

Aspaveli[®] ▼ (pegcetacoplan) travel guide

This booklet has been given to you because you, or someone in your care, has been prescribed Aspaveli (pegcetacoplan) as a treatment for paroxysmal nocturnal haemoglobinuria (PNH). This booklet provides guidance and advice for travelling with Aspaveli. It includes information on documents and supplies you will need to travel, how to handle, store and self-infuse Aspaveli during travel and trips away from home, as well as some helpful tips for a smooth experience when travelling with Aspaveli.

▼ This medicine 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. You can report side effects by contacting your doctor, nurse or pharmacist or you can report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard or search for MHRA Yellow Card in the Google Play or Apple App Store.

This guide is intended for patients who have been prescribed Aspaveli, and is initiated and funded by Sobi[™]. Please refer to the Aspaveli Patient Information Leaflet (PIL) provided by your doctor or nurse for further information. The PIL is also available at www.medicines.org.uk/emc.

The information provided in this guide is general educational information and does not take the place of professional medical advice. Always follow your doctor or nurse's instructions and talk with them about any questions or problems you have regarding your health and treatment.

Planning ahead for your destination

What supplies and documents will I need to pack for my trip?

As you start to pack for your trip, you can use the checklist below to gather the supplies you will need for taking Aspaveli during your trip.

To make sure you have enough supplies for the duration of your trip, pack based on how many infusions you will need while you are away. It is also a good idea to pack an extra vial of Aspaveli and an extra set of infusion equipment just in case.

Aspaveli infusions should be done at regular intervals twice a week as instructed by your doctor or nurse. In some circumstances, your doctor or nurse might change the frequency of your dose.

If you are travelling within the UK, it is possible to change the address where your Aspaveli will be delivered by contacting the HealthNet Pharmacy Customer Care team on +44 (0) 8000 833 060 or at healthnet.homecare@nhs.net at least 4 weeks before your planned trip.



Remember to speak with your doctor or nurse and homecare provider about your upcoming travel plans.

For each infusion you'll need:

- 1 Aspaveli vial individually packaged in its original carton
 - Keep vials in their outer cartons to protect against light and breakage
- 1 20 ml luer lock syringe
- 1 vial transfer device
- 1 infusion set including the infusion tubing, needles and transparent dressings (these will be in two separate packs)
- Alcohol wipes, gauze and tape

You'll also need:

- A cool box/bag to keep medication stored at 2°C to 8°C (35.6°F to 46.4°F)
- Infusion pump
- Sharps container
- **Aspaveli Patient Card** and **Aspaveli Travel Letter**
 - Keep your Aspaveli Patient Card and Aspaveli Travel Letter, signed by your doctor, with you when travelling
 - The Aspaveli Travel Letter explains your treatment with Aspaveli and the supplies that you need to administer your treatment. Presenting this letter to customs and security officials, along with your prescription, will help you to move through security

Handling and storing Aspaveli while travelling

How should I pack Aspaveli when travelling to my destination?

Take extra care while packing Aspaveli and when moving from place to place:

- When travelling, make sure that Aspaveli stays at a temperature between 2°C and 8°C (35.6°F and 46.4°F). Talk to your doctor or nurse or homecare provider for options on how to do this.
- Keep the vials in their outer carton to protect against light and breakage.
- When you're in transit or away from refrigeration, keep your medication somewhere close in a cool box/bag, where the temperature is controlled. Aspaveli must not become frozen, do not use Aspaveli if the content in the vial may have become frozen at any stage. Remember, your medication should not be left unattended during your journey.
- If you are travelling by plane, please note that Aspaveli is unsuitable for storage in the hold of an aeroplane and should be carried by hand at all times during your journey for safekeeping and temperature control.

How will I refrigerate Aspaveli when I arrive at my destination?

Aspaveli should be stored in a refrigerator at a temperature between 2°C and 8°C (35.6°F and 46.4°F). Consider the tips below to help you to refrigerate Aspaveli while travelling:

- Some destinations may not have a refrigerator. Call ahead to make sure you will have secure access to one and will be able to store your cartons of Aspaveli inside.
- Sometimes freezers can be mistaken as refrigerators. Double check or ask for help if you are unsure.
- Some hotels use key cards that provide electricity to the room. Make sure that removing the key card when leaving your hotel room does not turn off the power to the refrigerator and ask for help if you are unsure.
- Check the refrigerator is at a suitable temperature to store Aspaveli, between 2°C and 8°C (35.6°F to 46.4°F).
- Do not store Aspaveli at the back of the refrigerator to avoid freezing, or in the door to minimise changes in temperature when the refrigerator is opened and closed. Store Aspaveli on one of the shelves of the refrigerator for best temperature control. Do not use Aspaveli if the content in the vial is frozen.
- Aspaveli is a clear, colourless to slightly yellowish solution. Do not use the vial if:
 - The liquid looks cloudy, contains any bits, or is dark yellow
 - The protective purple lid is missing or damaged
 - The expiration date on the label has passed
- If Aspaveli becomes frozen or outside of the safe temperature range, between 2°C and 8°C (35.6°F and 46.4°F), or you have any concerns about the appearance of Aspaveli, contact your homecare provider for advice.

Helpful tips for a smooth experience while travelling

Let your medical team know when you are planning a trip

- Let your doctor or nurse and homecare provider know as soon as possible when you are planning a trip.
- Keep your **Aspaveli Patient Card** and **Aspaveli Travel Letter**, signed by your doctor, with you when travelling. Remember, your Aspaveli Travel Letter only needs to be signed once, you do not need a newly signed letter each time you travel.

Streamline your security checks when flying, or at border control, when travelling between countries

- Have your signed **Aspaveli Travel Letter** easily accessible, for example in a separate pocket or section of a bag, or with your medication, so you won't have to search your bags when you need it.
- Please visit your local authority's website and the website for the country you are travelling to (if travelling abroad) for more details, including information about volume limits.

Consider an alternative disposal container if a sharps container is not available

- Safely dispose of all used supplies as well as empty vials as recommended by your doctor or nurse or homecare provider.
- If you are not able to travel with a sharps container, use another hard/puncture-proof container for safe disposal of needle sets.

Re-establish your routine at your destination

- Aspaveli can be self-infused when you travel, as long as you can follow the same step-by-step instructions that you follow at home:
 - Consider whether you are travelling into a different time zone and if that impacts when your next infusion is due. Ask your doctor or nurse, or homecare provider if you have any questions about this.
 - Once you arrive at your destination, identify a comfortable, safe place where you will do your infusions
 - Re-establish your routine so you can infuse on your regular schedule as instructed by your doctor or nurse
 - Additional information about self-infusing can be found in the **Aspaveli Patient Information Leaflet** provided separately and in **Your guide to self-infusing Aspaveli**

Further Support Available

PNH Support

PNH Support is a registered charity (No 1161518) run by PNH patients and carers as a peer-to-peer support organisation for people living with PNH (and their carers and family members) in England, Wales and Northern Ireland. Our activities include: facilitating PNH patients and carers to share their experiences and support one another; advocating on behalf of PNH patients and carers with stakeholders; and providing or signposting to further information.

How to get in touch:

Email: contact@pnhuk.org

PNH Scotland

PNH Scotland is a charity dedicated to supporting anyone affected by PNH. Our main aim is to raise awareness of the condition and advance the education of patients, their families and interested health professionals. In particular, we aim to ensure all patients receive access to the treatment they require, provide up to date information and act as a point of contact for anyone needing help and advice.

How to get in touch:

Email: info@pnhscotland.org.uk

Tel: +44 (0) 7967 118762

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