I need the support of you, my GP

My GP is still my primary care provider for everyday medical issues. Being aware of my PNH helps you to recognise symptoms that may indicate I am haemolysing or experiencing serious complications such as a blood clot.

It also helps you interpret my blood tests and monitor treatment my haematologist has prescribed.

Your ongoing communication with my haematologist will ensure I get the best care available.

Please contact my haematologist for more detailed medical information on the primary care management of PNH.

My haematologist's contact details:

Name: ______________________________

Hospital/Practice: ______________________

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Email: ______________________________

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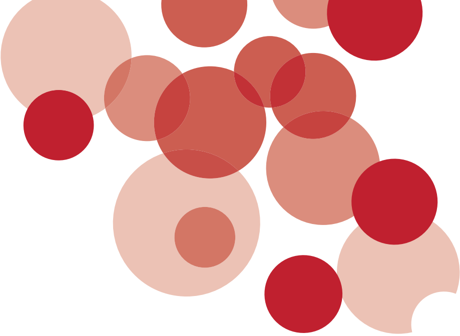
Phone: ______________________________



Support for GPs Managing People with PNH

- **Contact the referring haematologist.**
- **Contact The Royal Melbourne Hospital National PNH Support Service:**

Michael Brown: PNH Clinical Nurse Consultant
Email: Michael.Brown@mh.org.au
Phone: (03) 9342 7954
Mobile: 0426 973 807

pnhsaa | PNH Support Association Australia Inc

The PNHSAA aims to support PNH patients and their loved ones to manage their condition positively by providing access to accurate information, practical resources and a support network. It also provides opportunities to meet with other patients and caregivers to reduce the isolation often experienced by people with rare diseases. Visit: **www.pnhsaa.org.au**

This brochure is intended for distribution by the PNHSAA to its Members, so they can provide their General Practitioner with general information on PNH. This brochure is not designed to be patient-specific and has been developed and produced by the PNHSAA with the support of Alexion Pharmaceuticals Australasia Pty Limited. PNHSAA 2013. PNHSAA PO Box 472, South Yarra VIC 3141.

Understanding My Paroxysmal Nocturnal Haemoglobinuria (PNH)

Information for General Practitioners managing patients with PNH

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Understanding my PNH

What is PNH ?

PNH is an acquired (non-hereditary) disease that destroys my red blood cells. This is because some of my red blood cells are missing an important protective protein – without this protein, a part of my body's immune system attacks and destroys the affected red blood cells ("haemolysis"). In PNH, haemolysis happens constantly and is the main cause of PNH-related health problems.

What are the signs and symptoms of PNH ?

The signs and symptoms of PNH are caused by chronic haemolysis. They are nonspecific, unpredictable and may vary over time. Some of the PNH symptoms I may experience are: feeling exhausted and weak; abdominal and back pain; difficulty swallowing; shortness of breath; erectile dysfunction; dark coloured urine ("haemoglobinuria"). These signs and symptoms can affect my ability to perform everyday tasks.

My symptoms are inconsistent – some days I feel fine, and others very bad.

In PNH, chronic haemolysis is always taking place - whether I feel OK or whether I'm having a flare-up ("paroxysm"), such as during times of stress or infection. So PNH is always affecting my body, and some days it also affects how I feel. Haemolysis reduces my ability to supply oxygen to my body and causes extreme tiredness (fatigue). The severity of my fatigue will vary depending on the level of haemolysis taking place.

Complications of PNH

PNH can lead to serious health complications and consequences

PNH is a complicated disease with unpredictable consequences. It can lead to serious and life-threatening complications such as blood clots and problems with the lungs, liver, kidneys and digestive system. So it's important that my health is monitored regularly to detect any changes in my symptoms.

PNH and other bone marrow disorders

Some people with PNH have other medical conditions that affect the function of their bone marrow, such as Aplastic Anaemia or Myelodysplastic Syndromes. Unlike PNH (which destroys red blood cells), these conditions reduce the production of blood cells and further complicate PNH. In addition to the medical management of PNH, these bone marrow disorders require specific treatment.

Medical care of my PNH

PNH is a serious disease that can lead to life-threatening complications. There are various treatments that can help manage my PNH and these, along with the support of my healthcare team, family and friends, can help improve my quality of life.

I see a haematologist for my PNH

Since my PNH was diagnosed, I see a haematologist every 3 to 6 months, to check my blood tests and my symptoms, and to decide what treatment I may need.

Various treatments may be used to treat my PNH

Treatment may include blood transfusions and anticoagulant therapy. My haematologist may also decide to use other treatment options, depending on my medical needs.

I need regular blood tests for my PNH

My haematologist orders regular blood tests to track my PNH. Some of these are: complete blood count, serum lactate dehydrogenase (LDH; to measure the level of haemolysis), serum iron studies, renal function and liver function tests. Some elements of my blood test results may be consistently abnormal compared to the normal ranges. If you are concerned about any of my blood results, please contact my haematologist.