

Your appointment planner

As you begin treatment with FABHALTA[®] ▼ (iptacopan), you will likely have lots of questions about life with paroxysmal nocturnal haemoglobinuria (PNH) and your treatment. Planning and preparing for your appointments with your healthcare team is a good way to ensure all of your questions are answered.

How to use this guide

This guide is designed to support your discussions with your healthcare team. You can also use the treatment diary included in your starter kit to track your symptoms over time and plan for your appointments.

Reflect on your last month and fill in the different sections of the guide to prepare for your next appointment. Bring your completed guide to your next appointment and discuss it with a member of your care team.

Today's date:

Record today's date so you can monitor and reflect on how you're feeling over time.

Symptoms

If you have experienced any PNH symptoms lately, rank how each symptom has impacted your daily life. For further information on symptoms and side effects, please refer to the treatment guide included in your starter kit.

1 = hasn't impacted my daily life at all; 5 = has had a significant impact on my daily life

Abdominal pain

Chest pain

Breathlessness

Yellowing of skin/eyes

Difficulty swallowing

Erectile dysfunction

Fatigue

Dark urine

Others:

Emotions

How is your PNH affecting you emotionally? Use this box to describe how you have been feeling recently. You can include any worries or fears you have, as well as any positive feelings you've had.

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.

Managing your PNH

To enable you to live your life the way you want to, it's important to work with your care team to find a treatment that works well for you. Use the boxes below to rate how you feel about your PNH treatment. Tick the score that best reflects how you feel:

1 = not at all; 5 = extremely

How well does your PNH treatment help you to manage/prevent your symptoms?

 1 2 3 4 5

How satisfied are you with how often you take your treatment?

 1 2 3 4 5

Overall, how satisfied do you feel with your treatment and/or care?

 1 2 3 4 5

How easy is it to fit your treatment into your usual daily routine? (i.e. working, eating, family)

 1 2 3 4 5

How easy is it for you to take your treatment when your routine changes? (i.e. going on holiday, travelling for work)

 1 2 3 4 5

Additional comments:

If you are experiencing any side effects from your PNH treatment, please talk to your healthcare team.

Questions to ask your healthcare team

You may find it helpful to go to your appointment prepared with questions to ask your healthcare team. Below are some examples that you may wish to use. Feel free to also add your own.



About PNH

What do the blood test results (haemoglobin, platelets, etc.) mean for me?

Can I have a printout of the results?

Can you explain the types of tests to me?

What check-ups are necessary to monitor my treatment?



About iptacopan

How will I know if my treatment is working?

How long will I need to be on the treatment?

What are the side effects?

How long are the side effects likely to last?

Is there something I can do to help manage side effects?



Other questions

Are there any lifestyle changes I may need to make (e.g., do I need to change my diet or exercise)?

Who can support me with my mental wellbeing?

How and where can I find additional support?

Other questions I have:

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)
- Dizziness
- Feeling sick (nausea)
- Low levels of platelets
- Pain in the stomach (abdomen)
- 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
- Blood in your urine
- Blood clots (thrombosis)
- Tiredness
- Pain in your stomach (abdomen)
- Trouble swallowing
- Shortness of breath
- Erectile dysfunction (impotence)

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

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