



Member Newsletter Issue 8



December 2018

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- **Fundraising fun:** Thanks for a great start to the 2018/19 FY!

2018 ends on a high: New opportunities on the horizon and our best start to a new fundraising year yet!

Thank you to all FOP Australia supporters for a great year in 2018. After donating \$45,000 to the global research effort from 2017/18 activities, you have made the start of the 2018/19 financial year FOP Australia’s best start yet! New activities included the Collins’ family’s massive fundraising effort for the Bridge2Brisbane fun run/walk, a night at the opera in Mornington, and the Mt Gravatt Bowls club fundraising day. The bowls day led to one of the most wonderful surprises of the whole year, as it encouraged new supporter Jim Brown to set up a workplace fundraiser which raised \$6,920! In total, \$34,431.24 was raised in the first six months of 18/19 which puts us ahead of target for our fundraising goals for the financial year. It also demonstrates a gradual increase in support from the broader community which also means more awareness of FOP. But there is much, more that we hope to achieve in this financial year and throughout 2019, particularly in the areas of raising awareness, support grants and community engagement. Please take some time to read our KPIs on fopaaustralia.org (in the ‘About Us’ section) to learn more. Thank you for your ongoing support in 2019, and for helping each new year bring us all closer to a time when the devastating effects of FOP can be stopped.

Upcoming events

- **Now!**
Bright Star Kids Back to School fundraiser launch (online)
- **January 1:**
2019 Coffee Club launch (online)
- **February 28:**
Rare Disease Day and launch of new FOP Australia merchandise
- **March 11:**
Somerville Family Day stall



Congratulations Zach!

Congratulations to Zach Dean on an important milestone—Zach’s mum Laurin kindly gave us permission to share this photo of Zach at his year six graduation. It is lovely to see Zach’s big smile and pride in what he has achieved despite the barriers that FOP has put in his way. Congratulations Zach – we can’t wait to see what you can do next! **Have you got a story to share? We would love to hear from you!**

A little note with a BIG THANK YOU

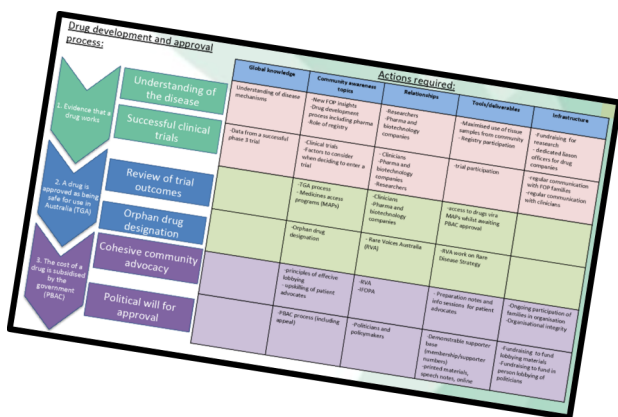
This time we acknowledge **Jim Brown** for organizing a very successful fundraiser with his colleagues and employers at Mylan
Find out how you can help at info@fopaaustralia.org

SUPPORT. RESEARCH. CURE
fopaaustralia.org

Advocacy strategy: Now online

Now that potential drugs for FOP are in the clinical trial phase, effective treatments may be on the horizon. Therefore FOP Australia needs to be getting ready to help people in Australia/NZ get access to treatments once clinical trials have identified an appropriate drug for registration. To help map out the road ahead, we have set out an advocacy strategy to keep our organisation focussed on activities that will grow a strong, informed and unified voice for our community.

Check it out on fopaustralia.org in the 'About Us' section.



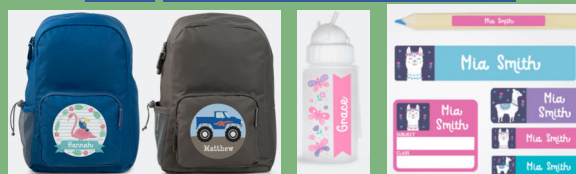
Stop lost property and go Back to School in style: Bright Star Kids

Is your child about to start or return to school? Are you looking for a personalised gift? Are you a teacher looking for educational material for next year?

FOP Australia is now fundraising with Bright Star Kids, who specialise in name labels, school supplies, personalised gifts & t-shirts, educational supplies, room decor, stationary and much, much, more!

20% of every order placed will go directly towards FOP Australia, all you have to do is select FOP Australia as the Fundraiser you'd like to donate too. It's that easy!

Bright Star Kids currently have up to 80% off name labels, perfect timing for families with school children. So please check them out & support FOP Australia by making your purchases through them. <https://www.brightstarkids.com.au>



Bridge2Brisbane: Running to stop FOP

Well done to the Collins family for braving wet weather to raise awareness and funds for FOP at the Bridge2Brisbane fun run/walk on the 26th August. Because of their amazing effort \$14,520 was raised towards research for a cure. They also road-tested our brand new FOP Australia merchandise which we will be launching in time for Rare Disease Day on February 28... keep an eye out online over the next month for more news!



Thank you Mt Gravatt Bowls Club!

Thanks to Dean Gaddes and everyone at the Mt Gravatt Bowls Club for getting behind Jarvis Budd and his family by holding a fundraising event on 22nd July. This event raised \$2606, and also resulted in building contacts with relatives of an overseas FOP family, AND inspired another fundraiser! It just goes to show how worthwhile it is to hold a local fundraiser in your community!

Have you got a fundraising idea? Please get in touch – we would love to help you #cureFOP!



Giving people with FOP a voice at the Rare Voices Australia 2018 summit

In November, Treasurer Talia Wilson and Secretary Brooke Scott attended the National Rare Disease Summit held in Melbourne. Attended by patient groups, pharma, clinicians, politicians and advocates, the Summit was opened by Greg Hunt MP announcing the governments support for a National Rare Disease Framework. This news was heartily welcomed by the rare disease community who have been calling for a framework for some time.

The weekend involved a variety of discussion topics and an emphasis was placed on collaboration, both with Rare Voices Australia and other rare disease patient groups within the community.

Key topics of interest were:

- **The NDIS** - the NDIS has been rolling out across the country for some time now and many patients of rare diseases are making or have made a transition from their existing services to the NDIS. Many patient advocates attending this workshop had found the transition onerous and insufficient. There was much discussion about how we could work together as a team to highlight these inadequacies to the government in a solutions based format.
- **Pharmaceutical benefits scheme** - As we move towards a treatment becoming available for FOP it will be important to understand the process of how a drug can be accessed. The PBS process is a topic we are keen to understand more and this will be a focus topic for 2019.
- **Advocacy** - is a key issue for FOP patients and families. We are keen to partner with RVA to ensure that all patients have equal access to any treatments that become available.

The Rare Disease Summit will be held every 2 years and we look forward to working with RVA in the future.

Online discussion: Navigating the NDIS

On the FOP Australia – Patients and Families Facebook page, we have started a discussion to share experiences of navigating the NDIS. Please join and share your thoughts: What resources have you found helpful? What is your advice to others? What else would you like to know?

2019 IFOPA Family Gathering announced: November, Florida USA

After the 2018 Family Gathering in Baltimore, IFOPA have announced they will be holding the next international family gathering in Orlando Florida in November 2019. A Drug Development Forum and meeting of the International Clinical Council on FOP will also be held in conjunction.