



# Living with Paroxysmal Nocturnal Haemoglobinuria

**Paroxysmal nocturnal haemoglobinuria (PNH)** is a potentially life-threatening bone marrow disease.<sup>1</sup>

PNH can affect anyone of any **age, race** or **gender**<sup>2</sup> and is caused (or 'acquired') when **haematopoietic stem cells** (responsible for making blood cells) in the bone marrow **mutate** and begin producing **defective blood cells**.<sup>1</sup>



## PNH is rare

The number of people **newly diagnosed with PNH globally** per year is estimated to be

**1.3 cases**

per million<sup>3</sup>

The number of people **affected by PNH globally** is approximately

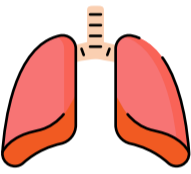
**12-13**

per million<sup>4</sup>

## PNH is associated with many serious, potentially fatal complications



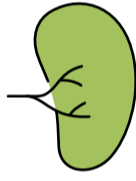
**Thrombosis** (blood clots)<sup>5</sup>



**Pulmonary hypertension** (high blood pressure in the vessels that supply the lungs)<sup>5</sup>



**Cardiovascular disease** (conditions that affect the heart or blood vessels)<sup>6</sup>



**Chronic kidney failure**<sup>7</sup>

## The symptoms of PNH can make daily life challenging

Of people living with PNH, up to:

**96%** experience fatigue<sup>8</sup>



**26%** experience haemoglobinuria (where haemoglobin is present in urine)<sup>9</sup>



Involuntary muscle contractions (muscle dystonia) can cause further complications, with up to:

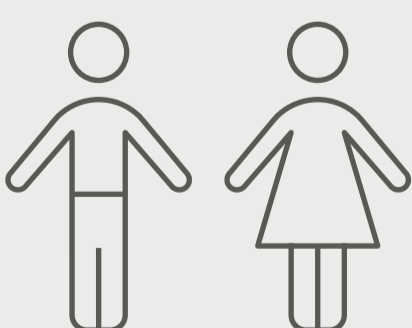
**66%** of people living with PNH experiencing **dyspnoea** (laboured breathing)<sup>5</sup>

**52%** experiencing **back and abdominal pain**<sup>5</sup>

**47%** experiencing **erectile dysfunction**<sup>8</sup>

**41%** experiencing **dysphagia** (difficulty swallowing)<sup>8</sup>

## Even with care, some people still struggle in their day-to-day life due to the severity of PNH



- **84.5%** of people undergoing treatment report **impaired activity**<sup>10</sup>
- Of those who are employed:<sup>10</sup>
  - Almost a third (**29.3%**) **miss time at work** because of ongoing symptoms
  - Over **70%** feel they are **less productive at work** because of their symptoms including **fatigue and cognitive impairment**

## Striving to help

PNH is a relatively unknown condition with symptoms that can make daily life challenging and is associated with many serious and potentially fatal complications<sup>1</sup>

Sobi is striving to help patients manage their disease and overall, improve their quality of life. For more information, visit [my-PNH.com](http://my-PNH.com).

### References:

1. Hill A, et al Paroxysmal nocturnal haemoglobinuria. *Nat Rev Dis Primers*. 2017;3:17028. 2. Devos T, et al. Diagnosis and management of PNH: Review and recommendations from a Belgian expert panel. *Eur J Haematol*. 2018;101:737-749. 3. Borowitz MJ, et al. Guidelines for the diagnosis and monitoring of paroxysmal nocturnal hemoglobinuria and related disorders by flow cytometry. *Cytometry B Clin Cytom*. 2010;78(4):211-230. 4. Jalbert J, et al. Epidemiology of PNH and Real-World Treatment Patterns Following an Incident PNH Diagnosis in the US. *Blood*. 2019;134:3407. 5. Mitchell R, et al. Path to diagnosis of paroxysmal nocturnal hemoglobinuria: the results of an exploratory study conducted by the aplastic anemia and MDS international foundation and the national organization for rare disorders utilizing an internet-based survey. *SM Clin Med Oncol*. 2017;1(1):1001. 6. Bektas M, et al. Paroxysmal nocturnal hemoglobinuria: patient journey and burden of disease. *Manag Care Spec Pharm*. 2020;26:S8-S14. 7. Brodsky RA. Paroxysmal nocturnal hemoglobinuria. *Blood*. 2014;124(18):2804-2811. 8. Meyers G, et al. Disease-related symptoms reported across and broad population of patients with paroxysmal nocturnal hemoglobinuria. *Blood*. 2007;110(11):3683. 9. Parker C, et al. International PNH Interest Group. *Blood*. 2005. 10. Panse J, et al. The burden of illness of patients with paroxysmal nocturnal haemoglobinuria receiving C5 inhibitors in France, Germany and the United Kingdom: Patient-reported insights on symptoms and quality of life. *Eur J Haematol*. 2022;109(4):351-363.