

# Treatment Diary

This diary is designed to help you monitor your experience with FABHALTA® and manage your paroxysmal nocturnal haemoglobinuria (PNH).

## Get the support you need with



**replenishEd**  
pnh education & support

As a patient starting treatment with Fabhalta® (iptacopan) you are invited to enrol in the **replenishEd patient support program**.

By joining **replenishEd** you will have the option to receive:

-  Educational emails on managing PNH with oral therapy
-  Monthly phone calls with a haematology nurse
-  SMS reminders about medication



Please scan the QR code to enrol in the replenishEd patient support program, or go to:  
[www.replenished-pnh.com.au](http://www.replenished-pnh.com.au)

Trouble signing up? Call 1800 290 652  
or email [support@replenished-pnh.com.au](mailto:support@replenished-pnh.com.au)

▼ There is additional monitoring in place for FABHALTA® (iptacopan) to help quickly identify new side effects. If you experience any side effects, talk to your doctor, nurse or pharmacist/other healthcare professional. This includes any possible side effects not listed in this guide. If you have any questions or concerns about FABHALTA®, speak with a healthcare professional.



## Why a treatment diary?

This treatment diary will help you keep a record of your appointments, medications, PNH test results and any side effects you may experience from taking your new treatment. It's an organised place where you can write down your thoughts, describe how you're feeling and make a note of any questions you have for your healthcare team.

Using this diary will allow you to monitor progress and keep track of important information relating to your PNH, which can support meaningful conversations with your healthcare team. You may find that keeping a diary can be a helpful way to understand your thoughts and feelings.



# Table of contents

**5**  
What's in my  
treatment diary?

**9**  
Let's track your Month 1

- Appointments
- Blood test results
- Treatment record
- Symptoms record
- Monthly calendar
- Progress tracker

**19**  
Let's track your Month 2

- Appointments
- Blood test results
- Treatment record
- Symptoms record
- Monthly calendar
- Progress tracker

**29**  
Let's track your Month 3

- Appointments
- Blood test results
- Treatment record
- Symptoms record
- Monthly calendar
- Progress tracker

**38**  
Find the support  
you need

**39**  
Common terms  
to know



# What's in my treatment diary?

The diary is easy to use, with clear sections to record some key pieces of information to help you along your treatment journey. You can make notes on your treatment for up to 3 months in this diary. If you would like to continue tracking your treatment past 3 months, you can download another booklet from our website (page 38).

These examples show you how to use each section:



## Appointments

Use this section to keep a record of upcoming appointments with your healthcare team over the next few months.

Here is an example of how to fill this out:

**Date** *12/02/24*

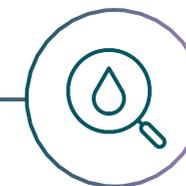
**Time** *2:45pm*

**Location** *Mill Road Surgery*

**With** *Dr. Wilson*

### Reason for appointment

*Follow up*



## Blood test results

Regular blood tests help your healthcare team to understand your overall health and know if your treatment is helping to effectively manage your PNH.

Use this section to record your test results:

Measurement	Reason	Normal range
Haemoglobin (g/L)	To check for anaemia	Men 130–180 g/L Women 120–160 g/L
Total bilirubin (mg/dL)	To check for increased rate of red blood cell breakdown	0.2–1.2 mg/dL
LDH (lactate dehydrogenase) (IU/L)	To check for tissue damage	105–333 IU/L
Granulocyte PNH clone size	To check the number of cells affected by PNH	Large clone: >50% Moderate clone: 10%–50% Small clone: <10%



## Treatment record

Use this to record which treatments you've taken and to note any times you missed taking your treatment.

You may have been recommended other treatments to take alongside FABHALTA® to help manage your PNH. Use this section to keep a record of them.

Taking charge of your PNH and playing an active role in your care can be a positive experience allowing you to gain a sense of control.

