HELPLINE

01474 369 231

Would members please note that our helpline is only manned at specific times, due to work and family commitments.

When it is not manned, an answer machine will be in operation.

Please leave name, phone number, day and time of message and someone will call you back as soon as possible.

Web: **www.porphyria.org.uk**

E-mail: **helpline@porphyria.org.uk**

Address: **BPA, 136 Devonshire Rd
Durham City, DH1 2BL.**

The BPA Newsletter is published by the BPA twice yearly.

Chairman: John Chamberlayne
Vice-chairman: Liz Gill
Treasurer: Anne Newton
Secretary: Sarah Pepperdine
Patrons: Prof.Timothy Cox, Prof.George Elder
Dr. Mike Badminton

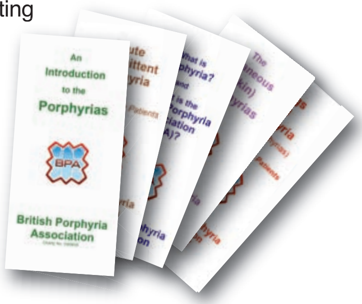
FACEBOOK

Just to remind those of you who use the Social Network site, Facebook, that the BPA has its very own site. Even if you are not already on Facebook, if you have access to the internet it is worth joining just so that you can access the BPA site. All you need to do is type “British Porphyria Association” into the search box on Facebook.

The best thing about being on the BPA Facebook site is that you can discuss issues, ideas and learn lots about all the different types of Porphyria. There have been discussions on the best types of sun cream to use for EPP sufferers, discussions on different types of drugs for those with acute porphyrias and loads more.

Leaflets

We have now finalised a new leaflet on inheritance and testing – this will be sent out to members with the January mailing.



Don’t forget that we also have five other leaflets on various aspects of porphyria:
- Introduction to porphyria
- Introduction to the BPA
- Skin porphyrias
- Acute intermittent porphyria
- Drugs in porphyria (acute)

Please let us know if you would like extra copies.
They are an ideal, handy reference for you and your family, or to provide to doctors.

Subs

After many years of remaining at the same rate, we have increased our subs rate to £15. Our subs year runs from January to December and, as usual, you will receive a letter in January detailing the many ways you can pay.

British Porphyria Association Registered Charity No.1089609

MEMBERSHIP / DONATION FORM & STANDING ORDER

TITLE: NAME:
ADDRESS:

POSTCODE:
EMAIL:
TELEPHONE:
TYPE OF PORPHYRIA:
DATE:

WAYS TO PAY
☐ I would like to pay my annual membership fee of £15
☐ I would like to make a donation of:
☐£10 ☐£15 ☐£20 ☐£25 ☐£50 ☐other £
☐ I would like to set up a standing order (please fill in the form opposite)
☐ I have set up a standing order using my internet banking*
☐ I enclose a cheque made payable to the ‘British Porphyria Association’ for £
☐ I have made a payment using my internet banking*
☐ I have made a payment using www.justgiving.com
☐ I would like a receipt

* Please use your name and postcode as reference for an on-line payment

By making a donation to the British Porphyria Association you will know that you are making a vital contribution to our work. Simply making a small donation will help us raise awareness, man our helplines or support research.

DO YOU PAY UK TAX?

If you pay UK tax, the BPA can reclaim 25p of tax on every £1 you give. The Government will pay to the BPA an additional 3p on every £1 you give between 6 April 2008 and 5 April 2011. This does not cost you anything and does not affect your personal tax position. Simply sign and date the Gift Aid declaration.

Standing Order BRITISH PORPHYRIA ASSOCIATION
Please send this form to: The Treasurer, British Porphyria Association,
11 Blakehill Terrace, Undercliffe, Bradford, West Yorks, BD2 3JS.

A monthly standing order or any donation you can give will make a difference.

