

This leaflet only applies to people with acute porphyrias. So it does NOT apply to people with PCT, EPP or CEP.

Why is it important to be careful with drugs in the acute Porphyrias?

For those suffering from an acute porphyria (AIP, VP, ADP or HCP) attacks can be precipitated by drugs. People with an acute porphyria must therefore take great care as many medicines are capable of triggering an acute attack.

It is important to ALWAYS check the safety of any medicine or remedy with your doctor or pharmacist.

This includes prescription medicines as well as over-the-counter treatments, tonics and herbal remedies, some of which have been known to cause attacks. While many drugs are considered suspect, there are many other drugs available and good alternatives can almost always be found.

Some people with porphyria may occasionally need a drug, perhaps for a serious illness, that carries some risk of triggering an acute attack or which has been introduced so recently that there is little information about its effect on porphyria. In this situation, your doctor (after discussing the risks with a porphyria specialist) may decide to prescribe the drug for you with special follow-up.

Even though acute attacks are very rare before puberty, it is safest for children if they also avoid all drugs that are not known to be safe in porphyria.

It is also very important for those who are suspected of having an acute porphyria (or are in the process of undergoing tests to eliminate the possibility) to be extremely cautious with drugs.

The response of people with porphyria to “unsafe” drugs is unpredictable. A reaction does not invariably follow in every case. When there is a reaction, it always takes the form of an acute attack, which develops within days of taking the unsafe drug.

Reactions such as dizziness, feeling faint, allergies or short-lived skin rashes (which may occur immediately or very soon after taking the drug) are common after taking drugs and rarely have anything to do with porphyria.

Particular places where you should be careful with drugs

Anaesthetics and surgical operations

You **must** tell your surgeon and anaesthetist in advance that you have porphyria. A special anaesthetic that is safe in porphyria will be needed.

The dentist

You **must** also tell your dentist that you have an acute porphyria. Dentists often use local anaesthetic agents and the safety of at least one of these has been questioned in the past.

However, it is important not to worry about immunisations: All vaccines licensed for human uses are safe to administer to people who have an acute porphyria.

Medic Alert Card/ Warning Jewellery

It is important at all times to wear a wrist bracelet, neck pendant and/or carry a card, to warn others that you have porphyria. Such warning is particularly helpful in emergencies when you may not have an opportunity to explain that you have porphyria. Details on warning jewellery can be obtained from the MedicAlert Foundation, www.medicalert.co.uk, or phone: 020 7833 3034.

Drugs and Porphyria

Attached to this handout is a basic list of SAFE drugs for use by sufferers of acute porphyria. However it is very important that you/your doctor check an up to date list of safe drugs before taking any medication.

The European Porphyria Initiative (EPI) website, www.porphyria-europe.com, contains more detailed information on prescribing in acute porphyria, including information on common prescribing problems (anaesthesia, pain relief, hormonal contraception) and can be freely accessed by you or your doctor. An updated, printable drugs list is also available at www.cardiff-porphyria.org or through the BPA website, www.porphyria.org.uk/links.

Evidence about the safety of drugs is drawn from three main sources:

- Clinical reports (reports by doctors)
- Experimental systems (e.g. cell culture)
- Drug metabolism data (how a drug is used in the body)

It is important to remember that a combination of drugs with other factors such as; stress, infection, malnutrition, may increase the risk of an acute attack.

Recommendations for the use of drugs in the Acute Porphyrias (AIP, VP, ADP or HCP)

This leaflet can only offer advice based on the evidence available at the time of publication. Individuals can vary widely in their reaction to drugs, and the effect of combinations of drugs is even less predictable. Prescription Medicine: The prescribing of drugs is always the responsibility of the doctor in charge. The British Porphyria Association cannot accept any responsibility.

Over the counter medicines and tonics: Patients must check the safety of anything they take, either with a pharmacist, or by using the EPI website. If in doubt, don't take it. Herbal remedies should be avoided.

When prescribing in acute porphyria, the benefit from using the ideal drug should always be assessed against the risk of provoking an acute attack, and the likely consequences of not using it. A drug should never be withheld if it is judged to be essential for optimum treatment, (e.g. chemotherapy for cancer). Support in deciding the best alternative can be obtained by telephoning the Welsh Medicines Information Centre (WMIC) on 029 2074 2251, or see www.cardiff-porphyria.org

Some people have used an unsafe drug without problems, even for many years, before being found – usually through family screening – to have latent porphyria. After discussion of the risk, these people often wish to continue on the drug and this is often allowed. However, if an additional drug needs to be prescribed, the possible risk of interaction provoking an acute attack needs to be carefully considered and a change to a safer combination may be required.

All individuals starting therapy should be advised to report any adverse reaction (e.g. abdominal pain or dark urine), immediately. Be aware that you can still have an adverse reaction to a drug which is unrelated to your porphyria.

SAFE DRUGS LIST

Please see the attached list which contains drugs considered **safe** for use in the acute porphyrias. The list is based on the most up to date information available; but please check our (BPA) web-site (web-links page) for a more up-to-date list.

Important Contact Information

Patient Support Group

The British Porphyria Association (BPA)
☎ **Help-line: 01474 369231**
Email: helpline@porphyria.org.uk
Website: www.porphyria.org.uk

Specialist Porphyria Laboratories

Department of Medical Biochemistry and Immunology
University Hospital of Wales
Heath Park
Cardiff CF14 4XW
Biochemistry Lab: Tel: 02920 743565
Fax: 02920 748383
www.cardiff-porphyria.org

Department of Clinical Biochemistry
King's College Hospital
Denmark Hill
London SE5 9RS
Tel: 020 7346 3856

Welsh Medicines Information Centre
Tel: 02920 743877
Fax: 02920 743879
www.wmic.wales.nhs.uk

Useful Website Addresses

www.porphyria.org.uk
www.cardiff-porphyria.org
www.porphyria-europe.com
www.porphyriafoundation.com (USA)
www.cpf-inc.ca (Canada)
www.drugs-porphyria.com

Drugs and Porphyria

(Acute Porphyrias)

Information for Patients



British Porphyria Association

Charity No: 1089609
www.porphyria.org.uk