Here is an example of how to fill this out:

Treatment	Dosage	When to take			Dosage changes
		Morning	Night	Frequency	
Ferrous fumarate	322 mg	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	Twice daily	n/a

Missed doses	Week 1			Week 2			Week 3		
	1	1-2	>2	1	1-2	>2	1	1-2	>2
FABHALTA®	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>				



## Symptoms record

You may have a range of complications or symptoms caused by PNH.

Use this section to make a note of them as soon as they happen. This will help you to note them accurately and will make discussions with your healthcare team easier.

Here is an example of how to fill this out:

Symptom: Headache  
 Date 1/02  
 Score 1

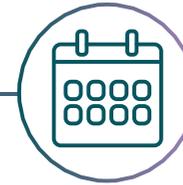
Symptom: Feeling tired/weak  
 Date 09/02  
 Score 2

Symptom: Dizziness  
 Date 18/03  
 Score 4

Symptom: Dizziness  
 Date 1/02  
 Score 3

Symptom: Dizziness  
 Date 18/03  
 Score 1

**Scale?**  
 1 = Mild  
 2 = Moderate  
 3 = High  
 4 = Severe  
 5 = Extreme



## Monthly calendar

A calendar can be a helpful tool to track any missed doses, changes in symptoms or other treatment-related events over the coming months.

Here is an example of how to fill this out:

Month February Year 2024

Monday			Tuesday			Wednesday		
12	am	<input checked="" type="checkbox"/> pm	13	am	pm	14	<input checked="" type="checkbox"/> am	pm
Follow up appointment - 2:45pm						Blood test - 11am		
Monday			Tuesday			Wednesday		
	am	pm		am	pm		am	pm



## Progress tracker

The progress tracker is for you to record your treatment progress and also to journal about your thoughts, feelings and any questions you may have.

Record questions and other information, such as symptoms, as soon as they come up. When used with the monthly calendar, it will help you quickly spot any trends or patterns as they emerge.

This will help you and your healthcare team communicate more efficiently about your PNH, your treatment and any concerns you may have.

Remember to bring your progress tracker with you every time you visit your healthcare team.

Here is an example of how to fill this out:

Thoughts: I think I'd like to apply again for

that promotion at work. I missed out last year

as I was too tired to take on a bigger role.

Feelings: I'm feeling more positive about

my PNH since my tiredness has improved.

Questions: Should I continue to take my

iron supplements even if I'm not feeling as tired?



# 1

## Let's track your month

Here are all the sections for you to complete for **Month 1** of your treatment with FABHALTA®.



**10**  
Appointments



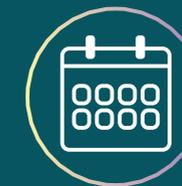
**11**  
Blood test results



**12**  
Treatment record



**14**  
Symptoms record



**16**  
Monthly calendar



**17**  
Progress tracker



# Appointments

Record your upcoming appointments with your healthcare team here. There are spaces for notes before/during/after your appointment. Please also refer to your separate appointment planner and remember to take it with you to your next appointment.

Appointment 1	Appointment 2	Appointment 3
<b>Date</b> .....	<b>Date</b> .....	<b>Date</b> .....
<b>Time</b> .....	<b>Time</b> .....	<b>Time</b> .....
<b>Location</b> .....	<b>Location</b> .....	<b>Location</b> .....
<b>With</b> .....	<b>With</b> .....	<b>With</b> .....
<b>Reason for appointment</b> ..... .....	<b>Reason for appointment</b> ..... .....	<b>Reason for appointment</b> ..... .....
<b>Notes</b> .....	<b>Notes</b> .....	<b>Notes</b> .....
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....



# Blood test results

Your healthcare team will monitor you with routine blood tests throughout your treatment with FABHALTA®. Some measurements may be taken more often than others. Record the results of your routine blood tests to capture the key measurements for monitoring your PNH. As well as the key measurements, there are additional spaces to record other blood results.

