

FOP AUSTRALIA

ANNUAL REPORT

2020 - 2021



PIC-COLLAGE



ACKNOWLEDGMENT OF COUNTRY

In the spirit of reconciliation, FOP Australia acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community.

We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples.

In recognition that we operate in Australia & NZ, FOP Australia acknowledges Māori as tangata whenua and Treaty of Waitangi partners in Aotearoa New Zealand.

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CHAIRPERSONS REPORT

\$68k

Raised in FY22

\$34k

Provided to
Global Research

\$17k

Set aside for in-
person Patient
Gathering

\$17k

Invested in FOP
Support Activities

Dear FOP Australia and New Zealand Community and our worldwide supporters,

The 2020/21 year has seen the continuation of the global pandemic COVID-19. As always, I hope everyone has been able to stay safe during these times.

We have continued to partner with IFOPA on events such as the community gathering in November 2020, which saw people from around the globe meet virtually and hear from a range of FOP experts and others from within our community. FOP Awareness Day held in April each year included a social media campaign during April to raise awareness of FOP, once again this campaign was a success and planning for 2022 will start soon.

Although the ability to hold some fundraising events in person has been impacted by COVID-19, the community raised \$68K during the 20/21 period. We saw a wide range of events over this time, half marathons, collection of old car batteries, AFL footy tipping competition, Facebook birthday fundraisers, bike rides, coffee club subscriptions, entertainment book purchases, stair climbs, birthday scuba dives and corporate donations to name just a few.

This has given FOP Australia the ability to donate the following amounts to further research into FOP. \$5K to Shore Lab at the University of Pennsylvania, \$14K to IFOPA's In Pursuit of a Cure – Gene Therapy Program and \$14K to drug development activities coordinated by IFOPA.

Our ability to make such generous donations would not be possible without the support of our community so thank you.

An Australia and New Zealand gathering of our FOP community remains a key priority when we are able to do so, we have allocated \$17K to ensure that when the time comes, we are ready to support this initiative.

A further \$17K has been allocated for support activities such as our Support Grant Program. This program has helped many people living with FOP with day-to-day activities. So far, we have providing funding for items such as ramps for the home, a laptop and mobile phone and an adjustable bed. I encourage everyone to visit the support grant page on our website to learn more and reach out if you have any questions.



It would not be possible to reflect on the past year without mentioning the sad loss of one of our own in April 2021.

Ollie Collins and his family have provided much support to everyone, not only in our community but globally. Ollie's diagnosis at a young age, propelled the Collins family into the community and they have been a strong presence since. A loss of someone within the community is always difficult, the loss of Ollie for me, was extremely difficult as he has been a constant provider of support to myself and many

within our small community. The outpouring of support and donations from not only in Australia but globally was humbling. Whilst I am grateful for the many donations that have come to FOP Australia in memory of Ollie, I wish the circumstances were much happier and he could be here to celebrate with us, most likely in a fancy pair of shoes and a velvet jacket.

Ollie was a strong disability advocate and champion for FOP Awareness. His words on social media resonated with many people around the world and within our small community.

In the words of Ollie "Whoever you are, and however you move through life – walking, rolling, running, limping, dancing whatever – always move to the beat of your own drum".

Thank you to Ollie and the Collins family for the work you have done for our community over many years, and to me personally during this journey. It is very difficult to put into words the gratitude I have, so please know we are thinking of you.

After much reflection, I made the tough decision to step down as Chair and the Board of FOP Australia. I initially became involved with FOP Australia when Julie Collins approached me before the formation of our Charity. My time has been rewarding, challenging and I have enjoyed working with our community as we move closer to finding a cure for FOP. I could not have gone this far without the support of the community in Australia, New Zealand and Globally, the IFOPA, FOP Australia founding board members, past board members and the current board.

I wish the current board all the best as they move towards new leadership of FOP Australia and I'm excited to see what is to come. I continue to remain in my current role as the local representative on the IFOPA International President's Council, which helps keep FOP families connected and informed about treatments and research. If you have not already done so, I would encourage you to register and attend the IFOPA FOP Family Gathering on 19-21 November 2021.

