



Member Newsletter Issue 1



February 2017

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Thank you and welcome...

... to our first quarterly member newsletter for 2017. Thank you for supporting FOP Australia and people with FOP here and around the world.

With your support FOP Australia had a very active 2016, making our first donation of \$34 000 to global research efforts via the International FOP Association (IFOPA). 2017 is already an exciting year for FOP Australia, with an FOP clinical trial enrolling in Australia for the first time! (see Research news on page 3).

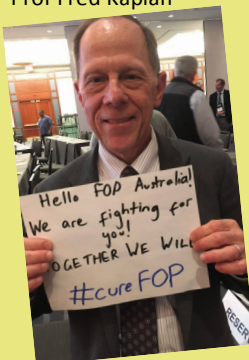
Thank you especially to the previous board directors who gave their time, sweat and tears to get our organisation running. Our 2015/16 AGM was held on the 8th December where we said goodbye to board directors Lara Boniface, Mark Boulton and Maris Stanley. Talia Wilson (treasurer) and Brooke Scott (secretary) and I are working to fulfill the goals in our Strategic Plan 2016/17, which we invite you to read in the 'About Us' part of our website. Keep an eye on our website throughout 2017 for more updates!

Best wishes, Lydia Scott, Chairperson

Upcoming events

- **February 10**
Sales for Jamberry Fundraiser open!
- **February 11**
Somerville Disco (Vic)
- **February 28**
Rare Disease Day
Jamberry Online Party
- **March 19**
Bay-City Fun Run (SA)
- **April 23**
FOP Awareness Day

Prof Fred Kaplan



Now online at fopaaustralia.org

One of the most popular sessions of the 2016 Australasian FOP Patient Gathering was the discussion with international experts Professor Fred Kaplan and Dr Robert Pignolo. They joined us live from Pennsylvania to answer questions from the nine FOP families at the meeting. A transcript is now available online on our website, along with other great resources.

A little note with a BIG THANK YOU

In this edition we would like to acknowledge **Troy Proudfoot**

Troy is a graphic designer who kindly designed and donated our great new logo.

SUPPORT. RESEARCH. CURE

fopaaustralia.org

Jamberry Online Party February 28th

Shan Carty, Independent

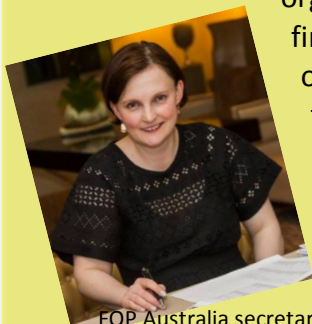


Consultant for Jamberry, is once again kindly donating her time and profits to us

by organising an online fundraising event this month.

Jamberry sells high quality durable nail wraps and a variety of professional nail lacquers, gel enamels and nail care products. Last year lots of FOP Australia members discovered the fun and easy to use products when Shan

organised our first ever online fundraising event, raising \$902.



FOP Australia secretary Brooke Scott models her Jamberry nail wraps at the 2016 FOP Australia launch party

Shan is hosting another online party for FOP Australia on February 28th to raise money for Rare Disease Day, and hope you can help us beat last year's total!

But you don't need to wait! Starting from February 10th you can buy Jamberry products at shancarty.jamberry.com and all profits will go to FOP Australia!

What is Rare Disease Day?

International Rare Disease Day takes place on the last day of February each year to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. It is a public campaign and also seeks to raise awareness amongst policy makers, public authorities, researchers, health professionals and anyone who has a genuine interest in rare diseases.

Rare Disease Day events are run by hundreds of patient organisations all over the world that work on a local and national level to raise awareness for the rare disease community in their countries. The campaign was launched by EURORDIS as a European event and has progressively become a world phenomenon, with participation in over 80 countries in 2016.

On rarediseaseday.org you can find information about the thousands of events happening around the world. FOP Australia would love you to join our online fundraising Jamberry party to mark the day. But we also

encourage members to hold their own local event, and to share the logo and information on social media to help give those with rare diseases a voice!



Information and logo by EURORDIS from rarediseaseday.org used in keeping with their stated Conditions of Use.

Every (bull)dog has their day!

