



Annual Report

2018/2019



www.fopaaustralia.org

info@fopaaustralia.org

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Our Mission

Our mission is to raise awareness of Fibrodysplasia Ossificans Progressiva (FOP), provide a support network for those individuals and families affected by FOP and establish and fund research towards treatment and a cure for FOP.

Overview of FOP Australia

The primary object for which the Company is established is to:

- a)** Promote and raise funds within the community for research into the cause(s), Treatments and cure(s) for Fibrodysplasia Ossificans Progressiva (FOP);
- b)** Conducting research that seeks to provide improved outcomes for people with FOP;
- c)** Raising awareness within the medical community of the particular characteristics and symptoms of FOP to eliminate incorrect diagnoses that leads to incorrect treatment which can have severe outcomes for people with FOP;
- d)** Assisting those with FOP and their families by providing support through networking with medical community, as well as information on the latest treatment guidelines and any advances in the search for treatments and a cure;
- e)** Doing all such other things as are incidental or conducive to the operation of the Company and otherwise for the attainment of all or any of the above objects of the Company

Structure and Management

FOP Australia was established in 2015, by those affected by FOP. Whether they were a patient, family member or friend. The first Annual General Meeting was held in Brisbane in May that year.

FOP Australia is registered with the Australian Charities and Not-for-profits Commission (ACNC) as a charity with Deductible Gift Recipient (DGR) status through the Australian Tax Office.

Our organisation is a company limited by guarantee; we have a board of directors and are accountable to our members. We have no paid employees and run purely through volunteers.

Board of Directors

The current board consists of:



Lydia Scott
Chairperson



Talia Wilson
Treasurer



Brooke Scott
Secretary



Olivia Sedgwick
Fundraising Co-ordinator

Chairperson's Report

Dear Supporters

Thank you for your generous support of FOP Australia over the 2018/19 year. By giving your time, commitment, energy and donations, you are helping us help people in Australia and New Zealand with Fibrodysplasia Ossificans Progressiva.

This year has seen several families in our region face a new diagnosis of FOP. As we welcome them to FOP Australia, this highlights the critical importance of expediting the work towards a cure, and of supporting each other through a disease that is poorly understood.

In that context, I hope everyone in the FOP community takes heart from the amazing fundraising efforts during this financial year. The 2018/2019 financial year saw more families holding more fundraising events than any previous year, which made it our most successful fundraising year yet! The amazing variety of fundraising events continues to increase, and I hope you all enjoy hearing about them in the Fundraising Report by Fundraising Co-ordinator Liv Sedgwick.

FOP Australia's fundraising success has meant that one of the biggest outcomes of the 2018/19 year has once again been a major financial contribution to the international FOP research effort. In keeping with the prospectively announced KPIs for this year, we dedicated over 90% of funds raised by FOP Australia to support research towards effective treatments to stop FOP. \$70,000AUD has been sent to the International FOP Association to support the round of ACT for FOP research grant program that is currently underway. This program sees researchers from around the world submit proposals to an independent selection panel, with those that are judged to be the most likely to impact on progress towards a cure selected for funding. We are extremely proud to once again be able to support this program. In keeping with previous years, \$5000AUD has again gone to the Shore Lab at the University of Pennsylvania. The Shore Lab have been fundamental in advancing the understanding of FOP, including the pivotal discovery of the FOP gene in 2006. Prof Eileen Shore and her team continue to work on breaking through barriers in our understanding of this disease, to enable academic and industry researchers keep working towards a treatment.

Apart from the financial contribution to research, the contributions by people with FOP to the FOP Registry are invaluable. This study will provide the baseline data against which all future treatments will be compared, so the data put in to it is critical. If you have FOP, or care for someone with FOP, and are not sure how to put your information into the registry, please contact us for help.

Although we are incredibly proud of the contribution to FOP research, this year the board has also reflected upon how we can fulfil the organisation's mission to also provide support to people with FOP and their families. During the 2018/19 year the Support Grant Program was prepared for launch, thanks to the help of our independent selection and advisory panel: Michelle Davis from IFOPA, Dr Felicity Collins and occupational therapist Georgie Hyder. This has been launched since the end of the 2018/19 financial year, so please stay tuned for further updates.

Our website, newsletters and social media pages also provide a source of continued communication within and from our community. The activity on these platforms continues to increase, and FOP Australia are very grateful to all contributors and to the volunteers that have set them up and continue to keep them up to date and functional.

BDO have provided us with ongoing pro-bono support with our financial audit. We remain extremely grateful for this support, and thank Gerry Collins for assisting with this since inception.

The board has continued to work on solidifying the organisational structure and process of the organisation. We have been extremely grateful for the work of Jo McAlpine, who volunteered to assist the board in 2018/19 and has made many important contributions throughout the year. This has included establishing links with legal firm King & Wood Mallesons, who have made an invaluable pro bono contribution to solidifying the organisation's policies and procedures.


With the framework of our organisation solidified, we were pleased to be able to seek guidance from our community to inform our strategic planning for the next financial year and beyond. Thank you for your contributions to this survey and for reading Jo McAlpine's report on the outcomes on page 30. Our 2019/20 KPIs and Advocacy Strategy are also outlined in this report. Please also take the time to read our review of 2018/19 activities against KPIs to learn more about what we have achieved together over the last year.

Board meeting structure and reporting processes have also continued to improve throughout the year, particularly as we come towards our Annual General Meeting. Being in the fortunate position of having all directors again willing to continue into next year, the board have decided to review all board roles after the AGM, so that the responsibilities can be re-delegated to test handover processes whilst the board is in a robust position. Having served for almost three years as Chairperson I hope to be able to hand over the role to another board director, in recognition of the need for ongoing renewal in a sustainable organisation. This will also enable my ongoing work as a board director to focus on maximising medical and research activities in our region as we come closer to the point when we can help people in Australia and New Zealand access effective treatment for FOP. I'm sure we all agree that day cannot come soon enough.

Thank you for your support that brings us all closer to that horizon.

May we help each other stay strong as we work towards it.

Yours sincerely,



Lydia Scott
Chairperson December 2016 – November 2019

Strategic Planning

As part of ongoing strategic planning the board has identified the following priorities, the board identified the goals below in 2016.

1. Provide a significant proportion of our fundraising to advances in research into treatments and/or a cure for FOP
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 FOP Patients
3. Build and maintain strong links with pharmaceutical companies, undertaking any drug trials that may have potential application to FOP patients.
4. Build and maintain strong links with the international community, specifically IFOPA, to assure new information and developments in medical research are provided to FOP Patients in Australia and New Zealand.
5. Position any treatment for FOP patients early in order to ensure Federal Government funding for the maximum number of FOP patients.

