

# RARE BUT REAL

NEWSLETTER ISSUE NO2 Feb 2013



*New Logo and Website*

## What's New: ReBranding

**T**he month of March is an exciting one for PNHSAA and its members with the re-branding of our logo along with the launch of our new look website.

The website will go live early March and the new look format will provide members, supporters and new users an enhanced experience through an easier to navigate platform. The website will be kept up to date with information, contacts, news and upcoming events.

The website redesign is based on members feedback through surveys completed at last year's Annual members meeting. The Committee welcomes and encourages feedback on the new look website so once you have had a chance to explore online please

let us know your thoughts, as the Committee appreciates all feedback.

We would like to thank Marc Bobolakis and his team at Larkscape Designs for their tireless effort in designing and reconstructing the site over numerous drafts and revisions.

From all of us here on the committee we hope you benefit from the new website format and we hope the refreshing change to our brand will bring some renewed vigour to public awareness of the PNHSAA and our objectives.

## A few words

# A message from the President

I would like to wish all our members and supporters a very Happy New Year and I hope you all enjoyed the holiday period, judging from my waist line I enjoyed it a little too much.

2013 is shaping up to be a big year for the PNHSAA and our members with the committee's focus very much set on the finalisation of our new look website due to go live in March 2013.

Along with the website I am pleased to announce that we will be unveiling the new look PNHSAA branding featuring our slick new logo and slogan 'Rare but Real'. We think this quote makes a statement about PNH as

a disease and can hopefully grab the attention of the community which is largely unaware of the disorder.

A big thanks to the committee and our graphic design team Larkscape for all their hard work in producing the works, I hope all our members appreciate the changes and find the website more user friendly and informative.

Enjoy the summer weather while it lasts and if you wish to contribute a story to the newsletter or have some ideas for the Committee please get in contact with us

Yours sincerely



Matt Dean, President

## Information

# PNH and Haemolysis: what's it all about?

People with PNH lack protective proteins on some or all red blood cells. Without these, a part of your body's immune system (called complement) destroys these red blood cells. This process of destruction is called haemolysis.

Haemolysis can be measured by blood tests for lactate dehydrogenase (LDH) and bilirubin. LDH is an enzyme found inside red blood cells. High LDH levels in your bloodstream may mean that a lot of red blood cells have been destroyed. Bilirubin is a waste product of haemoglobin (found in red blood cells) and high bilirubin levels in your bloodstream indicate haemolysis activity.

You might not notice haemolysis or you might experience one or more symptoms (see table). Haemolysis causes ongoing damage to your body and can result in serious health problems like blood clots, kidney failure, stroke, heart attack and damage to the lungs.

### Some Common Symptoms of PNH Haemolysis:

- Fatigue: Tiredness, difficulty performing daily activities, trouble concentrating, dizziness, weakness
- Pain: Stomach pain, leg pain or swelling, chest pain, back pain
- Other signs & symptoms: Dark-coloured urine, shortness of breath, difficulty swallowing, yellowing of the skin and/or eyes, erectile dysfunction

Any additional stress you experience can increase haemolysis activity. Stress may include infections (even

colds or tummy bugs), surgical procedures (including minor procedures e.g., tooth extraction, portacath insertion), pregnancy and labour, and everyday stress (work, family etc).

Haemolysis in PNH usually occurs within the blood vessels - intravascular haemolysis - but may also occur outside of the blood vessels - extravascular haemolysis - for example, in the spleen. Both extravascular and intravascular haemolysis can cause anaemia. People who continue to experience symptoms while on treatment to stop intravascular haemolysis, may need to be tested for extravascular haemolysis.

### What you can do about haemolysis

At times of stress you need to be aware of any haemolysis symptoms - get to know what triggers haemolysis for you, develop healthy living habits to minimise stress and infections, and contact your haematologist if your haemolysis symptoms return/increase.

Regardless of what treatment you are receiving for your PNH it's important to track your symptoms, get regular blood tests to check for haemolysis and always tell your haematologist if you notice any change in your health.

For further information about haemolysis or other aspects of PNH, please contact Michael Brown, Clinical Nurse Consultation at the Royal Melbourne Hospital PNH Support Service: Mb: 0426 973 807; Email: Michael.Brown@mh.org.au

## Share your story

# Mark Filmer

**W**hen the Committee caught up Mark Filmer at the PNHSAA National Conference in February 2012 he was about to embark on 27,000 kilometre journey around Australia with his partner Jasmine and two children. Not only were we in awe of his trip planning, but also incredibly happy to hear that his fortnightly Soliris treatment would not hinder his travel plans. Naturally, we asked Mark to share his five month adventure with the PNH family.

"It was the phone call to Michael Brown at the Royal Melbourne Hospital regarding Soliris treatments that would set the trip in motion..."

"So, Mick, do you reckon you could organise a dose (of Soliris) in Alice Springs for me?"

"I think so"

"Good, after that, how about two in Broome, one in Kununurra, two in Darwin, one in Mt Isa, two in Cairns, then one each in Brisbane, Sydney and Canberra before I get back to Ballarat?"