BANK/BUILDING SOCIETY NAME:
BRANCH ADDRESS:
POSTCODE:

Please pay the British Porphyria Association the sum of £
each month/quarter/year (delete as appropriate) from my account until further notice.

ACCOUNT NAME(S):
SORT CODE: ACCOUNT NO:
STARTING ON* (DATE):
*This date must be more than one month after today’s date

SIGNED: TODAY’S DATE:

This cancels all existing standing orders to the British Porphyria Association (please tick) ☐ yes ☐ no ☐ not applicable

Please pay to British Porphyria Association bank account:
20-43-63 7099 6904

GIFT AID DECLARATION

I am a UK tax payer and would like the British Porphyria Association (Registered Charity No.1089609) to treat all donations that I have made in the last six years and all future donations that I make from the date of this declaration as Gift Aid donations, until I notify you otherwise. I understand I must pay an amount of income tax and/or capital gains tax equal to the tax reclaimed on my donations. (I will advise the BPA if my tax status, name or address changes.)

DATE: SIGNATURE:

DESIGNED BY: KAW Design. www.kawdesign.net

The
British Porphyria Association
newsletter

Registered Charity No.1089609

ISSUE 21 • DEC 2010

International Patient Conference

(Cardiff - 14 April 2011)

Cardiff castle

The international Porphyrins and Porphyrias conference is held once every two years in a different location around the world. Last year the conference was in Stockholm, Sweden, but in April 2011, the UK is fortunate enough to be hosting this event. It is a three-day event (running 11 – 13 April) during which medical professionals and specialists in porphyria meet to present their findings of the latest research going on in the field.

This year, the British Porphyria Association is working with the conference hosts to hold an International Patient Conference once the main event has finished. This one-day event will take place on Thursday 14 April 2011, and will provide an unprecedented chance to speak with other patients, specialists in the field and other patient support groups from around the world.

Anyone who has been to our patient open days, will know how much can be gained from them, both in terms of knowledge on how to manage the condition better from specialists and fellow patients, and also psychologically, from chatting to other sufferers and their families and just knowing that you are not alone!

The day will be packed full of interesting presentations. We are hoping to have a brief review of the key topics covered in the main conference, except in easy to understand terms. We will also be having presentations from a number of clinicians, looking at both acute and cutaneous porphyrias. In addition, we hope to have a number of presentations from the patient perspective and talks from other patient support organisations around the world, including France and America. Finally, there will be plenty of time to ask questions.

We are expecting that the day will commence at 9am and will end at about 3.30/4pm. Lunch will be provided, as will tea and coffee breaks throughout the day.

This unique opportunity is unlikely to arise again for a long time and has been prepared with you, the patient, in mind. The BPA committee would like to welcome all who are able to come. Tickets are £10 per person, or £15 per couple/family.

And finally …

The evening before the conference (13 April 2011, 7.30pm) members of the BPA will be going out for a meal with other patient support groups and anyone who would like to attend. Please let us know whether you would like to come. It will be £15 per person.

Cardiff

The conference is being held in Cardiff, the capital city of Wales; why not combine attending the event with a long weekend away?

Cardiff facts

- Cardiff has a population of 328,000 and attracts more than 11 million visitors a year
- Cardiff was recently described as the ‘epitome of cool’ by renowned travel guide, Lonely Planet
- The Millennium Stadium has been voted one of the seven sporting wonders of the world according to Barclay’s Spaces For Sports
- Cardiff Castle: although originally a Roman fort, a Norman keep was erected over the site in 1091, after which it was enlarged and built upon several times, until becoming the place it is today.

If you need help finding places to stay, please let us know.

Autumn Conference and AGM 2010

This year we held our AGM in Cardiff. The committee largely remained unchanged, although it was noted that Anne Newton had taken over the Treasurer position from Alan Molyneux. He had undertaken the role for a couple of years, so many thanks to Alan! We also added two new members to the committee: Beth Ward took on the role of Public Relations Officer and Sue Critchley the role of Events Coordinator. Finally, Linda Emms replaced Sandra McNab-Beggs as our Scottish representative.