Each year since 2016/17, FOP Australia has set Key Performance Indicators to work towards the above goals and the board has reviewed these at the end of each period. The 2018/19 review of activities is included in this report, along with our 2019/20 goals, informed by the 2019 community survey.

One of our KPIs was to create a map of our advocacy strategy to help our supporters understand the pathway towards drug development and availability, and what community actions can contribute to that. This outline is also used to guide the KPIs for each year.

2018/2019 Activity Report – Key Performance Indicators

The 2018/2019 Key Performance Indicators were developed as part of ongoing strategic planning to meet the goals of FOP Australia. They were developed by the board at the start of the 2018/19 financial year and disseminated in the 2017/18 Annual Report and on the website.

For this review, activities undertaken during the 2018/19 year, as recorded in FOP Australia records (board meeting minutes and financial records), were compared against the KPIs. Further information can be provided upon request from info@fopaustralia.org.

KEY:

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

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

Not met	Some work done	Partially met	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.

Not met	Some work done	Partially met	Aims 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.

Not met	Some work done	Partially met	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.

Not met	Some work done	Partially met	Aims met
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5. Advocate for any therapies for FOP early in order to ensure Federal Government funding for the maximum number of FOP Patients.

Not met	Some work done	Partially met	Aims met
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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.

Not met	Some work done	Partially met	Aims met
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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 research

Including the amount we hope to allocate for support activities (\$5000), our total fundraising goal will therefore be \$40,000.

Because of the hard work and generosity of an increasing number of fundraisers, our fundraising goal was been exceeded, with \$70 000 being donated to IFOPA for the ACT for FOP research grant program, and \$5000 being donated towards the University of Pennsylvania Shore Lab. Please see the fundraising report for more details.

1.2. Extend fundraising capacity beyond the board, including:

1.2.1. An active fundraising subcommittee

An invitation to join the fundraising team has been promoted in the newsletter and social media with limited responses. Fundraising co-ordinator Liv Sedgwick will continue work on this in the 2019/20 year.

1.2.2. Exploration of grant opportunities

One grant application submitted successfully, with \$1400 funding received for video conferencing software (Zoom) to enable online community information sharing sessions in 2019/20.

1.2.3. Engaging our FOP families in fundraising activities

At least five fundraising activities were initiated and run by families (or contacts of families) not currently represented on the board, representing an expansion of the number of fundraising supporters.

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

Six online fundraising initiatives were initiated/continued in this financial year (online merchandise, Entertainment Books, Coffee Club, Eco-cups, CharityBuy and BrightStarKids)

1.3.2. Two major fundraising events (i.e. raising over \$8000 each; one per six months)

Two fundraising events (Bridge2Brisbane fun run and the Somerville Quiz Night) raised over \$8000 each.

Not met	Some work done	Partially met	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.

2.1. Maintaining our website as a source of up to date medical information, with twice yearly review of the content at a minimum.

One full review of the website content and function was undertaken half way through the financial year.

2.2. Twice yearly medical updates to clinicians

Two Clinician Updates were emailed: September 2018 and June 2019.

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.

The clinician database remained active and functional during this period. A reminder to clinicians to update their details was included in the Clinician Updates.

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

Not done, remains a goal for 2019/20.

2.4.2. At least three presentations to clinical staff

One completed, remains a goal for 2019/20.

Not met	Some work done	Partially met	Aims 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 invitation to address the 2018/19 AGM and invitation to contribute to our member newsletters.

Contact maintained throughout 2018/19.

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

Contact maintained with Clementia via videoconference meetings up to the transition to Ipsen. Since takeover by Ipsen, contact has been initiated with videoconference meetings and in-person presentation for FOP community members to Ipsen staff.

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.

Ongoing.

Not met	Some work done	Partially met	Aims met
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4. 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.

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.

Ongoing.

Not met	Some work done	Partially met	Aims met
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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.

Two board directors attended advocacy workshops held by Rare Voices Australia throughout this period. Several FOP Australia members gave input into the RVA Strategic Planning Survey. FOP Australia also facilitated contacted for input into the review of Disability Services from 3 community members with FOP.

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.

Introductory letters were sent to ten federal politicians (including local members for FOP community members, and holders of relevant portfolios) for FOP Awareness Day 23rd April 2019. Two in-person meetings were held with local members for FOP community members, including with the Federal Minister for Health, Greg Hunt MP.

5.3. Development of information package targeted at policy makers to communicate key messages.

Flyer developed and printed. Introductory letters for politicians developed as part of 5.2.

5.4. Enable opportunities for board directors and members to gain skills for effective advocacy.

All board members engaged in some form of skill development during this period: Secretary completed Diploma of Community Governance. Secretary and Treasurer attended RVA advocacy workshops. Chair and Fundraising Co-ordinator employed in roles including clinician education, including ongoing training.

Not met	Some work done	Partially met	Aims met
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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 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.

Survey launched May 2019, with outcomes disseminated via website, newsletter and annual report. Outcomes used to inform development of 2019/20 KPIs.

6.2. To build a sense of community amongst the FOP families and supporters. Measures to reflect this include:

6.2.1. Membership numbers

As of June 2018: 31 members, 11 clinicians, plus people with FOP.

6.2.2. AGM attendance

11 attendees at AGM held November 2018.

6.2.3. Tracking the number of interactions with social media channels

Social media users of June 2018: 813 Facebook followers, 135 Instagram followers, 70 Twitter followers.

Social media users as of June 2019: 909 Facebook followers, 192 Instagram followers, 108 Twitter followers.

6.2.4. Participation in fundraising activities

Increased number of supporters organising fundraisers, with five events held by supporters not currently on the board.

6.2.5. Nominations for roles on board or committees

One nomination for the fundraising subcommittee has been received. One volunteer throughout 2018/19 has indicated they will nominate to be on the board in 2019/20. All board directors have indicated that they will continue, including the one board director who is due to renominate at the 2018/19 AGM.

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

Four sent for the 2018/19 financial year. New software employed to facilitate this. The role of co-ordinating newsletters has been successfully handed over to a new volunteer.

6.3.2. Maintain our website as an up to date source of information with two formal reviews of content.

One full review of the website content and function was undertaken half way through the financial year.

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

Refer to treasurer's report. Board meeting reporting processes also consolidated during the year, with template used each month for standardised report.

6.4.2. If the fundraising target of \$40 000 is achieved in the 2018/19 financial year, to allocate \$5000 towards support activities

Completed.

