

# FY 2015/2016 ANNUAL REPORT

# **FOP AUSTRALIA LTD**



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### **Our Mission**

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

### **Our History**

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. During 2016 we held the following fundraisers:

Jamberry Nails online

Junction Park Primary

FOP Australia Launch

**Entertainment Book Sales** 

City2Surf - City2Surf – Sydney Prince of Wales Medics in particular Imogen Taylor (Imogen is working Australia at the moment and is the sister in law of one of our international FOP community patients in the UK, Lucy Pratt.

### **Overview of FOP Australia Ltd**

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

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

# **Our People**

The current board consists of:

Chairperson	Lara Boniface	
Treasurer	Mark Boulton	
Secretary	Brooke Scott	
Director	Maris Stanley	
Director	Lydia Scott	
Director	Talia Wilson	

# **Structure and Management**

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

Our organisation is a company limited by guarantee; we have a Board of Directors and are accountable to our members.

We have no paid employees and run purely through volunteers.

### **Chairpersons Report**

#### **Dear Members**

Thank you for your support of FOP Australia in our first year of operation. This year has been extremely successful, albeit with its challenges.

Firstly, the creation of FOP Australia is an achievement in itself. Setting up a desperately needed organisation here in Australia was imperative to our national and international community. This was achieved through the dedication of patients, families and friends of the Australian FOP community.

FOP Australia provides a local support group for our FOP patients and families. It also puts us in good stead for future drug trials and as advocates for potential drug availability - when they find that treatment and or cure. We have also shown the international FOP community that Australia is contributing to the international effort in finding a treatment and/or cure for FOP. I would like to acknowledge Julie Collins's dedication to IFOPA for many years as the IPC representative for Australia. She was a contact for our Australian community and attended many conferences on Australia's behalf. I look forward to Brooke Scott, the new IPC representative for Australia, working closely with IFOPA and other international organisations to bring FOP Australia into the realm of the international community.

Our greatest achievement was donating \$34,000 to research. Not bad for a charity in its first year. We couldn't have donated this amount to IFOPA without the help of members and supporters. Our Launch Party was our biggest event and many thanks goes out to those who attended. It was a fantastic night with a fantastic outcome.

That weekend also saw the first patient gathering in 10 years thanks to Clementia Pharmaceuticals. It was a great opportunity for those that could attend, to meet again and meet the new members. We were blessed with the attendance of Dr Fred Kaplan and Dr Bob Pignolo, the FOP experts from the USA, via teleconference. Patients, their families and doctors were able to question the experts regarding FOP and expand their knowledge of this condition.

I would like to personally thank all Board members, both past and present, and volunteers, for their extremely hard work in achieving one of our most important objectives. There were many months dedicated to the Launch Party and Clementia gathering, by all of us.

It has been an honour to serve as Chairperson on the first FOP Australia Board. The past 18 months have provided a lot of lessons learned, a lot stress, yet a lot of accomplishment. Unfortunately, my time on the Board has come to an end and it is with a heavy heart that I will not be renominating for Chairperson or the Board. Amongst other things, my 5 year old son is under constant attack from FOP. I can no longer dedicate the time or energy to FOP Australia that it deserves.

FOP Australia will always have my support and I hope it will have yours. I look forward to its continued success over the coming years.

Many thanks for your support

Lara Boniface



Junction Park State School – Rare Disease Day Awareness February 29





Jamberry Fundraiser with Shan Carty <a href="https://www.facebook.com/shancarty.jamberry/">https://www.facebook.com/shancarty.jamberry/</a>



