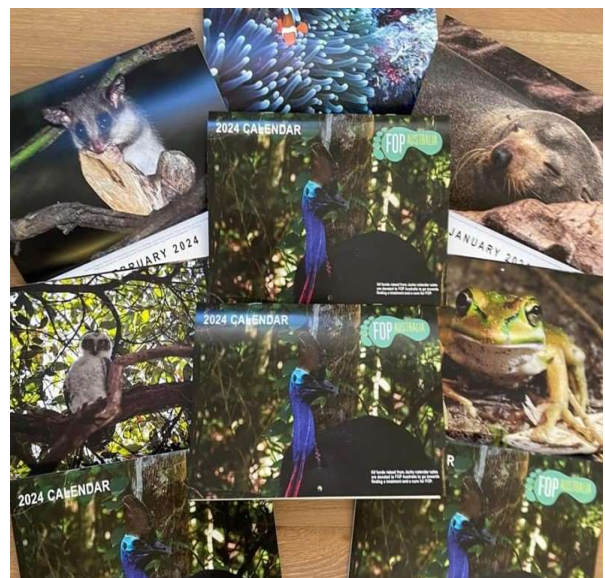




2023/2024 Annual Report





ACKNOWLEDGEMENT 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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Cover photos:

- Jack Fegan with some of his photography, as featured in the 2024 Wildlife Photography Calendars.
- FOP Australia Board Directors, Talia Wilson and Lydia Scott at Rare Disease Day Parliamentary Event in Canberra 2024.
- Tyson Stanley and supporters at his 2023 Footy for FOP day in Somerville, Victoria.
- Tyson Stanley with his family.
- Jack Fegan’s 2024 Calendar images.

Overview of FOP Australia

FOP Australia was established in 2015, with the first Annual General Meeting 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.

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.

2023-2024 Board of Directors

Talia Wilson (Chairperson)

Jo McAlpine

Lydia Scott (Treasurer)

Lauren Gibson (Secretary)

Chairpersons Report

Deputy Chairperson's Report

Thank you for your ongoing support of FOP Australia during the 2023/2024 financial year.

It is not possible to describe this year without first acknowledging the loss of Tyson Stanley. Tyson was a much loved member of our community and an active fundraiser, research participant and advocate. His unexpected death in April was heartbreaking and a huge shock for his family, friends, and everyone in FOP Australia. Tyson's mum is FOP Australia champion Talia Wilson, our Chair and long term board director. Our thoughts remain with Talia, Dan, Ashlee, Phoenix, Jett, Zac and Tyson's whole family. As an organisation, we would like to acknowledge and thank the whole community for your support, patience and understanding shown towards the FOP Australia board of volunteers during this time. As we move forward in to another year, we hope that our ongoing work will help honour Tyson's memory.

Only days before his passing, Tyson shared his story in a FOP Awareness Day presentation for staff at pharmaceutical company Ipsen. We also appreciate everyone who displayed FOP Australia socks, shoelaces and social media messages on April 23rd to help more people learn about FOP.

Throughout the year sales of our socks and shoelaces continued to help raise awareness, but a definite fundraising highlight was the opportunity to help promote the excellent 2024 Wildlife Photography Calendars showcasing the work of Jack Fegan. Following the success of Jack's 2023 calendars these were snapped up quickly and raised \$3000 for FOP Australia. If you have not already, we recommend checking our Jack's work at [jacks_wildlifeaus](#) on Instagram, or Jack's Movement on Facebook.

Other fundraising highlights have included Andrew and Amy Moore's Gold Coast Half Marathon, Frankston YCW Stonecats' hosting an FOP fundraiser round, Tyson's Footy Day, the Trivia Night supported by Programmed in Bennettswood Victoria, the Run Melbourne fundraisers (led by Talia), and Brendan and Brooke Scott's AFL Footy Tipping competition. Dean Jamieson, father of our IFOPA IPC rep Brooke, also facilitated several donations during promotional speeches in South Australia for his book, They Called Me Lightning, with book sales also contributing to fundraising. We also continue to raise funds through the collection of used batteries for scrap metal throughout the Kimberley region of Western Australia, largely through the generosity of truck drivers. Board Director Lauren Gibson has also set up Containers for Change accounts for recycled bottles and cans in WA and Queensland. In addition to this diverse range of activities, our online fundraisers continue through CharityBuy, Entertainment Memberships, Bright Star Kids and our planned giving Coffee Club program; Thank you to everyone who has supported these through fopaaustralia.org.

This year has been one of our most significant years for advocacy activities. Through the support of Rare Voices Australia and Ipsen, Talia and I represented the FOP community at Parliament House for the Parliamentary Rare Disease Day event and the launch of National Recommendations for Rare Disease Health Care. This gave us the opportunity to connect with several federal politicians and other advocates, allowing us to help others learn about FOP and also for us to learn from other rare disease organisations.