6.4.3. Complete consultation for the establishment of a support grant program and launch the program

Terms of Reference finalised with plan to launch shortly after the end of the 2018/19 year.

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

Pro bono support from King & Wood Mallesons legal firm enabled completion of two policies by the end of June 2019, with six more near completion for endorsement.

6.5.2. Development of an operational handbook for board directors

Not yet completed. Board identified need to prioritise this in the months between end of 2018/19 financial year and AGM in October 2019, to facilitate handover of roles.

- 6.5.3. Clarify and consolidate board reporting processes to ensure appropriate records are kept efficiently

Meetniq software has been implemented for agenda, minutes, task lists and automatic reminders. Board reporting templates have been implemented for Financial, Fundraising and Membership reports.

- 6.5.4 Review audit and regulatory processes after completion of 2017/18 audit to consider how we can more efficiently comply with requirements

Monthly financial reports have enabled prompt collation of records at the end of financial year for the auditor, with use of a shared drive to enable auditor to have full access to relevant documents. Auditing services continue to be kindly provided pro bono by BDO. Ongoing review by board of how we can keep up with regulatory permit renewal.

- 6.5.5. Enable opportunities for education of board and committee directors to help them fulfil their responsibilities to members and the FOP community

All board members engaged in some form of skill development during this period: Secretary completed Diploma of Community Governance. Secretary and Treasurer attended RVA advocacy workshops. Chair and Fundraising Co-ordinator employed in roles including clinician education, including ongoing training.

Not met	Some work done	Partially met	Aims met
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Key Performance Indicators 2019/20

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 (e.g. 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.
 - 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 (i.e. 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 the 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.**
 - 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 video conference) 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

Fundraising activities

Fundraising activities

The amounts raised in fundraising events in 2018/19 are detailed below.

Table 1: Amounts raised by Fundraising events in 2018/19:

Fundraiser	Funds Raised	Month of event/launch	Description	Online platforms used
Charity Buy	\$60.19	Ongoing	Perpetual online fundraiser established. Zero set up costs.	CharityBuy website
Eco Cups	\$1,972.21 = 127 cups	Ongoing	First merchandise item for sale; combined with launch of monthly giving program.	Stripe
Coffee Club	\$1,220	Monthly subscription Ongoing	Monthly giving program.	Stripe
Entertainment Books (online)	\$302	Ongoing	Included hardcopy sales in Queensland.	Entertainment book platform
Bright Star Kids	\$23.70	Ongoing Launched Dec 2018	Online fundraiser giving 15% commission on purchases. Zero set up costs.	Bright Star Kids platform
Memberships	\$340	Ongoing	Yearly membership to join FOP Australia.	Stripe
Individual cash/EFT/stripe donations	\$25,275 (EFT/cash) \$590 (stripe) \$2900 Give now	Ongoing	Includes donations given with memberships.	Stripe EFT/Square Give now

Fundraiser	Funds Raised	Month of event/launch	Description	Online platforms used
Give Now/My cause	\$1495 (give now monthly donations) \$440 (my cause portfolio donations)	Ongoing	Includes all monthly donations from individual donors.	Give now My cause
Broome Markets	\$271	July	Utilised banner, flyers and eco-cups.	
Brisbane Bridge Run	\$14,520	August	Fundraiser organised by the Collins family.	Give now
Oklahoma Performance	\$715	August	Ticket sales donated from this performance by a Victorian Home-school group.	
City To Bay Fun Run	\$1,400	September	Fundraiser organised by the Scott family.	
Mylan Giving Program	\$6,920	September, October, December 2018	Jim Brown of Mylan set up an employee payroll giving program where employees can donate to FOP Australia.	3 separate donations via EFT.
Mt Gravatt Bowls Day	\$2,606	November	Organised by Dean Gaddes and the Mt Gravatt Bowls club in support of Jarvis Budd.	
Harmony in the twilight	\$669.61	November	Event run by families on the Mornington Peninsula.	
2018 Christmas appeal	\$580	December	Appeal for donations.	Give now

Fundraiser	Funds Raised	Month of event/launch	Description	Online platforms used
Bunnings BBQ	\$907.80	January	A joint fundraiser between FOP Australia and The IMatter Foundation	
Kathryn's Birthday fundraiser (Paypal)	\$1,178.18	March	Birthday fundraiser organised by Kathryn to donate direct to FOP Australia.	Paypal
Kimberley Rural Ladies Lunch	\$5,000	May	Donation from the ladies involved in the rural ladies lunch.	
Trivia Night	\$9,612.80	June	Yearly event held in Mornington. Utilised banner, eco-cups, flyers. Cash donations made on the night.	Stripe Square reader EFT
Open Gardens SA Donation	\$2,978.05	June	One off donation.	
Kununurra half marathon	\$1,250	June	Fundraiser organised by Lydia Scott.	Give now
TOTAL 2018/19	\$83,226.54	18/19 financial year		



Bridge to Brisbane Run, organised by Ellie Collins in support of FOP Australia, raising \$14,520!!



Thank you to Daniel, Harmony and Autumn for their performances at “Harmony in the Twilight” in November, a joint fundraiser with I Matter Foundation in Victoria



Thank you to the TAG home school students and director Emery Sheeran who raised \$715 for FOP Australia at their performance of the musical "Oklahoma! In Pakenham, Victoria.



Mt Gravatt Bowls Day - In support of Jarvis Budd and FOP Australia



Kununurra Half Marathon: June 2019

Team FOP (from left) Lydia Scott, Lauren Gibson, Hayley Potter, Janet San De Miguel ran 21.1km each in the tropical northern WA town of Kununurra to raise money and awareness for FOP Australia. Thanks to Red Terrain Contracting for donating our great FOP Australia running shirts!



Bunnings BBQ in Victoria - A joint fundraiser between FOP Australia and The IMatter Foundation



Broome Courthouse Markets: Lydia Scott, Tala Gooden, Cassie Yates pictured at one of several market stalls in Broome throughout 2018 to sell the FOP Australia Eco-Cups and raise awareness for FOP. Lydia and Cassie are also wearing some of the new FOP Australia merchandise which is available online.



Facebook Fundraiser: Darwin based supporter Kathryn Pettersen turned her birthday into a FOP fundraiser. Kathryn used Facebook to set up a donation page, and gave donors the chance to cut off her long red hair!



Kimberley Rural Ladies Lunch: Proving that you can raise money for FOP wherever you are, the ladies of the Kimberley region held a lunch in Fitzroy Crossing which including an auction and raffle. This raised \$5,000 towards FOP research.



Quiz night in the Mornington Peninsula – Organised by Talia Wilson and Tyson Stanley, raising 9,612.80 for FOP Australia!



