

Paroxysmal Nocturnal Hemoglobinuria (PNH)

Living with paroxysmal nocturnal hemoglobinuria (PNH)

Novartis commitment

At Novartis, we believe people with blood disorders have the right to live their daily lives without limitations. For more than 20 years, we have been an industry leader in hematology, advancing treatments and transforming what it means to live with a blood cancer or serious blood disorder.

What is PNH?

PNH is a rare, complex, and debilitating blood disease that can cause a range of signs and symptoms including anemia, fatigue, headaches, brain fog, shortness of breath, abdominal pain, and dark or blood-colored urine (hemoglobinuria).¹⁻⁶ If left untreated, PNH can be life-threatening.^{3,5}

The impact of PNH

PNH is caused by the premature destruction of red blood cells (RBCs) by a part of the immune system called the complement system.¹⁻⁶ Because the main job of RBCs is to carry oxygen – via hemoglobin – to organs and tissues throughout the body, people living with PNH can have low hemoglobin levels, which can lead to debilitating symptoms including anemia.^{1,2,6-8} These symptoms may impair patients' ability to perform everyday activities.^{1,5,6} Severe PNH can be fatal when blood clots develop that may cause heart attack or stroke – the leading causes of death for people with PNH.³

A rare disease with a lifelong burden

Due to its rarity and the variety of the symptoms associated with the disease, there are often delays in diagnosis, which can result in disease progression.⁷ PNH may significantly impact patients' physical and mental health, as well as their ability to work.^{1,3,5,6}

Even after a diagnosis and while on treatment, many people with PNH continue to face persistent anemia, fatigue, and dependence on RBC transfusions.^{1,2,6,9,10} Most treatments require scheduled infusions, which can cause people to miss out on important moments and activities.^{5,6,9,10} Novartis has worked hard to change how PNH is treated, with an aim toward improving patients' everyday lives.

Additional resources for people living with PNH

At Novartis, we're committed to understanding the challenges of the PNH community and providing patients and their families with support as they manage their condition. Explore PNH is our disease education campaign focused on raising awareness of PNH and addressing management needs. On the [website](#), people living with PNH can learn more about the disease, its causes and symptoms, and hear from patients and access helpful resources.

References

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