

RARE BUT REAL

NEWSLETTER ISSUE NO3 JULY 2013

Information

Battling the Bugs – Healthy Living with PNH

PNH is a disease best known for its destruction of red blood cells (“haemolysis”), but PNH may also have an effect on some of your other blood cells, including your white blood cells and platelets. White blood cells help in protecting the body from disease and infection, and platelets help your blood to clot. Many people with PNH may also have some bone marrow dysfunction which means that the bone marrow may not produce enough of these blood cells.

Due to these and other factors, it’s not uncommon for people with PNH to “pick up bugs” more easily than others and experience more severe infections from common bugs that circulate in the community. Even a simple cold can trigger or increase haemolysis as the body is put under stress trying to fight the infection, leading to the worsening or return of PNH symptoms – whether or not you’re on treatment. This is why even a cold can seem to be more severe for someone with PNH – the haemolysis causes you to feel even worse than just having a cold.

So if you have PNH, taking some common sense precautions to protect against infection should become a part of everyday life.

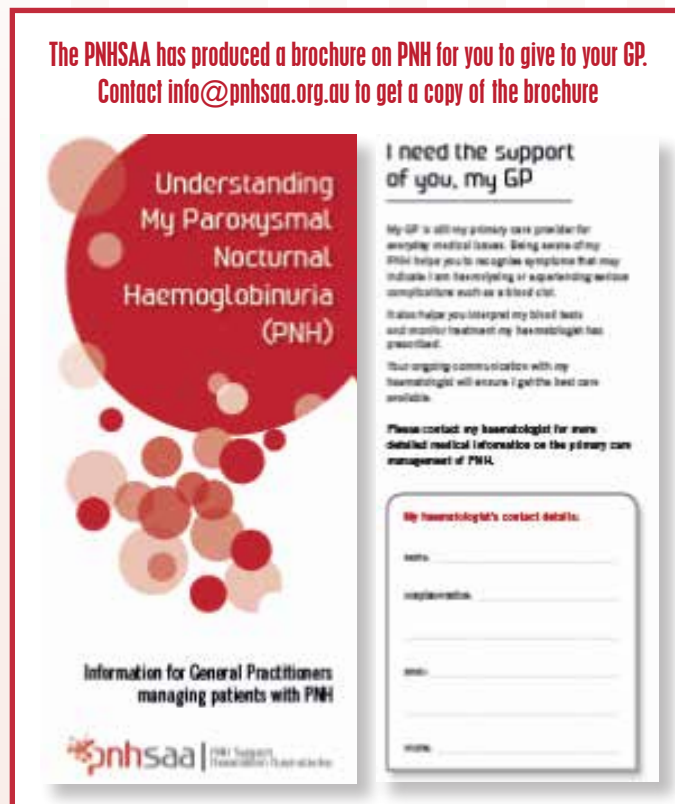
Tips to Beat the Bugs:

- Regular hand washing – the best way of preventing transmission of germs
- Avoid large crowds in flu season
- Get the annual influenza vaccination
- Stay as fit and healthy as you are able
- Avoid or minimise stress (stress releases the hormone cortisol, which suppresses the immune system)
- Aim for regular sleep hours to get sufficient rest
- Keep surfaces clean at home
- Have good air circulation in your home (bugs hang around in stagnant air)
- Avoid smoking and excessive alcohol intake (both lower the immune system)
- Practice safe sex to minimise the risk of sexually transmitted infections

These tips seem pretty easy in the perfect world...

Day to day life will always expose you to the risk of infection – working with others, having young children in your life, using public transport. But by following these tips you’ll still help to minimise your risk of catching bugs.

It’s also important to look after yourself when you do inevitably pick up a bug. Try to get rest as soon as you feel an infection coming on – it may save you an extra few days of being sick, or a trip to hospital or blood transfusion. *(continue page 2)*



What about Vitamins, Minerals and Supplements?

Some people like to take these with the aim of boosting their overall health. But it's very important to tell your haematologist of any over-the-counter medications or herbal remedies that you may also be taking as these may have unexpected effects on other medicines being used to treat your PNH. For example, did you know that taking Vitamin K while on warfarin will reduce the effect of warfarin?

Get to know your GP

While your haematologist is your first contact for anything to do with your PNH, having a GP who is willing to learn about PNH (and any other health issues you have) is also

very important. A GP who understands PNH will support you when these "everyday" health issues come your way, as he/she will understand the need to treat these as soon as possible and monitor other aspects of your health.

So take the time to find a good GP, then make sure that GP gets in touch with your haematologist, so they can work together to give you the best healthcare possible.

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

Article by Michael Brown R.N.

A few words

A message from the President

Greetings members and supporters, I hope all is well and you are fighting through the cold winter weather. First up I would like to send out a huge congratulations to Jenny and Lucas Sturrock on the recent birth of their beautiful baby girl Annabell Lorraine Sturrock, we wish Mum, Dad and baby all the best from the PNHSAA.

It has been a productive and busy couple of months for the PNHSAA with the launch and go live of our new look website in April along with the associated rebranding of our logo and identity. If you haven't already, please jump onto the website as we believe that it contains beneficial material and content for members and supporters. In addition please feel free to provide any feedback or comments on the site, especially on how we can improve any aspect of any services that are currently provided by the PNHSAA.