City to Bay fun run organised by the Scott family. Thank you to Brendan Scott, Guy Tuck, Joyce Pettersen and Margaret Scott



Thanks to SR Global at the Success Summit Event, Horden Pavilion, Sydney. All volunteers were given a FOP Australia coffee cup as a thank you gift for their time and energy during the sell out two day event. Thank you for your support!

Treasurer's Report

It has once again been such a great experience to be a part of this small but dedicated team here at FOP Australia and I am pleased to be able to present you this report on our 2018/2019 financial circumstances.

I hereby submit to members a statement of the accounts of FOP Australia, namely the financial statements of FOP Australia for the year ended 30th June 2019, and the auditor's report dated 18th October 2019, including:

- Income and Expenditure during the last financial year; and
- Assets and Liabilities in the last financial year;

The financial statements determine that FOP Australia made a net profit of \$46,717 for the financial year. And as at 30th June 2019 FOP Australia had equity of \$93,225. This allows us to make a valuable contribution of \$75,000 to research efforts and set aside almost \$10,000 for our support programs.

It is exciting to show FOP Australia's continual financial growth over the last few years, with the 2018/19 financial year ongoing in that upward trajectory. Our financial position remains stable and we are well placed to address our financial commitments, now and in the future. The involvement of our supporters greatly adds to this stability.

FOP Australia's main sources of income have been major fundraising events held by members, smaller more continual fundraising efforts and individual donations. It has been pleasing to see the FOP community becoming increasingly involved in these fundraising efforts. Thank you for your time and commitment.

Expenses have been maintained at an absolute minimum. The procurement of a \$1,400 volunteer grant allows us the opportunity to build our capabilities in the coming year, while also ensuring that the monies raised by FOP Australia, it's members and supporters is being funnelled into continual and newer projects to benefit the Australian and New Zealand FOP community.

We are looking forward to another year of growth. It will be exciting to share future successes with you all. Thank you all for your support and I look forward to continuing my incredibly privileged work as a part of the FOP Australia board of directors.



Talia Wilson
Treasurer, FOP Australia
December 2016 - Present

Financial Statements and Auditor's Report

The financial statements and independent auditor's report for the 2018/2019 financial year are included on the following pages.

FOP Australia Ltd

ABN 51603 200 871

Financial Statements

For the year ended 30 June 2019

FOP Australia Ltd
ABN 51 603 200 871

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FOP Australia Ltd
ABN 51603 200 871
Directors' Report

Your directors present this report on the company for the financial year ended 30 June 2019.

Directors

The names of the directors in office at any time during or since the end of the year are:

Brooke Scott
Lydia Scott
Talia Wilson
Olivia Sedgwick (Appt. 14/12/17)

Directors have been in office since the start of the financial year to the date of this report unless otherwise stated.

Operating Result

The profit of the company for the financial year after providing for income tax amounted to \$46,717 (2018: \$1,503)

Principal Activities

The principal activities of the company during the course of the year were that of a charity focused on the disease Fibrodysplasia Ossificans Progressiva (FOP). The objectives of the company are:

- 1/ Promote and raise funds for research into the causes of FOP
- 2/ Raise awareness within the medical community of the characteristics and symptoms of FOP
- 3/ Assist those with FOP and their families by providing support through networking with the medical community, as well as information on the latest treatment guidelines.

No significant change in the nature of these activities occurred during the year.

Significant Changes in the State of Affairs

No significant changes in the company's state of affairs occurred during the financial year.

After Balance Date Events

No matters or circumstances have arisen since the end of the financial year which significantly affected or may significantly affect the operations of the company, the results of those operations, or the state of affairs of the company in subsequent financial years.

Future Developments

The company expects to maintain the present status and level of operations and hence there are no likely developments in the operations in future financial years.

Environmental Issues

The company's operations are not regulated by any significant environmental regulation under a law of the Commonwealth or of a State or Territory.

Dividends

No dividends were declared or paid since the start of the financial year. No recommendation for payment of dividends has been made.

Share Options

No options over issued shares or interests in the company were granted during or since the end of the financial year and there were no options outstanding at the date of this report.

Directors Benefits

No director has received or has become entitled to receive, during or since the financial year, a benefit because of a contract made by the company or related body corporate with a director, a firm which a director is a member or an entity in which a director has a substantial financial interest.

Indemnifying Officer or Auditor

No indemnities have been given or agreed to be given or insurance premiums paid or agreed to be paid, during or since the end of the financial year, to any person who is or has been an officer or auditor of the company.

Proceedings on Behalf of Company

No person has applied for leave of Court to bring proceedings on behalf of the company or intervene in any proceedings to which the company is a party for the purpose of taking responsibility on behalf of the company for all or any part of those proceedings. The company was not a party to any such proceedings during the year.

FOP Australia Ltd
ABN 51603 200 871
Directors' Report

Signed in accordance with a resolution of the Board of Directors on 18 October 2019:



Lydia Scott
Director



Talia Wilson
Director

FOP Australia Ltd
 ABN 51 603 200 871
 Statement of Profit or Loss and Other Comprehensive Income
 For the year ended 30 June 2019

	Note	2019 \$	2018 \$
Conference and fundraising		93,409	33,848
Total Income		93,409	33,848
Donations to uPenn		(5,010)	(5,010)
Donations to IFOPA		(40,020)	(25,044)
Other		(1,662)	(2,291)
Profit before income tax		46,717	1,503
Income tax (credit) expense		-	-
Profit for the year		46,717	1,503
Other comprehensive income		-	-
Total comprehensive income for the year		46,717	1,503

FOP Australia Ltd
 ABN 51 603 200 871
 Statement of Financial Position
 As at 30 June 2019

	Note	2019 \$	2018 \$
ASSETS			
Current Assets			
Cash assets		<u>93,225</u>	<u>46,508</u>
Total Current Assets		<u>93,225</u>	<u>46,008</u>
Total Assets		<u>93,225</u>	<u>46,008</u>
Net Assets		<u>93,225</u>	<u>46,008</u>
EQUITY			
Retained Profits		46,508	45,005
Current Year Profit		<u>46,717</u>	<u>1,503</u>
Total Equity		<u>93,225</u>	<u>46,508</u>

FOP Australia Ltd
ABN 51603 200 871
Notes to the Financial Statements
For the year ended 30 June 2019

Note 1: Summary of Significant Accounting Policies

FOP Australia Ltd is a company limited by guarantee, incorporated and domiciled in Australia.

The company is registered with The Australian Charities and Not for Profits Commission and holds Deductible Gift Recipient Status.

