



Member Newsletter Issue 4



December 2017

In this issue...

- **FOP Australia Coffee Club:** Help #cure FOP for the cost of a coffee a week!
- **Building our capacity for advocacy:** Finding our voice with RVA
- **Research news:** Your supports funds research into new FOP therapies!
- **Introducing the board:** Meet the team for 2017/18

Merry Christmas and Happy New Year!

We wish all our members and supporters a happy and healthy Christmas and New Year. Thank you for your support in 2017, a year that has seen the global research effort make major steps towards a treatment for fibrodysplasia ossificans progressiva. We are now in the clinical trials era, which brings hope and new challenges to our community. Our current opportunities only exist because of the hard work of volunteers over many decades, and much more work is needed to make the most of these opportunities.

As described in our research news on page 3, your generous support has made an impact on the research that can be done, and we look forward to bringing you more exciting research news in 2018!

Thank you to everyone who attended the annual general meeting on December 14th, where we presented the annual report and audit for the 2016/17 financial year, now available on our website. The AGM also gave us an opportunity to thank Gerry Collins for arranging for BDO to undertake our audit pro bono, and to elect and welcome Olivia Sedgwick to the board (see page 3). It was great to share our work so far, and we hope you will help us achieve even more in 2018!

Upcoming events

- **Online now!**
CharityBuy
- **January**
Coffee Club launch
- **January**
Support grant program launch
- **February 28**
Rare Disease Day
- **April 23**
FOP Awareness Day

Cody helps FOP research... in Australia!

One of the most exciting stories from the Australian FOP community in 2017 was hearing that Cody Wilson was able to enroll in a phase II clinical trial and participate within Australia! Thank you Cody and family for contributing to FOP research, to the team at QUT in Brisbane for their work with Clementia for people with FOP.



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 **Raf Cammarano** of www.rafcammarano.com for help with our new online membership form

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Developing our advocacy capacity

With three potential treatments now in clinical trials, one of our most important goals this year is developing our advocacy capacity. When drugs have proven to be effective for FOP, we need to be ready to advocate with regulatory and industry bodies to ensure they are available to patients in Australia and New Zealand. Developing a cohesive and strong voice for the FOP community is important in this process, and that is part of why your support of FOP Australia is so important. Communicating our key messages clearly, building links with industry, and learning about drug development are other important steps we have already been working on in 2016/17, but in 2017/18 we will formalize an advocacy strategy. With this in mind, we were very excited to hear about Rare Voices Australia's (RVA) advocacy



workshops in November and December, so that we could learn strategies and share ideas about influencing decision makers in the drug approval process. Treasurer Talia Wilson attended in Melbourne, and member Lara Boniface attended in Brisbane. We can't wait to put these ideas in to practice!



RVA workshops in Melbourne (top) and Brisbane. Source: RVA

Join our Coffee Club in 2018!

Starting in January 2018, you can support FOP research for the cost of a coffee a week! By joining the FOP Australia Coffee Club and donating \$5 per week throughout 2018, you can help FOP Australia support the global research effort and to link and support people living with FOP in Australia and New Zealand. And to thank you for your support you will get a FREE reusable FOP Australia coffee cup – so it is good for the environment as well!



You will get updates during the year to show what your generosity is helping to achieve.

We can not wait to launch this soon! Stay tuned to Facebook, Twitter and our website to make sure you don't miss out!

FOP Australia reusable coffee cups will also be available for purchase at \$15 each.

Have you tried CharityBuy yet?

You can support FOP Australia while shopping online at over 200 stores! Simply choose your store at charitybuy.com.au/fop-australia/ and part of your sale will be donated! And keep an eye out for discounts to help you save too!



Julie and Oliver Collins
ifopa.org/2017_winners

IFOPA 2017 Jeannie Peeper Awards

It was exciting to see Australia's Julie Collins recognized by IFOPA this year with a Jeannie Peeper Award for Outstanding International Leadership. As noted in IFOPA's announcement "Throughout her tenure with the IFOPA and FOP Australia, she has worked to connect newly diagnosed FOP patients with expert doctors and researchers; secure funding for FOP research; do interviews about FOP with various media outlets; and provide guidance and support to FOP families in Australia and New Zealand." Congratulations on your award Julie!

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Introducing your board for 2017/18



Olivia Sedgwick is a Critical Care trained Registered Nurse. Olivia is married and has one child and lives in Melbourne. Olivia is a close friend of Tyson Stanley and has been part of his journey with FOP since his birth, and has also been involved with fundraising towards FOP research. Olivia is new to the board and is looking forward to the journey ahead with FOP Australia, including her new role as fundraising co-ordinator.



Brooke Scott was diagnosed with a variant form of FOP at the age of 29 after many years of misdiagnoses. Brooke is currently the FOP Australia secretary and also the International Presidents' Council representative for Australia. Brooke is a founding director of FOP Australia and has been re-elected at the December 2017 AGM. She lives in Adelaide with her husband, cat and dog, and works full-time in the utilities industry.



Treasurer **Talia Wilson** is mumma to 16 year old FOP patient, Tyson Stanley. Following a long and tedious experience in diagnosis and understanding of FOP for Tyson, Talia was eager to join the FOP Australia board in September 2015. Her hope is to assist all FOP patients in their journey and to help potential patients reach a diagnosis more quickly and easily than Tyson had. Talia was elected to Treasurer in December 2016. Also mumma to Phoenix, Ashlee, Jett and Zac, you can find Talia homeschooling all of her kids, with partner Daniel, on the beautiful Mornington Peninsula, Victoria.



Lydia Scott is the sister-in-law of Brooke Scott. Lydia lives in Broome, Western Australia, and works as a general medical consultant across the Kimberley region. Lydia has been on the board since 2015 and chairperson since December 2016, and is also on the IFOPA Research Committee.

You are welcome to contact us at info@fopaustralia.org. And you don't need to be on the board to be involved! If you can help with marketing, IT, accounting, fundraising, or if you want to know how you can help, please get in touch!

FOP Australia supports groundbreaking research

Because of your hard work fundraising and generous donations in 2016/17, FOP Australia was able to sponsor an IFOPA Competitive Research Grant, allowing the CRG program to enable more research projects than ever before.

We are very proud to be supporting Associate Professor Ed



Hsiao and Professor Pam Yelick (pictured here at the 2017

Drug Development Forum) in their work on interrogating new FOP therapeutics, which will involve development of completely new in vivo models of FOP to help better understand the disease. This project is a great example of the collaborative spirit essential to the global effort to find a cure for FOP, and we look forward to bringing you news of progress.

Now on

fopaustralia.org...

Read the full report from the 2017 FOP Italia/IFOPA Drug Development Forum in the news section of our website.