Thank you for your support, as FOP Australia relies on volunteers, you are the heartbeat of our organisation. Without you we cannot achieve our goals and move towards a cure of FOP. Any support we receive, whether it be your time, clicking share on our social media posts or by donating is greatly appreciated.

Many thanks

A handwritten signature in black ink, appearing to read 'Brooke Scott'.

Brooke Scott

Chair, FOP Australia, October 2018 – July 2021



THE FOP STORY

Our Mission

Our mission is to raise awareness of Fibrodysplasia Ossificans Progressiva (FOP), and to 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

FOP Australia was established in 2015, with the first Annual General Meeting held in Brisbane in May that year. Through links with the International FOP Association (IFOPA), we aim to improve the lives of individuals and families affected by FOP by:

- Raising awareness of FOP
- Providing a support network for families and individuals with FOP
- Furthering research towards treatment and a cure

With the FOP research effort entering the clinical trial phase, in late 2018 the board mapped out an [Advocacy Strategy](#) for the charity to guide future strategic planning. You can read more about the development of the strategy [here](#).

In working towards these goals, we are inspired by the work of the international FOP community, and are so grateful for the support of FOP champions

Primary Objectives of FOP Australia

Promote and raise funds within the community for research into the cause(s), Treatments and cure(s) for Fibrodysplasia Ossificans Progressiva (FOP)



FOP AUSTRALIA

Conducting research that seeks to provide improved outcomes for people with FOP

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

FOP AUSTRALIA



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

Doing all such other things as are incidental or conducive to the operation of FOP Australia and otherwise for the attainment of all or any of the above objects



History & Structure

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.

This 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.

2020-2021 Board of Directors



Tahlia Wilson

Chairperson



Lydia Scott

Medical Officer



Jo McAlpine

Secretary



Emma Atkin

Treasurer



Brooke Scott

Chairperson to
July 2021

TREASURERS REPORT

I would like to thank our members and the rest of the board for again entrusting me with the role of treasurer for FOP Australia. It has been a fantastic experience to work with our small team and be a part of each of the achievements throughout the year. I am very pleased to be able to present this report on our 2020/2021 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 2021, and the auditor's report dated 24th November 2021, including:

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

Key Highlights

Key highlights from a financial perspective this year, include:

- FY21 profit of \$39,087
- Cash on hand at 30th June 2021 is \$106,734
- \$29,381 from the funds raised in FY21 will be donated towards projects supported by IFOPA
- \$5,000 from the funds raised in FY21 will be donated to Shore Lab at the University of Pennsylvania
- \$17,190 from the funds raised in FY21 will be allocated for support activities
- \$17,190 from the funds raised in FY21 will be allocated for our future patient gathering

The 2020-2021 Statement of Financial Position, Statement of Profit and Loss and Statement of Cash Flows are attached. This shows the years profit at \$39,087 for FOP Australia for the 2020/2021 financial year.

As at 30th June 2021 FOP Australia had equity of \$106,734. The fundraising efforts of FOP Australia and its members in FY21 will allow us to contribute \$5,000 to the Shore Lab at the University of Pennsylvania, and a total of \$29,381 towards projects supported by IFOPA. The remainder of our fundraising efforts from this year will be allocated to support activities (\$17,190) and our future patient gathering (\$17,190). While we have been affected by the continual restrictions of the Covid 19 pandemic in our ability to run face to face fundraisers, it is pleasing to see that we have maintained the support of our regular donors as well as been able to carry out some great online fundraising events.

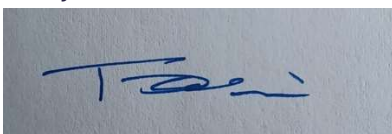
FOP Australia continues to be in a stable financial position and well placed to further grow our fundraising capacity to address our financial commitments, now and in the future. We are eager to introduce new and exciting projects to best utilise these funds and further support the FOP community, as well as continue to provide the current support structures that we have in place.

FOP Australia's main sources of income remain to be pod fundraisers and individual donations. It has been pleasing to see our base of supporters grow and carry out fundraisers in their own unique ways. We are always grateful for each person's efforts and not only the fundraising aspect but also the contribution to raising awareness that comes with each event.

