



Member Newsletter Issue 7



September 2018

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- **Renew your membership for 2018/19:** Sign up online in just a few clicks
- **Advocating for FOP awareness:** Ollie, Tyson and Jarvis share their stories
- **Fundraising fun across the country:** Communities supporting FOP research

### Because of your support this year FOP Australia is donating \$45,000 to research!

During the 2017/18 financial year communities across Australia took part in a wide range of fundraising activities to show their support for people living with Fibrodysplasia Ossificans Progressiva. Because of your support, our goal of raising \$20,000 to give to FOP research was greatly exceeded. Therefore \$40,000 will be given to the International FOP Association to support the global research effort into developing FOP therapies, and \$5000 will be given to the Shore Lab at University of Pennsylvania for ongoing research into understanding this devastating disease and how to stop it.

A review of 2017/18 activities, and targets for 2018/19, are available online in the 'Aims' page of our website.

In keeping with our strategic plan and KPIs, \$4000 from the 2017/18 fundraising has also been allocated for support activities, and the board are currently consulting with experienced clinicians and patient advocates about establishing a program to use this most fairly and effectively. Thank you again to all the supporters, members and donors who got behind the 2017/18 fundraising efforts. It is exciting to see several families already holding exciting new events in 2018/19, with more new initiatives to come later this year!

### Upcoming events

- **Now:** Membership renewals due (online)
- **September 16:** City to Bay fun run and walk (Adelaide) fundraiser
- **October 25:** Annual General Meeting 2017/18 (to be confirmed)
- **November 16-18:** IFOPA Family Gathering (Baltimore USA)

### Lyn's big (P!NK) night out!

It is always wonderful to hear from our Australians with FOP, so it was exciting to hear about **Lyn Smith's** big night out with friends at the P!NK concert in Melbourne recently. Although FOP has restricted Lyn's mobility, Lyn was able to join the AGM last year by videoconference, and always helps spread FOP awareness messages online. Thank you for your help Lyn, and for letting us share these pictures!



Have you got a story to share? We would love to hear from you!

### A little note with a BIG THANK YOU

This time we acknowledge **Louise Meagher** for joining our fundraising team.

To join, email fundraising coordinator Liv Sedgwick at [info@fopaustralia.org](mailto:info@fopaustralia.org)

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## Hello from San Francisco: Update from UCSF A/Prof Ed Hsiao on FOP Australia sponsored research

We are delighted to receive the support from the IFOPA and FOP Australia to support our work. Our project focuses on how a patient's genetic background affects the severity of FOP. In the clinic, we observe that FOP patients who have the classical ACVR1 R206H mutation show a wide range in the severity of their bone formation. This suggests that a person's genetic background might contribute to variations in disease severity. This grant is allowing us to understand how these other genes or pathways could be targeted to make better therapies for FOP, or might be important for other types of heterotopic ossification.

**Good luck to Ed and the UCSF team (below) for their ongoing work in understanding FOP and which targets are most helpful for FOP treatments**



## A superhero effort sends Tyson to Comic-Con

Well done to **Stu Cunningham** for a superhuman effort to help **Tyson Stanley** and family get to San Diego for Comic-Con. In a private fundraiser for this purpose, Stu raised over \$24,000!

Stu sought sponsorship for a number of physical challenges including swimming, cycling, running and Crossfit. The effort paid off, with Tyson making it to USA for the event and having an unforgettable holiday. And there's even more good news, because Stu will put any further donations received to FOP Australia!

Learn more about Stu's fantastic effort at: <https://au.gofundme.com/operationtyson>

**Left: Tyson Stanley in a graphic from Stu's page. Right: Deadpool and Clark Kent (but the real superheroes are Tyson and Stu!)**



## Ollie, Tyson and Jarvis advocate for awareness

Although followers of this newsletter will know that much-loved FOP community member **Oliver Collins** (top right) is now a qualified lawyer, he took time to raise awareness about FOP at a speech about Teenage Adventure Camps Queensland recently. Ollie explained in an emotive and entertaining speech to attendees, including **Jann Stuckey** (MP for Currumbin), what it is like to have FOP, "to go to sleep every night, wondering if you may wake up tomorrow and not be able to do something you've done every single day of your life, something as simple as reaching for a glass of water". Ms Stuckey was so moved that she subsequently mentioned FOP in a speech to the Queensland parliament.