Blood test appointment			
<b>Date</b> .....		<b>Time</b> .....	
<b>Location</b> .....		<b>With</b> .....	
Measurement	Reason	Normal range	Result
<b>Haemoglobin (g/L)</b>	To check for anaemia	Men 130–180 g/L Women 120–160 g/L	
<b>Total bilirubin (mg/dL)</b>	To check for red blood cell breakdown	0.2–1.2 mg/dL	
<b>LDH (lactate dehydrogenase) (IU/L)</b>	To check for tissue damage	105–333 IU/L	
<b>Granulocyte PNH clone size</b>	To check the number of cells affected by PNH	Large clone: >50% Moderate clone: 10%–50% Small clone: <10%	
<b>Thrombocytes (x 10<sup>9</sup>/L)</b>	To check for thrombocytopenia	150–400 x 10 <sup>9</sup> /L	
<b>Leukocytes (x 10<sup>9</sup>/L)</b>	To check for neutropenia	3.5–10.5 x 10 <sup>9</sup> /L	
<b>Ferritin (µg/mL)</b>	To check the body's iron stores	Men <300 µg/mL Women <150 µg/mL	
<b>ARC (absolute reticulocyte count) 10<sup>9</sup>/L</b>	To check production of red blood cells	Normal range: 0.2–2%	



# Treatment record

Use this chart to keep track of all your treatments, the prescribed doses and when to take them. Make a note of any dosage changes, along with any other treatment events you think your healthcare team should be aware of. The FABHALTA® row has been filled in for you.

Treatment	Dosage	When to take					Dosage changes
		Morning	Midday	Evening	Night	Frequency	
FABHALTA®	200 mg	✓			✓	Twice daily	n/a

Staying committed to your treatment is really important, but it may take time. Use this table to keep a note of the times when you may have missed a dose.

- If you find you have had no missed doses, that's great, and you should keep it up to control your symptoms
- If you have missed one or two doses each week, remember it's important that you stay on track with your treatment. Try to stick with your scheduled doses to avoid any symptoms
- Two or more missed doses will increase your risk of worsening symptoms. You might need extra support to help you stay committed to your treatment. You can use the **staying on track stickers** found in your starter kit to help you stay on track with your treatment

Having a record of this might help you to make changes in your routine to keep your treatment on track. It's very important that you DO NOT SKIP any doses to avoid the appearance of serious symptoms of PNH.

	Week 1			Week 2			Week 3			Week 4			Week 5		
Missed doses	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2
FABHALTA®															



# Symptoms record

Monitoring and keeping a record of your symptoms is very important for managing your PNH. In addition, it's helpful to be aware of any other health events that may have had an impact on your wellbeing over the same period. You can share this information with your healthcare team.

Please scan the QR code on page 38 to access the digital symptom tracker tool.

**Scale?**  
 1 = Mild  
 2 = Moderate  
 3 = High  
 4 = Severe  
 5 = Extreme

**Below is a list of symptoms, which you may or may not have experienced. For each symptom, write the number that best describes how it has affected you this month and on what date.**

<b>Feeling tired/weak</b>	<b>Shortness of breath</b>	<b>Erectile dysfunction</b>	<b>Chest pain</b>
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

<b>Dizziness</b>	<b>Yellowing of skin/eyes</b>	<b>Abdominal pain</b>	<b>Difficulty swallowing</b>
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

**Colour of urine in the morning**

Pale Yellow      Yellow      Amber      Dark Brown      Red

**List any other symptoms not mentioned on the left and write the number to show how they have affected you this month and on what date.**

Symptom: .....	Symptom: .....	Symptom: .....	Symptom: .....
.....	.....	.....	.....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

**Alongside the symptoms of your PNH, it is useful to keep a note of any important health events, such as infections, illnesses or physical events that you may experience. You can note these here together with the start date and how long they lasted.**

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....



# Monthly calendar

Use the calendar to record any missed doses or change in symptoms. If you miss a dose, or doses, it's important that you take one dose of FABHALTA® as soon as possible, even if it's shortly before your next dose is due. Together with the progress tracker, this will help you identify any patterns that emerge.