June patient gathering – Patients and Clinicians



June Patient Gathering –Patients and Families



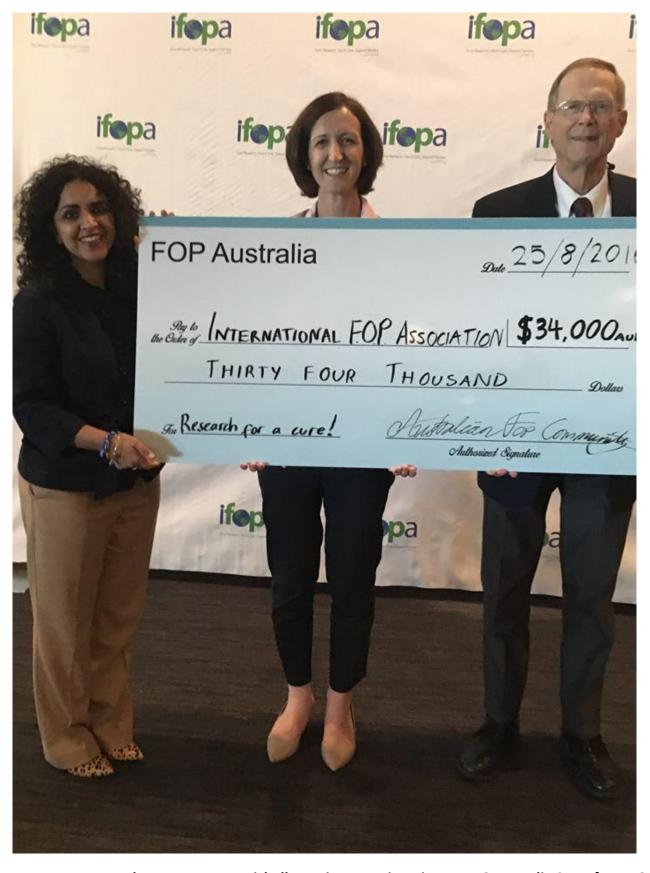


FOP Australia Launch – Brisbane





City2Surf – Sydney – Prince of Wales Hospital



Boston Drug Development Forum Michelle Davis, Executive Director IFOPA, Lydia Scott from FOP Australia and Paul Brinkman, Chair of the IFOPA.

## **FOP Australia Ltd**

ABN 51 603 200 871

Financial Statements
For the year ended 30 June 2016

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## FOP Australia Ltd ABN 51 603 200 871 Directors' Report

Your directors present this report on the company for the financial year ended 30 June 2016.

### **Directors**

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

Lara Boniface

Mark Boulton Appointed 29 July 2015

Alton Budd

Julie Collins

**Brooke Scott** 

Lydia Scott Appointed 29 July 2015

Talia Wilson Appointed 24 September 2015

Helen Gillies Appointed 28 April 2016

Maris Stanley Appointed 29 July 2015

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

### Operating Result

The profit of the company for the financial year after providing for income tax amounted to:

Year ended	Year ended
30 June 2015	30 June 2016
\$	\$
_	35 194

### **Principal Activities**

The principal activities of the company during the course of the year were that of a Charity focused on the disease Fibrodysplaisia 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/ Assiust those with FOP and their famillies 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.

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 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 51 603 200 871 **Directors' Report**

Signed in accordance with a resolution of the Board of Directors:

Director

Mark Boulton
Director

Dated: 11/11/2016

# Statement of Profit or Loss and Other Comprehensive Income For the year ended 30 June 2016

	Note	2016 \$	2015 \$
Conference and fundraising		43,506	-
Grant from Clementia Pharmaceutical		16,975	-
Other		12,062	
Gross profit		72,543	_
Conference		(36,019)	-
Other		(1,642)	
Profit before income tax		34,882	-
Income tax (credit) expense			
Profit for the year		34,882	
Other comprehensive income: Items that will not be reclassified to profit or loss: Items that will be reclassified subsequently to profit or loss when specific conditions are met:			
Total other comprehensive income for the year, net of tax			
Total comprehensive income for the year		34,882	

### Statement of Financial Position as at 30 June 2016

	Note	2016 \$	2015 \$
Assets			
Current Assets			
Cash assets		34,882	
Total Current Assets		34,882	
Total Assets		34,882	
Net Assets		34,882	
Equity			
Retained profits	_	34,882	
Total Equity		34,882	

### Statement of Cash Flows

### For the year ended 30 June 2016

	2016 \$	2015 \$	
Cash Flow From Operating Activities			
Receipts from customers	64,643	_	
Payments to Suppliers and employees	(29,761)	-	
Net cash provided by (used in) operating activities	34,882		
Net increase (decrease) in cash held	34,882	-	
Cash at the beginning of the year	_		
Cash at the end of the year	34,882		

### Notes to the Financial Statements For the year ended 30 June 2016

### Note 1: Summary of Significant Accounting Policies

FOP Australia Ltd is a company limited by guarantee, incorporated and domiciled in Australia. FOP Australia Ltd was incorporated on 24 December 2014 and was dormant until 19 September 2015.

