

FOP Australia

Annual Report 2021/2022





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 & New Zealand, FOP Australia acknowledges Māori as tangata whenua and Treaty of Waitangi partners in Aotearoa New Zealand.

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Chairpersons Report

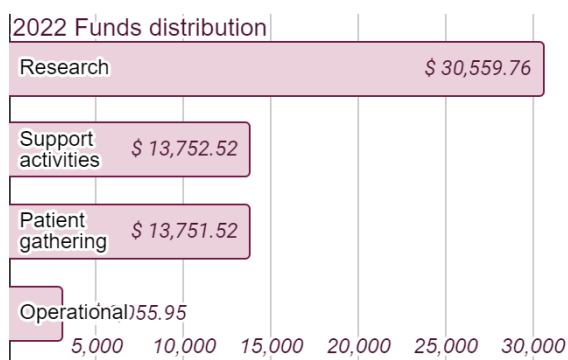
2022 - A year in review

February of 2022 signalled 7 years since the founding of FOP Australia by a small group of families and friends of those living with FOP within Australia. Over those 7 years our generous supporters have helped us raise nearly \$350,000, allowing us to significantly contribute to the global research efforts and move ever closer to our goal of finding a cure for FOP. In this time, we have also welcomed into the fold our friends from New Zealand.

While 2021 continued to make an impact on our ability to run some of our face-to-face fundraising events due to the global pandemic, we have worked within our constraints, and our fundraising efforts continue to reap rewards.

Raised this year

We know it's important to you that your donations and fundraising efforts are being used effectively. It's important to us, too. Our funds raised for the financial year came to \$61,119.52. These contributions will be distributed in the following manner:



International Research initiatives

FOP Australia works with IFOPA who have expertise and resources to manage effective research efforts. In 2022, we contributed \$25,559.76 to the IFOPA's in pursuit of a cure campaign which includes the STOPFOP trial and University of Massachusetts gene therapy work. We were also able to contribute a \$5,000 donation to the University of Pennsylvania which is used toward research into understanding the disease process and identify potential treatment targets.

Drug trials

With 5 active drug trials operating on the world stage – Palovarotene, IPN60130 (Falkon trial), INCB000928 (Incyte trial), Saracatinib and Garetosmab (OPTIMA trial) we welcome the future of treatments.

We are fortunate to have one available within Australia offering the community easier access for our Australian and New Zealand patients to participate.



Major fundraisers

International FOP Awareness day is a major milestone of the year. 2022 saw the launch of another hugely successful sock fundraising event. This fundraising event sees us not only raising funds but also an increased capacity to share about FOP and the work we do at FOP Australia with family and friends across the country in a fun and inclusive way.

2022 is the second year that we have had participants in Melbourne's annual Run Melbourne event. Thanks to the backing of Programmed Facility Management, this year's Run Melbourne fundraising total came to a whopping \$15,000. Tyson Stanley was also able to meet with many of the team at Programmed and share with them about living with FOP.

The Fegan family has taken a pro-active role toward fundraising, running several fundraising events and we would like to thank them for their considerable contributions to our yearly tallies and efforts to raise awareness.

We continue to see a wide range of events through the year, and we are so grateful for every fundraising initiative that is begun by our dedicated community. Everyone has the capacity to contribute to our goals, whether that be running a fundraiser or sharing our work with the people they know and love.

Teamwork

I was appointed the role of Chair on the departure of Brooke Scott in July of 2021, moving from the role of treasurer in which I served for 4 years. I am the parent of Tyson Stanley, who was diagnosed with FOP at 8 years old and is now about to turn 22.

As a board, we have laid the groundwork to ensure that we are running within the expectations placed upon us, by regulatory bodies and our community. We are a fully remote organisation.

Part of our coming focus will be to grow the team to ensure longevity and the efficiency of FOP Australia to fulfill our goals. We invite our community to reach out and join us in whatever capacity they can, while we will begin to create role descriptions to be filled. We are small and dedicated and value your commitment and generosity.



Patient gathering

A patient gathering has been in our thoughts for some time. As Brooke previously alluded to in her 2020 Chairperson's report, the power of connection is so important. We have been allocating funds each year since 2019 to the running of an in-person patient gathering and have reached a sizeable amount. We can see the fulfilment of this goal on the horizon. This coming year we will look to begin the planning process of this major goal.

Thank you

Our state and national reporting has become more streamlined. This has resulted in the elimination of the audited documentation requirement. We would particularly like to thank BDO for all their work with FOP Australia over the years and recognise Gerry Collins' fundamental involvement in this process.