This year also included the milestone announcement that palovarotene was approved by the Australian Therapeutic Drug Administration as the first treatment for FOP. The next step in regulatory processes to facilitate supply in Australia is the review by the Pharmaceutical Benefits Advisory Committee in November 2024. This process gives us our most significant opportunity yet to explain to federal regulatory bodies what FOP is, and represent the lived experiences of people with FOP, and why a treatment is needed. It is therefore a significant opportunity to inform future reviews of further treatments, not just palovarotene. FOP Australia are proud and grateful to have had the opportunity to collate input from many of our community, and have sent this to PBAC along with a request for further discussion and ongoing engagement throughout this process.

We are proud to continue contributing to global research to develop effective treatments for FOP, and celebrated contributions to the International FOP Association's In Pursuit Of a Cure campaign to support gene therapy, as well as donations to the University of Pennsylvania Shore Lab for ongoing foundational science research. We also want to acknowledge the invaluable contribution of people with FOP in our community who enrol in clinical trials and contribute to the FOP Registry.

FOP Australia also continue to offer financial support to people in Australia and New Zealand with FOP (or their caregivers) through the Support Grant Program and the Oliver Collins Education Grant program. We are grateful for the work of the many volunteers who contribute to facilitating these grants, and the generous donations that make them possible.

We look ahead to another very big year, as we await the outcome of the PBAC review, and progress plans towards our Australia/New Zealand patient gathering in July/August 2025, and look towards further research progress and hope for future treatments on the horizon.

Yours sincerely

Lydia Scott - Deputy Chair

With thanks to Chair Talia Wilson

Treasurer's Report

Treasurer Lydia Scott and I are proud to share with you our financial statements for the year ending on June 30, 2024.

One of the main developments in FOP Australia's financial management this year was our transition between banking service providers. Following several fraudulent transactions from our account in the previous financial year (with all funds subsequently recovered), a review was undertaken of options to better secure our greatly appreciated donated funds. Subsequently we have established new accounts with a new provider, with extra security measures implemented. Additionally we now have been able to reduce banking fees to zero and accumulate a significant amount of credit interest. We would like to acknowledge the research and contributions of former Treasurer Emma Atkin in obtaining guidance on this process.

Our next aim in securing and improving our financial management is to facilitate voluntary external audit processes. Although external audit is no longer a mandatory requirement for charities of this size, our board have determined that in order to ensure we appropriate governance and support our volunteer directors, that we will voluntarily engage in external review. We are currently seeking options to do this through the most cost effective way possible, and would welcome suggestions or support from our community in pursuing this.

As detailed in these statements, our total funds raised throughout FY 23/24 was \$43,231.33. Every dollar represents the generosity of our volunteer fundraisers and donors, and is greatly appreciated. In this challenging year for our organisation, we are more grateful than ever for our fundraisers that have enabled the work towards our goals to continue.

In keeping with allocation of funds in previous years, we have again allocated the maximum possible amount towards research (being limited to 50%, the maximum percentage we can allocate to sites overseas), which will comprise of a \$5000 donation to the University of Pennsylvania with the remaining \$16,615 going via IFOPA to be allocated to research projects. Regarding the remaining funds: 30% will be directed towards support activities (this includes the patient gathering fund, and support grants). We have set aside 10% for set-up costs for fundraising activities, and also allocate up to 10% for operational costs which will include our administrative costs (less than \$1500 per year) and funds to build our operational sustainability further during the next financial year.

In recent years we have been setting aside money each year from the support activities allocation to plan a future patient gathering. We are proud to have accumulated enough funds to enable planning now, and we anticipate spending our savings on a gathering in late 2025. We will also be seeking external sources of funding for this event.

Thank you for taking the time to review our financial status and for contacting us with any queries or suggestions.

Talia Wilson

Chair and Former Treasurer

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 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 24.

The IFOPA's pursuit of a cure campaign was held in September 2023. The 2023 theme was "Relentless". The campaign video featured Parveen and Annaya from Pakistan, who highlighted the increased need for treatments for FOP. You can watch the video here: <https://www.youtube.com/watch?v=yJbF7HqSAHo>. The campaign raised over \$325K to fund the next phase of gene therapy research.

The 6th FOP Drug Development Forum (DDF) was held in Stockholm in June. The DDF is designed only for researchers, clinician scientists, pharmaceutical/biotech employees, and employees of regulatory agencies, with patients involved in panel discussions as invited. This year we were represented by the Fegan Family who joined a panel discussion virtually. Thank you to the Fegan's for helping to explain the personal impacts of FOP.

The DDF is also an opportunity for the IPC to meet in person and virtually. A number of IPC representatives from around the globe were able to attend in person with some attending virtually. This time together, allows us to focus on our common goal and understand how different countries support their FOP communities.

The IFOPA provide many services for the FOP community, see below for some helpful links:

YouTube – There are several presentations on a range of topics <https://www.youtube.com/@IFOPA>

Ability Toolbox – helps to empower individuals with FOP by promoting independence using tools and home adaptations. I highly recommend reading more at the link: https://www.ifopa.org/ability_toolbox_program

Resilient Living Program – focuses on the emotional well-being of families, including siblings, caretakers, spouses, and partners. https://www.ifopa.org/resiliency_program

Support Resources: https://www.ifopa.org/resources_for_support

Medical treatment guidelines are available at this link, including resources on Covid-19: https://www.ifopa.org/for_medical_professionals

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

Brooke Scott, IPC Representative

Medical Report

The most significant local development in management of FOP has been the approval of palovarotene by Australia's Therapeutic Drug Administration. Whilst supply arrangements are still to be determined by the pending PBAC review of palovarotene, this milestone offers us the opportunity to engage with regulatory bodies to help them understand the importance of helping people with FOP get access to treatment. We see this as a step forward in contributing to future reviews of further treatments, not just palovarotene.