We then had a number of talks, the first being from Dr Mike Badminton. Dr Badminton told us about the EPNET project, a European attempt to provide "better healthcare for patients and their families". It had four objectives: to provide information in the patient's own language; to standardise information on drugs for the acute porphyrias (which involved looking at the use of drugs and the problems they cause); to undertake External Quality Assurance (EQA) for the diagnosis of porphyria; and to collect epidemiological data for public health authorities and the EU (i.e. get some idea of how many porphyrics there are and what services they are likely to need).

As a result of this project, many leaflets are now available in a variety of languages for all the porphyrias. With regard to medicine use, information collected on drug safety has helped reclassify a number of drugs, which has changed the Welsh Medicines Information Centre (WMIC) list. Please go to www.wmic.wales.nhs.uk/porphyria_info.php and click the link to 'safe drugs list' for an up-to-date list.

Diagnostic EQA was more difficult. Diagnostic techniques are very different in different centres around Europe, and the results from standard quality assurance samples varied considerably. It was noted that partners were very supportive in offering help to those labs that were struggling to maintain high diagnostic standards.

The fourth aim involved collecting data on newly diagnosed cases. This was also difficult. Some countries use private labs, so information on their diagnoses cannot always be accessed, giving falsely low numbers. Here, the structure of the NHS works very well, as in the UK we have few patients and labs undertaking work privately and results being missed. The study found that Sweden and Switzerland appear to have higher numbers of newly diagnosed cases of AIP, while Norway, Switzerland and the UK appear to have a higher incidence of newly diagnosed cases of EPP.


Mike Badminton and Alex Anstey

EPNET has a year's extension, where the intention is to extend to other countries, improve diagnostic quality, and extend the reporting to improve knowledge of prevalence. There will also be further work on the drugs database. More information is available on the EPI website: www.porphyria-europe.com

Next, Beth Ward, an EPP sufferer, provided us with a very interesting talk on her experience as a patient. She proved that it is possible to do many of the things that people think impossible when suffering from a condition like EPP, including travelling to Australia, it just requires a bit of proper planning!

Finally, we had a talk from Alex Anstey, a dermatologist with a special interest in porphyria. Dr Anstey discussed various aspects of the cutaneous porphyrias, including:

Beta-carotene – some people with EPP find taking beta-carotene capsules helpful, although in reality, Dr Anstey mentioned that many patients stop taking it after a number of years as they feel it makes little difference. The capsules are available on prescription from your GP, and often give the skin a slight orange colour.

Phototherapy – narrow-band UVB and PUVA therapy is a form of ultraviolet light therapy used in dermatology departments. It involves careful exposure to artificial ultraviolet light, allowing the skin to thicken slightly and develop a tan. This acts as a natural sun block and can improve tolerance to sun exposure.

Vitamin D deficiency – to prevent a vitamin D deficiency a proper diet and sun exposure is necessary, however sun exposure can be difficult for those suffering from EPP. It is important to get vitamin D levels checked.

Liver checks – EPP sufferers should see their doctor regularly, at least once a year, to have a blood test to determine whether their liver is being damaged by protoporphyrin. Although this is rare, if it does happen, it is important to detect it as early as possible.

Finally, Dr Anstey provided an overview on the Clinuvel trials taking place in the UK at the moment.

Darnley trail charity walk: Gravesend

On 16th May, nearly 60 people took part in the Darnley Trail Walk in aid of the BPA. It is a 10km circular walk through countryside and woodland, with some challenging uphill sections. The weather was kind to us and the first people back completed the walk in just a little over one and half hours. A group of about 10 intrepid runners were first home in just over one hour, which was quite some going.

We charged a £6 entry fee to everyone and encouraged them to raise sponsorship money. We were thrilled to have raised around £700 and are now considering whether or not to make this an annual event.

