

Monitoring changes in your symptoms and level of activity is an important part of managing your paroxysmal nocturnal hemoglobinuria (PNH)

THIS FORM CAN HELP YOU MONITOR YOUR PNH SYMPTOMS AND DAILY ACTIVITY. PLEASE USE THIS AS A GUIDE WHEN SPEAKING WITH YOUR DOCTOR.

Patient Name: _____ Date of Prior Appointment: _____ Date of Next Appointment: _____

Symptom tracker

Signs and symptoms	None	Mild	Moderate	Severe
Tiredness or weakness				
Pain (e.g., chest pain, back pain, stomach pain)				
Shortness of breath				
Difficulty swallowing				
Dark urine				
Other:				

Report any new or worsening symptoms to your doctor right away.

Lifestyle tracker

Using the scale below, please mark one number per row to indicate how each statement applies to you.

Date: _____	Doesn't apply: X	Not at all: 0	Rarely: 1	Sometimes: 2	Often: 3	Very often: 4
Leisure and recreation	I visit/socialize with friends and family					
	I attend social events					
Employment and education	I work regular hours					
	I can work for short periods without needing a break					
	I carry a regular course load at school					
Walking	I can walk one block					
	I can walk several blocks					
	I can get up a flight of stairs					
Exercise	I am able to bike					
	I can run or jog					
	I am able to go to the gym					
Household chores	I can clean my house					
	I am able to prepare food					
	I can do the laundry					
	I can do yard work					
Errands	I am able to go grocery shopping					
	I can attend my doctor appointments					
Other mental or physical activities						

Please record any personal goals you have that you might like to discuss with your doctor.

Goal: _____ Notes: _____

Goal: _____