Also getting the word to our political leaders were **Tyson Stanley** and **Talia Wilson**, who took an opportunity to meet Federal Minister for Health **Greg Hunt** MP at his local electorate office (middle right). Minister Hunt took the time to listen to information about FOP and accepted a FOP Australia cup. Well done also to **Jarvis Budd** (bottom right) and his mother **Lara Boniface** for helping FOP get in to the national media last month, with a story on Channel 7 news about FOP. See our Facebook page for a link to the video.



### Thank you to our fantastic fundraisers!

Thank you to everyone who has organized or supported our event so far in 2018. We have already had our best start to a new financial year in July and August, and are so grateful for each of these events:

- **Mornington Trivia Night (Victoria):** Thanks to Talia Wilson, Daniel Petrovic, Tyson Stanley, Liv Sedgwick and their supporters for putting on the biggest FOP Australia event of the year and raising an incredible \$10,646!!
- **Bridge2Brisbane fun-run/walk:** Well done to the Collins family on an amazing fundraising effort, raising \$14,520. More news (and photos!) in our next edition.
- **Mt Gravatt Bowls Day (Queensland):** Thank you Dean Gaddes and the Mt Gravatt Bowls Club for showing your support for Jarvis Budd and others with FOP on July 22<sup>nd</sup>. This event led to even more good news, sparking an exciting new fundraising activity led by a new supporter! *See item below...*
- **Broome Courthouse Markets (WA):** Thanks Cassie Yates, Tala Gooden and Eli Gooden and Lou Cross for selling eco-cups and raising awareness at several market days
- **Coffee Club:** Thank you to the members of our Coffee Club planned giving program, your commitment to a monthly donation been vital for our charity this year. To give the cost of a coffee every week to FOP research, join our coffee club online through the "Fundraisers" page of our site.
- **Kate and Yvonne's Wedding (NT):** It was incredibly kind of Tyson Stanley's aunties to request guests donate to FOP Australia instead of give presents. Congratulations Kate and Yvonne and a special thank you for showing such generosity on your special day!
- **FOP Awareness Day stall (Victoria):** Louise Meagher, Talia Wilson and Liv Sedgwick ran a stall in Waverley Gardens Shopping Centre on April 23<sup>rd</sup> to raise funds and awareness
- **Entertainment Books:** Thanks to everyone who again bought a membership, and especially to Lara Boniface for selling books in Brisbane for FOP Australia again
- **Brooke's Birthday Crowdraiser (SA):** Thanks to our secretary Brooke Scott who used the GiveNow platform to ask her friends to give to FOP Australia in place of presents. If you are interested in this option, it is easy to set up a Crowdraiser for your birthday through GiveNow
- **Eco-cups:** Thanks to everyone who has bought cups, and especially to Lara Boniface, Alex Laurisson, Jo Baker and Lauren Brew who have volunteered to sell them. It was also very exciting to make our first New Zealand cup sales to Carey Wenn in Tamarunui. Cups are still available for purchase on our website through our secure online credit card payment facility
- **Oklahoma! Fundraising performance (Victoria):** *O what a wonderful morning* it was when got this lovely surprise donation from ticket sales for a performance of this Victorian school show!
- **Kununurra Half Marathon (WA):** Well done to our chairperson Lydia Scott and her supporters in a 21km effort raising awareness and funds for FOP research on June 17<sup>th</sup>
- **CharityBuy:** Thanks to everyone who has bought from the 200+ online shops that will donate to FOP Australia with each purchase via [www.charitybuy.com.au/fop-australia/](http://www.charitybuy.com.au/fop-australia/)
- This month the Scott family will be fundraising in Adelaide's **City to Bay** event – photos to come!

### Mylan employees launch payroll giving program for FOP Australia

Living with an ultra rare disease like FOP can be very isolating, and it is always wonderful to know that there are people in the broader community that care enough to get behind the fight for a cure. In July, FOP Australia were lucky enough to be contacted by **Jim Brown** of Mylan, who has worked with the company to set up a payroll giving program. This initiative will run for three months and give employees the option of making a pre-tax donation to FOP Australia. As a very small charity FOP Australia greatly appreciate this opportunity and are very grateful for any donations received from Mylan employees. We are especially grateful to Jim who only recently heard of FOP, through the Mt Gravatt Bowls Day in Brisbane (which was organized by **Jarvis Budd's** supporters – great work guys!).

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