



Member Newsletter Issue 6



April 2018

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FOP Awareness Day: April 23

Every year the international Fibrodysplasia Ossificans Progressiva community mark the anniversary of the announcement of discovery of the FOP gene on April 23rd with FOP Awareness Day.

Around the world, FOP families and their supporters hold local fundraisers and events to help more people become aware of this ultra rare disease, and of the global fight to find a cure for it.

This year for FOP Awareness Day, as well as continuing our online efforts to provide information through social media, FOP Australia have planned pop-up stalls to raise awareness in person throughout the country. To help with this we have received generous support from businesses and volunteers to make educational flyers and a new banner. If you would like to raise awareness by sharing FOP Australia flyers, or by holding a stall in your area, we would love to hear from you at info@fopaustralia.org.

Alongside raising awareness, our efforts to raise funds to support research continue. We have several online fundraisers and plans for further events in several states this year, but welcome new ideas and events as well. Thank you for your ongoing support to help #cureFOP.

Upcoming events

- **Online now!**
Eco-cups and Entertainment Books available
- **May 3**
IFOPA Webinar: Clementia MOVE trial
- **May 15**
IFOPA Webinar: Regeneron LUMINA-1 trial
- **June 17**
Kununurra Half Marathon FOP team
- **June 30**
Somerville Quiz Night



Well done Zach!

Zach Armstrong had a very busy first term of year six in 2018. Not only did he meet the Premier of New South Wales and the state's minister for Sport (Gladys Berejiklian and Stuart Ayres, pictured left with Zach and friend), but he was also chosen to be on the Student Representative Council!

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

A little note with a BIG THANK YOU

In this edition we would like to acknowledge **Leonie Starnawski** for help editing content for our new flyers! We had many helpers to get these made! (See page 2)

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New resources to raise awareness about FOP

In preparation for FOP Awareness Day and our pop-up awareness stalls, several businesses got behind FOP Australia and the fight to #cureFOP, donating their time and resources to developing our new banner and flyers.

A huge thank you to graphic designer **Jarryd Bravo** who donated his services free of charge, and got our banner and flyer design ready to go in no time! We recommend contacting Jarryd for your illustration, photography or graphic design needs:

- Website: <http://www.jarrydbravo.com>
- Facebook: <https://www.facebook.com/jbthecreativeone>
- Instagram: <https://www.instagram.com/jarrydbravo.com>

Michelle Crouch from **Peak Digital** kindly donated printing services for 1000 high quality A5 flyers. We recommend www.peakdigital.com.au for printing in Melbourne.

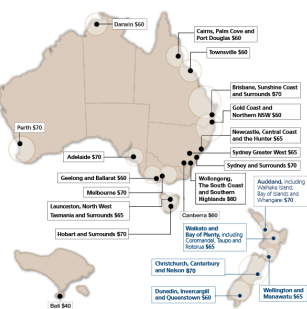
Glenn May at **Signforce PL** provided our banner and we are thrilled with the result! For signage in Melbourne, go to www.signforcepl.com.au or their Facebook page. We are extremely grateful to these businesses for their high quality work and efforts to help us raise awareness. But who also - by donating their time - have helped make sure that funds donated to FOP Australia can be used to support the global research effort.

A special thank you to the FOP families who kindly allowed us to use their photos. Sharing your pictures and stories is invaluable in helping others understand why we need to beat FOP.



Because of these generous donations, the FOP Australia banner and flyers were ready for the 2018 Somerville Family Day, where Talia Wilson, Liv Sedgwick, Tyson Stanley and Daniel Petrovic proudly displayed them alongside the FOP Australia Eco-cups for sale. The resources and the day were a big success, with cup sales, new memberships and over \$200 going towards FOP research! Well done team!

Do you have an upcoming event where you could do a similar stall to raise FOP awareness? We can help provide resources and ideas, and assist in making sure appropriate permits are in place for your state. Or, if you would like to raise awareness by sharing copies of the FOP Australia flyer via your business, friends or family, please contact us and we will happily share hard copy or PDF versions. You can see pictures of our banner and flyers in more detail on our website.



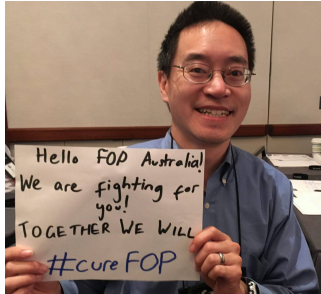
2017/18 Entertainment Books

This year we are again partnering with Entertainment Books to help you save money on holidays, eating out, shopping and much more.... All while supporting FOP Australia! The Entertainment Books make a great present, and available for 25 sites throughout Australia and New Zealand! Every book also has deals that you can use nationally. Find the link to buy your digital or hard copy on our website.