Education grant

We announced the introduction of a new grant for those living with FOP. In honour of Oliver Collins, we are initiating the Ollie Collins education grant. Ollie believed that the development of the mind is integral especially to those living with FOP as their bodies begin to deteriorate. We are establishing the terms of reference and look forward to offering this grant 2023.

From the beginning it's been our mission 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. We have worked from the ground up to establish a community that achieves each of these goals. Our community has grown, and we have stepped ever closer to a treatment. We continue to provide support where we can and spread awareness and recognition of FOP in the wider community thanks to the work of those who stand along side us.

We are encouraged by the support of our community, strengthened by the families we serve and inspired by the individuals and teams who work with us. We look forward to a prosperous **2023**.

Many thanks,



Talia Wilson

Chair, FOP Australia, July 2021 - present

We are on a mission to find a cure for FOP. With the help of passionate supporters, an incredible team, and world-class partners who made 2022 a great year, we're closer now than ever.

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

Organisational Aims

Advocacy

Advocate for people with FOP in Australia and New Zealand to have access to any effective FOP therapies, including subsidised funding of therapies

Fundraising

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

Build and 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.

Build and Maintaining strong links with FOP Research

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.

Build and Maintaining Strong Links with the International Community

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

Establishing and 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.

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.

2021-2022 Board of Directors

Talia Wilson

Brooke Scott

Jo McAlpine

Emma Atkin

Lydia Scott

Treasurer's Report

I would like to thank our members and the rest of the board for affording me the opportunity to assume the role of treasurer for FOP Australia. I am very pleased to be able to present this report on our 2021/2022 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 2022, including:

Income and Expenditure during the last financial year; and

Assets and Liabilities in the last financial year.

Key Highlights

Key highlights to this years' financial statements and Treasurer's report, include:

FY22 profit of \$61,119.52

Cash on hand at 30th June 2022 is \$127,602.79

\$25,559.76 donated towards projects supported by IFOPA

\$5000 donated to Shore Lab at the University of Pennsylvania

Member numbers remain steady at 60 (including 20 patients and 29 Clinicians).

The 2021-2022 Statement of Financial Position, Statement of Profit and Loss and Statement of Cash Flows are attached. This shows the years profit at t\$61,119.52 for FOP Australia for the 2021/2022 financial year.

As at 30th June 2022 FOP Australia had equity of \$127,602.79. The incredible fundraising efforts of FOP Australia and its members has allowed us to contribute \$5,000 to the Shore Lab at the University of Pennsylvania, and a total of \$25,559.76 towards projects supported by IFOPA. The remainder of our fundraising efforts have been allocated to support activities (\$13751), our future patient gathering (\$13751) and operational activities (\$3055 - 5% of our income).

This year we have seen the much anticipated return of face-to-face and public fundraising events after the COVID pandemic, lockdowns and restrictions made these events much less possible over recent years. In conjunction with these larger-scale events making a return, we have seen the continuation of online fundraising efforts too and it is incredible to see the many varieties of fundraising taking place concurrently, helping to not only raise money for FOP Australia but also much needed awareness of our charity and of FOP as a condition.

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. We have been thrilled to see our supporter numbers growing and the number of new fundraisers being carried out which provide a variety of ways that people can learn about and support FOP Australia. We are always grateful for the efforts of our entire community to both fundraise but just as important, to raise awareness 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 2022-2023 financial year, with no considerable differences being foreseen. We continue to explore ways of growing our fundraising base, continuing work towards regular contributions and introducing new and engaging fundraising ideas that will promote the growth of FOP Australia for the benefit of Australian and New Zealand patients.

Thank you all for your support and I look forward to continuing my incredibly privileged work as Treasurer for FOP Australia. It will be exciting to share our future successes with you all.

Many thanks,

Emma Atkin

Treasurer, FOP Australia, September 2021 – Current

IFOPA International Presidents Council Report

The International Presidents Council (IPC) is a network of volunteers from around the world who work together to keep our community connected and informed. We meet regularly throughout the year and discuss several topics related to FOP such as trial information, FOP gatherings around the world, and how we can better meet the needs of the community. Please see below for an update on some of the international activities held in FY 22.

The IFOPA's annual "In pursuit of a Cure" campaign was launched in August 2021 with the theme "Invest in Progress, Believe in Hope". The campaign provided an update on the current FOP research which helped launch gene therapy at the University of Massachusetts. FOP Australia donated \$14,690.50 AUD towards further gene therapy research, and a further \$14,690.50 towards other research initiatives working towards potential treatments.

In August 2021, IFOPA announced the winners of the 2021 Jeannie Peeper awards, with FOP Australia director, Lydia Scott winning the Outstanding International Leadership Award. Thank you to Lydia for her ongoing dedication to FOP Australia and the IFOPA Research Committee.