The financial statements were authorised for issue on 18 October 2019 by the directors of the company.

Basis of Preparation

The directors have prepared the financial statements on the basis that the company is a non-reporting entity because there are no users dependent on general purpose financial statements. The financial statements are therefore special purpose financial statements that have been prepared in order to meet the requirements of the Collections Act 1966.

The company is a not for-profit entity for financial reporting purposes under Australian Accounting Standards.

The financial statements have been prepared in accordance with the mandatory Australian Accounting Standards applicable to entities reporting under the Corporations Act 2001 and the significant accounting policies disclosed below, which the directors have determined are appropriate to meet the needs of members. Such accounting policies are consistent with the previous period unless stated otherwise.

The financial statements, except for cash flow information have been prepared on an accruals basis and are based on historical costs unless otherwise stated in the notes. The material accounting policies that have been adopted in the preparation of the statements are as follows:

Accounting Policies

(a) Cash and Cash Equivalents

Cash and cash equivalents include cash on hand deposits held at call with banks, other short-term highly liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within short-term borrowings in current liabilities on the statement of financial position.

FOP Australia Ltd
ABN 51603 200 871
Notes to the Financial Statements
For the year ended 30 June 2019

(b) Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable after taking into account any trade discounts and volume rebates allowed.

Interest revenue is recognized using the effective interest method which for floating rate financial assets is the rate inherent in the instrument.

Revenue recognition relating to the provision of services is determined with reference to the stage of completion of the transaction at the end of the reporting period and where the outcome of the contract can be estimated reliably. Stage of completion is determined with reference to the services performed to date as a percentage of total anticipated services to be performed. Where the outcome cannot be estimated reliably, revenue is recognized only to the extent that related expenditure is recoverable.



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Australia

INDEPENDENT AUDITOR'S REPORT

To the members of FOP Australia Ltd

Report on the Audit of the Financial Report

Qualified opinion

We have audited the financial report of FOP Australia Ltd (the Entity), which comprises the statement of financial position as at 30 June 2019, the statement of profit or loss and other comprehensive income, and the statement of cash flows for the year then ended, and notes to the financial report, including a summary of significant accounting policies, and the directors' declaration.

In our opinion, except for the effects of the matter described in the *Basis for qualified opinion* section of our report, the accompanying financial report presents fairly, in all material respects, the financial position of the Entity as at 30 June 2019 and of its financial performance and its cash flows for the year then ended in accordance with the basis of accounting described in note 1.

Basis for qualified opinion

Cash donations and cash collected at fundraising events is a significant source of revenue for FOP Australia Limited. FOP Australia Limited has determined that it is impracticable to establish control over the collection of cash donations and other cash collections at fund raising events prior to entry into its financial records. Accordingly, as the evidence available to us regarding fundraising revenue from these sources was limited, our audit procedures with respect to cash donations and cash collected at fundraising events had to be restricted to amounts recorded in the financial records. We therefore are unable to express an opinion whether cash donations and cash collected at fundraising events is complete.

We conducted our audit in accordance with Australian Auditing Standards. Our responsibilities under those standards are further described in the *Auditor's responsibilities for the audit of the Financial Report* section of our report. We are independent of the Entity in accordance with ethical requirements of the Accounting Professional and Ethical Standards Board's APES 110 *Code of Ethics for Professional Accountants* (the Code) that are relevant to our audit of the financial report in Australia. We have also fulfilled our other ethical responsibilities in accordance with the Code.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our qualified opinion.

Emphasis of matter - Basis of accounting

We draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist the Entity to meet the requirements of the Collections Act 1966. As a result, the financial report may not be suitable for another purpose. Our opinion is not modified in respect of this matter.

Other information

The directors are responsible for the other information. The other information obtained at the date of this auditor's report is the directors' report.

BDO Audit Pty Ltd ABN 33 134 022 870 is a member of a national association of independent entities which are all members of BDO Australia Ltd ABN 77 050 110 275, an Australian company limited by guarantee. BDO Audit Pty Ltd and BDO Australia Ltd are members of BDO International Ltd, a UK company limited by guarantee, and form part of the international BDO network of independent member firms. Liability limited by a scheme approved under Professional Standards Legislation.



Our opinion on the financial report does not cover the other information and accordingly we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial report, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial report or our knowledge obtained in the audit, or otherwise appears to be materially misstated.

If, based on the work we have performed on the other information obtained prior to the date of this auditor's report, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Responsibilities of management and those charged with governance for the Financial Report

Management is responsible for the preparation and fair presentation of the financial report, and have determined that the basis of preparation described in Note 1 is appropriate to meet the requirements of the Collections Act 1966 and for such internal control as management determines is necessary to enable the preparation and fair presentation of a financial report that is free from material misstatement, whether due to fraud or error.

In preparing the financial report, management is responsible for assessing the Entity's ability to continue as a going concern, disclosing, as applicable, matters relating to going concern and using the going concern basis of accounting unless management either intends to liquidate the Entity or to cease operations, or has no realistic alternative but to do so.

Those charged with governance are responsible for overseeing the Entity's financial reporting process.

Auditor's responsibilities for the audit of the Financial Report

Our objectives are to obtain reasonable assurance about whether the financial report as a whole is free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with the Australian Auditing Standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of this financial report.

A further description of our responsibilities for the audit of the financial report is located at the Auditing and Assurance Standards Board website (<http://www.auasb.gov.au/Home.aspx>) at:

http://www.auasb.gov.au/auditors_responsibilities/ar4.pdf

This description forms part of our auditor's report.

BDO Audit Pty Ltd

BDO

A J Whyte
Director

Brisbane, 18 October 2019

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FOP Australia Ltd
ABN 51 603 200 871
Directors' Declaration

The directors of the company declare that:

1. The financial statements and notes:
 - (a) Comply with accounting policies described in Note 1 to the financial statements; and
 - (b) Give a true and fair view of the company's financial position as at 30 June 2019 and of its performance for the year ended on that date;
2. In the directors' opinion, there are reasonable grounds to believe that the company will be able to pay its debts as and when they become due and payable.

This declaration is made in accordance with a resolution of the Board of Directors.



