



PNHSAA

PNH Support Association of Australia Inc.

Supporting Australians with Paroxysmal Nocturnal Haemoglobinuria

RARE BUT REAL

NEWSLETTER ISSUE No1 JULY 2012



'PNHSAA Members Meeting 2012 – 50 plus members in attendance'

PNHSAA National Conference

The PNHSAA held its first national conference at the Sebel Albert Park Hotel in Melbourne on Saturday, 25 February 2012. The Association had an overwhelming response with 55 PNHSAA members representing VIC, NSW, WA and QLD coming together to meet each other as well as widening their knowledge about PNH. A video presentation on PNH 101, presented and recorded by Dr. Monica Bessler (MD, PhD) at the 2010 AA & MDS International Conference in Washington DC, commenced the informative session of the Conference. This presentation answered many questions to those in attendance but also provided an opportunity to raise questions about the disease and treatment.

Following the presentation, Prof. Jeff Szer, Clinical Haematologist at the Royal Melbourne Hospital, led a discussion on PNH fundamentals and facilitated the much eager 'question and

answer' session in which topics such as available treatments, blood transfusions, splenectomy and new research were discussed.

Following the informative session of the conference, PNH members enjoyed a banquet dinner which provided all an opportunity to share stories, discuss the presentations of the day and form friendships.

The Committee would like to thank all members who attended the event and your positive feedback. We would also like to extend our thanks to the AA & MDS International Foundation which supplied us with Dr. Bessler's video presentation, Prof. Jeff Szer, special guest Michael Brown from the Royal Melbourne Hospital and all the staff at Sebel Albert Park Hotel for their assistance in making the conference a success.

A few words

A message from the President

In August 2011 I was elected to be President of the Association at the Annual General Meeting. While this position is by no means a small feat, I am enthusiastic about the challenges the role will bring and encouraged by what the Committee can provide its members. I am further encouraged by the passionate, dedicated and wonderful people who make up the Committee and the skills and experience they bring so that each year we are blessed with the tools to continue to develop a strong platform of support to those diagnosed with PNH and their supporters.

The Committee is formed around five creative and devoted people, all in successful full time employment, some caring for their family, and three diagnosed with PNH. The triumphs and successes over the past few years provide us with more drive to continue to provide support and information to those that need. I would like to send a sincere thank you to each Committee Member for dedicating their spare time to the Association, and their loved ones for their unconditional support and understanding.

Good progress has already been made this year as the Committee has been able to focus its resources on continuing to build a strong member base and therefore

obtaining feedback as to what our members want. Through our member surveys, the Committee has discovered issues which are important to our members such as diverse ways to communicate to members, travel issues, need for peer support groups, forum for sharing stories and experiences, and gaining access to new information published about PNH and related issues.

I would also like to mention the success of our first National PNH Conference which was held at the Sebel Albert Park Hotel in Melbourne on Saturday, 25 February 2012. The Association had a tremendous response, with members from all around

Australia participating in the afternoon. The positive feedback was overwhelming and we look forward to organising similar events in the future both National and state by state.

Finally, I would like to send a heart-warming thank you to everyone who is committed to supporting those with PNH – husbands and wives, mums and dads, siblings, children, extended family and friends – without all of you, the success of this Association would not be possible.

Yours sincerely



Matt Dean, President



'Treasurer Michael Patterson presented thank you gift to guest speaker Dr Jeff Szer'.

What you asked for

PNHSAA Members Survey

Over the past several months the Committee asked all its members to fill out our Member Survey and let us know what services you would like us to be focusing on.

The top requests are:

- Formal newsletter to update members with latest news.
- Material regarding research updates on PNH and treatments.
- Information regarding lifestyle and healthy living for those with PNH.
- Sharing of patient and supporter stories and their experiences.
- Fundraising, conferences and social events (state by state and a national event bringing all members together).
- Information regarding travel and travel insurance.

The Committee appreciates all members' feedback and we will endeavour to provide all relevant information and organise events, as well as provide support.

Current Projects

Travel insurance

For many Australians, obtaining travel insurance is merely a process of filling out an application form and handing over a credit card. For PNH sufferers it is not so easy (based on results from PNHSAA Travel Insurance Survey). Results from our Travel Insurance Survey indicated that many PNH sufferers have been refused travel insurance cover for their existing medical condition at some stage during their organising of travel plans. While the survey suggests that some have travelled without cover for the existing medical condition, others have been lucky enough to have been approved cover.

While this is a positive outcome for PNH sufferers, it is evident that an inconsistency exists between insurance

companies as to which ones will approve full cover. Another hurdle is the amount of medical information which the insurers seek in addition to the application forms and questionnaires.

The PNHSAA recognises these difficulties and over the next 12 months our aim is to collaborate with other Rare Disease organisations both in Australia and globally to better understand these hurdles, and investigate whether or not these organisations have sought consistency and transparency in the process of obtaining travel insurance.

Let us know your travel insurance stories and experiences at info@pnhsaa.org.au.