Following our email to our members you should all now be aware of the plight by our ANZAC counterparts the PNH Support Association of New Zealand (PNHSANZ) and the struggle to have Soliris funding approved by the government. We urge you all to help partition on

their behalf and write to the appropriate organisation Pharmac, the details and templates for letters are available on the PNHSANZ website.

Finally you all should have received the information pack detailing the upcoming Annual General Meeting (AGM) on 10 August 2013. The AGM is always a good chance to catch up with those members you may not have seen for while whether it be in person or via the phone conferencing facilities that will be available on the day and it is the perfect forum to make your voice heard and put forward any suggestions to the PNHSAA.

I look forward to seeing and talking to some of you in August and look out for further updated material and links on the website over the coming months, take care.

Regards,



Matt Dean, President

What's new

A new addition to the PNHSAA family



The Sturrock family

Annabell Sturrock was born Thursday 13th June 2013 and shares her birthday with another PNH favourite John Smeaton!

Proud parents Jenny and Lucas Sturrock couldn't be more thrilled with the safe arrival of their precious little girl. Thanks to the amazing support from the crew at the Royal Melbourne and Royal Women's, Jenny's PNH was relatively issue free during the pregnancy. Interestingly Annabell is the first baby in Australia to be born to a Mum who is on Soliris for the treatment of her PNH.

We couldn't be happier for you Jenny and Lucas!

Annabell's birth stats:

Born: 11pm on 13 June 2013.

Weight: 3.4KG

Length: 50cm

Chinese PNH Patient meets with PNHSAA members



Photo (from left to right): Huiying Hu, Jenny Sturrock, Tina Tsolos and Cody McKnight.

On Saturday 6 April 2013 a couple of the PNHSAA members met with Ms Huiying Hu who is a PNH patient from China and was out in Australia visiting friends. Whilst she was here she was keen to meet with some Australian PNH patients. PNHSAA organised an informal gathering in Knox to share stories together and with Huiying. It was excellent to be able to compare differences in treatment with China yet it was sad to hear funding and access for Soliris wasn't yet available.

Huiying was diagnosed with Aplastic Anaemia during 2002 and then PNH in 2004. She lives in GuangZhou which is in southern China. Her treatment for PNH includes blood transfusions as well as taking some Chinese herbal medicines and attending Church regularly to keep her peaceful. Interestingly Huiying explained that in China blood transfusions were provided where PNH patients have a HB of 60 or lower, if the person is not experiencing symptoms. Her lowest HB has been just under 50!

It is always amazing how much I learn when PNH people get together and share their stories. I know Huiying was very pleased to have been able to meet with some PNH members who were at the informal gathering.

Article by Jenny Sturrock

Help the cause

PNHSAA New Zealand continues to fight for treatment

On Tuesday 21 May PHARMAC, the NZ Government's medicines funding agency, abruptly ended negotiations to provide patients living with PNH with access to the life-saving treatment, Soliris.

As we are all too well aware, the situation is dire. The PNHSANZ asked that Australian members express their support for PNH patients in New Zealand by making a submission to PHARMAC before 31 July 2013. We thank those who did so.

Further to these individual submissions, the PNHSAA has made a formal submission to PHARMAC and written to NZ Minister of Health.

We will continue to update PNHSAA members and supporters on this issue and we encourage you to take some time to show your support so that the PNH patients in NZ have the opportunity to receive Soliris treatment.

Let us continue to show NZ that we care and that Soliris is worth the fight!

Committee spotlight

Meet Grace Dean

When people ask me 'what are your interests' or 'describe yourself in 20 words or less' I usually say the same thing; a girl who loves living in Melbourne and enjoys everything this city has to offer! I grew up in a suburb just 7 kilometres west of Melbourne and now find myself living in an apartment just two kilometres south. After a busy week working as a Property Advisor, my usual weekend is walking into the city and meeting up with friends for shopping, lunches, dinner, drinks, seeing live bands and dj's, and of course heading to the football to support the North Melbourne Kangaroos which I have passionately had a love-hate relationship with since I was 13 years old.

I suppose good food, expensive shoes and football are my biggest weaknesses and I am grateful to share two out

of three of these passions with my husband of two years, Mathew (just to be clear, it's not the shoes!). On the odd occasion when Melbourne gets 'a bit too full on' Mat and I like to get away for a weekend for a hike. My latest and greatest challenge was a 20km day hike around Wilsons Prom, with the views more breathtaking than I had ever imagined. My new challenge will be tackling the Cinque Terre again when we head to Italy for 8 weeks in August.

I was diagnosed with PNH in 2008. I am blessed to have found a support group and am honoured to be part of the PNHSAA Committee for the past three years. It also warms my heart that Mat has joined the Committee as President. I have met the most wonderful and courageous people through the PNHSAA and look forward to building on these friendships.

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.

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.

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.

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 are made up PNH patients and supporters for all the support, encouragement and donations made to the Association this financial year. We look forward to evolving and growing our community.