Lydia Scott
Director

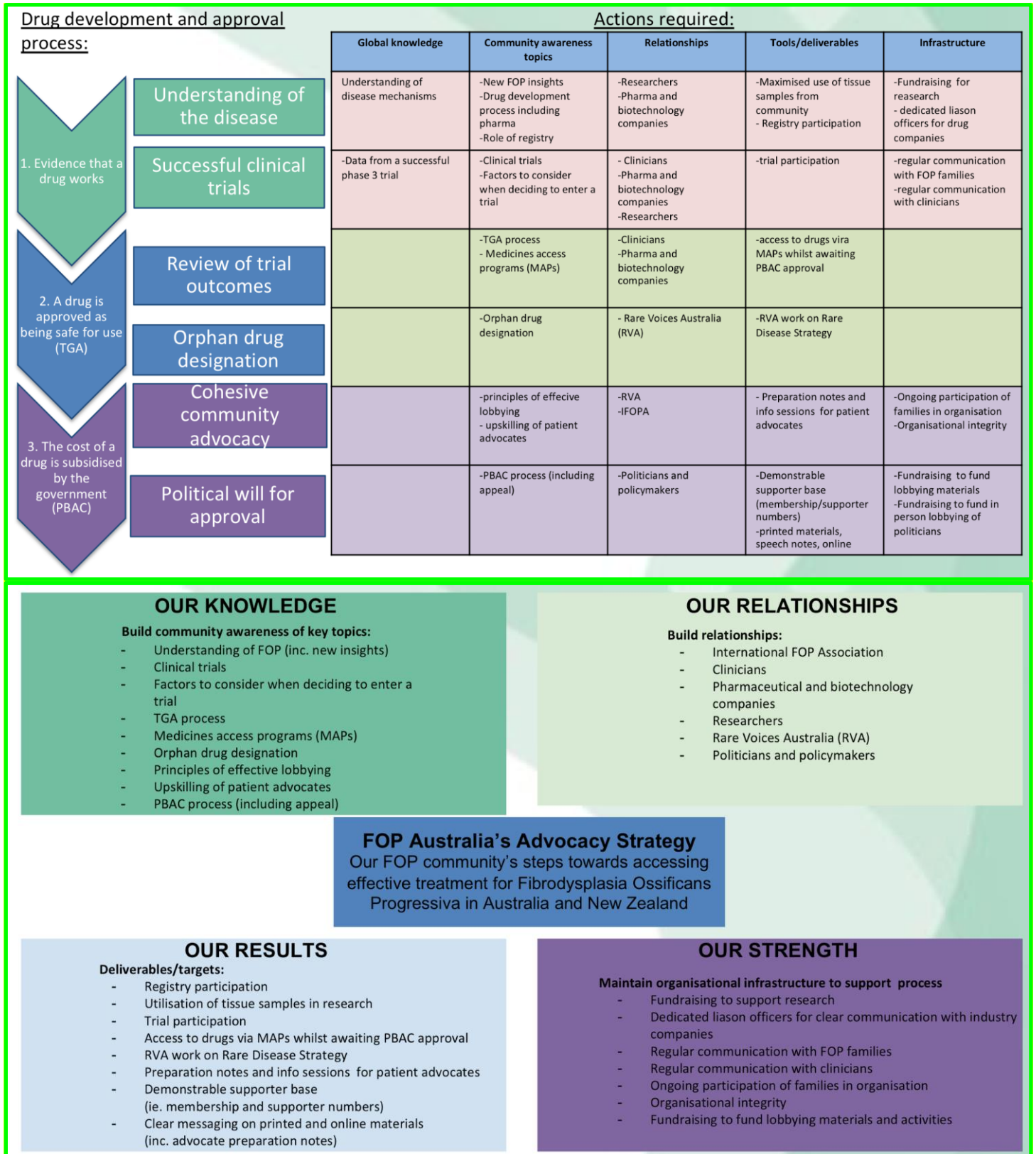


Talia Wilson
Director

Date: 18 October 2019

Advocacy

During 2018/19 we created a map of our advocacy strategy to help our supporters understand the pathway towards drug development and availability, and what community actions can contribute to that. Please take the time to familiarise yourself with this and consider where you may be able to contribute - or help our organisation contribute - to this important mission.



One of the tools we have been using throughout the year to help use raise awareness of FOP Australia at events is a banner and an A5 flyer. We are very grateful to graphic designer Jarryd Bravo, content editor Leonie Starnawski, Glenn May (banner printing) Peak Digital (flyer printing), and the families who agreed to the use of their photographs in this document. Please contact FOP Australia if you would like copies of the flyers to distribute.



Supporting people with Fibrodysplasia Ossificans Progressiva and research for a cure.

FOP is an ultra rare genetic disease, affecting only 1 in 2 million people. The disease causes bone to form in muscle and soft tissue, leading to progressive, painful and permanent loss of movement.

Extra bone growth can be triggered by trauma, medical tests, or happen spontaneously. Bone forms throughout the body and locks joints, causing loss of mobility, independence and other complications which can be fatal.



FIRST SIGNS: Painful lumps and swellings, typically in the shoulder, head or back. The swelling eventually resolves, leaving behind hard bone and locked joints.

DIAGNOSIS: Often the only clue is big toes which are short, bent, curved inward or otherwise malformed. Missing this important sign can lead to unnecessary tests such as biopsies.

DISEASE PROGRESSION: Invasive tests, surgery and intramuscular injections in people with FOP can be catastrophic, causing even more bone to form, and more immobility. There can also be unprompted growth of bone throughout the whole body.


WHAT CAN BE DONE? FOP bone growth cannot be stopped. FOP bone cannot be removed as this triggers more bone growth. There is no cure. You can help us change that.





fopaustalia.org
SUPPORT. RESEARCH. CURE.

info@fopaustalia.org FOP Australia FOPAustalia fop_austalia



FOP Australia is a registered charity run by a small group of volunteers linked with the International FOP Association and other similar grassroots community groups worldwide.

We work towards...

- raising awareness of Fibrodysplasia Ossificans Progressiva
- providing a support network for families and individuals with FOP
- furthering research towards treatment and a cure

To support our ongoing work, check out our website at

fopaustalia.org

All donations are greatly appreciated, and can be made through our secure online platform.

Our website also includes information for people living with FOP, for health professionals, and for the broader community to help raise awareness for this disease.