Share your story

Aaron Lee

Aaron Lee, better known as 'Northie' to his mates and fans, is a young PNH patient living in New South Wales. Despite his challenges with the disease, Aaron remains enthusiastic and passionate about music and is dedicated to continuing his career in the music industry. He shares his story with the Committee about his latest live music act adventure where he performed at Easterfest in Toowoomba, QLD during the Easter long weekend.

"My live music act was performing at Easterfest this year. The festival goes for 4 days and nights from Easter Thursday through to Sunday.

We were booked to play one set every day for the four days across various festival grounds and city venues. This required quite a lot of energy as it was basically like a non-stop touring schedule.

We travelled up to Brisbane (driving) a few days prior to the festival and I managed to be awake for 36 hours straight! - barely slept on the drive because I was having too much fun talking with mates, and as soon as we got to Brisbane we caught up with friends and went straight out to dinner. The following day we celebrated a band member's 21st. Very surprised with my own endurance those few days and the festival hadn't even started yet.



Mostly all four days of the festival consisted of performance prep, our set, radio interviews, filming, catching other artists' sets, catching up with friends and barely any downtime. But it's the most energised I've ever been on a series of shows.

Performance wise I was fine each and every set (one was even at 11am, which is crazy for me as I'm a chronic late bloomer). Except for the general puffed out feeling straight after a set - I held fine and my vocal performance was also more than sufficient I felt.

There was quite a lot of napping on the drive home as I was winding down, but I didn't feel any hindrance from PNH or

any anaemic setbacks."

Check out the video doco from our Easterfest weekend at: <http://www.youtube.com/watch?v=p32-nMqrtUI>

Aaron Lee

The Committee thanks Aaron for being part of the Association and sharing his passion for music with us. To share your story for our next newsletter, email us at info@pnhsaa.org.au.

Click of a button

Our new website

We are committed to providing our members with the most up to date information and a better and more efficient way of contacting us, and each other, by the click of a button. Over the next month we will be rebuilding our website at www.pnhsaa.org.au. The re-build will include updating all our information,

providing relevant links to other useful websites, reporting on current events, and provide a streamlined way for our members to provide feedback, contact us and donate. We look forward to re-launching our website soon. Your suggestions for the website are welcome at info@pnhsaa.org.au.

Committee spotlight

Meet: Jenny Sturrock, Secretary

Jenny Sturrock is proud to be the Secretary of the PNHSAA. She was diagnosed with PNH in her late twenties in 2010 and has been on Soliris since January 2011. Outside of PNH she has many hobbies and interests including her job as a weather forecaster for the Bureau of Meteorology. She also enjoys travelling both abroad and through Australia. She is blessed to have been able to see many places in the world including New Zealand, Europe, America and Canada as well as finding time to have visited countless towns across all states and territories

that make up our beautiful country. One of her great adventures so far in life has been living in Darwin for 5 years. After enjoying many wet season storms Jenny and her husband Luke decided to migrate back home to Melbourne. They both love being back down south closer to family and friends. Jenny wishes to thank everyone for building this wonderful PNH community. Jenny has benefitted from the friendships formed and she looks forward to continuing those connections as the years roll on.

Committee spotlight

Meet: Michael Patterson, Treasurer

Michael Patterson is our Association's Public Officer / Treasurer. He helped set up the PNHSAA by formulating the model rules of the association and attending to all the legal requirements to have the association approved as a Deductible Gift Recipient. Michael is married to Wendy who was diagnosed initially in 1994 with Aplastic Anemia and then in 2003 with PNH. They have been married for 29 years and have raised two children (Rob 24 and Kate 22). Wendy was a participant

on the trial for the drug Ecluzibab (Soliris). Since being on this treatment Wendy's health has improved and stabilised greatly meaning that life is fairly routine these days (apart from annual trips overseas together – which they enjoy two weeks at a time!!).

Michael is one of six partners in an Accounting Practice in South Melbourne. He enjoys playing golf and following AFL football.

Get Involved : Calling all volunteers

At times information cannot be readily available or updated and events may not be organised as timely as the Association would like. We appreciate the support and assistance of volunteers to aid us in bringing to our members the information, material and events you have asked for. Your support can be as minimal or as 'hands on' as you would like. Please contact us at info@pnhsaa.org.au to become a volunteer.

Hello : We'd like to hear from you

The PNHSAA would like to hear from its members with suggestions or fundraising ideas, newsletter stories or other charity events the Association can get involved in. Email your suggestions at info@pnhsaa.org.au.

Team Support : Become a member

Become a member and support the Association which aims to help connect Australians affected by Paroxysmal Nocturnal Haemoglobinuria, increase awareness and understanding of the disease, and advocate best possible care for patients in order to reduce the confusion and isolation that comes with a PNH diagnosis. To become a member, email us at info@pnhsaa.org.au.

Power of money: Donations are welcome

As we are a small and newly formed Association we have very limited funding to assist us in providing support services, information and hosting educational and social events for our members around Australia. We appreciate your support and donations. Donation cheques can be forwarded to PO Box 472, South Yarra Vic, 3141.

The big T: Thank you

The Committee wishes to thank all of its members which included PNH patients and supporters for all the encouragement, support and donations made to the Association this financial year.

We look forward to evolving and growing our community.



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Contact Details

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