Month \_\_\_\_\_ Year \_\_\_\_\_

Monday			Tuesday			Wednesday			Thursday			Friday			Saturday			Sunday		
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm



# Progress tracker

Use this space to record your treatment progress. You may want to write down your thoughts and feelings as you continue your treatment. If you have questions for your healthcare team, you can also record them here. Add stickers here to visualise your progress over time.



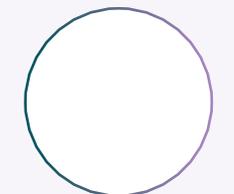
Thoughts: \_\_\_\_\_



Feelings: \_\_\_\_\_



Questions: \_\_\_\_\_





# 2

## Let's track your month

Here are all the sections for you to complete for **Month 2** of your treatment with FABHALTA®.



**20**  
Appointments



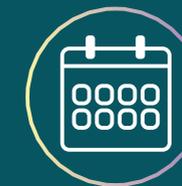
**21**  
Blood test results



**22**  
Treatment record



**24**  
Symptoms record



**26**  
Monthly calendar



**27**  
Progress tracker



# Appointments

Record your upcoming appointments with your healthcare team here. There are spaces for notes before/during/after your appointment. Please also refer to your separate appointment planner and remember to take it with you to your next appointment.

Appointment 1	Appointment 2	Appointment 3
<b>Date</b> .....	<b>Date</b> .....	<b>Date</b> .....
<b>Time</b> .....	<b>Time</b> .....	<b>Time</b> .....
<b>Location</b> .....	<b>Location</b> .....	<b>Location</b> .....
<b>With</b> .....	<b>With</b> .....	<b>With</b> .....
<b>Reason for appointment</b> ..... .....	<b>Reason for appointment</b> ..... .....	<b>Reason for appointment</b> ..... .....
<b>Notes</b> .....	<b>Notes</b> .....	<b>Notes</b> .....
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....



# Blood test results

Your healthcare team will monitor you with routine blood tests throughout your treatment with FABHALTA®. Some measurements may be taken more often than others. Record the results of your routine blood tests to capture the key measurements for monitoring your PNH. As well as the key measurements, there are additional spaces to record other blood results.

Blood test appointment			
<b>Date</b> .....		<b>Time</b> .....	
<b>Location</b> .....		<b>With</b> .....	
Measurement	Reason	Normal range	Result
<b>Haemoglobin (g/L)</b>	To check for anaemia	Men 130–180 g/L Women 120–160 g/L	
<b>Total bilirubin (mg/dL)</b>	To check for red blood cell breakdown	0.2–1.2 mg/dL	
<b>LDH (lactate dehydrogenase) (IU/L)</b>	To check for tissue damage	105–333 IU/L	
<b>Granulocyte PNH clone size</b>	To check the number of cells affected by PNH	Large clone: >50% Moderate clone: 10%–50% Small clone: <10%	
<b>Thrombocytes (x 10<sup>9</sup>/L)</b>	To check for thrombocytopenia	150–400 x 10 <sup>9</sup> /L	
<b>Leukocytes (x 10<sup>9</sup>/L)</b>	To check for neutropenia	3.5–10.5 x 10 <sup>9</sup> /L	
<b>Ferritin (µg/mL)</b>	To check the body's iron stores	Men <300 µg/mL Women <150 µg/mL	
<b>ARC (absolute reticulocyte count) 10<sup>9</sup>/L</b>	To check production of red blood cells	Normal range: 0.2–2%	



# Treatment record

Use this chart to keep track of all your treatments, the prescribed doses and when to take them. Make a note of any dosage changes, along with any other treatment events you think your healthcare team should be aware of. The FABHALTA® row has been filled in for you.

Treatment	Dosage	When to take					Dosage changes
		 Morning	 Midday	 Evening	 Night	 Frequency	
FABHALTA®	200 mg	✓			✓	Twice daily	n/a

Staying committed to your treatment is really important, but it may take time. Use this table to keep a note of the times when you may have missed a dose.

