

# What advice should be given to patients with porphyria who intend to travel?

## Background

The porphyrias can be split into two types according to whether they cause acute attacks or whether they have mainly skin effects (1). This advice is intended for patients with an acute type of porphyria (acute intermittent porphyria, ALA dehydratase deficiency porphyria, hereditary coproporphyria, variegate porphyria) in whom some medicines can precipitate a painful acute attack (1). Generally, in patients with a non-acute (cutaneous) type of porphyria (congenital erythropoietic, erythropoietic protoporphyria and porphyria cutanea tarda), all medicines are considered safe (1). However, while their condition is being treated, it is advised that patients with active porphyria cutanea tarda do not take oestrogens (2). Chloroquine is used in small doses 2-3 times weekly to treat porphyria cutanea tarda (2,3). It is effective because it releases porphyrins from the liver, but large doses of chloroquine can cause hepatitis (2) and should be avoided until the porphyria cutanea tarda is in remission i.e. until the active porphyria cutanea tarda has been treated and urine porphyrin excretion has returned to normal (4).

## Answer

### Before travel

Travel insurance, travel vaccines, malarial prophylaxis and medical care in the destination country are worth considering well in advance of travel. With regard to travel insurance, whether or not cover can be obtained is determined on a case by case basis. The British Porphyria Association (BPA) [www.porphyria.org.uk](http://www.porphyria.org.uk); helpline: 0300 30 200 30 or [helpline@porphyria.org.uk](mailto:helpline@porphyria.org.uk) can suggest who to contact in the first instance.

Most travel vaccines are safe in the acute porphyrias. However, there has been an unpublished report of an acute porphyria attack following yellow fever vaccination (5). Caution may be warranted with live vaccines. Consider contacting the Welsh Medicines Information Centre (Tel: 029 2184 2251 for further information or advice.

The following antimalarials are considered safe in acute porphyria (if appropriate for the destination) (5):

- Chloroquine\*
- Malarone (atovaquone and proguanil)
- Mefloquine
- Proguanil
- Doxycycline

\*chloroquine in antimalarial doses as treatment or prophylaxis should be avoided in patients with active porphyria cutanea tarda, see background for more information.

Be aware of the healthcare facilities in the destination country – it is important to have access to hospital facilities and appropriate porphyria care in the event of illness. Try getting in touch with the British Embassy or Consulate closest to the destination for information on local healthcare facilities. Contact details for Embassies/Consulates can be obtained from The Foreign and Commonwealth Office. In case you need medication while abroad, take a copy of the safe list produced by the Welsh Medicines Information Centre available at:

<http://www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/>

Consider using a bracelet, necklace or other item which indicates that the wearer has porphyria.

Details of medical ID jewellery can be obtained from the MedicAlert Foundation:

The MedicAlert Foundation  
327 Upper Fourth Street  
Milton Keynes  
MK9 1EH  
United Kingdom  
Tel: 01908 951045

Website: [www.medicalert.org.uk](http://www.medicalert.org.uk)

In transit

International air travel has been identified as a risk factor for acute porphyria attacks (6). There is a published report on five individuals, each of whom experienced an acute attack following international travel. In these cases, possible precipitants of the attacks included dehydration, starvation, alcohol use, infection, stress and the hormonal changes that occur during the premenstrual period (6).

Taking measures to avoid/minimise attack triggers is advisable. If flying, avoid drinking alcohol and drink plenty of non-alcoholic fluids during the flight. Other preventative measures include not missing meals, consuming meals with high carbohydrate content, and choosing to travel at times other than during the premenstrual period.

If medication is required for travel sickness, hyoscine hydrobromide and promethazine are safe options in acute porphyria (5).

#### At destination

Take measures to avoid mosquito bites, e.g. use nets and repellent, clothing that covers the skin such as trousers and long-sleeved shirts, avoid going out at dawn and dusk. Bear in mind factors that have been linked with acute porphyria attacks (dehydration, alcohol use, fasting, infection, stress, hormone fluctuations, e.g. premenstrual) and note standard advice in porphyria such as restricting alcohol intake. Also, take extra care to prevent dehydration by drinking plenty of clean water (bottled, if necessary) or other non-alcoholic liquids, and employ measures to reduce the risk of contracting food poisoning. In the event of vomiting or diarrhoea, take rehydration sachets. Hot climates may have an appetite suppressing effect, but missing meals is not advisable.

