

This material has been developed and funded by Novartis Pharmaceuticals UK Ltd and is intended only for UK patients with paroxysmal nocturnal haemoglobinuria (PNH) who have been prescribed iptacopan.

Treatment diary

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

This material does not replace the patient information leaflet (PIL) that comes with your medication. You should read the PIL carefully before you start taking this medicine because it contains important information for you.

If you have any questions, ask your doctor or care team.

Connected – Stronger Together is a patient support programme developed and funded by Novartis Pharmaceuticals UK Ltd.

Reporting side-effects

If you get side-effects with any medication you are taking, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the information leaflet that comes in the pack.

▼The medicine referred to in this material is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side-effects you may get. Please see www.mhra.gov.uk/yellowcard for instructions on how to report side effects.



Why a treatment diary?

This treatment diary will help you keep a record of your appointments, medications, paroxysmal nocturnal haemoglobinuria (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 your 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.

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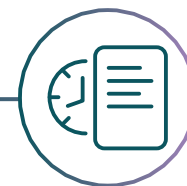
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What's in my treatment diary?

This diary has 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 (see page 42).

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:

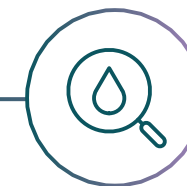
Date 12/02/25

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 iptacopan 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
Iptacopan	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>					<input checked="" type="checkbox"/>



Symptoms record

You may have a range of symptoms caused by PNH.

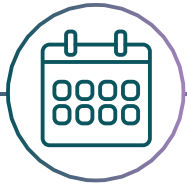
Use this section to make a note of them as soon as they happen. This will help you to note them accurately and will make discussions with your healthcare team easier.

Here is an example of how to fill this out:

Symptom: <u>Headache</u>	Symptom: <u>Feeling tired/weak</u>
Date <u>1/02</u>	Date <u>09/02</u>
Score <u>1</u>	Score <u>2</u>
Date <u>18/03</u>	Date <u>10/02</u>
Score <u>4</u>	Score <u>1</u>

Symptom: <u>Dizziness</u>
Date <u>1/02</u>
Score <u>3</u>
Date <u>18/03</u>
Score <u>1</u>

Score?
 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 2025

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?

Will I have any side effects from my iptacopan treatment?

As with all medicines, side effects can occur. Although not everyone experiences them, there is a chance that you may experience some unwanted side effects while taking your treatment.

In clinical studies, the most common side effects reported by more than 1 in 10 people taking iptacopan were:

- Infections of the nose and throat (upper respiratory tract infection)
- Headache
- Diarrhoea

The most commonly reported serious side effect is urinary tract infection.

If you experience any symptoms of serious infection you should immediately contact your doctor. Information on the symptoms to look out for can be found in your guide: Patient and caregiver guide to treatment with FABHALTA®▼ (iptacopan). Some people taking iptacopan may also experience a decrease in their blood platelet count. This is a common side effect that can occur in up to 1 in 10 people taking iptacopan. This may cause you to bleed or bruise more easily.

Some other common (may affect up to 1 in 10 people) side effects include:

- Persistent cough or irritation of the airways (bronchitis)
- Low levels of platelets
- Dizziness
- Pain in the stomach (abdomen)

- Feeling sick (nausea)
- Joint pain (arthralgia)

Uncommon (may affect up to 1 in 100 people) side effects include:

- Lung infection (which can cause chest pain, cough and fever)
- Itchy rash (urticaria)

What are platelets?

Platelets are small cell fragments found in your blood. They help your blood form clots, which is important to control bleeding. A low platelet count means your body doesn't have enough platelets to form clots. This may cause bleeding or bruising more easily than normal.

What should I do if I get side effects from my iptacopan treatment?

Whilst no one wants to have side effects from their treatment, just remember that it isn't unusual to experience them. What's most important is that you speak to your healthcare team immediately, so that they can advise you on how to proceed. You may also wish to report your side effects to the MHRA Yellow Card scheme at: www.mhra.gov.uk/yellowcard.

Should I stop taking my treatment if I experience side effects?

Stopping your treatment with iptacopan can make your condition worse and may increase your risk of red blood cell breakdown (haemolysis). It is important that you adhere to the scheduled treatment regimen. **Do not stop taking iptacopan without talking to your healthcare team first.**

If your healthcare team decides to stop your treatment, you will be monitored closely for at least 2 weeks for any signs of haemolysis due to PNH. Your healthcare team may prescribe a different PNH medicine or have you restart iptacopan treatment.