Expenses have been kept to an absolute minimum, rising slightly from last year as we grow our online reach. These are expected to remain stable during the 2021-2022 financial year, with no considerable differences being foreseen. Growing our fundraising base, implementing, and continuing work towards regular contributions and introducing new and engaging fundraising ideas will cement future growth for FOP Australia and allow us to continue to assist those within the FOP community.

Thank you all for your support and I look forward to continuing my incredibly privileged work within the new role of Chair at FOP Australia. It will be exciting to share our future successes with you all.

Many thanks

A handwritten signature in blue ink, appearing to read 'Talia', on a light-colored background.

Talia Wilson

Treasurer

FOP Australia, December 2016 – August 2021

STRATEGIC PLAN & KPI'S

FOP Australia sets Key Performance Indicators (KPI's) at the beginning of each financial year. They are an evolution of the previous year's KPI's and are reviewed on a quarterly basis.

FY20 KPI's and Summary of Assessment of Organisational Performance

Not met	Some work done	Partially met	KPI met
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1	Advocate for people with FOP in Australia and New Zealand to have access to any effective FOP therapies, including subsidised funding of therapies	Partially Met
2	Provide a significant proportion of our fundraising to advances in research into treatments and/or a cure for FOP.	Partially Met
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.	Partially Met
4	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.	Aims met
5	Build and maintain strong links with those undertaking FOP research, including academic centres and pharmaceutical companies.	Aims met
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

1. Advocacy

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			
Develop preparation notes to aid community members with awareness presentations	Presentation notes developed but further review is required	Partially Met	
Develop preparation notes with key talking points for advocates meeting politicians/policymakers	Presentation notes developed but further review is required	Partially Met	

The website and flyers remain our main information materials to share. The plan to obtain more FOP Australia flyers for distribution has begun. Presentation notes have not been finalised, and this action is to be carried over to the subsequent year.

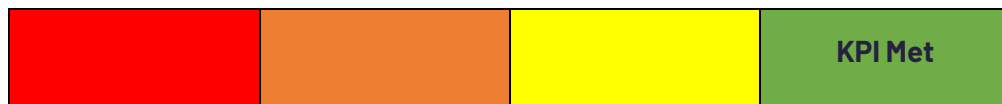
We remain a member of the Rare Voices Australia network and receive updates regarding their work on Rare Disease Advocacy. RVA helped share online information for FOP Awareness Day. The FOP Australia Chair attended the virtual RVA Parliamentary event, engaging federal politicians with rare disease advocacy.

Federal Minister for Health Greg Hunt was directly approached with a request to assist with promoting FOP Awareness Day, though this did not go ahead. Minister Hunt provided a letter of support for the Footy Day fundraiser (though that event had to be postponed due to COVID restrictions).

2. Fundraising

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

A. Funds raised in 2020/2021 will be allocated in keeping with the community priorities demonstrated in the results of the 2019 community survey



Direct all unallocated funds in accordance with the priorities required by FOP Australia	Of the undirected pool of money (general funding pool) raised in FY 2020/2021 we will donate 50% to research, 25% to other support activities, and 25% to a patient gathering	KPI Met
Funds received from corporate/government grants would be directed in keeping with the application process and terms of reference for that grant	No funds were received from grants during this period	KPI Met
A total of \$34,381 (50% of the funds raised during 2020/21) will be donated towards furthering the global research effort. This met the predetermined KPI, and the maximum threshold of funds that can be sent overseas according to regulatory requirements.		
A total of \$68,762 was raised in the 2020/21 financial year. In a difficult fundraising climate, the funds donated to FOP Australia increased from \$25,000 in the previous financial year.		
To ensure maximum impact from your donations and fundraising work, the board decided to distribute this across a range of research initiatives.		
<ul style="list-style-type: none"> \$5000 of funds raised has been allocated to the Shore Lab at the University of Pennsylvania, whose work in understanding the basis of FOP (including the previous discovery of the FOP 		

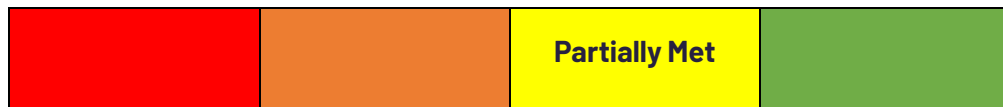
gene mutation, and their ongoing work to understand how the disease works) underpins the ongoing global research effort to find a cure.