Follow us on our social media channels to stay up to date with the latest news:

info@fopaustalia.org FOP Australia FOPAustalia fop_austalia

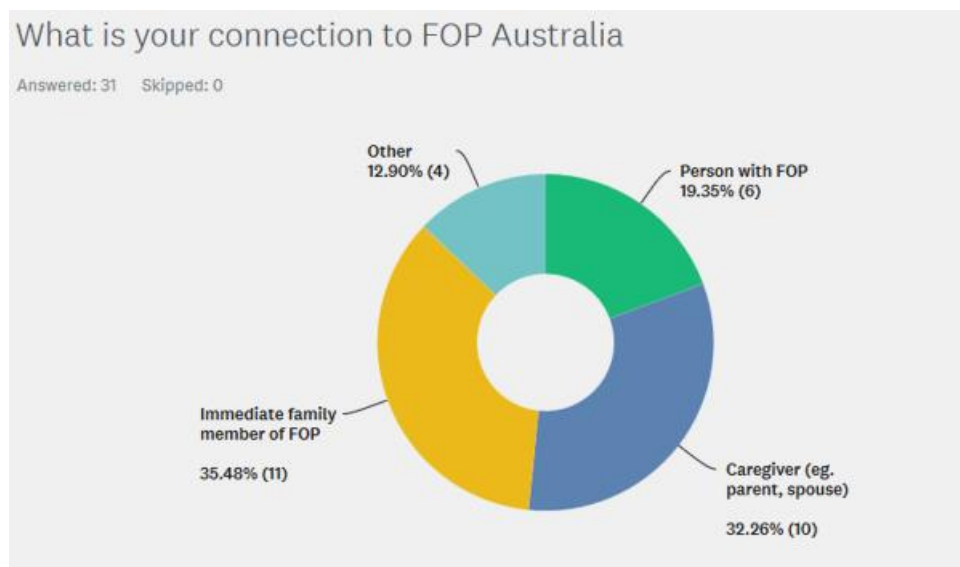
We hold a range of fundraisers around the country, and online. Check out upcoming events on our website or contact us about your fundraiser.

Anyone is welcome to join FOP Australia. We provide regular updates to our members, and to treating clinicians. Membership is free to health professionals interested in learning more about FOP. Join online in just a few clicks or by contacting us at info@fopaustalia.org.




FOP Australia and New Zealand Community Survey

This year we initiated our first FOP Australia and New Zealand Community Survey. It was an important step for the Board to receive direct feedback on key issues and strategic priorities. The survey was sent to all members of the Australia and NZ families and patient group. We had 31 people respond and below is a breakdown of the connection to FOP Australia.



The top three strategic priorities as selected from the respondents:

1. Advocating for access to a treatment when available– 87% ranked this as the number one priority
2. Build and maintain links with academic centres and pharmaceutical companies to bring up to date trial and drug information/opportunities to the FOP community – 84% ranked this as the second priority
3. Connection with IFOPA and other international FOP communities was ranked the third highest with 68%

These will remain core KPIs for the board in 2020.

Patient Family Gathering:

We shared the concept of working together to develop a patient family gathering within the next five years. The results were clear in that this is something of importance and value to this community.

Brooke Scott is drafting a proposal to outline the activities involved and in the development of such an event and will seek volunteers through the quarterly newsletter in the upcoming months. Or alternatively if you are interested in volunteering please contact Brooke Scott.

FOP Australia in person gathering - Please select all statements that match how you feel about a gathering in Australia for people with FOP

Answered: 31 Skipped: 0

ANSWER CHOICES	RESPONSES
It is a really high priority for me and one of the most important things FOP Australia could do, and it should happen as soon as possible	35.48% 11
I think it's important and FOP Australia should aim to do it within the next five years	35.48% 11
I hope FOP Australia hold a gathering at some stage but it isn't a priority compared to the other goals of the organisation	12.90% 4
FOP Australia should time a gathering to maximise the impact on lobbying to get access to a drug	35.48% 11
Holding patient gatherings is an important part of fulfilling FOP Australia's goal to support people living with FOP	58.06% 18
I would prefer FOP Australia provide support to people living with FOP through means other than holding a patient gathering	6.45% 2
It isn't a high priority for me but I would probably go	3.23% 1
It isn't important to me at all, I would prefer FOP Australia focus on other things instead	3.23% 1
I am likely to be able to attend	48.39% 15
I am unlikely to be able to attend	12.90% 4
I would not be able to attend without financial assistance with transport	3.23% 1
Other (please specify) Responses	6.45% 2

Communication, Information and Support

Facebook is the most followed social media platform and our quarterly newsletter, website (fopaaustralia.org), Facebook and email announcements is how the majority of you prefer to receive news/announcements.

We were delighted to hear how much you agreed that the information you receive through FOP Australia is informative (94% agreed) and relevant (97% agreed).

Communication, Information and Support

Answered: 31 Skipped: 0

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	TOTAL
▼ The information I receive through FOP Australia is informative	0.00% 0	0.00% 0	6.45% 2	48.39% 15	45.16% 14	31
▼ The information I receive through FOP Australia is relevant	0.00% 0	0.00% 0	3.23% 1	48.39% 15	48.39% 15	31
▼ It is clear to me when I should reach out to FOP Australia	0.00% 0	3.23% 1	35.48% 11	38.71% 12	22.58% 7	31
▼ It is clear to me how I reach out to FOP Australia	0.00% 0	3.23% 1	22.58% 7	48.39% 15	25.81% 8	31
▼ It is clear to me who I should reach out to at FOP Australia	0.00% 0	9.68% 3	19.35% 6	54.84% 17	16.13% 5	31
▼ The support I have received from FOP Australia has met my expectations	0.00% 0	9.68% 3	19.35% 6	45.16% 14	25.81% 8	31

We have opportunities to improve the community's understanding of when you should reach out to FOP Australia, who you could get in touch with and how you would do this. Each Board member brings different strengths and knowledge and after the reshuffle of board role allocation, we will update the profiles on the website to better articulate the most suitable person to connect with in the first instance.

19.35% said they neither agreed nor disagreed that the support received from FOP Australia met their expectations. We would be very interested in better understanding this and encourage you to let us know the specifics, if you are comfortable.

Continuing to raise awareness, fundraise, advocate with key members of the communities in which we live remain key to our success more broadly. A focus for 2020 will be to look for ways to broaden the community we regularly communicate with to include interested bystanders (i.e. not only the families and patients impacted by FOP but to include broader networks without needing to be a "member" of FOP Australia).

Many of you in the survey expressed your own personal interest to play a part with fundraising. We have added a page on our website to help you [create a fundraiser](#), and you can find out about ongoing [fundraising activities](#) as well.

Fundraising for FOP Australia

Answered: 31 Skipped: 0

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	TOTAL	WEIGHTED AVERAGE
I intend to organise a fundraising event for FOP Australia	3.33% 1	10.00% 3	36.67% 11	30.00% 9	20.00% 6	30	3.53
I know how to go about organising a fundraising event	6.67% 2	20.00% 6	20.00% 6	36.67% 11	16.67% 5	30	3.37

Comments (11)

We will continue to try to make it easier for people to know how to get involved.