With four trials active in Australia, and one in New Zealand, our community continues to participate and contribute to the ongoing battle for a cure. Royal North Shore Hospital (RNSH, Sydney) and Murdoch Children's Research Institute (Melbourne) are both sites for Incyte's PROGRESS Phase 2 trial of INCB000928 (with Starship Children's Hospital in Auckland having also had discussions about potential participation). RNSH is also involved in Ipsen's PIVOINE Rollover trial of palovarotene, Regeneron's OPTIMA Phase 3 trial of garetosmab, and Ipsen's FALKON phase 2 trial of fidrisertib. Globally, the STOPFOP trial of saracatinib and the Incyte trial of zilurgisertib are also continuing. Each of these agents holds promise and we look forward to sharing the outcomes of these trials with you when results are available. IFOPA's website is a great resource for staying up to date with clinical trial news, and for checking the global map of active clinical trial sites at https://www.ifopa.org/ongoing_clinical_trials_in_fop/#trial_locations_map.

The FOP Registry remains one of the most pivotal ongoing research projects, which enables new and deeper insights into FOP each year. Thank you to everyone who has contributed their information to this critical project. We encourage everyone who can to contribute https://www.ifopa.org/fop_registry_hcp and to please reach out to FOP Australia or IFOPA with any queries.

The generous donations of FOP Australia supporters in FY 23/24 will again support research projects via the International FOP Association and also directly support the University of Pennsylvania Shore Lab research into the foundational science of FOP.

The International Clinical Council for FOP released a statement regarding use of off-label medicines in May, available here:

<https://assets.nationbuilder.com/ifopa/pages/1043/attachments/original/1719585756/20240530-ICC-Off-Label-Statement-Update.pdf?1719585756>

We anticipate that FY24/25 will be another big year for research progress, and also hope to utilise the upcoming opportunities to increase clinician knowledge of FOP, in the setting of the ongoing regulatory review of palovarotene, and the upcoming FOP Australia community gathering.

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
- International FOP Association (IFOPA)
- Oliver Collins Education Grant selection panel members: Ellie and Will Collins, Ian Cali, Brooke Scott (and reserve selection panel volunteers Amanda Cali, Daniel Atkin and Alison McAlpine)
- 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
- FOP Awareness Socks and Shoelaces
- 2024 Wildlife Calendars
- Battery Collection
- Birthday Fundraisers
- Run Melbourne
- Entertainment books
- Charity Buy
- GC Marathon
- Frankston YCW Stonecats FOP Footy round
- Tyson's footy day
- Programmed Trivia Night
- Footy tipping
- They Called Me Lightning book sales
- Containers for Change

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 is \$10 per person per financial year 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_australia

Appendix 1: Financial Statements

Statement of Profit or Loss and other comprehensive income

	2024	2023
	\$	\$
Fundraising	43,231	48,494
Gross Profit	43,231	48,494
IFOPA contribution	-17,497	-25,559
UPenn contribution	-5,000	-5,000
Other	-4,982	-7,699
Total overheads	-27,479	-38,258
Profit before income tax	15,752	10,236
Income tax (credit) expense		
Profit for the year	15,752	10,236
Total comprehensive income for the year	15,752	10,236

Statement of Financial Position

FOP Australia
ABN 51 603 200 871
Statement of Financial Position
As at 30 June 2024

	2024	2023
	\$	\$
Assets		
Current assets		
Cash assets	153,590	137,838
Total current assets	153,590	137,838
Total assets	153,590	137,838
Net assets	153,590	137,838
Equity		
Retained profits	137,839	127,603
Current year profit	15,752	10,236
Total equity	153,590	137,839

Statement of Cash Flows

FOP Australia
ABN 51 603 200 871
Statement of Cash Flows
For the year ended 30 June 2024

	2024	2023
	\$	\$
Cash flow from operating activities		
Receipts from customers	43,231	48,494
Payments to suppliers		-4,199
IFOPA contribution	-17,497	-25,559
UPenn contribution	-5000	-5,000
Unapproved transactions – money returned		-3,499
Net cash provided by (used in) operating activities	15,752	10,236
Net increase (decrease) in cash held	15,752	10,236
Cash at the beginning of the year	137,839	127,603
Cash at the end of the year	153,590	137,839

Appendix 2: Notes to Financial Statements

FOP Australia

ABN 51 603 200 871

Notes to the Financial Statements For the year ended 30 June 2024

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 27th September 2024 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 they 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

ABN 51 603 200 871

Directors Declaration

The directors of the company declare that:

1. 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 2024 and of its performance for the year ended on that date;
2. 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
29th September 2024