- If you find you have had no missed doses, that's great, and you should keep it up to control your symptoms
- If you have missed one or two doses each week, remember it's important that you stay on track with your treatment. Try to stick with your scheduled doses to avoid any symptoms
- Two or more missed doses will increase your risk of worsening symptoms. You might need extra support to help you stay committed to your treatment. You can use the **staying on track stickers** found in your starter kit to help you stay on track with your treatment

Having a record of this might help you to make changes in your routine to keep your treatment on track. It's very important that you DO NOT SKIP any doses to avoid the appearance of serious symptoms of PNH.

	Week 1			Week 2			Week 3			Week 4			Week 5		
Missed doses	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2
FABHALTA®															



# Symptoms record

Monitoring and keeping a record of your symptoms is very important for managing your PNH. In addition, it's helpful to be aware of any other health events that may have had an impact on your wellbeing over the same period. You can share this information with your healthcare team. Please scan the QR code on page 38 to access the digital symptom tracker tool.

**Scale?**  
 1 = Mild  
 2 = Moderate  
 3 = High  
 4 = Severe  
 5 = Extreme

**Below is a list of symptoms, which you may or may not have experienced. For each symptom, write the number that best describes how it has affected you this month and on what date.**

<b>Feeling tired/weak</b>	<b>Shortness of breath</b>	<b>Erectile dysfunction</b>	<b>Chest pain</b>
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
<b>Dizziness</b>	<b>Yellowing of skin/eyes</b>	<b>Abdominal pain</b>	<b>Difficulty swallowing</b>
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

### Colour of urine in the morning



**List any other symptoms not mentioned on the left and write the number to show how they have affected you this month and on what date.**

Symptom: .....	Symptom: .....	Symptom: .....	Symptom: .....
.....	.....	.....	.....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

**Alongside the symptoms of your PNH, it is useful to keep a note of any important health events, such as infections, illnesses or physical events that you may experience. You can note these here together with the start date and how long they lasted.**

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....



# Monthly calendar

Use the calendar to record any missed doses or change in symptoms. If you miss a dose, or doses, it's important that you take one dose of FABHALTA® as soon as possible, even if it's shortly before your next dose is due. Together with the progress tracker, this will help you identify any patterns that emerge.

Month \_\_\_\_\_ Year \_\_\_\_\_

Monday			Tuesday			Wednesday			Thursday			Friday			Saturday			Sunday		
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm
	am	pm		am	pm		am	pm		am	pm		am	pm		am	pm		am	pm



# Progress tracker

Use this space to record your treatment progress. You may want to write down your thoughts and feelings as you continue your treatment. If you have questions for your healthcare team, you can also record them here. Add stickers here to visualise your progress over time.



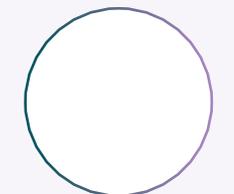
Thoughts: \_\_\_\_\_



Feelings: \_\_\_\_\_



Questions: \_\_\_\_\_





# 3

## Let's track your month

Here are all the sections for you to complete for **Month 3** of your treatment with FABHALTA®.



**30**  
Appointments



**31**  
Blood test results



**32**  
Treatment record



**34**  
Symptoms record



**36**  
Monthly calendar



**37**  
Progress tracker



# Appointments

Record your upcoming appointments with your healthcare team here. There are spaces for notes before/during/after your appointment. Please also refer to your separate appointment planner and remember to take it with you to your next appointment.

Appointment 1	Appointment 2	Appointment 3
<b>Date</b> .....	<b>Date</b> .....	<b>Date</b> .....
<b>Time</b> .....	<b>Time</b> .....	<b>Time</b> .....
<b>Location</b> .....	<b>Location</b> .....	<b>Location</b> .....
<b>With</b> .....	<b>With</b> .....	<b>With</b> .....
<b>Reason for appointment</b> ..... .....	<b>Reason for appointment</b> ..... .....	<b>Reason for appointment</b> ..... .....
<b>Notes</b> .....	<b>Notes</b> .....	<b>Notes</b> .....
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....