The free text comments at the end of the survey helped give us further context to some of the responses. The comments ranged from asking for more practical and immediate support (we hope the new grant program will assist here), design of clothing and tools to support FOP patients at varying stages of the disease, requests for more information on NDIS and the FOP medical guidelines and a number of you expressed your gratitude for the efforts of the board.

Thank you to everyone who completed the survey.

#FunFeet4 FOP Campaign – FOP Awareness Day

April 23rd is FOP Awareness Day, this day is significant in the FOP calendar as it celebrates the day it was announced that the FOP gene, ACVR1, had been discovered.

This year we joined the global campaign of #Funfeet4FOP, the hashtag and concept was created by FOP Friends in the UK and is now used across the global to help raise awareness. This year we asked the community to help us spread awareness by taking a picture of their feet with the tag #FunFeet4FOP Thank you to everyone who was involved in this campaign.



Acknowledgments

We would like to acknowledge the efforts of all our supporters, without their help we would not have achieved the great outcomes that we did, thank you for supporting FOP Australia.

- Australian and New Zealand FOP Patients and Families
- FOP Australia Members
- International FOP Association (IFOPA)
- FOP clinicians, including Professor Matt Brown, Linda Bradbury and team at Queensland University of Technology
- Fundraising activity co-ordinators, including Tyson Stanley and Stuart Cunningham
- Harmony in the Twilight: Belinda Cowie, Harmony Lee, Daniel Felton, Autumn Lee
- Bridge to Brisbane run: Ellie Collins, Gerry Collins, Gabby Kelly, Russell Walkinshaw
- Mylan Payroll giving program: Jim Brown
- City to Bay fun run: Brendan Scott, Joyce Pettersen, Margaret Scott, Guy Tuck
- Bunnings Sausage sizzle: Belinda Cowie, Bob Wilson, Daniel Petrovic, Sarah Langford, Andrew Langford, Kirsty James
- Trivia night: Helpers; Lou Meagher, Kirsty James, David Hayes, Tyson Stanley, Sherrie Petrovic, Steph Hartnett, Holly Schroder
 - Donators; Our 5 tradies - Daniel Petrovic, Andrew Marshall, Adam Todd, Michael Petrovic, Nick Cooper, Elfreds of the Peninsula, Mornington Peninsula chocolaterie & ice creamery, Gravity Zone, The Eagle - Arthurs Seat, The Green Room Plant Co, Moose Toys, Steph Bolton, Belle Eve Fitness, Jaymak, TSIC, Baked by Mel, Infinite Fitness Peninsula, Ranfurlie Range, PGA of Australia, Aus GP - Elise Dawson, Callaway Golf, Ego pharmaceuticals, Image Hair by Amy Monty, Eleven Australia, Place of Haven, Swordfish Tapas Bar, Isabelle Amy Photography, Locked In Escape Room - Mornington, Bundameer Nursery, Somerville Hotel, GFS Graphics, SMAPS, Heidelberg Golf Club, Coca Cola Amatil, Samsara Salon, Direct Chemist Outlet Somerville, Somerville Newsagent, Petersens, Kings Creek Hotel, Little Woolie Makes Yarn, Salon D'Cazbar, Discount Chemist Hastings, Terry White Chemist, PARC aquatic centre Frankston, Mornington Railway, Eos Bathrooms, Bridgestone Frankston, The Low Tox Fox, Bayviews Golf Course, Kelly House, Dak Dak cafe, Miss Moose cafe, Redemption Tattoo Studio, Clear Blinds Australia
- Mt Gravatt's bowls day: Lara Boniface
- Broome Courthouse Markets: Cassie Yates, Tala Gooden , Eli Gooden, Louise Cross, Kerry Cross Dags Cross
- Flyers: Leonie Starnawski
- Eco-cups: Joyce Pettersen, Alex Laurisson , Jo McAlpine, Jo Baker, Lauren Turner, Lara Boniface
- Kimberley Rural Ladies Lunch: Bronwyn Cooke, Jami Elliot
- Kununurra Half-Marathon: Janet San De Miguel, Lauren Gibson, Hayley Potter and Red Terrain Contracting for donating the running shirts

Corporate & community partners

- BDO
- Rare Voices Australia
- King & Wood Mallesons (KWM)
- SR Global

How you can help

Here are lots of ways to help FOP Australia and the fight to cure FOP, and many of them don't cost a cent!

● Spread the word

- Follow us on Facebook, Twitter and Instagram like and share our posts and ask your friends to do the same
- Read and share our member newsletter and clinician updates (emailed to members and available at fopaustralia.org)
- Encourage friends and family to sign up as members online. Membership for the 2019/2020 financial year is \$10 per individual. Lifetime free membership is offered to those living with FOP, or clinicians interested in learning more about FOP.

● If you/your child has FOP

- Register for the FOP Connection Registry and update your data every six months
- If you/your child have FOP are likely to lose a tooth, please let us know so we can help develop sample transport processes
- Share your story, photos and news in our member newsletter, or the 'My Life With FOP' page on fopaustralia.org

● Support our fundraising activities

- Buy a reusable eco-cup from our website. For \$15 each you can help research and the environment!
- Use CharityBuy to support us while you shop, at no extra cost to you
- Subscribe online to the FOP Australia Coffee Club, where you pledge to donate the cost of a cup of coffee per week towards FOP research
- Many of our fundraising activities are designed for communities across Australia to get behind at a local level. Recurring activities such as Entertainment Books can expand in your area with your support. Contact us to learn how you can help
- Launch your own fundraiser using our mycause.com platform or contact us for support in developing your ideas
- Join our fundraising team in 2018
- Follow our website and social media to hear of upcoming activities, and spread the word!

● Become a corporate partner

- There are many opportunities for businesses to contribute financially or through other means such as sharing administrative, legal, marketing, IT, graphic design and printing expertise.
- Establish a payroll giving program within your company
- Contact us to discuss how your business can contribute to FOP Australia's goals and activities

● Direct donations

- Single or recurring donations can be made through the 'Donate' button on our website at any time, with automatic tax receipts issued. Donations over \$2 are tax deductible.
- Contact us for bank details to arrange donation by direct transfer

● Share your time, knowledge and skills

- Considering a term as a board director? Get in touch with us to discuss how to learn more (standard term length is three years)
- If you have marketing, IT, legal, accounting, graphic design, lobbying, communications, governance, fundraising, social media or event planning experience, you can help!

Whatever your skill set is, and whatever you have time to contribute, we can help you find a way to help the global effort to #cureFOP!

Contact Us

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www.facebook.com/FOPAustralia

Twitter @FOPAustralia

Instagram fop_australia