

PKS PERSPECTIVE

MAY 2015 EDITION

PRESIDENT'S REPORT

A hearty welcome to all members and affiliates. The past 12 months has been busy for the Foundation and it is credit to all, the dedication our members and volunteers to keep the Foundation going. Administratively and financially the PKSFA is tracking well, meeting all our obligations, state-by-state and nationally. We have embraced two new PKS families last year. Contact from both the parents and professionals, in both cases, came about as a result of our web page. Our presence in the community will only improve. It has been a long time since our first newsletter, for which I apologise. The new look newsletter will contain regular segments as well as new topics. I hope you enjoy the new format.



THE PKSFA GRANT PROGRAM

The Foundation now has an open grant program for PKS individuals meaning there are no deadlines to apply for any grant funding. We have been working over the past few months to draft up the guidelines to which the grant committee will use in order to assess each case. Each request will be kept confidential. Grants up to \$2 000 are available. Please do not hesitate to contact the Foundation should you wish to access some funding. Examples where funding could be used include:

- Additional Physiotherapy and Occupational Therapy sessions/programs.
- Minor modifications to equipment or rooms.
- Travel and/or accommodation for PKS related conferences.
- Respite – preferably through a respite service provider.
- Equipment: e.g. Strollers, OT equipment, stimulation toys, iPads, software programs, feeding utensils.

SUPPORT FOR MALAKAI

PKSFA was in the lime light last month as a result of a New Zealand mother (Stacy Maitai) who gave birth to a baby boy, Malakai, in Perth in the middle of last year. Malakai was diagnosed with PKS just after he was born. I received a phone call from the hospital social worker in August soon after Malakai was diagnosed with PKS. The social worker admitted their department had not heard of the condition and a quick google search showed our web page at the top.

In January this year Stacy contacted Terzita and they had a good long discussion about PKS, coping and life in general. Fortunately, the team now looking after Malakai has experience with PKS because of Alessia.

The “Story of Malakai” was aired on the local Channel 9 News on Monday 23rd March (*the video of the news story is found on our [web page](#)*). The news story highlighted how Stacy had to stop working in order to look after Malakai and that her social benefits (Centrelink) would only provide a maximum cover of \$180 per fortnight.

The executive committee decided that the Foundation would help Malakai with a grant/donation of \$2 000 to purchase some vital equipment when he returns home. We will work closely with the healthcare providers. The publicity this has given the Foundation has been amazing. Interestingly our web page views went from 258 in January to 620 in March, the time of the news report. The short YouTube video about PKS which is on our front page, showed pleasing results. Between 10th January and 22nd March we had a total of 26 views, since the airing of Stacy’s story a further 800 views!

Geographically they have been from all over the world from USA, UK, Singapore, South Africa, Canada, Germany and twenty other places. The presentation of a cheque to Stacy on Friday 28th March clearly had a positive impact on the promotion of the Foundation. The story has also been published in New Zealand, USA and UK among others. The statistics they quote in the news story come directly from our web page, which is also linked on their publications. An Australian publication, *Kidspot*, also took up the story as well as describing the life and times of three of our PKS children (Sarah P, Yash B, Alessia A). In time we will place these links on our web page.

NEWSLETTER EDITOR

It is my great pleasure to introduce you to Steve Wickham (Perth) to our team. Steve and Sarah contacted the Foundation last year after the news of their unborn child’s (Nathanael) diagnosis. Steve felt that he should help the Foundation in some way. Steve is a wordsmith and has offered to compile the newsletter. PKS Perspective is important form of communication to our members and supporters. This will show community what we are doing and keeps our members abreast with the latest news. There will be regular topics as well as other interesting information that may appear from time to time.

If you have any suggestions or input to the newsletter, please do not hesitate to contact Steve directly. From time to time Steve may contact you directly with regards to the newsletter. Steve’s number is +61424 404 911 and he is available through email and Facebook. Here are some words here from Steve: *Hello everyone. Our lives changed in July 2014, when we learned of our son’s condition. Within hours I was in contact with Nic through the PKSFA webpage via email. We subsequently met the Acquarola family. Nathanael was stillborn on 30 October. Sarah and I felt we wanted to contribute to the PKSFA because of the support we had received. Please feel free to contact me if or whenever it is relevant.*



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.