- \$14,690.50 will be donated to the research in to gene therapy via IFOPA's 'In Pursuit of a Cure' campaign
- \$14,690.50 will be donated to the International FOP Association to support other research projects focussing on furthering progress for potential treatments.

We look forward to providing our community with updates from these projects over coming years.

No grant funds were received during this period.

B. Continue development of the fundraising team by facilitating 2 meetings of the active group and encouraging new members from within the community



Engaging our FOP families in fundraising activities, including by:

1. Developing a how to guide update from KPI's on how to create a fundraiser, giving options for Facebook fundraisers, quiz nights, birthday donations, fun runs etc
2. including the above information on how to help fundraise in two newsletters.

KPI Met

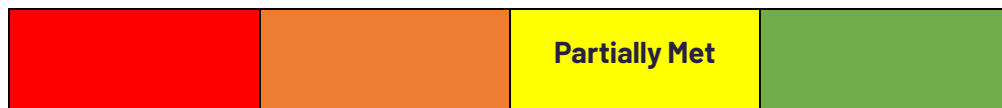
Several fundraisers have been set up by individuals and families that have not previously run activities and are not on the board, suggesting positive progress in enabling more broad community input in to fundraising. These fundraisers have utilised Facebook's fundraising function, Grassrootz, mycause and the GiveNow Crowdraiser options. Notes on operating fundraisers have also been added to the board's operational handbook. A fundraising group has been established and has met,

though more members and input would be warmly welcomed. A page on how to run a fundraiser has been included in the website and promoted on social media and in our newsletter. An additional fundraising platform (Grassrootz) was added to our existing platforms.

The end of the financial year including preparing a grant submission for a highly competitive federal grant program, the Rare Disease Support Education and Training Grant Opportunity. The process of drafting the application provided an opportunity for board directors to learn more about the process, and to prepare content that can also be used for future grant applications.

The board remain keen to develop processes to better recognise contributions to the charity, in order to ensure donors know how very appreciated they are, and to understand how the donated funds are utilised. Thank you certificates have been sent to acknowledge the non-financial contributions of several volunteers during the year, but this process could be made more consistent.

C. 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	Several online fundraisers held, detailed below	KPI Met
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Two major fundraising events (i.e. raising over \$8000 each; one per six months)	See detail below	Not met
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The target number of fundraising activities was exceeded this year. Several fundraising events (Xmas trivia night, Online quiz night) had to be postponed or cancelled, largely due to COVID restrictions. No individual fundraising activities raised more than \$8000, but several raised more than \$2000. In challenging times for fundraising, this is representative of the hard work from many community members. However, the board recognise the benefit of the organisation aiming to develop large scale fundraisers as part of ongoing planning.

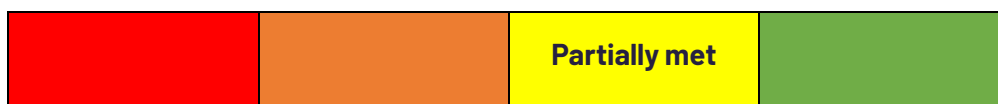
The board is very grateful for everyone who contributed through individual donations, organising or participating in fundraising activities, including:

- 7 Summits for FOP

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- RunMelbourne Half Marathon
 - Birthday Crowdfunders and Facebook fundraising pages
 - Ride4FOP
 - Team Keely fundraiser
 - AFL Footy Tipping competition
 - Proceeds from book sales "They Called Me Lightning"
 - Kimberley Battery Drive
 - Ongoing online fundraising activities: Entertainment Book, CharityBuy, Coffee Club, BrightStarKids, Eco-cups, Print-to-order merchandise
 - Individual donations were also received through GiveNow and direct deposit, some of which were associated with publicity efforts for the above fundraising events
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3. Build & Maintaining Links with Medical Community