If you stop treatment, be aware of signs or symptoms of haemolysis, including:



Lower level of haemoglobin in your blood



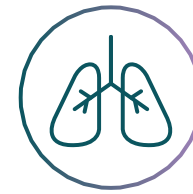
Tiredness



Blood in your urine



Pain in your stomach (abdomen)



Shortness of breath



Blood clots (thrombosis)



Trouble swallowing



Erectile dysfunction (impotence)

If you experience any of these symptoms or problems after stopping treatment, please contact your healthcare team immediately.



1

Let's track your month

Here are all the sections for you to complete for **month 1** of your treatment with iptacopan.



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Appointments



13
Blood test results



14
Treatment record



16
Symptoms record



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Monthly calendar



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Progress tracker



Appointments

Record your upcoming appointments with your healthcare team here. There are spaces for notes before, during or 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
Date	Date	Date
Time	Time	Time
Location	Location	Location
With	With	With
Reason for appointment	Reason for appointment	Reason for appointment
Notes	Notes	Notes
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Blood test results

Your healthcare team will monitor you with routine blood tests throughout your treatment with iptacopan. 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			
Date		Time	
Location		With	
Measurement	Reason	Normal range	Result
Haemoglobin (g/L)	To check for anaemia	Men 130–180 g/L Women 120–160 g/L	
Total bilirubin (mg/dL)	To check for 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%	
Thrombocytes (x 10⁹/L)	To check for thrombocytopenia	150–400 x 10 ⁹ /L	
Leukocytes (x 10⁹/L)	To check for neutropenia	3.5–10.5 x 10 ⁹ /L	
Ferritin (µg/mL)	To check the body's iron stores	Men <300 µg/mL Women <150 µg/mL	
ARC (absolute reticulocyte count) 10⁹/L	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 iptacopan row has been filled in for you.

Treatment	Dosage	When to take					Dosage changes
		 Morning	 Midday	 Evening	 Night	 Frequency	
Iptacopan	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

It's very important that you DO NOT SKIP any doses to avoid the appearance of serious symptoms of PNH. If you miss a dose, or doses, take one dose of iptacopan as soon as you remember, then take the next dose at the usual time.

	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
Iptacopan															



Symptoms record

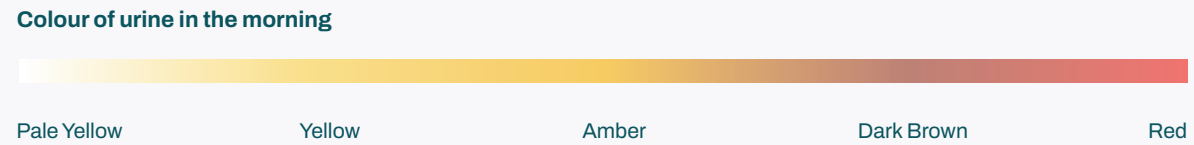
Monitoring and keeping a record of your symptoms is very important for managing your PNH. In addition, it's helpful to be aware of any other health events that may have had an impact on your wellbeing over the same period. You can share this information with your healthcare team.

Score?
 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.

Feeling tired/weak	Shortness of breath	Erectile dysfunction	Chest pain
Date	Date	Date	Date
Score	Score	Score	Score
Date	Date	Date	Date
Score	Score	Score	Score

Dizziness	Yellowing of skin/eyes	Abdominal pain	Difficulty swallowing
Date	Date	Date	Date
Score	Score	Score	Score
Date	Date	Date	Date
Score	Score	Score	Score



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.

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Monthly calendar

Use the calendar to record any missed doses or change in symptoms. If you miss a dose, or doses, take one dose of iptacopan as soon as you remember, then take the next dose at the usual time. 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.



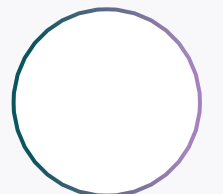
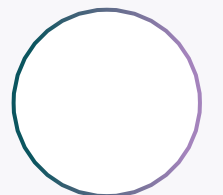
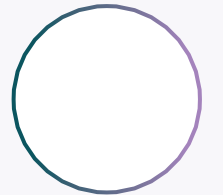
Thoughts: _____



Feelings: _____



Questions: _____





2

Let's track your month

Here are all the sections for you to complete for **month 2** of your treatment with iptacopan.



