [IPC representative attended 2 IPC meetings held by videoconference.](#)
- [Chairperson attended as proxy IPC meeting held at Drug Development Forum 2017.](#)
- [IPC updates provided to the board at each monthly board meeting](#)
- [Promotion of the FOP Registry to members via newsletter and website.](#)
- [Dissemination of IFOPA videos for FOP Awareness Day via social media.](#)
- [IFOPA webinars on clinical trials promoted and shared via social media.](#)

			Aims met
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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.
- Treasurer and member attended RVA advocacy workshops in Melbourne and Brisbane respectively. Chair registered for Perth workshop but the event was cancelled. Learnings from RVA workshops presented to the board.
 - Materials provided to Rare Voices Australia as part of arrangement for RVA to promote information about FOP Australia and FOP Awareness Day.
 - Information about the Pharmaceutical Benefits Advisory Committee disseminated to board directors. Board discussion about successful PBAC application for a Spinal Muscular Atrophy therapy, including key role by SMA Australia, with consideration to lessons learned for our future lobbying.
 - Advocacy strategy planning in early draft form

	Some work done		
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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 include:
- 6.1.1. Tracking the number of interactions with Facebook page.
813 Facebook likes in June 2018 compared to 544 in June 2017 and 422 in July 2016, reflecting increased growth in social media engagement.
70 Twitter followers and 135 Instagram followers June 2018.
See 4.2.
- 6.1.2. Website engagement.
Awareness campaigns undertaken online for Rare Disease Day and FOP Awareness Day with engagement from national and international community.
Website does not enable tracking page visits. Increasing use of the website in relation to fundraisers and online membership form in order to encourage use of this resource.
- 6.1.3. The dissemination of quarterly updates to our members via email and posted on our website.
See 4.2
- 6.1.4. Membership numbers.
43 paying members, 11 patient members, 20 clinician members (total 74) at end of financial year (compared to 35 paying members, plus people with FOP and FOP clinicians at end of 2016/17 financial year)
The option of joining via an online membership form was added to increase accessibility of membership.
- 6.1.5. Participation of members through fundraising activities, subcommittee/working group participation, or nominating for future board positions.
The AGM was held via videoconference with representatives from five FOP families and apologies from members of two further FOP families.
See 1.2.
- 6.1.6 Drafting of a letter /introductory package commenced for those confronted with a new diagnosis of FOP.
Board directors were informed of two people newly diagnosed with FOP in Australia and that the families were aware of FOP Australia.

	Partially met		
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SUPPORT. RESEARCH. CURE

- 6.2. Maintaining our website as a source of up to date information, with twice yearly review of the content at minimum.
- See 2.1.
- 6.3. To finalise, endorse and enact the draft policies and procedures manual developed during 2016/17.
- Ongoing work on draft policies and procedures and handbook manual with expected timeframe for completion prior to 2017/18 AGM (scheduled for October). This incorporates and builds on contributions by board directors in 2016 and 2017.
 - Secretary began Diploma of Business (Governance) with subsequent access to training and Our Community Policy Bank utilised to obtain sample policies approved through Moore Legal Services
 - Chairperson spoke with FOP Friends UK chairperson and IFOPA executive director to learn from their policies and procedures.
 - Avenues for pro bono legal advice on draft manual explored with identification of a possible provider.

	Some work done		
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- 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.
- ACNC reporting and reports for state fundraising permits for Victoria, Queensland and New South Wales were submitted as required. A fundraising permit for Western Australia was obtained. A permit for raffles within Victoria was obtained.
 - Storage of permit related information in an online archive was set up. Responsibilities for fundraising within South Australia clarified with SA Consumer Affairs.
 - A receipt register and inventory of stock owned by FOP Australia was established in online archive.
 - Regular regulatory report included in each monthly board meeting
 - Multiple issues with NAB have been addressed with their customer service liaison officer, including delays and errors in changing account access for board directors.
 - Process for standardised monthly financial reporting implemented May 2018
 - BDO undertook audit of the 2016/17 financial year pro bono, and kindly agreed to do this again for the 2017/18 audit.

		Partially met	
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- 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.
- See progress made on development of support grant program in 6.5.3.
 - Funds allocated from 2016/17 but not yet utilised, remain in account to be used for support activities.
- 6.5.2. Up to 10% of funds raised in 2017/18 to be allocated to fund support activities.
- \$4000 allocated for support activities from the 2017/18 financial year.
- 6.5.3. Develop a support grant process to enable community members to apply and access funds that have been allocated for support activities.
- Draft terms of reference and application form for support grant program completed and reviewed by advisors experienced in running similar programs and disability services.
 - Selection panel for support grant program chosen in keeping with draft terms of reference and approved by the board.
 - At end of financial year, awaiting further feedback from advisors on terms of references before seeking board approval for revised version.



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- Program will subsequently be reviewed by legal advisors prior to launch to ensure the program is adequately protected from being affected by conflicts of interest.
- 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.
- At this stage the support activities planned to utilise allocated support funds is the support grant program as described above.



In conducting this review of the activities of FOP Australia in 2017/18, the board acknowledge the contributions, commitment and generosity from all FOP families, members, volunteers, donors and supporters.
Thank you.