THE PERTH HIGH TEA

Perth held its second High Tea on 2nd November 2014. Again, it had the same theme as the inaugural event in 2012. We had 240 guests, which completely sold out in 5 days (there were also 20 people on the waiting list). The event was held in the heritage listed Perth Town Hall.

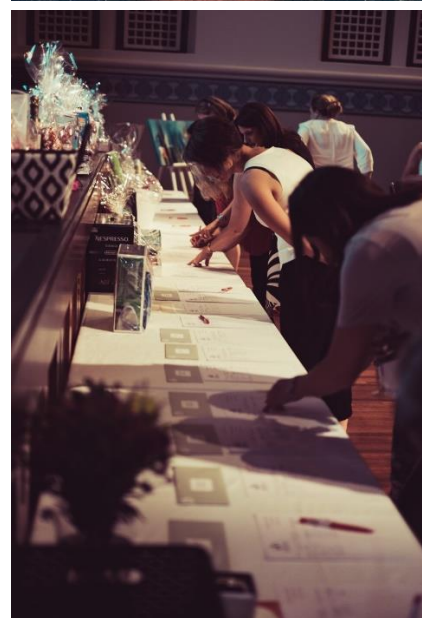
Gillian O'Shaunnesy, ABC TV and Radio announcer, kindly donated her time and expertise to be our MC. Australian Winter Olympian and World Winter champion Lucy Chaffer and Federal Minister for Fremantle Melissa Parke were our two very special guests.

The guests were welcomed with an ice cold glass of Champagne on arrival (it was a 37 degree day!) and then proceeded to the main hall. The event started with a short video (the one which is on our web page) and Nic Acquarola then formally welcomed the guests.

Twenty-five students from Iona Presentation College kindly donated their time to help serve the food platters to each table. These girls were outstanding!

Guests were treated to a two course High Tea which the first course comprised of 10 traditional and not so traditional tasty treats. Special dietary requirements were catered for.

Following the first course, the guests were entertained with a fashion parade. A short break followed for the guests to make some generous bids on our silent auction items.



Commencing at 9am on the day we also had a unique Facebook auction for a beautiful pearl pendant valued at \$4 000, which was generously donated by Kallis Jewellers.

The guests were kept up to date of the bidding during the day. The pearl had attained three zealous bidders each trying to outbid each other.

The eventual highest bidding winner paid \$2 300 for this work of art. The story is that the person that won the prize purchased it for his wife's 50th wedding anniversary.

Following the break, the second course was served which comprised of no less than seven different desserts. The guests were treated to loose leaf tea, plunger coffee, bottled still water and, of course, Champagne. The event had attracted over 150 donated items, vouchers or services, ranging from \$20—\$350 in value. The generosity and interest was worth the hard work our organising committee put in over the previous twelve months. Please go to our web page for photos and more details. \$25 000 was raised from the event. This report concludes with more photos overleaf...



Food about to go out and a table set.



At a table.



A prize hamper!



Another perspective!



The Perth High Tea 2014 Team.



A stunning venue.

THE PERTH GREAT RACE

The Perth Charity Adventure Race <http://charityadventurerace.com.au> held its inaugural “The Amazing Race” style competition on Sunday 18th May 2014.

Teams of four people raced around Perth and Fremantle collecting clues to the answers to their next destination.



Alessia’s cousins Luke and Marc Zagami, Daniella Carcione and Adrian Emmanuel decided they wanted to do something for the Foundation.

“Team Alessia” successfully raised \$6 620! Only seven teams competed in this first event, of which “Team Alessia” came second. Well done guys.

The T-shirts were kindly donated and printed by Warren’s Menswear.

WHAT'S HAPPENING IN THE NEAR FUTURE?

- *Bollywood Night* is being held on 10th October 2015.

Namita Biswal and Nazreen Nameed (NSW) have been working tirelessly over the past few months organising this fundraising event. Details will follow. Should you have any contacts who may be able to help with donations etc. please do not hesitate to contact Namita directly.

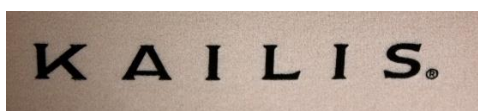
- PKS conference to be held in Sydney in 2016. Details will follow.

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



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