Devoted Western Bulldogs supporter Tyson Stanley was thrilled to be at the MCG last year to watch his beloved team win their first AFL premiership in 62 years. Though FOP has affected Tyson's mobility, with local support he got there to cheer them on.



Tyson with Bulldogs captain Bob Murphy

Email us your stories to share with the FOP community!

Research news: IFOPA Drug Development Forum



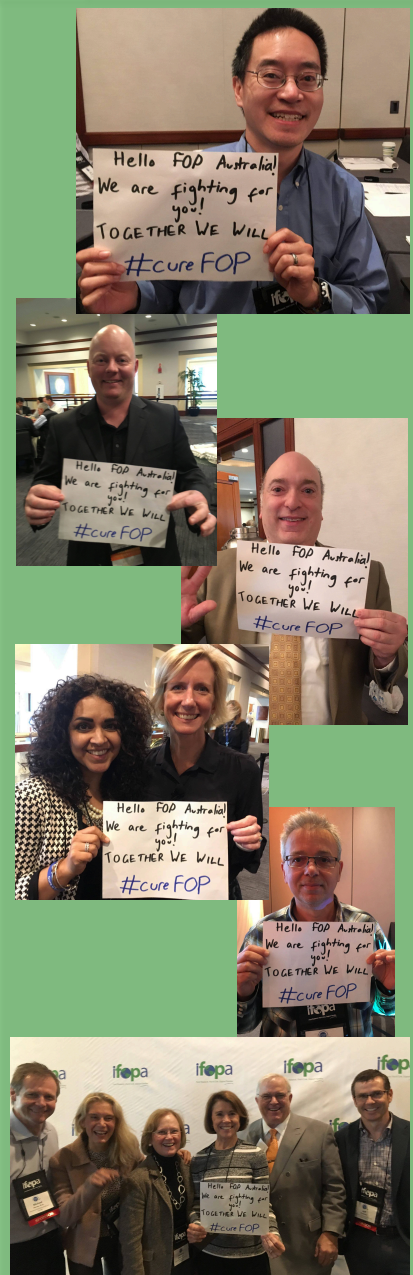
IFOPA hosted the 2016 DDF for over 180 participants from over 35 different centres and over a dozen countries. Lydia Scott represented FOP Australia at the two day meeting in Boston, which included updates on the current, upcoming and potential clinical trials.

Clementia Pharmaceuticals have released early data from their phase II trial of palovarotene. This demonstrates an acceptable adverse effect profile, with all adverse effects either treatable by over the counter products or not attributable to the drug. Efficacy data suggests a trend towards reduction in new bone formation, but doesn't reach statistical significance. The second stage of this trial will observe the effects of palovarotene over a longer period. **Enrolment for this trial has now opened in Australia through QUT.** Contact Linda Bradbury linda.bradbury@qut.edu.au for more information.

Other companies were also anticipating commencing clinical trials for potential FOP treatments in 2017. Clementia discussed plans for **the first ever phase III clinical trial for FOP**, to further assess palovarotene. There are no current plans for this phase III trial to be held in Australia, but FOP Australia will maintain close communication with Clementia to maximize any opportunity to do so in the future.

Diverse presentations included new information on the:

- ongoing search for a reliable biomarker to predict FOP flares
 - natural history (including FOP Connection registry data)
 - role of IFOPA in preparing patients for the clinical trial era
 - Patient Narrative study results, including Australian data
- For more information contact FOP Australia or visit us online.



Above: Some of the researchers and community advocates from around the world who were very excited to say hello to FOP Australia's Facebook followers from the Boston DDF. From top: Dr Ed Hsiao from UCSF, Chris Bedford-Gay from UK group FOP Friends, Dr Robert Plgnolo from Mayo Clinic, Michelle Davis and Betsy Bogard from IFOPA, Aris Economides from Regeneron Pharmaceuticals, and the team from Clementia Pharmaceuticals. **See more on our Facebook page!**

Somerville Disco February 11th

Tyson Stanley is organizing a disco to raise money for FOP Australia. Tyson has organized several disco events, and we are excited that this year he has chosen to donate the proceeds to FOP Australia. So if you are in Victoria, get along to the Somerville Scout Hall in Clarinda St from 6pm to show your support, have fun, and win some prizes!



Have you got an idea for a fundraiser? Contact us at info@fopaustralia.org and we can help you get started!