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. Website Maintenance		
Maintaining our website as a source of up-to-date medical information, with minimum annual review of all content	Annual review of medical content of website undertaken August 2020	Partially met
B. Medical Updates to Clinicians		
Twice yearly medical updates to clinicians	Continued focus required in early 2021	Partially Met
C. Database of Treating Clinicians		
Maintain and expand the database of treating clinicians in order to enable effective dissemination of information	Clinician database reviewed and updated May 2021	Partially Met
Broaden the reach of known treating clinicians to include NZ	No NZ contacts have been added to this as yet	Not done
D. Clinician Learning & Development Activity		
	One clinician update emailed April 2021.	KPI Met
Develop educational activities targeting clinicians who are likely to be involved in initial recognition of FOP, diagnosis, and management	At least three presentations to clinical staff	Some Work Done (deferred)
	No webinars have been held within Australia or New Zealand for clinicians or community, but several international webinars have	Not done

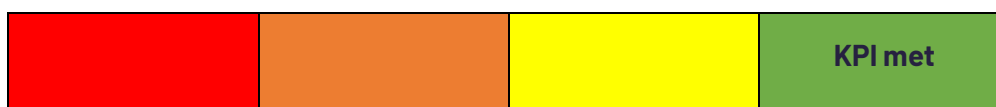
been held to educate clinicians, which were promoted to clinicians in our database. Prof Craig Munns has agreed to participate in future webinars held by FOP Australia.

E. Community Learning & Development Activity

Hold at least one webinar for the community that includes a clinician presentation	Zoom is the preferred platform	Some Work Done
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4. Building & Maintaining Strong Links with FOP Research

Build and maintain strong links with those undertaking FOP research, including academic centres and pharmaceutical companies.



A. Representative Contact with Pharmaceutical & Biotech Companies

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 the FOP community when permitted by the drug company. Links with IPSEN

Ongoing KPI measured every year

KPI Met

B. IFOPA Membership

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 KPI measured every year

KPI Met

C. FOP Connection Registry Participation

Encourage maximum participation by people from Australia and New Zealand in the FOP Connection Registry

Registry information has been shared in the newsletter and on Facebook

KPI Met

Board directors have met with Ipsen Australia staff throughout the year with reports back to the board. This has provided an opportunity to monitor for any potential local engagement in trials. These included giving feedback from our community regarding the Burden of Illness project, which did not include people in Australia and New Zealand.

FOP Australia was approached by a third-party company ascertaining information about numbers of patients within Australia and New Zealand for an unidentified pharmaceutical company to run a clinical

trial in the future. This information was provided but there was no further progress by the end of the financial year.

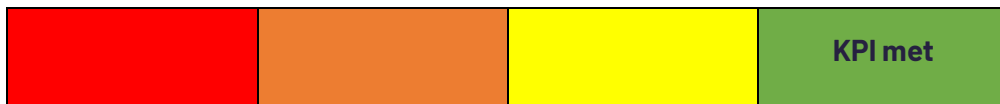
Membership of the IFOPA research committee has been maintained.

A board representative met with new IFOPA Research Director Danielle Kerkovich to ensure that the needs and challenges of people with FOP in Australia and New Zealand are understood and are considered as part of future research activities. This included discussion that the Australian and New Zealand community members want to have opportunities to be included in future trials or other opportunities to further the global research effort.

Participation in the registry has been promoted within FOP Australia newsletters and online.

5. Building & Maintaining Strong Links with the International Community

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. Representation at IFOPA IPC Meetings

Have a 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

IPC meetings have been occurring regularly with reports provided after each meeting

KPI Met

B. IFOPA Newsletter Updates

Include an IFOPA update in each newsletter

Update from IFOPA included in each newsletter and posted on Facebook as appropriate

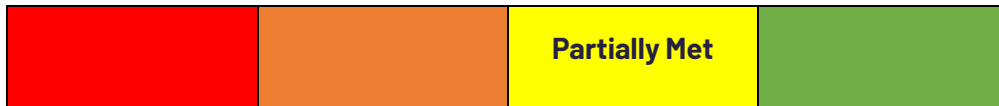
KPI Met

The FOP Australia IPC rep attended IFOPA IPC meetings by videoconference throughout the year.

