



Member Newsletter Issue 2



April 2017

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FOP Awareness Day: Spread the word on April 23rd



FOP Awareness Day is Sunday April 23 2017, to mark the eleventh anniversary of the discovery of the FOP gene. The gene discovery was a major breakthrough in understanding FOP, and in identifying targets for possible treatments.

Promoting awareness is vital for any rare disease organisation, but in FOP it is especially critical, as a lack of information can lead to misdiagnosis and serious harm through unnecessary investigations.

Keep an eye out for:

- **16 FOP Facts:** We will promote 16 facts through social media (one for each person living with FOP in Australia and NZ).
- The #FunFeet4FOP campaign run by FOP Friends in the UK
- Social media and information resources on fopaustralia.org for you to use to raise awareness in your own communities.
- During April we are also hoping to reach 1000 Facebook followers, as part of increasing our capacity to promote FOP. So find us on Facebook and invite a friend to follow us as well!

We would love to hear the other ways you help spread the word too!

Upcoming events

- **April - July**
Entertainment Books available online
- **April 23**
International FOP Awareness Day
- **June 24**
Quiz Night Extraordinaire (Victoria)
- **June 30**
Membership renewal due for 2017/18

Congratulations Ollie!

Oliver Collins, a much-loved member of the Australian and global FOP community, completed his double degree in Law and Commerce in 2016 and has started full time work as a clerk in Brisbane. We would like to congratulate Ollie and the Collins family on his success.



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 **Jayo Archer** of FOX Racing for his guest appearance at Tyson Stanley's fundraising disco.

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fopaustralia.org



Quality of LIFE Awards

The Quality of LIFE “Living Independently with Full Equality” Awards were developed by IFOPA to help members around the world with purchasing items that improve the welfare and independence. Since the Awards were established in 2006 over \$USD 50,000 has been granted to individuals, including Australians. (NB: the Awards do not assist with medical related services). Find more information and access the application process at: http://www.ifopa.org/quality_of_life_award.

Applicants must be current members of IFOPA. IFOPA membership is free to people with FOP. For information or assistance joining IFOPA visit their website or contact Brooke Scott (FOP Australia secretary and International Presidents’ Council representative) at info@fopaaustralia.org.

Trivia Night Extraordinaire!

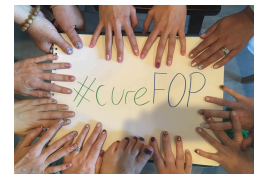


Join us on June 24th at the Mornington Civic Bowls Club for a night of fun, trivia and prizes. This will be our major Victorian event for 2017 to raise funds for FOP research. Tickets are \$20 each and will be available through our website and email closer to the event.

Australia’s FOP Fundraising Frenzy!

Because of your support during February and March, FOP Australia raised over \$5000 for FOP research. This was the result of a diverse range of activities all over the country, and contributions from hundreds of people. Every contribution, whatever size, is hugely appreciated as a sign of support for those with FOP.

- Tyson Stanley and his mates organised a superhero themed disco in Somerville, raising \$538!
- Shan Carty’s online Jamberry fundraiser during February raised \$941, beating last year’s total!
- By the end of March our Entertainment Book sales had already raised \$114. Thank you Amy Ellingworth and Lara Boniface for their ongoing work on this.
- FOP Australia has also been very lucky to receive over \$600 through the ‘Donate Now’ button on our website. We were particularly excited to see our first regular monthly donation set up through this facility!
- Another lovely surprise was the \$970 raised by the Peninsula City Church Quiz Night on March 17th
- The 12km Bay-City fun run was the first FOP Australia fundraiser in South Australia.



\$2010 was donated to our team of eight runners and walkers who did the 12km in t-shirts promoting FOP.

The fun run was also the first time we have used our new ‘mycause’ platform. mycause will help us to expand our fundraising, and help our supporters to fundraise using events or ideas of any size, whether it raises \$20 or \$20,000! As well as making it easier to manage funds for large events, it can also help people create gift cards, accept donations for FOP in lieu of birthday/anniversary gifts, or support individual pledges. If you have ideas or questions about mycause, please get in touch by email. Please see our website for more information on fundraising activities and strategic planning.

From top: Tyson and fellow DJs; Treasurer/Superhero Talia with family at Tyson’s disco in Victoria; Ladies of Broome WA show their support with Jamberry nails; SA Bay-City team

FOP Clinical Trial Centre at Princess Alexandra Hospital, Brisbane: Prof Matt Brown

To help Australian FOP patients participate in clinical trials without having to travel internationally, a team of researchers at Princess Alexandra Hospital Brisbane have established a local FOP clinical trial centre.

The team is led by Prof Matt Brown, a rheumatologist and genetics researcher, who with Professor Kaplan's Philadelphia team identified the FOP gene back in 2006. The team includes Linda Bradbury and Kelly Hollis, two expert rheumatology nurses, and Dr Ben Whitehead, a paediatric rheumatologist based at Brisbane's Lady Cilento Children's Hospital.

The Brisbane centre has enrolled patients in the Clementia Natural History Study, the aim of which is to determine the best ways of measuring progression of FOP. More recently patients have also been enrolled in the Clementia palovarotene phase 2 study. This saves Australian patients from having to travel to the US to participate in these exciting studies.

The team recognise the critical relationship FOP patients in Australia have with their own caring physicians, and aim to work with those physicians to enable Australian FOP patients to participate in these trials.

FOP Australia would like to thank Prof Matt Brown and his team for providing the above update. Heartfelt thanks also for their ongoing support of FOP patients and families, and for all of their previous and ongoing work in FOP research.

FOP Connection Registry

The global FOP Connection Registry was launched in July 2015. Sponsored by IFOPA, the Registry is a vital collection of demographic and health data from individuals with FOP. 178 patients worldwide registered in the first year of operation. An additional registry portal for clinicians is also planned.

It is open to all individuals and families living with FOP, regardless of whether you consider yourself an 'IFOPA member' or not. All consent, data collection and information storage processes have been approved by an ethics committee.

FOP Australia encourages every person or family with FOP to contribute to this critical component of the global research effort to understand FOP, and how to cure it! See more information at ifopa.org.



Now on fopaaustralia.org...

As part of the April FOP Awareness Day activities, there is now a **'My Life with FOP'** page in the 'Living with FOP' section. This includes profiles kindly shared by Derek Bowles, Jarvis Budd and Jasmin Floyd to help people unfamiliar with the disease start to develop some understanding of how FOP affects peoples' lives. If you live with FOP, please consider adding your story to this page through info@fopaaustralia.org to help raise awareness. FOP Australia would also be grateful to receive any photos you would be willing to share on the website.

Available Now!

2017/18 Entertainment Book memberships (including digital versions) are available for over 20 cities in Australia and New Zealand. Follow the links on our website to save on dining,



shopping, travel and much more! 20% of every sale goes to FOP Australia.