# Blood test results

Your healthcare team will monitor you with routine blood tests throughout your treatment with FABHALTA®. Some measurements may be taken more often than others. Record the results of your routine blood tests to capture the key measurements for monitoring your PNH. As well as the key measurements, there are additional spaces to record other blood results.

Blood test appointment			
<b>Date</b> .....		<b>Time</b> .....	
<b>Location</b> .....		<b>With</b> .....	
Measurement	Reason	Normal range	Result
<b>Haemoglobin (g/L)</b>	To check for anaemia	Men 130–180 g/L Women 120–160 g/L	
<b>Total bilirubin (mg/dL)</b>	To check for red blood cell breakdown	0.2–1.2 mg/dL	
<b>LDH (lactate dehydrogenase) (IU/L)</b>	To check for tissue damage	105–333 IU/L	
<b>Granulocyte PNH clone size</b>	To check the number of cells affected by PNH	Large clone: >50% Moderate clone: 10%–50% Small clone: <10%	
<b>Thrombocytes (x 10<sup>9</sup>/L)</b>	To check for thrombocytopenia	150–400 x 10 <sup>9</sup> /L	
<b>Leukocytes (x 10<sup>9</sup>/L)</b>	To check for neutropenia	3.5–10.5 x 10 <sup>9</sup> /L	
<b>Ferritin (µg/mL)</b>	To check the body's iron stores	Men <300 µg/mL Women <150 µg/mL	
<b>ARC (absolute reticulocyte count) 10<sup>9</sup>/L</b>	To check production of red blood cells	Normal range: 0.2–2%	



# Treatment record

Use this chart to keep track of all your treatments, the prescribed doses and when to take them. Make a note of any dosage changes, along with any other treatment events you think your healthcare team should be aware of. The FABHALTA® row has been filled in for you.

Treatment	Dosage	When to take					Dosage changes
		 Morning	 Midday	 Evening	 Night	 Frequency	
FABHALTA®	200 mg	✓			✓	Twice daily	n/a

Staying committed to your treatment is really important, but it may take time. Use this table to keep a note of the times when you may have missed a dose.

- If you find you have had no missed doses, that's great, and you should keep it up to control your symptoms
- If you have missed one or two doses each week, remember it's important that you stay on track with your treatment. Try to stick with your scheduled doses to avoid any symptoms
- Two or more missed doses will increase your risk of worsening symptoms. You might need extra support to help you stay committed to your treatment. You can use the **staying on track stickers** found in your starter kit to help you stay on track with your treatment

Having a record of this might help you to make changes in your routine to keep your treatment on track. It's very important that you DO NOT SKIP any doses to avoid the appearance of serious symptoms of PNH.

	Week 1			Week 2			Week 3			Week 4			Week 5		
Missed doses	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2
FABHALTA®															



# Symptoms record

Monitoring and keeping a record of your symptoms is very important for managing your PNH. In addition, it's helpful to be aware of any other health events that may have had an impact on your wellbeing over the same period. You can share this information with your healthcare team.

Please scan the QR code on page 38 to access the digital symptom tracker tool.

**Scale?**  
 1 = Mild  
 2 = Moderate  
 3 = High  
 4 = Severe  
 5 = Extreme

**Below is a list of symptoms, which you may or may not have experienced. For each symptom, write the number that best describes how it has affected you this month and on what date.**

<b>Feeling tired/weak</b>	<b>Shortness of breath</b>	<b>Erectile dysfunction</b>	<b>Chest pain</b>
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

<b>Dizziness</b>	<b>Yellowing of skin/eyes</b>	<b>Abdominal pain</b>	<b>Difficulty swallowing</b>
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

**Colour of urine in the morning**

Pale Yellow      Yellow      Amber      Dark Brown      Red

**List any other symptoms not mentioned on the left and write the number to show how they have affected you this month and on what date.**

Symptom: .....	Symptom: .....	Symptom: .....	Symptom: .....
.....	.....	.....	.....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....
Date .....	Date .....	Date .....	Date .....
Score .....	Score .....	Score .....	Score .....

