

# PKS PERSPECTIVE

## JULY 2017 EDITION

### PRESIDENT'S REPORT

Hello members and friends, 2017 has been a very productive year for the PKSFA community. Most of our energy has been directed to the conference. Tracey Hilton has sent out details about the PKSFA conference which is held in Adelaide this year. We will have a detailed Q&A available soon which will be sent to all the families.



Tracey has secured at least two informative speakers for the conference and we are working on a few more to complement the theme. We have been reassured the Adelaide Resort and its surrounds are wheelchair and child friendly. We have done our best to ensure that the facilities we have booked are suitable. We have been able to secure the services of a special needs organisation in Adelaide, CARA ([www.cara.org.au](http://www.cara.org.au)) to care for our PKS children for the duration of the sessions. We had a similar setup at the Melbourne conference (2015), which the parents greatly appreciated so that they can focus on the conference. Our siblings will not miss out as well as we are in talks for similar carers/supervisors to keep them entertained (*and we know how easy it is to keep them entertained don't we?*). This will be weather dependent and we will book the appropriate places closer to the conference. But they will be appropriately supervised and entertained. We are extremely cognisant of the importance of suitably screened and trained people, and that is why we will only use renowned organisations. The program looks exciting and we will provide this soon. Further details will be sent in the week or so.



In the February newsletter, we wrote about the FDNA Project. I received notification that the results have been accepted for publication in the Clinical Genetics Journal, which is entitled "Next generation phenotyping in Emanuel and Pallister Killian Syndrome using computer-aided facial dysmorphology analysis of 2D photos". Thank you again for those that provided the photos for this study.

We welcome two new families to the Foundation, both from Queensland. This brings our membership to 14. Most have already introduced yourselves to them through social media.

It also comes with tremendous sadness that we inform you that one of our PKS members sadly passed away on 23<sup>rd</sup> March. Jared Martin was one of our oldest members, he loved being the centre of attention when we all met him at the Melbourne conference in 2015.

(Continued on page 2)



Jared and his family also attended the 2015 “Bollywood Mania” fundraiser (photograph of some Martin family above) organised by Namita Biswal, and to Sue and Glenn and family, we extend our sincere condolences.

## THE PKSFA GRANT PROGRAM

Grants are available to families to help with your child’s care and support. Please do not hesitate to contact the Foundation if you would like to seek some funding.

## THE FOUNDATION COMMITTEE

The Committee once again excelled to the keep the Foundation running smoothly. Without your contribution we would not be in such a strong position to continue to provide such a valuable service. This now leads us to the AGM. We will be sending out the agenda and notification soon. Please do consider offering your support as all positions are open.

## RESEARCH AND PKSFA WEB PAGE

This has been updated to include relevant medical journal articles published up to beginning of 2017. Refer to our web page for details. The Foundation will consider participating in any form of research, so if your medical service provider has any suggestion or thought, please refer them to the Foundation. We have been updating the web page on a more regular basis this year. Please visit the site for new and interesting information. Any improvements, corrections or suggestions please let the committee know.

## PKSFA FUNDRAISING

Namita has continued with the Entertainment Book sales for 2017, it's not too late to purchase one or if any of your friends have still not got one. Just contact Namita ([namita.biswal@pks.org.au](mailto:namita.biswal@pks.org.au)) for details.

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**RENEW NOW**

WA's long-term supporter Marcel LaMacchia of One Residential has set up a My Cause account called "Marcel LaMacchia reaching out for PKS" where Marcel is kindly donating \$100 per house sale to the Foundation. His goal of \$5000 is currently standing at \$2000. This is a novel initiative where an organisation can commit a set amount per sale of a property to the Foundation. If you think you have someone that would like to support the Foundation in a novel way please do not hesitate to pass on our details.

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