



Member Newsletter Issue 5



February 2018

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- **Eco-Cups available online now!**: Help FOP Australia and the environment!
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Show you care on Rare Disease Day February 28

Every year on the last day of February, people with rare diseases all around the world join together to draw the globe's attention to conditions that are uncommon and often poorly understood. FOP Australia is one of thousands of rare disease organisations around the world joining global leaders like EURORDIS in this effort. On our website, our Facebook page, and throughout this newsletter we show you ways you can help, and challenge you to show your support and to spread the news to others. Some of the ways you can do this are:

- Add words of hope to our social media FOP word cloud
- Use the Rare Disease Day profile pictures and banners online
- Sign the petition for a fair go for all Australians (page 3)
- Help others learn about FOP by sharing Jarvis' story (page 3)
- Join our fundraising team (page 2)
- Buy, use or gift our Eco-Cups (page 3)

What other ways are you helping on Rare Disease Day? Share your ideas with us on Facebook, @fopaaustralia on Twitter or fop_australia on Instagram.



Upcoming events

- **Online now!**
Eco-cups available for purchase
- **February 28**
Rare Disease Day
- **March**
Entertainment Book sales launch
- **April 23**
FOP Awareness Day
- **June 17**
Kununurra Half Marathon FOP team



Congratulations Brooke!

FOP Australia secretary and IFOPA International Presidents' Council representative Brooke Scott has been selected for the 2018 Community Directors Award Program by the Women's Leadership Institute of Australia and the Institute of Community Directors Australia. This will include training in governance and management of community organisations, and will help make sure FOP Australia stays strong and achieves our goals.

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

A little note with a BIG THANK YOU

In this edition we would like to acknowledge volunteer **Joyce Pettersen** for managing the postage of our online Eco-Cup sales. It would not be possible without you Joyce!

SUPPORT. RESEARCH. CURE
fopaaustralia.org

Join our new fundraising team!

Are you keen to help raise money for FOP research? Have you got an idea for a local fundraiser? Have you got ideas to help fundraise online, or at an event? Or maybe you don't know where to start, but you just want to help?



Fundraising co-ordinator and board director Olivia Sedgwick would love you to join a fun and passionate team to help FOP Australia meet our goals. People from every state in Australia (and from NZ!) are very welcome to join - in fact, the further spread out we are, the further we can spread the word! You do not need to join the board to contribute, and all ideas are welcome.

Supporters are also very welcome to run their own events independently. In previous years we have had amazing and generous contributions from individuals who have organized local church group quizzes, gym classes and casual days at schools. All contributions of any size are welcome and the FOP Australia board are happy to assist in any way we can to make it easier for you to help people living with FOP.

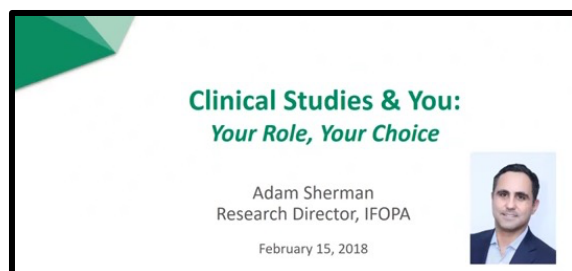
FOP Australia is a registered charity donations are tax-deductible, which helps people maximize their donations to our fundraisers. Supporting the global research effort through FOP Australia also shows the international research community and national authorities that the FOP community in Australia are strong, passionate and motivated to have a voice in every aspect of the battle to cure FOP!

To join the fundraising team, or to discuss a fundraising idea, contact Olivia at info@fopaaustralia.org.

Learn more about clinical trials

With clinical trials currently enrolling around the world, and the involvement of an Australian trial site on the horizon, now is the time for our community to learn more about clinical trials.

This year the International FOP Association (IFOPA) recorded and released a webinar on 'Clinical Studies and Trials: Your Choice, Your Role, Your Responsibility'. In the webinar, Adam Sherman, IFOPA Director of Research Development and Partnerships, gives an overview of the drug development and approval process, including the role of clinical trials. The webinar goes for just over 36 minutes and addresses many of the questions people have when trying to understand a clinical trial, especially when they are considering enrolling in a trial.



The webinar, and other resources, are available at www.ifopa.org/clinical_trials and we encourage you to check it out. The page also includes a list of all active FOP trials.

Remember that by joining the FOP Registry you can select the option to be notified of arising opportunities to participate in research (including clinical trials). As well as providing this link, entering data in to the FOP Registry is an invaluable contribution to FOP in itself, and is a way that all people with FOP can help the global effort to understand and beat Fibrodysplasia Ossificans Progressiva.



Eco-cups available online!

Launching in January, we had an amazing response to our very first piece of FOP Australia Merchandise, our high quality reusable Eco-Cups!

Our first batch sold out in just one week!! But we have just got a big new batch in and would love for you to help us spread the word!

For only \$15 (plus postage), each cup is BPA-free with a heat resistant silicon band, tight sealing lid and are microwave friendly. Our logo and website address are displayed on the cup, so they are a great conversation starter to help you raise awareness about FOP.

- Buy online today (or direct from a nearby board member to save on postage!)
- Share the link with family and friends to help them save on reusable coffee cups
- Are you able to sell cups at your school, office or at a local market?
- Do you have a local café or shop that would be interesting in helping sell the cups? Let us know at info@fopaustralia.org
- Send us a photo of where you use your FOP Australia Eco-Cup!

Here are some snaps we have received of our cups in action around the country - keeping drinks warm, saving reusable plastic, and promoting FOP awareness... all before you've finished your morning cuppa!



Thanks to Rob Olsen, Chevaun Hedley and Charmaine Grott for sending these pictures of their FOP Australia Eco-Cups at in use in the kitchen, at work, and school!

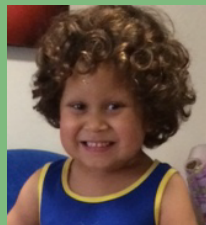
Time for 'a fair go' for Australians with rare diseases

FOP Australia is a proud partner of Rare Voices Australia, the national alliance of people living with a rare disease. Through RVA we can show our support for people with Fibrodysplasia Ossificans Progressiva and many other rare diseases. RVA lobby for Australians to have access to best practice for diagnosis, treatment and support services for rare diseases.

At fairforrare.com.au Rare Voices Australia ask you to show your support by signing the Fair for Rare petition. Please take a moment to add to the growing number of Australians demonstrating to policy makers that we want 'a fair go' for everyone.



Now on fopaustralia.org...



To help promote awareness and understanding of FOP on Rare Disease Day, Jarvis Budd and his mum Lara Boniface are kindly sharing his story online. Inaugural

board director Maris Stanley wrote this profile of Jarvis to help others understand the challenges faced by people with FOP.

Sharing the stories of those living with FOP is a powerful way to help the broader community understand why FOP research, and supporting people living with rare diseases, is so important. We ask you to share the link to Jarvis' story to at least 1 person for Rare Disease Day this week to help better understanding in the community.

If you have a story to share about life with FOP, we would be grateful of the chance to help you share it via info@fopaustralia.org.