

PKS PERSPECTIVE

JULY 2015 EDITION

PRESIDENT'S REPORT

It is with tremendous sadness that I bring you the news that little Malachi Maitai passed away due to various medical complications, on Wednesday 15th July. The PKS community sends their condolences to Stacy and extended family on their loss. The back story to Stacy's plight with Malachi is included on the website, [here](#).



On a less sad note, a researcher in the UK is undertaking a study looking into neurodevelopment disorders and rare genetic syndromes. This will be in an online questionnaire format. I am not sure of the details they will be asking. I requested for a copy of the ethics approval documents, then I will follow it up with their office. We are supportive of any information we can provide for medical research. Your details will not be sent to any person rather we will forward their request to you individually and it is up to you to decide if you wish to participate.

We have had excellent response to the May newsletter; thank you to those who emailed me and Steve. Please do not hesitate to contact Steve if you have any news which can be placed in the newsletter. Nothing too trivial is too small to publish.

A reminder that Namita is organising an inaugural fundraising event in Sydney. Let's give her as much support as possible. Having some insight to the event, I can tell you that it will be amazing. I urge you to support this event, even better organise get a table or three of family and friends. Speaking from our experiences with the high tea events in Perth, by including your family and friends will show solidarity to the cause. Remember that we hold these events for your child, so please do support us as much as possible. Money raised at these events help us fund the grants program as well as the conferences, which the last event we were able fund 75% of the conference. Please do not hesitate to contact Namita if you are able to provide her with a reliable contact for sponsorship.

Finally, I want to mention something special. Bec Paton, over the past three years, has been working tirelessly with another project in Ballarat, a Livvi's Place inclusive play space. The *Touched By Olivia Foundation* originally started in Sydney and the goal of the organisation was to set up these inclusive play areas, "Livvi's Place's" around Australia. As a result of Bec's hard work for the Ballarat play space, her work with PKSFA and as a disability advocate, she was nominated for *The Barnado's Mother of the Year*. Bec made the finals and was runner up in the Victoria division.

THE PKSFA GRANT PROGRAM

A reminder of the PKSFA grants program. No matter how large or small you are seeking, the Foundation is there to help support you.

If you are interested in attending any of the international PKS conferences, please do not hesitate to contact the committee to discuss grant support.

PKSFA INPUT IN THE UNIVERSITY OF MELBOURNE (TUOM) STUDY

The PKSFA was identified as one of 117 rare disease patient organisations in a UoM study. The Study confirmed that patient organisations were very interested in research and supportive of funding from the community. It also found that there is considerable pressure on people who run patient organisations, and personal and financial sacrifices are often made.

ANNUAL GENERAL MEETING

The AGM will be held on 23rd August 2015 at 4pm EST via an internet link. All positions will be available to be filled. If you are passionate about the future of the Foundation please do not hesitate to put your hand up and help out, whether it's in an executive or a general committee role.

Formal notification and the details of the past 12 months will be sent out soon.

ACADEMIC PUBLICATIONS

Nic has updated the medical journal publications, which are now also on our web page. The intention is to keep this as current as possible on a yearly basis. You are able to download and print it should you wish to show any of your medical specialists. Nic is also planning to provide a review of a publication for all to understand. Over time, PKSFA will be looking at some research. Nic will discuss this further in a later publication; for instance, what is involved with medical research especially with a rare syndrome like PKS.

BOLLYWOOD MANIA

Fun, colour, excitement and everything **Bollywood** is the flavour of our upcoming fundraiser in NSW.

On the 10th of October, one of our PKS families and their dedicated team of volunteers are putting up a spectacular show with Bollywood dance and drum performances, DJ, dance-floor, 3-course authentic Indian meal, auctions, raffles, prizes and heaps, heaps more. There is 50% discount on the ticket prices for the PKS families and PKS kids are FREE. The funds raised will go towards the next PKS Conference and grants to support PKS families and kids. Please share this event with your family and friends and like the Facebook Page: **PKS Bollywood Mania – Fundraiser.**



pkS
Pallister-Killian Syndrome
Foundation of Australia
Education • Awareness • Support

bollywood mania
10th October
6:30 pm
मिठानु बार्क हॉल, चेन्नयोरबोर

Lip-smacking 3 Course gourmet Indian cuisine, selected alcoholic & non-alcoholic beverages, scintillating performances by Mystik Bollywood, drums by IndOz Rhythms, Live auctions, Raffle draws and more...

Even better, this is a fundraiser to support kids with a rare genetic disorder - Pallister Killian Syndrome.

Tickets
Single: \$79 • Couple: \$150 • Kids 4-12: \$50
Family (2 Adults & 2 Kids): \$249

For inquiries, contact Nazreen: 0432 745 900,
To book online, visit www.pks.org.au

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MEET JARED MARTIN (AND PARENTS, GLENN AND SUE)

Glenn, Sue and Jared live in New South Wales. Jared is the first person with PKS that we are aware of who is now an uncle. Jared is also our oldest known Australian with PKS.

The Martins were good enough to answer “ten questions,” and next edition we are profiling our next oldest: Sarah Hilton.

How old is Jared? 21.



When was he diagnosed with PKS? When Jared was 12 months old they gave him a very good geneticist skin biopsy.

What was Jared’s most memorable experience? The most exciting time in Jared’s life was last year at his eldest brother’s wedding where he was page boy. He had the biggest smile on his face the whole day. Now he is an uncle! Every time we call him uncle Jaz his face lights up. *(Cont’d over...)*

What was Jared's saddest experience? The saddest times in Jared's life have been the numerous times he's been sick in intensive care.

As parents, what are the hardest times for you? As parents the hardest times are watching Jared in hospital. We feel helpless and it's very hard when you're told numerous times he will not make it through the night but he is such a fighter and always manages to prove them wrong. He's one tuff little man.

What makes you as Jared's parents smile? It makes us smile just by seeing Jared happy which is most of the time.

What does Jared enjoy most of all? Jared most enjoys life when we are on holidays by the beach and just being around people and of course music. We know when Jared is happy by his beautiful smile and the way his whole face lights up.

How did you find out about PKSFA? We found PKSFA on Facebook.

As parents, what are your hopes for Jared? Our hopes and dreams for Jared are that he continues to be the happy little bloke that he is most of the time and that he stays healthy.

WHAT'S HAPPENING IN THE NEAR FUTURE?

- PKS conference to be held in Sydney in 2016. Details will follow.

If you would like to organise a fund raising event in your area please discuss it with one of the committee first as we have the appropriate certifications for you to produce. Remember: help us to help you.

WEB PAGE AND IT

The web page is a work in progress, which will be updated from time to time. Don't forget to check regularly on any updates. Of course, any comments would be appreciated. Facebook, Twitter and Instagram have all been established and are useful in getting short messages out about any upcoming events.

PKSFA MAJOR SPONSORS