In November 2021, the IFOPA hosted a virtual Family Gathering. Although Covid has been a difficult time for many of us, one benefit has been the increased use of technology allowing more people to participate in events like the IFOPA Family Gathering. This event helps to bring together people from around the globe and provides an opportunity to hear from FOP experts on a variety of topics. Even if you were unable to attend the gathering at the time, registering for the event enables access and the ability to watch the recordings on-demand.

This financial year saw the IPC meet with several of the pharmaceutical companies that are undertaking drug trials for FOP. It is always fantastic to see the great work that the companies undertake towards a cure for FOP. Since my diagnosis, there has been much progress in this space which has been helped by donations from the FOP Australia community.

In January 2022, Ipsen announced the approval of Health Canada for the use of Sohonos™ (Palovarotene capsules) for the reduction of formation of heterotopic ossification in adults and children aged 8 years and above for females and 10 years and above for males with FOP. This announcement marks the first approved treatment for FOP and is a fantastic step forward for the community.

FOP Awareness Day in April is a global event and planning for how we will celebrate it, starts months in advance. The theme for 2022 was “Hope, Believe, Wish” with 15 national FOP organisations representing 19 countries taking part in raising awareness of FOP. April 23 celebrates the discovery of the FOP gene, with 2022 marking the 16th anniversary of this discovery.

The IFOPA provide several services for the FOP community including a podcast series which is available on Spotify and iTunes and includes a wide range of topics such as Advocacy, fundraising and career advice. The Ability Toolbox Program is very useful to help remain independent when living with FOP, [click here](#) to find out more about the Ability Toolbox Program

I look forward to bringing you further updates from the international community.

Brooke Scott

IFOPA International Presidents Council Representative

Medical Report

It is a remarkable time to be involved in the global research effort to find a treatment for Fibrodysplasia Ossificans Progressiva. In just a few years, we have seen our community celebrate the first clinical trial and then progress rapidly to the point where 5 clinical trials are running simultaneously. This is exciting, but creates another set of unique challenges for the international FOP community. With a small global patient population able to enrol in clinical trials, excellent trial design is more important than ever to make sure that every trial is adding as much information as possible about potential FOP treatments.

Research in to palovarotene progressed during FY22 to the point where Ipsen are preparing their filing with the FDA (US Food and Drug Administration). Ipsen also continue to study palovarotene (in the PIVOINE trial, available only to those who completed the phase III MOVE trial as a follow-on study from that project) as well as studying kinase inhibitor IPN60130 in the Phase II FALKON trial. Incyte have commenced a Phase II trial of kinase inhibitor INCB000928, enrolling people 12 years or older, in 18 different sites including Australia. Meanwhile the STOPFOP trial of kinase inhibitor saracatinib continues in Germany, The Netherlands and the UK, with the support of the International FOP Association community. At the end of FY22 Regeneron were also preparing to enrol in a phase III trial of garetosmab (OPTIMA trial). At the end of FY22 BioCryst Pharmaceuticals had also been progressing plans to research their kinase inhibitor (Note: in November 2022, BioCryst announced they would discontinue development of their kinase inhibitor as “several [drugs] targeting the same mechanism of action [...] are positioned to reach approval and be available to patients earlier [...]. This lessens the benefit that BCX9250 may uniquely bring to the community [...] and may in fact slow down other clinical trials and approvals given the competition for enrolment).

Apart from the challenges posed by having several FOP trials running concurrently, the COVID-19 pandemic has also posed new and unique challenges for commencing and continuing clinical trials. This has made it more difficult for companies seeking to establish trial sites in Australia, where geographic and travel costs can already be restricting factors. It has also delayed progress in some trials, including STOPFOP, which had

already started enrolling when Covid-related delays threatened the continuation of the study. Thankfully, with the support of the FOP community around the world, the trial will be able to complete follow-up and analysis, and hopefully provide answers as to whether saracatinib could help people with FOP all around the world.

The funds raised by FOP Australia in the 2021/2022 financial year will contribute to the international research effort in several ways. This includes the ongoing gene therapy research program at University of Massachusetts, supporting the STOPFOP trial in to kinase inhibitor saracatinib, and supporting the foundational research by the University of Pennsylvania Shore Lab into understanding the disease process of FOP itself. We are very proud to be able to support so many potential research pathways, and hope that by supporting multiple research programs we are maximising the value of your contribution to make sure that your generous support leads to treatments that will help our loved ones living with FOP.

However financial support is not the only way that FOP Australia members contribute to the growing research effort. By participating in the FOP Registry, people with FOP in Australia and New Zealand continue to shape the world's understanding of what FOP is. This will become the foundation of future efforts to improve medical treatments, and is crucial for informing future trial design so that future research has maximum possible impact. If you need help contributing to the FOP Registry, please reach out to us at info@fopaustalia.org.