Each newsletter included updates on international and IFOPA news, with topics including the IFOPA Advocacy series of webinars, the 'In Pursuit of a Cure' gene therapy campaign, the 2020 Virtual Community Gathering and the ICC guidelines for management of COVID in people with FOP

6. Establishing & Improving the Function of FOP Australia

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. ANZ Patient Gathering

Based on the results of the 2019 community survey, to work towards an ANZ patient gathering within the next five years	Assess feasibility from a financial and logistical perspective	Partially Met
	Identify community priorities for the gathering	Partially Met
	Plan a timeframe for the gathering	Partially Met

B. FOP Family & Supporter Community

To build a sense of community amongst the FOP families and supporters.	Membership numbers: 32	
	Increase of 1 on FY21 membership of 31	KPI met
	AGM attendance: The AGM was held via videoconference with 12 attendees from 5 different families (2 apologies) FY20 Attendance was 13	KPI met
Measurements that will be used to gauge this, include:	Social Media Interactions:	
	<ul style="list-style-type: none"> Instagram = 322 followers (40% increase), estimated reach = 1,505 Twitter = 171 followers (22% increase) Facebook = 1055 Followers (10% increase), 1035 "likes", estimated reach = 15,668 	KPI's Met

Participation in activities

- Several fundraising activities this year were held by individuals and families that have not previously organised activities, and that are not on the board KPI's Met
- The role of returning officer for the Support Grant Program was transitioned from a board director to a volunteer

Email Subscription list to be opened to those who have not signed on as members

The subscriber list has 329 subscribers who receive our quarterly newsletter KPI's Met
This list will be further developed in 2020/21

Nominations for Board positions and other tasks

- We welcomed new Board Director **Emma Atkin** to the Board, who was successfully nominated the previous AGM. KPI's Met
- We also welcomed new members of the fundraising team

Regarding further support activities:

- Three \$1000 support grants were awarded during this period, facilitated by a volunteer returning officer and an independent selection panel of volunteer experts.
 - A supply of extended flexible straws were obtained and distributed to people with FOP who expressed interest in these.
 - Peer advice regarding access support via the NDIS has been drafted by volunteers including support worker, parent and person with FOP perspectives. This will be shared via the website.
-

-
- Private Facebook group for FOP Australia Patients and Families has continued to give opportunities for people to seek and provide peer support and advice.

Most pages of the website were updated, though at the end of the financial year some updates were still in progress (specifically content providing peer advice regarding seeking support via the NDIS was in draft form at that time).

In order to maximise opportunities for FOP awareness and engagement amongst the broader community, we have broadened distribution of our newsletter to all subscribers, rather than limiting it to those who pay to be members each year. Membership enables supporters to have a vote at the AGM and to nominate for the board, and as such provides opportunities for those who wish to guide the development and direction of the charity

Four member newsletters were emailed throughout the year. Website posts were added in all months except October, May and June.

Policies and procedures were finalised and uploaded to the website. Board directors contributed content to ongoing development of an operational handbook, for continual updating over time

In the context of limited local member and volunteer capacity, progress has not been made towards seeking registered charity status in New Zealand. However, we have maintained contact with people with FOP in New Zealand, including provision of a support grant to a resident of New Zealand. We will continue to include people with FOP and their families and supporters from New Zealand in the activities of our organisation.

MEDICAL REPORT

The last year has seen development in resources available to clinicians treating people with FOP:

- The International Clinical Council for FOP released an updated version of ‘The Medical Management of Fibrodysplasia Ossificans Progressiva: Current Treatment Considerations’ in April 2021. This is the main document used by treating clinicians around the world and is accessible by a link at the top of every page of the FOP Australia website (fopaaustralia.org). We encourage all people with FOP to make sure their treating clinicians know how to access this.
- Travel restrictions in recent years have seen many medical conferences move online and an expansion in the range of clinical resources available online. Clinicians managing patients with FOP now have a range of online resources to access, as listed at <https://www.ifopa.org/fop-medical-education-programs>.
- FOP Australia share information about resources and key updates with our clinician database by email. Please encourage your treating doctors and multi-disciplinary care team to join by emailing info@fopaaustralia.org.

The global research effort continues to evolve and expand, with pharmaceutical companies Ipsen and Regeneron continuing their FOP clinical trial programs throughout the 2020/2021 financial year. Announcements from both companies continue to be shared through the IFOPA and FOP Australia social media platforms to keep you up to date on the latest developments. FOP Australia remain in contact with pharmaceutical industry representatives directly and through the IFOPA to monitor for opportunities for local clinical trial involvement.