## Summary

- Most travel vaccines are safe in the **acute** porphyrias, but there has been an unpublished report of an acute porphyria attack following yellow fever vaccination. Caution may be warranted with live vaccines.
- The following antimalarials are suitable for use in acute porphyria: chloroquine (not suitable in active porphyria cutanea tarda, a **non-acute** porphyria), Malarone (atovaquone and proguanil), mefloquine and proguanil.
- Travellers should take measures to avoid mosquito bites (e.g. use of nets, repellents, long-sleeved shirts and trousers, avoiding going out at dawn and dusk)
- Be aware of the healthcare facilities in the destination country in case of illness. The British Embassy or Consulate closest to the destination may have relevant information.
- Consider using a bracelet, necklace or other item which indicates that the wearer has porphyria.
- International air travel is a risk factor for acute porphyria attacks, which may be triggered by dehydration, alcohol use, fasting, infection, stress, hormone fluctuations, e.g. premenstrual. It is advisable to avoid/minimise these factors when travelling by air or other means.
- If medication is required for travel sickness, hyoscine hydrobromide and promethazine are safe options in acute porphyria.

- The British Porphyria Association (0300 30 20030; [helpline@porphyria.org.uk](mailto:helpline@porphyria.org.uk)) can provide suggestions on travel insurance.

### Limitations

This advice is intended for patients with acute porphyria (acute intermittent porphyria, ALA dehydratase deficiency porphyria, hereditary coproporphyrin, variegate porphyria). Further information on the safety of medicines in acute porphyria, and a list of medicines that are safe in the acute porphyrias can be obtained from the Welsh Medicines Information Centre; Tel: 029 2184 2251 or at:

<http://www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/> . Information on prescribing in the non-acute porphyrias is available here: <https://www.sps.nhs.uk/articles/what-are-the-restrictions-on-prescribing-for-patients-with-non-acute-porphyria/>

### References

1. European Porphyria Network. Information for patients and families -Introduction to Porphyria [cited2019 Dec 16]. Available from: <http://porphyria.eu/en/content/introduction-porphyria>
2. Porphyria South Africa. Porphyria cutanea tarda [cited2019 Dec 16]. Available from: <http://www.porphyria-professionals.uct.ac.za/ppb/porphyrias/management-pct>
3. Badminton MN and Elder GH. Management of acute and cutaneous porphyrias. Int J Clin Pract 2002;56(4):272-78.
4. Personal communication. Dr M Badminton, Honorary Consultant and Clinical Lead, National Acute Porphyria Service (Cardiff), University Hospital of Wales (2014 Nov 6)
5. Welsh Medicines Information Centre. Drugs that are considered to be SAFE for use in the acute porphyrias. Prepared 04/2019 [cited 2019 Dec 20]. Available from: <http://www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/>
6. Peters TJ and Deacon AC. International air travel: a risk factor for attacks in acute intermittent porphyria. Clin Chim Acta 2003;335:59-63.

### Quality Assurance

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## Search strategy

1. Embase (exp porphyria/ AND travel/)
2. PubMed (porphyria AND travel)
3. In-house database (Porphyria AND Travel (keyword search)) Internet Search (Google; porphyria and travel)
4. Micromedex (travel)
5. NICE Evidence (porphyria AND travel)
6. BIPNET. British and Irish Porphyria Network. Available from: <http://www.bipnet.org.uk/>
7. EPNET. European Porphyria Network. Available from: <http://www.porphyria-europe.com/>
8. Porphyria South Africa. Available from: <http://www.porphyria.uct.ac.za/>

Welsh Medicines Information Centre. Drugs that are considered to be SAFE for use in the acute porphyrias.  
<http://www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/>

Mae'r daflen hon hefyd ar gael yn Gymraeg. This leaflet is also available in Welsh.