"Mmmm"

And so it was that planning was set in motion for a quick 5 month trip to take in 27,000 kilometres of mostly remote or outback Australia. Of course, I had the easy part of the gig; I just had to compromise a little on dosing locations. The unflappable Michael set the wheels in motion with Liz Marshall from OneSource coordinating infusion appointment arrangements.

After a dose in Ballarat, we left Victoria on the 6 April 2012, heading for Central Australia. Having lived in these parts pre children I have very fond memories of the Centre, and it was a joy sharing its secrets with my wife and young children. We spent two weeks exploring the centre before being 'dosed' in Alice.

We shot off across the Tanami Desert, heading for Broome via the Bungle Bungles. I hadn't been into the Bungles before, so that was a bit of a treat. From there we arrived in Broome with time to slip up the Dampier peninsula and camp in Paradise for a few days. After a quick flight south to Perth for my next Soliris dose, where

the seasoned professionals looked after me beautifully, I arrived back in Broome where we had a fortnight to head south down to Exmouth and Ningaloo before being back in Broome to fly south to Perth again!

The next part of the trip was a much anticipated highlight, and we spent two magnificent weeks enjoying the Gibb River Road and all its gems before arriving in Kununurra, leaving the family and flying to Darwin for the first of three Soliris doses. On return we started heading by road for Darwin, which was to be our base as we explored Arnhem Land, Kakadu and other Northern treasures. Darwin, its surrounds and its lifestyle really grew on all of us, and it was a sad day when we left Darwin for the last time, heading for Cairns. This part of the trip,

along The Savannah Way via Borroloola, Roper Bar, Nathan River Rd, Lawn Hill, up to Karumba and across to Cairns was also a highlight.

After being 'dosed' in Cairns I left the family and went Barra fishing up Cape York for a week, before coming back and turning south (with much regret).

We met some friends in Rockhampton and we all headed down to Fraser Island for a few terrific,

but cold, days. At this point we were supposed to head south down to Brisbane, onto Sydney, Canberra and home, but it was just way too cold. Fortunately, we were able to change our plans and have extra Soliris doses in Cairns and enjoy a bit more sunshine.

Michael Brown, Liz Marshall, Jeff Szer, along with my Ballarat specialist all had a hand in pulling this amazing show off, and I am indebted to them. I am sure there were plenty of headaches for all these people, but as true professionals, they didn't let it show.

My only advice would be to start planning early. But, most importantly get out and do it!"

The Committee thanks Mark for being part of the Association and sharing his adventure with us. To share your story for our next newsletter, email us at [info@pnhsaa.org.au](mailto:info@pnhsaa.org.au)





## Event Spotlight

## Annual General Meeting 2012

The Annual General Meeting (AGM) for 2012 was held in August in Melbourne and received good attendance including several people phoning in from interstate. The AGM provided the opportunity to reflect on the 'year that was' including the 2012 National Conference held in Melbourne in February, growing membership, feedback received and first issue of the PNH Newsletter 'Rare but Real'. It also provided a forum to discuss the Committee's plans for 2013, particularly rebranding the PNH name and upgrading the PNH website.

The Committee Members were voted in for 2013 as follows:

- President: Mathew Dean
- Treasurer: Michael Patterson
- Secretary: Jenny Sturrock
- Committee Representatives: Grace Dean & Chhean Khoun

The Committee looks forward to another successful year in 2013.

## Help the cause

## New Zealand lobby for Soliris funding

New Zealand PNH patients continue to lobby the NZ government to get funding for Soliris just like Australia had to do nearly two years ago. As you supported us, please help support our friends by signing the online petition. Go to [www.thepetitionsite.com](http://www.thepetitionsite.com) and type 'soliris' into the search engine to find the webpage. Also for those on facebook: [www.facebook.com/PNHSANZ](http://www.facebook.com/PNHSANZ)

## Committee spotlight

## Meet Chhean Khoun (Committee Representative)

Having migrated from war torn Cambodia at a tender age, the world seemed like a jig saw puzzle waiting to be put back in place piece by piece. Since being diagnosed with PNH in 1998, this view has helped me to understand that there is a world to be explored despite having such a rare disease and the many challenges we may face every day.

My curiosity and fascination for the world includes travelling to places in contrast to the rural province where I once grew up. Having lived in the open grass land filled with questions and dreams, places such as New York reminds me that the world is not flat.

I have developed a passion for food which has guided me to all sorts of places and faces throughout the world. The smell of fried chicken and corn bread in a Brooklyn diner would drift me away from my daily life as a project Architect, stuck in an office filled with white walls, tracing paper and endless pen marks on my fingers. My other hobbies include photography, comedy and art. My focus for the next couple year is to do more travelling given how much I have progressed from the days of being tired day to day.

## 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](mailto: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](mailto: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](mailto: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.

## Contact Details

PNH Support Association of Australia Inc. PO Box 472, SOUTH YARRA VIC 3141,  
Phone: 0432 321 207, Email: [info@pnhsaa.org.au](mailto:info@pnhsaa.org.au)