22
Appointments



23
Blood test results



24
Treatment record



26
Symptoms record



28
Monthly calendar



29
Progress tracker



Appointments

Record your upcoming appointments with your healthcare team here. There are spaces for notes before, during or 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
Date	Date	Date
Time	Time	Time
Location	Location	Location
With	With	With
Reason for appointment	Reason for appointment	Reason for appointment
Notes	Notes	Notes



Blood test results

Your healthcare team will monitor you with routine blood tests throughout your treatment with iptacopan. 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			
Date		Time	
Location		With	
Measurement	Reason	Normal range	Result
Haemoglobin (g/L)	To check for anaemia	Men 130–180 g/L Women 120–160 g/L	
Total bilirubin (mg/dL)	To check for 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%	
Thrombocytes (x 10⁹/L)	To check for thrombocytopenia	150–400 x 10 ⁹ /L	
Leukocytes (x 10⁹/L)	To check for neutropenia	3.5–10.5 x 10 ⁹ /L	
Ferritin (µg/mL)	To check the body's iron stores	Men <300 µg/mL Women <150 µg/mL	
ARC (absolute reticulocyte count) 10⁹/L	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 iptacopan row has been filled in for you.

Treatment	Dosage	When to take					Dosage changes
		 Morning	 Midday	 Evening	 Night	 Frequency	
Iptacopan	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

It's very important that you DO NOT SKIP any doses to avoid the appearance of serious symptoms of PNH. If you miss a dose, or doses, take one dose of iptacopan as soon as you remember, then take the next dose at the usual time.

	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
Iptacopan															



Symptoms record

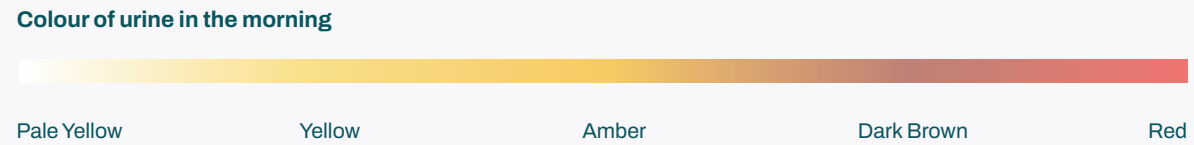
Monitoring and keeping a record of your symptoms is very important for managing your PNH. In addition, it's helpful to be aware of any other health events that may have had an impact on your wellbeing over the same period. You can share this information with your healthcare team.

Score?
 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.

Feeling tired/weak	Shortness of breath	Erectile dysfunction	Chest pain
Date	Date	Date	Date
Score	Score	Score	Score
Date	Date	Date	Date
Score	Score	Score	Score

Dizziness	Yellowing of skin/eyes	Abdominal pain	Difficulty swallowing
Date	Date	Date	Date
Score	Score	Score	Score
Date	Date	Date	Date
Score	Score	Score	Score



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.

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Monthly calendar

Use the calendar to record any missed doses or change in symptoms. If you miss a dose, or doses, take one dose of iptacopan as soon as you remember, then take the next dose at the usual time. 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.



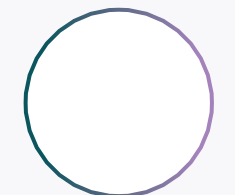
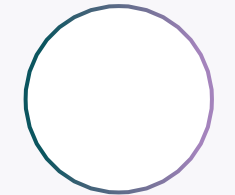
Thoughts: _____



Feelings: _____



Questions: _____





3

Let's track your month

Here are all the sections for you to complete for **month 3** of your treatment with iptacopan.



32
Appointments



33
Blood test results



34
Treatment record



36
Symptoms record



38
Monthly calendar



39
Progress tracker



Appointments

Record your upcoming appointments with your healthcare team here. There are spaces for notes before, during or 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
Date	Date	Date
Time	Time	Time
Location	Location	Location
With	With	With
Reason for appointment	Reason for appointment	Reason for appointment
Notes	Notes	Notes
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Blood test results

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Blood test appointment			
Date		Time	
Location		With	
Measurement	Reason	Normal range	Result
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Total bilirubin (mg/dL)	To check for red blood cell breakdown	0.2–1.2 mg/dL	
LDH (lactate dehydrogenase) (IU/L)	To check for tissue damage	105–333 IU/L	
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Treatment record

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Missed doses	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2	1	1-2	>2
Iptacopan															



Symptoms record

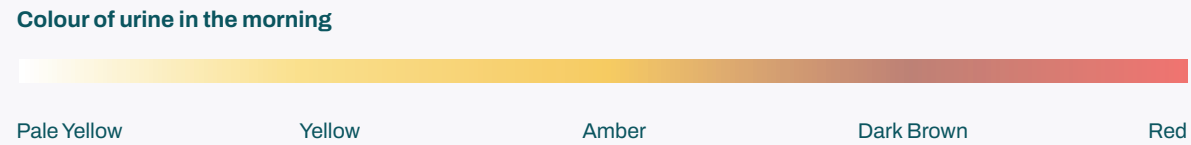
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Below is a list of symptoms, which you may or may not have experienced. For each symptom, write the number that best describes how it has affected you this month and on what date.

