

What are the porphyrias?

The porphyrias are a group of relatively **rare** genetic disorders. In each porphyria, a specific enzyme needed to complete a step in the pathway to produce **haem** (a necessary element of blood), is faulty. **Porphyrins** accumulate causing severe medical problems.

The type of porphyria varies according to the enzyme which is affected. The porphyrias are broadly divided into **acute** and **cutaneous** (skin), although some porphyrias cause both sets of symptoms (VP and HCP). The severity of symptoms varies dramatically in all types of porphyria.



Skin porphyrias

The skin porphyrias experience extreme sensitivity to sunlight and visible light which can vary from sensitivity and burning to severe blistering and scarring.

Acute porphyrias

In the acute porphyrias, severe pain, paralysis and sickness can be experienced when in an acute attack.

Hospitalisation is usually required to treat attacks of the acute porphyrias to monitor and treat the patient's condition.

No matter which type, the more knowledgeable about their condition a patient is, the more likely they are to stay well.

All donations made to the BPA will go towards our vital work supporting and advocating for patients affected by porphyria.



How does the British Porphyria Association help?

The porphyrias are often portrayed in a dismal light. Although the disorders can in some cases be very severe, there are many reasons to be optimistic and with the right information, many can experience fulfilling lives. Early diagnosis is vital if we are to improve the quality of life for those affected by it.

The BPA's primary aim is to **support** and **educate** patients, relatives and medical professionals about the porphyrias, so as to improve the lives of those living with the effects of the conditions.

Additionally, we aim to promote **research** into this group of rare conditions.



- The BPA aims to improve **understanding** of the condition, raising awareness and ensuring that the portrayal is always accurate.
- The BPA raises funds to **educate** patients and their families about their condition.
- The BPA aims to provide an **emotional support system** for patients and their families and provides contacts with doctors and specialists.
- The BPA aims to facilitate **understanding** for doctors and other healthcare professionals.
- The BPA raises funding for **new research** into the field of porphyria and encourages new research projects.
- We provide **information and vital support** to our patients, providing a telephone and email helpline, a newsletter, open days, conferences, and patient meetings. We help with medical research projects and push forward with education for patients and their families, as well as education for medical staff.

About the BPA

The British Porphyria Association (BPA) was established in 1999 by a group of patients and relatives who had experienced isolation and difficulties due to a general lack of understanding in diagnosing and treating their conditions. The BPA became a registered charity in 2001 and was run solely by a committee of volunteers until March 2015, when a paid administrator was appointed to work 6 hours a week to meet our members' needs. This was later increased to 12 hours. The charity is now run by 3 paid part-time administrators in collaboration with the committee of volunteers.

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