



Member Newsletter Issue 3



September 2017

In this issue...

- **Thank you!:** \$30,000 donated to FOP research because of your support!
- **2017 FOP Trivia Night:** News and photos from our major Victorian fundraiser
- **More clinical trials on the horizon:** Regeneron announces REGN2477 trial
- **#cureFOP while you shop!:** Online fundraiser CharityBuy launching soon

Thank you for your support in 2016/2017!

Because of your support FOP Australia exceeded their fundraising target for the last two quarters of 2016/17, and are proud to donate \$25,000AUD to the International FOP Association to further FOP research. With potential therapies being trialled, now is a critical time in the global research effort and your donations will help make sure that precious opportunities do not get missed.

As the fundraising target (of \$10,000) for the donation to IFOPA was exceeded significantly, FOP Australia are also donating \$5000AUD to the Shore Lab at the University of Pennsylvania. This will help support their ongoing research into understanding the disease process, which will guide the ongoing search for a cure.

\$3000 of funds raised has also been allocated for future support activities, and the framework for a support grant process is currently being developed, to make sure this money is used effectively and transparently to support the FOP community. We hope that this will be finalized by the start of 2018.

Thank you showing the FOP community your support in 2016/17!

Upcoming events

- **Memberships due Online now!**
- **2016/17 AGM**
Date to be confirmed after completion of annual audit
- **IFOPA 2017 Drug Development Forum**
12th to 14th October
Hosted in Sardinia by FOP Italia and IFOPA.
- **Charity Buy launch**
November 2017

Jarvis joins the Bombers



Thanks to the Starlight Foundation Jarvis Budd met the Essendon Football Club players and ran out with them on the field to toss the coin. Well done Jarvis!



Photo caption

Have you got a story to share? Contact us at info@fopaustralia.org

A little note with a BIG THANK YOU

to **Justine DeBruyn** of HOT Fitness in Broome for choosing FOP Australia as one of the charities supported by proceeds from her 'Sango' dance classes

SUPPORT. RESEARCH. CURE
fopaustralia.org

Research news from Regeneron

It is an exciting time for the global FOP research effort, with USA company Regeneron Pharmaceuticals announcing plans for a clinical trial of their potential drug (REGN2477). Regeneron is the second company to begin clinical trials in FOP, following the commencement of clinical trials of palovarotene by Clementia Pharmaceuticals.

The main aim of this phase II trial is to see if the new drug is safe and tolerable for people with FOP. However the investigators will also collect data on whether it affects the rate of new bone formation, how it affects pain, and how it affects activin A levels and immune function.

Although there are no current plans for this trial to enrol in Australia, FOP Australia are very excited about this new development and look forward to seeing the results in the coming years. Learn more about the trial at <https://clinicaltrials.gov/ct2/show/NCT3188666>.

FOP Australia chairperson Dr Lydia Scott will attend the IFOPA 2017 Drug Development Forum in October to learn more about the latest news in FOP research.

Right: Dr Aris Economides, Executive Director of Regeneron Pharmaceuticals.



2017 Trivia Night

Thank you and well done to our amazing Victorian supporters at the FOP Trivia Night on the 24th June in Mornington. Thanks for getting in to the spirit, and getting in to



costume as something starting with F, O or P!

With your support the night raised \$5876 for FOP Australia!



During the evening FOP Australia treasurer Talia Wilson debuted our introductory presentation 'What is FOP Australia?', aimed at helping new supporters understand our needs, aims and how they can help. You can see the 'What is FOP Australia?' video on our Facebook page.

- From top:**
- Fred Flinstone, Freddie Mercury and friends get into the competition
 - FOP Australia's Tyson Stanley and friend and the quiz night
 - One of our smallest supporters – a panda and a pirate

Join or renew your membership online!



Joining FOP Australia just got a whole lot easier with our new electronic membership form. With just a few clicks you can sign up, update your details and pay your \$10 annual fee.

Become a member today to:

- Receive regular updates on FOP news
- Hear about the latest fundraisers
- See what your donation has achieved
- Help shape this new organization

Photo caption

Photo caption

...and to show your support for the FOP community! Printable forms also

SUPPORT. RESEARCH. CURE

fopaustralia.org

Help our cause with mycause

Want to help FOP Australia but don't know how to start?

Have an idea for a fundraiser but not show to collect donations and advertise?

The mycause platform is a tool to help everyone in our diverse community contribute to FOP Australia in their own way, no matter where they are.

It is a great tool to collect donations and sponsorship for events. Using mycause, FOP Australia supporters in Adelaide collected \$2000 for the City to

Bay fun run this year! Even if you are only one person, mycause can help you make a difference and raise funds by asking for donations in lieu of birthday/Christmas presents. Check out the link on our website to find out more!

DONATE

Donate now

Make a regular donation

Start a donation portfolio

Donation gift cards

Pledge your birthday

FUNDRAISE



Challenge

climb, run, swim, walk



Celebration

birthday, wedding, anniversary



Events

any organised event



Memory

tribute to a loved one

Annual General Meeting

After completion of the annual audit process we will be able to release our Annual Report and confirm details for our Annual General Meeting.

This year the AGM will be held in Adelaide, with members around Australia and New Zealand invited to join by videoconference. Details of how to join will be sent with notification of the AGM. This will also include a call for nominations for the 2017/18 board.

Members are also welcome to volunteer to assist our activities in other ways. FOP Australia would benefit from skills in marketing, IT, fundraising, design, research, advocacy, legal and accounting expertise. In fact no matter your skills are, we will find a way to use it to help #cureFOP! Email us to find out more: info@fopaustalia.org

Now on fopaustalia.org...



Our goals for 2017/18 are available online in our Strategic Plan 2017/18 Key Performance Indicators. You can find it in the 'About Us' section. While you are there, check out the review of the 2016/17 KPIs to read about what you helped achieve for the FOP community in the 2016/17 financial year.

Coming soon: CharityBuy

In November FOP Australia will be joining CharityBuy – a partnership with over 200 online stores, where registered charities benefit from your shopping! Help #cureFOP while you shop! And just in time for Christmas...