The international patient registry remains on the most important research projects. The patient data from this registry provides the basis for understanding FOP, and being able to

interpret current and future research projects studying potential treatments, Thank you to everyone who has contributed data to the FOP registry, Find out more at:

https://www.ifopa.org/fop_registry_hcp

Many thanks

Dr Lydia Scott

Board Director (Medical Portfolio)

ACKNOWLEDGEMENTS AND CONTACT DETAILS

We would like to acknowledge the efforts of everyone who has supported our community over the last financial year.

Community Acknowledgements

- Australian and New Zealand FOP patients and families
- FOP Australia members
- FOP Clinicians
- FOP Friends
- Fundraising Committee - Tyson Stanley, Lou Meagher, Ashleigh Chalmers, Bianca Bakaniuzos, Olivia Sedgewick & Emma Atkin
- IPSEN Australia Staff Members - for showing their support for our #FunFeet4FOP campaign
- Team Keely Fundraiser
- The International FOP Association (IFOPA)
- Support Grant Program volunteers: Georgie Hyder, Dr Felicity Collins, Michelle Davis (IFOPA) and Jada Carr

Fundraiser Acknowledgements

A special thank you to volunteers who have coordinated fundraiser events:

- **Battery Drive:** Cassie Yates, Don Harris, Lauren Bell, Lauren Gibson, Margie and Pup Olsen, Bronwyn Cooke, Charmaine Grott and all the battery donors in the Kimberley region of WA
- **BooBoo's Café,** Somerville
- **Brendan Scott:** The Million Dollar Bike Ride
- **Brendan Scott:** Footy Tipping Competition
- **Dan Atkin & Naomi Bramham:** Ran the 'Run Melbourne' half marathon
- **Dean Jamieson:** *They Called Me Lightning* book sales

- **Eco Cups:** Joyce Pettersen for managing stock and postage
- **Harley Collier:** The 7 Summits for FOP
- **Hope for Jarvis association**
- **Jarvis Budd/FOP Australia Quiz Night:** Nici Bickley and Lara Boniface
- **The Runway Café,** Broome

Corporate and Community Partners



BDO Australia Limited

Website: <https://www.bdo.com.au>

Phone: +61(1300) 138 991

Email: media@bdo.com.au



Rare Voices Australia

Website: <https://www.rarevoices.org.au/>

Phone: +61(497) 003 104

Email: info@rarevoices.com.au

FOP AUSTRALIA: HOW YOU CAN HELP?

Spread the word on Social Media: follow us on Facebook, Twitter and Instagram. "Like" and share our posts

Newsletter: Encourage others to sign up as members online and share our quarterly newsletter with family and friends on Social Media

Membership for FY21 is \$10 per person and is free for those living with FOP or clinicians interested in learning more about FOP

FOP Connection Registry: If you or your child has FOP, please register on the FOP Connection Registry and update your data every 6 months.

Fundraising: Support our fundraising activities or even come up with your own fundraising ideas

Corporate Partnership: Become a Corporate Partner

Donate money: Direct donations through our website – all donations are tax deductible and are channelled toward our FOP community

Donate your Time: Donate your time to helping our community through leading a fund-raising event or consider joining our board

FOP AUSTRALIA: CONTACT US



<https://fopaustralia.org/>



info@fopaustralia.org



<https://www.facebook.com/FOPAustralia/>



<https://twitter.com/fopaustralia>



https://www.instagram.com/fop_australia

ADDENDUM:

12th December 2022:

Thank you to members for taking the time to read our FY21 Annual Report and send feedback to help us ensure our communications to members about our activities are as clear as possible. Your feedback is important and appreciated to the Board, as we take our responsibility to people with FOP and to FOP Australia supporters very seriously. As a result of feedback, we have made the following edits in order to clarify several parts of this report:

- Page 7: Correcting the Board of Directors to include all directors. Due to human error, the initial version inadvertently did not include Brooke Scott in this section. We apologise to Brooke for this mistake.
- Page 8: We have amended the text to clarify where references are made to how the amounts raised in the 2020/2021 financial year will be allocated. The initial version did not make it clear that the transfer of those funds occurred after the end of the 2020/2021 financial year, and hence appeared discrepant from the financial statements included with the report. We are proud to report that the planned donations were indeed allocated and transferred as planned during the 2021/2022 financial year, and again thank our supporters for their generosity.
- Page 11 and 16: We have updated the coloured headings to reflect that the KPIs relating to aims 1 and 3 were graded as “Partially met” not “Some work done”. This now matches the summary table on page 10.
- Page 22: The membership numbers were corrected. The initial report stated there were only 11 members, which was an error.