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IFOPA Webinars

The International FOP Association are continuing their new series of online information sessions about key issues for the international FOP community. In the next month they are focusing on the current clinical trials:



May 3: Clementia MOVE trial

Led by Dr Ed Hsiao, UCSF

1200-1300 American Eastern Time

May 15: Regeneron LUMINA-1 trial

Led by Dr Bob Pignolo, Mayo Clinic

1200-1300 American Eastern Time

You must register in advance for each webinar separately if you wish to attend. So that these sessions can be accessed by the FOP community around the world (and so you don't need to get up in the middle of the night to watch them!) IFOPA will also release recordings online after each event.



You can find the links to register for these webinars (and information about many FOP related events around the world) at http://www.ifopa.org/calendar_of_events.

Now on fopaustralia.org...

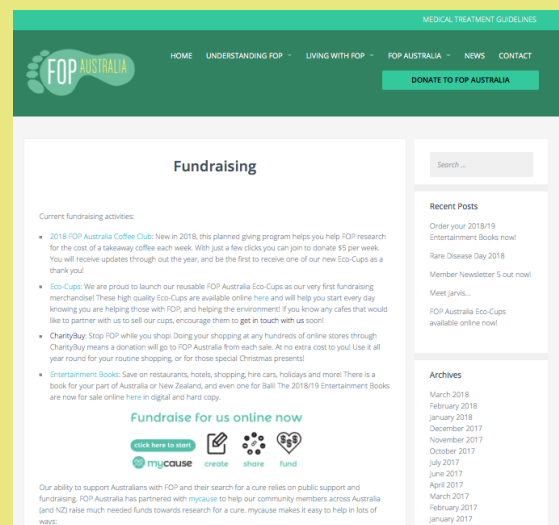
Want to help FOP Australia but you're not sure how? Have friends and family that want to help the battle to cure FOP, but are not sure where to start?

Check out the Fundraising page of our website to see information and links about our current fundraisers (under 'FOP Australia' in the main menu).

Currently this includes links to several online fundraising events, so that you can support people living with Fibrodysplasia Ossificans Progressiva from anywhere around Australia, New Zealand, or the world! Find links to:

- **CharityBuy:** Shop from 200+ online stores and a percentage will go to FOP Australia
- **2017/18 Entertainment Books**
- Our popular FOP Australia **Eco-Cups**
- 2018 FOP Australia **Coffee Club**
- Our **mycause.com.au** platform where you can support upcoming events, or even start one yourself!

There is also a **'Donate to FOP Australia'** link at the top of every page on our website, which will lead you to our secure online facility to make a tax-deductible donation (with automatic receipts).



The screenshot shows the 'Fundraising' page on the FOP Australia website. At the top, there is a navigation bar with 'HOME', 'UNDERSTANDING FOP', 'LIVING WITH FOP', 'FOP AUSTRALIA', 'NEWS', and 'CONTACT'. A prominent green button says 'DONATE TO FOP AUSTRALIA'. The main content area is titled 'Fundraising' and lists several fundraising activities:

- 2018 FOP Australia Coffee Club:** New in 2018, this planned givng program helps you help FOP research for the cost of a takeaway coffee each week. With just a few clicks you can join to donate \$5 per week. You will receive updates through out the year, and be the first to receive one of our new Eco-Cups as a thank you!
- Eco-Cups:** We are proud to launch our reusable FOP Australia Eco-Cups as our very first fundraising merchandise! These High quality Eco-Cups are available online here and will help you start every day knowing you are helping those with FOP, and helping the environment! If you know any cafes that would like to partner with us to sell our cups, encourage them to get in touch with us soon!
- CharityBuy:** Stop FOP while you shop! Doing your shopping at any hundreds of online stores through CharityBuy means a donation will go to FOP Australia from each sale. At no extra cost to you! Use it all year round for your routine shopping, or for those special Christmas presents!
- Entertainment Books:** Save on restaurants, hotels, shopping, hire cars, holidays and more! There is a book for your part of Australia or New Zealand, and even one for Bali! The 2018/19 Entertainment Books are now for sale online here in digital and hard copy.

Below the list, there is a section 'Fundraise for us online now' with icons for 'click here to start', 'mycause', 'create', 'share', and 'fund'. At the bottom, a small text block states: 'Our ability to support Australians with FOP and their search for a cure relies on public support and fundraising. FOP Australia has partnered with mycause to help our community members across Australia (and NZ) raise much needed funds towards research for a cure. mycause makes it easy to help in lots of ways.'