If you would like to take part next year, or could help with organising and/or marshalling please call Karen on the helpline 01474 369231.

Financial support

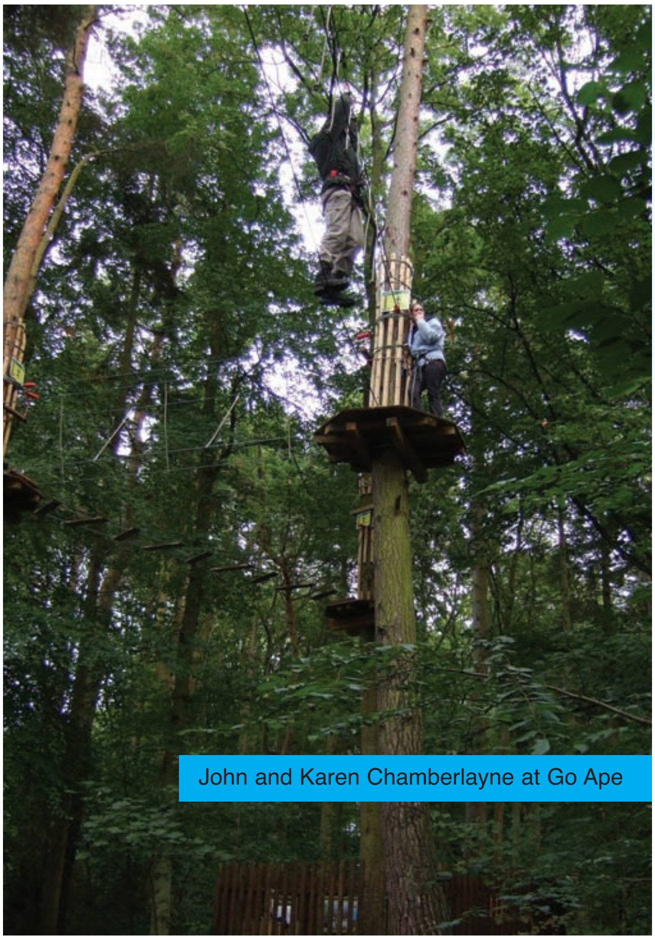
REMEMBER: we also provide a grant/aid fund through which members can apply for help with certain costs incurred because of their condition. We have recently helped an EPP sufferer with the costs incurred in fixing protective films to car windows. Or, if you are interested in coming to meetings/events, but feel you may not be able to attend due to financial difficulty, please let us know and we will see if there is any way we can help.

Latest research

Members may remember that a short while ago we donated £5,000 to Helen Murphy at Liverpool University to help with research into AIP. Unfortunately, Helen is no longer able to undertake this research due to a change in circumstances, so the money is winging its way back to the BPA until another researcher can be found to continue the project.
We will keep you updated!

Clinuvel Trials for EPP

Clinuvel Pharmaceuticals Ltd is an Australian company focused on the development of SCENESSE (afamelanotide). SCENESSE is a drug which is currently undergoing clinical trials in Europe, Australia and the USA. The aim of this drug is to reduce the severity and frequency of phototoxic reactions in EPP patients. If the trials are successful it may mean in the future that there is a drug available to help those with EPP and ultimately reduce their suffering. We will keep you updated on the findings in due course.



John and Karen Chamberlayne at Go Ape

Member's stories

If you suffer from a form of porphyria, the likelihood is you have a story to tell that others will relate to. Send us your stories and we will try to publish them.

CALENDAR COMPETITION

We are pleased to announce that we had some great entries for the calendar competition. Winners will be notified by post and announced in the next newsletter. We are producing a 2011 calendar priced at £6.50, including postage and packing, which are available now.

Please send cheques payable to the
British Porphyria Association,
to Karen Harris, 14 Mollison Rise,
Gravesend, Kent, DA12 4QJ.