Thank you for your patience in reviewing this errors. FOP Australia is run by a small number of volunteers who care deeply about our organisational aims, and appreciate your understanding and support.

APPENDIX 1: FINANCIAL STATEMENTS & AUDITORS REPORT

FOP Australia Ltd

ABN 51603 200 871

Financial Statements

For the year ended 30 June 2021

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 2021.

Directors

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

Brooke Scott (Stepped down 1/7/21)
Lydia Scott
Talia Wilson
Olivia Sedgwick (Stepped down 1/12/20)
Jo McAlpine
Emma Atkins (Joined 1/12/20)

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 period amounted to \$39,087 (2020: \$25,577 loss).

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.

FOP Australia Ltd
ABN 51603 200 871
Directors' Report

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 in 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 24 November 2021:

A handwritten signature in black ink, appearing to read 'Talia Wilson', positioned above a horizontal line.

Talia Wilson
Chair

FOP Australia Ltd
ABN 51 603 200 871
Statement of Profit or Loss and Other Comprehensive Income
For the year ended 30 June 2021

	Note	2021 \$	2020 \$
Conference and fundraising		<u>68,883</u>	<u>52,336</u>
Gross Profit		68,883	52,336
Donations to IFOP		(25,020)	(70,040)
Donations to uPenn		0	(5,010)
Other		<u>(4,776)</u>	<u>(2,864)</u>
Total Overheads		(29,796)	(77,914)
Profit before income tax		<u><u>39,087</u></u>	<u><u>(25,577)</u></u>
Income tax (credit) expense			
Profit for the year		<u><u>39,087</u></u>	<u><u>(25,577)</u></u>
Total comprehensive income for the year		<u><u>39,087</u></u>	<u><u>(25,577)</u></u>

FOP Australia Ltd
ABN 51 603 200 871
Statement of Financial Position
As at 30 June 2021

	Note	2021 \$	2020 \$
ASSETS			
Current Assets			
Cash assets		106,734	67,648
Total Current Assets		106,734	67,648
 Total Assets		 106,734	 67,648
 Net Assets		 106,734	 67,648
 EQUITY			
Retained Profits		67,648	93,225
Current Year Profit		39,087	(25,577)
Total Equity		<u>106,734</u>	<u>67,648</u>

FOP Australia Ltd
ABN 51 603 200 871
Statement of Cash Flows
For the year ended 30 June 2021

	2021 \$	2020 \$
Cash Flow From Operating Activities		
Receipts from customers	68,883	52,336
Payments to suppliers and employees	(4,776)	(2,864)
Donations to IFOP	(25,020)	(70,040)
Donations to uPenn	0	(5,010)
	<hr/>	<hr/>
Net cash provided by (used in) operating activities	39,086	(25,578)
	<hr/>	<hr/>
Net increase (decrease) in cash held	39,086	(25,578)
	<hr/>	<hr/>
Cash at the beginning of the year	67,648	93,226
Cash at the end of the year	<u>106,734</u>	<u>67,648</u>

FOP Australia Ltd
ABN 51603 200 871
Notes to the Financial Statements
For the year ended 30 June 2021

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 24 November 2021 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 Australian Charities and Not-for-profits Act 2012 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.

(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.

FOP Australia Ltd

ABN 51603 200 871

Notes to the Financial Statements

For the year ended 30 June 2021

Interest revenue is recognised 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 recognised only to the extent that related expenditure is recoverable.

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 2021 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.



Talia Wilson
Director

Date: 24 November 2021

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 2021, 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 2021 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.

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



A J Whyte
Director

Brisbane, 24 November 2021