Feeling tired/weak	Shortness of breath	Erectile dysfunction	Chest pain
Date	Date	Date	Date
Score	Score	Score	Score
Date	Date	Date	Date
Score	Score	Score	Score

Dizziness	Yellowing of skin/eyes	Abdominal pain	Difficulty swallowing
Date	Date	Date	Date
Score	Score	Score	Score
Date	Date	Date	Date
Score	Score	Score	Score



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.

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Monthly calendar

Use the calendar to record any missed doses or change in symptoms. If you miss a dose, or doses, take one dose of iptacopan as soon as you remember, then take the next dose at the usual time. 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.



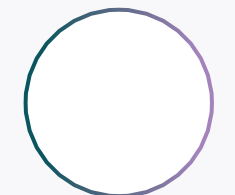
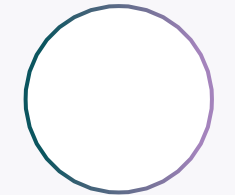
Thoughts: _____



Feelings: _____



Questions: _____





Iptacopan summary



Who is it for?

Adults with paroxysmal nocturnal haemoglobinuria (PNH) who have haemolytic anaemia.



How is it taken?

One 200 mg capsule of iptacopan is taken by mouth twice daily, with or without food.

Please refer to the patient information leaflet (PIL) for more information.



What type of medicine is it?

Iptacopan is a Factor B complement inhibitor. It works by stopping part of the complement system, a part of your body's immune system.

Please refer to the PIL for more information.



Very common side effects of treatment (more than 1 in 10 people)

- Infections of the nose and throat (upper respiratory tract infection)
- Headache
- Diarrhoea

Please refer to the PIL for more information.



Common side effects of treatment (up to 1 in 10 people)

- Decrease in blood platelet count (usually this is mild and short-lived)
- Persistent cough or irritation of the airways (bronchitis)

Please refer to the PIL for more information.



Switching to iptacopan from any other PNH treatment

- Remember to take iptacopan exactly as your healthcare team have instructed
- If you have any questions throughout the switching process, please contact your healthcare team

Please refer to the PIL for more information.



Signs of serious infection (that may occur with treatment)

- Fever
- Headache
- Confusion
- Body aches with flu-like symptoms
- Clammy skin
- Eyes sensitive to light

Please refer to the PIL for more information.

Find the support you need

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



Scan here to be directed to the **Connected – Stronger Together** website or visit: www.fabhalta-connected-stronger-together.co.uk



Scan here to sign up to the **Connected – Stronger Together** support programme or visit: www.fabhalta-cst.co.uk

The National PNH Service

The National PNH Service is a world-renowned UK-based service, with expertise in managing patients with PNH. The Service provides education to further the knowledge of diagnosis and management of PNH, with the aim to improve patient care worldwide. Find out more at: www.pnhserviceuk.co.uk.

PNH Dedicated Centres

- A** Leeds Teaching Hospitals
- B** King's College Hospital
- C** King's College Hospital catchment area

PNH Scotland Outreach

- C** Lanarkshire Monklands Hospital

PNH Outreach Clinics

- D** Royal Liverpool University Hospital
- E** Manchester Royal Infirmary
- F** Birmingham Queen Elizabeth Hospital
- G** Peterborough City Hospital
- H** Oxford Churchill Hospital
- I** Bristol Southmead Hospital
- J** Southampton Central Hospital



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.

Complement inhibitors

Medicines that reduce the activity of the complement system, a part of the immune system.

Complement system

A part of the immune system that helps fight infection and removes damaged blood cells.

Factor B

A protein which increases activity of the complement system.

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.

Haemoglobinuria

High amounts of haemoglobin in the urine.

Haemolysis

Destruction of red blood cells.

Haemolytic anaemia

Form of anaemia caused by premature destruction of red blood cells.

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

Happens suddenly, occurs over and over again.

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.

Platelet

A small, colourless, disc-shaped cell fragment, found in large numbers in blood and involved in clotting.

Proteins

Large molecules which have various roles in the body, including building and repairing tissues, enzymes and hormones.

Red blood cells

Blood cells that carry oxygen from the lungs to the rest of the body.

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.

Thrombosis

Clotting of the blood.



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Reporting side-effects

If you get side-effects with any medication you are taking, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the information leaflet that comes in the pack.

▼The medicine referred to in this material is subject to additional monitoring. This will allow quick identification of new safety information. You can help by reporting any side-effects you may get. Please see www.mhra.gov.uk/yellowcard for instructions on how to report side effects.