Keeping track of my health.

→ To learn more about PNH signs and symptoms—and the importance of recording them—visit PNHSource.com.

PNHSource™
Paroxysmal Nocturnal Hemoglobinuria (PNH)

My PNH and My Health

Keep your lab test results in this folder.

Keep track of your PNH—and your health.

Record your signs and symptoms and speak with your healthcare team.

As you may know, PNH is a serious, unpredictable, and life-threatening disease. No single sign, symptom, or lab test result provides a complete picture of your PNH. That's why it's important to keep track of all of them using this PNH assessment tool. By logging your signs and symptoms and letting your healthcare team know how you're feeling, you can all work together to make the right decisions about managing your PNH.

In PNH, knowing your LDH is important.

LDH (lactate dehydrogenase) is an enzyme found inside your red blood cells. High levels of LDH mean you have high levels of hemolysis—which refers to the destruction of red blood cells and is the underlying cause of PNH signs and symptoms. Knowing your LDH level can help you and your doctor keep better track of your PNH.

How to use this tool.

- Record all your signs and symptoms using the forms to the right, completing one vertical column before each doctor's appointment
- Bring this tool to your doctor's appointment
- Keep your lab test results in the pocket located behind the forms
- Download additional forms at PNHSource.com/tools

For more information about PNH and the steps you can take to help stay healthy, visit PNHSource.com/patients.

For monitoring your lab values.

Record and track key indicators of your PNH status.

Please update prior to your next doctor's visit.

Patient name: _____

Flow cytometry results	Date:	Date:	Date:	Date:	Date:
Sensitivity limit					
Clone size					
Erythrocytes (RBC)					
Granulocytes (WBC)					
Monocytes					
Red blood cell type	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %
Lactate dehydrogenase (LDH)	Value:	Value:	Value:	Value:	Value:
Hemoglobin					
Haptoglobin					
Platelet count					
Reticulocyte count					

Conducting high-sensitivity flow cytometry every 6-12 months is recommended.

Diagnosed with aplastic anemia

Date of diagnosis _____ Treatment(s) _____

Diagnosed with myelodysplastic syndromes

Date of diagnosis _____ Treatment(s) _____

Diagnosed with Coombs-negative hemolytic anemia

Date of diagnosis _____ Treatment(s) _____

Diagnosed with unexplained cytopenia

Date of diagnosis _____ Treatment(s) _____

Diagnosed with unexplained thrombosis (venous or arterial)

Date of diagnosis _____ Treatment(s) _____

Diagnosed with hemoglobinuria

Date of diagnosis _____ Treatment(s) _____

History of thrombosis

Date(s) _____ Location(s) _____

Hospital visits

Date(s) _____ Reason(s) for visit _____

HCP-reported signs and symptoms	**Visit 1** Date:	**Visit 2** Date:	**Visit 3** Date:
Chief complaint			
End organ signs of hemolysis			
Glomerular filtration rate <60	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Glomerular filtration rate >60 with proteinuria	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Elevated creatinine	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Shortness of breath	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Abnormal LFT	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Abdominal pain	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

To download additional assessment forms, go online at PNHSource.com/HCPtools.

For monitoring your signs and symptoms.

Record and track key indicators of PNH progression.

Please update at each patient visit.

Patient name: _____

	Visit 1 Date:	Visit 2 Date:	Visit 3 Date:
Signs and symptoms			
Dark-colored urine	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Shortness of breath	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Difficulty swallowing	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Yellowing of the skin and/or eyes	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Erectile dysfunction	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Cold or infection since last visit	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Pain			
Stomach pain	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Leg pain or swelling	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Chest pain	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Back pain	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Fatigue			
Tiredness	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Difficulty performing daily activities	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Trouble concentrating	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Dizziness	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Weakness	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe

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Patient name: _____

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Red blood cell type	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %	☐ I _____ % ☐ II _____ % ☐ III _____ %
Lactate dehydrogenase (LDH)	Value:	Value:	Value:	Value:	Value:
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Diagnosed with hemoglobinuria

Date of diagnosis _____ Treatment(s) _____

History of thrombosis

Date(s) _____ Location(s) _____

Hospital visits

Date(s) _____ Reason(s) for visit _____

HCP-reported signs and symptoms	**Visit 4** Date:	**Visit 5** Date:	**Visit 6** Date:
Chief complaint			
End organ signs of hemolysis			
Glomerular filtration rate <60	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Glomerular filtration rate >60 with proteinuria	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Elevated creatinine	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Shortness of breath	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Abnormal LFT	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Abdominal pain	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

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Please update at each patient visit.

Patient name: _____

	Visit 4 Date:	Visit 5 Date:	Visit 6 Date:
Signs and symptoms			
Dark-colored urine	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Shortness of breath	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Difficulty swallowing	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Yellowing of the skin and/or eyes	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Erectile dysfunction	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Cold or infection since last visit	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
Pain			
Stomach pain	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Leg pain or swelling	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Chest pain	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Back pain	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Fatigue			
Tiredness	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Difficulty performing daily activities	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Trouble concentrating	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Dizziness	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe
Weakness	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe	☐ None ☐ Moderate ☐ Severe

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