

IS YOUR **PNH** UNDER CONTROL, OR IS GETTING THROUGH YOUR DAY A STRUGGLE?

Whether or not you're currently on treatment, you may be struggling with challenges like **fatigue**, **shortness of breath**, and **brain fog**. Find out more.



Patient portrayal.

PNH, paroxysmal nocturnal hemoglobinuria.

 **NOVARTIS**

LIVING WITH PNH CAN TAKE THE WIND OUT OF YOUR SAILS

Paroxysmal nocturnal hemoglobinuria (PNH) is a rare and complex blood disease. The true impact of PNH can be felt physically and emotionally.

This guide will help you:

- Recognize the challenges that come with PNH
- Understand the role of hemolysis in these challenges
- Gain the confidence to advocate for yourself to better manage your disease



UNDERSTANDING PNH IS THE FIRST STEP IN GETTING IT UNDER CONTROL

PNH can be complicated, so let's break it down into its simplest terms.

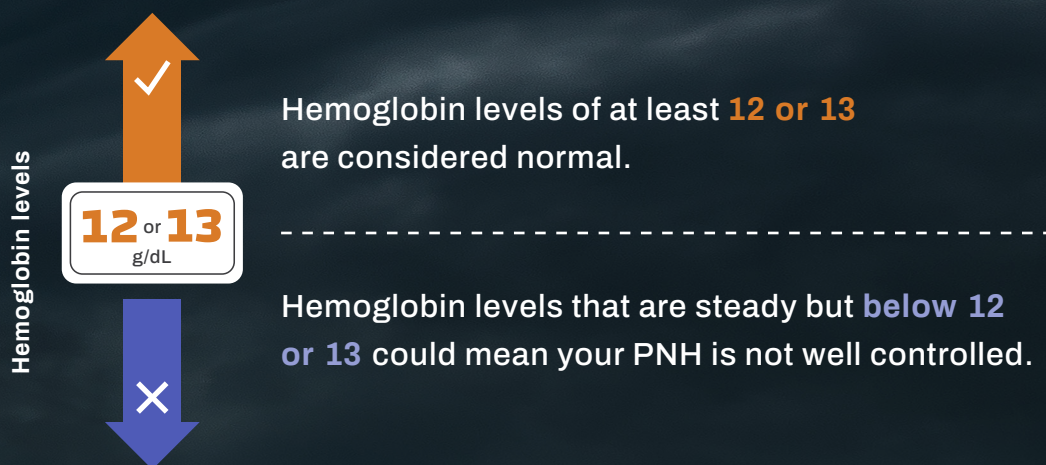


With PNH, some of your red blood cells are missing certain proteins that protect them. Without this protection, they are attacked and destroyed by a part of the immune system called the complement system. This **destruction of red blood cells** is called **hemolysis**.



Hemolysis **lowers your level of hemoglobin**, the protein in your red blood cells that carries oxygen throughout your body. These lower hemoglobin levels result in PNH symptoms, like fatigue and shortness of breath.

IT'S IMPORTANT TO BE AWARE OF YOUR HEMOGLOBIN LEVEL



Normal adult hemoglobin levels vary, but generally are:



12 to 16 g/dL for women



13 to 18 g/dL for men

“ MY HEMOGLOBIN IS STEADY IN THE 8 RANGE.
I WOULD LOVE TO SEE DOUBLE DIGITS AT
SOME POINT IN MY LIFE. ”


– Leslie, living with PNH, currently on infusion treatment




ANY SYMPTOMS, MILD OR SEVERE, MAY BE A SIGN YOUR PNH ISN'T FULLY CONTROLLED


One person may have mild symptoms while, for another, symptoms could be severe and require blood transfusions. Either way, **it's important to let your doctor know how you're feeling.**

Are you currently experiencing any of the following signs and symptoms?

 **Fatigue or weakness**

 **Shortness of breath**

 **Brain fog**

 **Headaches**

 **Anemia**

 **Bruising/bleeding easily**

 **Dark-colored urine**

 **Abdominal pain**

WHAT'S CAUSING THIS STORM?

There are 2 types of hemolysis that occur when you have PNH.



Intravascular hemolysis (IVH)

Your red blood cells are destroyed within the blood vessels (like veins and arteries).



Extravascular hemolysis (EVH)

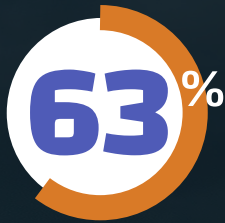
Your red blood cells are destroyed outside the blood vessels, within the spleen and liver.

**BOTH IVH AND EVH—TWO KEY DRIVERS OF PNH—SHOULD
BE ADDRESSED**

CURRENT PNH TREATMENTS MAY NOT BE ENOUGH

The most common treatments available today are called C5 inhibitors, and are given by infusion. C5 inhibitors only address IVH, not EVH. This can lead to ongoing hemolysis and lower-than-normal hemoglobin levels.

In one study,



OF PEOPLE ON C5 INHIBITOR TREATMENTS

SHOWED SIGNS OF ONGOING HEMOLYSIS*

*63% of people on treatment continued to experience some form of ongoing hemolysis, in which hemoglobin levels were below 11 and/or blood transfusions were required.

This means you may still need red blood cell transfusions.



~1 OUT OF 3 PEOPLE ON C5 INHIBITOR

TREATMENTS MAY STILL REQUIRE

BLOOD TRANSFUSIONS

INFUSIONS REQUIRED BY CURRENT TREATMENTS CAN BE DISRUPTIVE

Most treatments require scheduled infusions or hospital and clinic visits, which can cause people to miss out on important moments and activities.

“ I ALWAYS WORRY ABOUT MAKING PLANS BECAUSE I DON'T WANT TO CANCEL. ”

– Amanda, living with PNH, currently on infusion treatment



“ I COULDN'T TRAVEL TO INDIA WHEN MY DAD PASSED AWAY BECAUSE MY INFUSION WAS THAT WEEK. ”

– Puja, living with PNH, currently on infusion treatment



You may feel like your only choice is to cope in silence or manage on your own. But that doesn't have to be the case. **Speaking up about your struggles to others can help you feel more supported.**

TAKING PNH RESEARCH FURTHER

Both IVH and EVH should be accounted for in the management of PNH

C5 inhibitors focus only on the part of the complement system responsible for IVH. Because EVH is left unaddressed, your PNH red blood cells are still vulnerable to attack.

Additional research is being conducted to study other parts of the complement system, such as Factor B, Factor D, and C3. Focusing on these areas of the complement system may impact both IVH and EVH.

CONTINUED RESEARCH CAN PROVIDE HOPE FOR PEOPLE WITH PNH

KEEP HAVING CONVERSATIONS WITH YOUR DOCTOR

By taking a more active role in managing your PNH, you can confidently advocate for yourself and your needs.

- Don't settle for hemoglobin levels that are below normal
- Discuss the symptoms that are troubling you—including fatigue, shortness of breath, and brain fog
- Tell your doctor if you have any struggles with your current treatment



FOR MORE INFORMATION AND

SUPPORT FOR LIVING WITH PNH,

VISIT [EXPLOREPNH.COM](https://www.explorepnh.com)

YOU ARE NOT ALONE ON THIS JOURNEY



Patient portrayals.

People with PNH are fighters and deserve the full support of the medical community. NOVARTIS is committed to listening to the PNH community, while working to improve the lives of each and every person living with PNH.



TO LEARN MORE ABOUT PNH, VISIT

EXPLOREPNH.COM