We are also very grateful for the ongoing work of the global experts on the International Clinical Council for FOP, who maintain 'The Medical Management of Fibrodysplasia Ossificans Progressiva' guidelines. This document provides crucial guidance to clinicians all around the world, including in Australia and New Zealand where many doctors caring for people with FOP may not have ever met another patient. This document is available at the top of every page on the FOP Australia website, including the front page, and was last updated in May 2022. We recommend you share it with your treating team if you haven't already done so. Please also encourage the clinicians involved in your care to stay up to date with FOP research and news by joining our clinicians contact list, by contacting us at info@fopaustalia.org.

Lydia Scott

Board Director

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
- Fundraising Committee - Tyson Stanley, Lou Meagher, Ashleigh Chalmers, Talia Wilson & Emma Atkin
- IPSEN Australia Staff Members - for showing their support for our #FunFeet4FOP campaign

- 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:

- Coffee Club participants
- 7 Summits for FOP
- Battery Collection
- Birthday Fundraiser
- Run Melbourne and Run Melbourne 2
- Entertainment books
- In Memory of Ollie Collins
- Charity Buy
- Jack's movement
- Socks
- Fire Brigade Open Day
- Special Thanks to the Fegan Family.

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 FY22 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://fopaustalia.org/
		info@fopaustalia.org
		https://www.facebook.com/FOPAustalia/
		https://twitter.com/fopaustalia
		https://www.instagram.com/fop_austalia

Appendix 1: Financial Statements

Statement of Profit or Loss and other comprehensive income

Statement of Financial Position

Statement of Cash Flows

In the interest of transparency, please note; two illegal transactions were carried out in the 2021/2022 financial year totalling \$9,088. All monies illegally removed were returned upon follow up with NAB. The amounts are included in the totals seen throughout the financial documents, in particular the 'Conference and fundraising' and 'Other' overheads seen in the Statement of Profit and Loss, as well as 'Receipts from customers' and 'Unapproved transactions' found in the Statement of Cash Flows. The Board have since decided on several measures to increase the security of our funds, including changing our Bank Account structure and Provider.

As noted in the Chairpersons report, the requirements for regulatory reporting have been streamlined this year, making an annual external audit no longer required. To preserve transparency for future reports we will look to provide more itemised information about our incomings and outgoings. In the interim, please feel free to follow up with us if you have questions regarding these occurrences.

FOP Australia
ABN 51 603 200 871
Statement of Profit or Loss and Other Comprehensive Income
For the year ended 30 June 2022

	Note	2022 \$	2021 \$
Conference and fundraising		70,208	68,883
Gross Profit		70208	68,883
Donations to IFOPA		-29,401	-25,020
Donations to Upenn		-5,060	0
Other		-14,878	-4,776
Totals Overheads		-49339	-29,796
Profit before income tax		20869	39,087
Income tax (credit) expense		20869	39,087
Profit for the year		20869	39,087
Total comprehensive income for the year		20,869	39,087

FOP Australia Ltd
ABN 51 603 200 871
Statement of Financial Position
As at 30 June 2022

	Note	2022 \$	2021 \$
Assets			
Current assets			
Cash Assets		127,603	106,734
Total Current Assets		127,603	106,734
 Total Assets		 127,603	 106,734
 Net Assets		 127,603	 106,734
 Equity			
Retained Profits		106,735	67,648
Current Year Profit		20,869	39,087
Total Equity		<u>127,604</u>	<u>106,735</u>

FOP Australia Ltd
ABN 51 603 200 871
Statement of Cash Flows
For the year ended 30 June 2022

	2022	2021
	\$	\$
Cash Flow From Operating Activities		
Receipts from customers	70,208	68,883
Payments to suppliers and employees	-5,790	-4,776
Donations to IFOPA	-29,401	-25,020
Donations to Upenn	-5,060	0
Unapproved transactions - money returned	-9,088	
Net cash provided by (used in) operating activities	20,869	39,086
Net increase (decrease) in cash held	20,869	39,086
Cash at the beginning of the year	<u>106,734</u>	<u>67,648</u>
Cash at the end of the year	<u><u>127,603</u></u>	<u><u>106,734</u></u>

Appendix 2: Notes to Financial Statements

FOP Australia Ltd
ABN 51 603 200 871
Notes to the Financial Statements
For the year ended 30 June 2022

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 authorized for issue on 9th December 2022 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 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

- **Cash and cash equivalents**
Cash and cash equivalents include cash on hand and 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 borrowing in current liabilities on the statement of financial position.
- **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.

Appendix 3: Directors Declaration

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 2022 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
Chair

Date; 9 December 2022