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 7 November 2016 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 dependant on general purpose financial statements. The financial statements are therefore special purpose financial statements that have been prepared in order to meet the requirements of the Collections Act 1966.

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

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

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

#### **Accounting Policies**

### (a) Cash and Cash Equivalents

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

### (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. Any consideration deferred is treated as the provision of finance and is discounted at a rate of interest that is generally accepted in the market for similar arrangements. The difference between the amount initially recognised and the amount ultimately received is interest revenue.

### Notes to the Financial Statements

For the year ended 30 June 2016

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 2016 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.

Lara Boniface

Director

Mark Boulton
Director
Dated: 11/11/16



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#### INDEPENDENT AUDITOR'S REPORT

To the members of FOP Australia Ltd

#### Report on the Financial Report

We have audited the accompanying financial report, being a special purpose financial report of FOP Australia Ltd, which comprises the statement of financial position as at 30 June 2016, the statement of profit or loss and other comprehensive income and statement of cash flows for the year then ended, notes comprising a summary of significant accounting policies and other explanatory information, and directors' declaration.

#### Directors' Responsibility for the Financial Report

The directors are 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 is appropriate to meet the needs of the members. The directors' responsibility also includes such internal control as the directors determine 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.

#### Auditor's Responsibility

Our responsibility is to express an opinion on the financial report based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial report is free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial report. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial report, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial report in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the directors, as well as evaluating the overall presentation of the financial report.

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

#### Independence

In conducting our audit, we have complied with the independence requirements of the Australian professional accounting bodies.

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#### 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.

#### Qualified Opinion

In our opinion, except for the possible effects of the matter referred to in the Basis for Qualified Opinion paragraph, the financial report presents fairly, in all material respects, the financial position of FOP Australia Ltd as at 30 June 2016, and its financial performance and its cash flows for the year then ended in accordance with Australian Accounting Standards to the extent described in Note 1 to the financial statements.

#### Basis of Accounting

Without modifying our opinion, we draw attention to Note 1 to the financial report, which describes the basis of accounting. The financial report has been prepared to assist FOP Australia Ltd to meet the requirements of the Collections Act 1966. As a result, the financial report may not be suitable for another purpose.

BDO Audit Pty Ltd

A J Whyte Director

Brisbane, 11 November 2016

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### **Acknowledgments**

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

Australian and New Zealand FOP Patients and Families

**FOP Australia Members** 

International FOP Association (IFOPA)

Julie Tronc

Jennifer Morton

Alton Budd

Julie Collins

**Helen Gillies** 

Shan Carty - Jamberry Nails

Jacqui Bundy – Creative Bundy

Di Gillies

**Denise Collins** 

Nicole Jackson - BDO

Melita Laxon

**Imogen Taylor** 

**Professor Matt Brown** 

Dr Ben Whitehead

Dr Jim McGill

Anita Inwood

**Linda Bradbury** 

**Kelly Hollis** 

ilve

**Oliver Collins** 

**Kurtis Pirotta** 

Maria Anello – New Farm Deli

### **Corporate & community partners**

Paul Paxton – Paul Paxton Lawyers Junction Park State School Rydges Hotel - Brisbane Clementia Pharmaceuticals BDO

### How you can help

#### Become a member

Please contact us at <a href="mailto:info@fopaustralia.org">info@fopaustralia.org</a> to become a member of FOP Australia. Membership for the 2016/2017 financial year is \$10 per individual.

### Make a donation

https://www.givenow.com.au/fopaustralia

### Support an event or fundraising activity

Keep up to date with upcoming events via our facebook page www.facebook.com/FOPAustralia

### Become a corporate partner

Please contact us at <a href="mailto:info@fopaustralia.org">info@fopaustralia.org</a>

### Looking to the future

As part of ongoing strategic planning the board has identified the following priorities, and are in the process of operationalising this by developing Key Performance Indicators for 2017

FOP Australia Ltd – Strategies 2016-2017

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

# **CONTACT US**

www.fopaustralia.org info@fopaustralia.org www.facebook.com/FOPAustralia @FOPAustralia on twitter