**Alongside the symptoms of your PNH, it is useful to keep a note of any important health events, such as infections, illnesses or physical events that you may experience. You can note these here together with the start date and how long they lasted.**

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....



# Monthly calendar

Use the calendar to record any missed doses or change in symptoms. If you miss a dose, or doses, it's important that you take one dose of FABHALTA® as soon as possible, even if it's shortly before your next dose is due. Together with the progress tracker, this will help you identify any patterns that emerge.

Month \_\_\_\_\_ Year \_\_\_\_\_

Monday		Tuesday		Wednesday		Thursday		Friday		Saturday		Sunday	
	am pm		am pm		am pm		am pm		am pm		am pm		am pm
	am pm		am pm		am pm		am pm		am pm		am pm		am pm
	am pm		am pm		am pm		am pm		am pm		am pm		am pm
	am pm		am pm		am pm		am pm		am pm		am pm		am pm



# Progress tracker

Use this space to record your treatment progress. You may want to write down your thoughts and feelings as you continue your treatment. If you have questions for your healthcare team, you can also record them here. Add stickers here to visualise your progress over time.



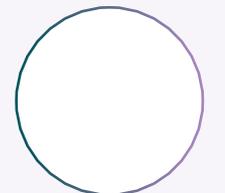
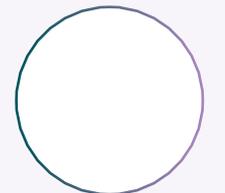
Thoughts: \_\_\_\_\_



Feelings: \_\_\_\_\_



Questions: \_\_\_\_\_



# Find the support you need

Beginning a new treatment can be overwhelming. Our website and patient support program are here to provide further information and resources, and to guide you through any questions you may have.

As a patient starting treatment with Fabhalta® (iptacopan) you are invited to enrol in the **replenishEd patient support program**. By joining replenishEd you will have the option to receive:

- Educational emails on managing PNH with oral therapy
- Monthly phone calls with a haematology nurse
- SMS reminders about medication



Please scan the QR code to enrol in the replenishEd patient support program, or go to:

[replenished-pnh.com.au](https://replenished-pnh.com.au)

Trouble signing up? Call 1800 290 652



Please scan here to visit our patient website to find more information, and to access electronic copies of your Fabhalta® onboarding materials



## Common terms to know

### Anaemia

A low level of healthy red blood cells in the blood.

### Bilirubin

A yellowish substance that comes from the breakdown of red blood cells in your body.

### Ferritin

A protein that stores and releases iron.

### Granulocyte PNH clone

Are only found in individuals with PNH and vary in size between different PNH patients. The size of the granulocyte PNH clone generally impacts the symptoms an individual patient experiences with a larger clone size leading to greater symptoms.

### Haemoglobin

A protein in red blood cells that transports oxygen around the body.

### Lactate dehydrogenase

An important enzyme in PNH frequently tested to give an idea of how much haemolysis is occurring in the body. High levels of lactate dehydrogenase can mean red blood cell haemolysis.

### Leukocytes

White blood cells that help to protect the body from infections.

### Paroxysmal nocturnal haemoglobinuria (PNH)

A rare and serious blood disorder in which red blood cells break apart more easily, leading to anaemia and other complications.

### Reticulocytes

Immature red blood cells that develop in the bone marrow and circulate in the blood stream for about a day before developing into mature red blood cells.

### Thrombocytes

Also known as platelets, are small colourless disc-shaped cell fragments, found in large numbers in the blood and involved in clotting.



This material has been produced by Novartis Pharma AG. This material is intended only for patients with paroxysmal nocturnal haemoglobinuria (PNH) who have been prescribed FABHALTA<sup>®</sup>. This is provided for information/educational purposes only and is not intended to replace discussions with your doctor or care team.

AU-28518 | Date of preparation: October 2025  
©2025 Novartis Pharmaceuticals Australia Pty Limited.  
Sydney, NSW  
ABN 18 004 244 160 All rights reserved.