The
British Porphyria Association
newsletter

Registered Charity No.1089609

Issue No.10 • April 2005

WE NEED YOUR SUPPORT!

When we speak to members both old and new, we are constantly being asked about local support groups.

Questions like the ones below are regularly put to us.

- Are there any support groups in my area?
- Is there anyone living near me, who also has porphyria?
- I feel isolated, as though I am the only person with porphyria and I would like to meet other people with porphyria.

Having listened to your requests for more patient support and contact, over the past year, instead of having our committee meetings in one place, we have been taking them to different locations around the country, and have invited those members living within about one hours drive to come along. We usually hold our committee meeting (open to any members) as well as a quiz night or something similar in the evening.

These events take quite some planning and the committee, who you will remember are all unpaid volunteers, puts a lot of effort into them.

Sadly, we have to report, that to our disappointment, members have not been taking these opportunities to meet.

Our next two meetings are being planned at present. Our first in June to coincide with National Porphyria Awareness Day is expected to be in the South West, somewhere along the M4 corridor, and our October AGM meeting will be in the Manchester area.

PLEASE, PLEASE PLEASE, help us to continue to help you, come along and support us at one of these events.

Porphyria and the Royal Question!

Many of you have read that some historians have speculated that King George III of England suffered from porphyria, namely variegate porphyria. According to notes made by the physicians attending him at that time, he suffered similar symptoms to those seen in an acute attack of porphyria; abdominal pain, constipation, rashes, confusion and severe weakness in his limbs. They also mentioned that he had dark reddish urine during these sieges and that he was often "mad." The royal physicians were not permitted to conduct extensive physical examinations, so they had to greatly depend on what King George told them about his condition.

On one particular occasion when he was having one of the relapses of the mental and physical symptoms, Parliament was debating his ability to maintain his position as King. Interestingly, he spontaneously recovered. Since George III ruled during the American Revolution, he was thought to have had a significant impact on Britain's loss to the revolutionaries. His mental and physical lapses were blamed for much of the mishandling of the war. In 1811, George suffered a severe relapse and subsequently was dethroned by the Prince of Wales.

After researching the physician's reports, Drs. Ida Macalpine and Richard Hunter proposed that King George might have had one of the acute porphyries. They published their theory in the British Medical Journal in 1966 and later wrote a book, George III and the Mad Business, which presented more detailed accounts of King George's malady. It is important to note that a number of porphyria specialists and other physicians disagree with their theory. However, over the years it has been widely publicized.

Another book called The Purple Secret, Genes, 'Madness' and the Royal House of Europe, written by John Rohl, Martin Warren and David Hunt, also looks at the possibilities of the 'royal link' with porphyria and makes interesting reading.

There has also been much speculation in the media over the years and indeed various television programmes about porphyria, many of which sadly continue to perpetuate some of the old myths surrounding the porphyrias.

The British Porphyria Association is constantly striving to raise awareness of porphyria, and at the same time dispelling myths and incorrect assumptions about it.

Members of the association can help by being vigilant and reporting to us any articles, newspaper stories or television programmes that appear to sensationalise symptoms, or distort the truth about porphyria, so that we can alert those responsible of their errors.

DESIGN AN EMBLEM COMPETITION

The Association is looking for a new emblem to symbolize Porphyria, which could ultimately by used worldwide. The committee has come up with several suggestions; however, we have been struggling to find something that is both innovative and memorable. We are therefore running a competition for members.

The design that you choose should not be used in any form by any other charity or business that you know of. It should be of a simplistic nature, so that it can be easily replicated.

Anyone can enter the competition; so ask your family and friends to enter too.

The winning design will be chosen by the committee at their next meeting in June and announced at the AGM in October.

The winner will be invited along to the AGM in Manchester, all expenses paid, (travel and overnight accommodation if needed) to receive their prize of £50 in vouchers.

Entries should be sent, by 30th May to: Emblem Competition, The British Porphyria Association, 14 Mollison Rise, Gravesend, Kent. DA12 4QJ.

DONATION FROM THAMES MOUTH LODGE

In December Karen was delighted to travel to Essex to meet Peter Scott, husband of Marilyn, a member of the British Porphyria Association.

Peter belongs to THE THAMES MOUTH MASONIC LODGE and has served as Grand Master of the Lodge for the past year. Each year the new Grand Master of the Lodge chooses one or more charities to support throughout the year.

Peter kindly chose the British Porphyria Association as one of his charities. At the meeting, Peter told Karen and her husband Graham, all about the work of the Masons and handed over cheques to the value of £2730. The photograph shows Karen accepting the cheques on behalf of the British Porphyria Association.

We would like to take this opportunity to thank both Peter and Marilyn for their hospitality, also the members of the Masons who worked so hard to raise the funds.

RECENT DONATIONS

£87 From Karen Harris (helpline administrator/ trustee) Raised at a friends and family Christmas Disco

£55 Mr & Mrs Fearn

£436 Carol and John Smith, who organised a Christmas Concert in their home town.

£50 Mr & Mrs RS & V Smith, Cambridgeshire
£10 Marianne Bailey and Keith Perkin

Webb Ivory Commission from Xmas purchase by members and friends
£ 30.90

£170.40 from staff at the Abbey for a 'dressdown' day, which was matched by The Abbey Charitable Trust making a total donation of £340.80

£40 Sylvia King

£20 Beth Ward

£40 Anthony Mills

£40 Mrs Von Glos

We have received a further 13 donations of between £5 and £20 in addition to the £10 subscriptions.

DO YOU SHOP ON-LINE?

Do you ever search the Internet for bargains, when looking for specific household items?

Do you buy your groceries and frozen goods on-line for home delivery?

Do you buy CD's, DVD's, videos, games, books and gifts on the Internet?

If you have answered YES to any of the above, please have a look at our new Web Shop at www.buy.at/BPA

You will have access to 100's of retailers, who will pay commission to the British Porphyria Association every time you, our members, friends or families buy goods or services through the Web Shop.

Retailers like Marks & Spencer, Lloyds TSB, More Than, Amazon, Index, LX, Comet, Iceland and many more are happy to give the BPA commission of varying amounts for purchases through the web shop.

Each retailer states how much per purchase, either in £'s or % they will donate to the BPA, so you will be able to work out exactly how much your purchase will be worth us.

Anyone can use our Web Shop, so pass on the details to your friends, family and work colleagues.

We will keep you up to date with the funds raised through this endeavour.

KIDNEY DISEASE IN PORPHYRIA PATIENTS

Following enquiries from a member who has recently been diagnosed as having early stage kidney disease, we asked our medical advisors how common this is and if they know why it happens.

Dr Badminton from the University Hospital of Wales in Cardiff told us:

"A proportion of patients with acute porphyria can develop impaired renal function. (kidney disease) We don't know why some do and some do not, nor what causes it. There are no published recommendations, but patients should have a blood test of their renal function if they are worried. I don't think there is any way of stopping it, but it can be slowed down by making sure any high blood pressure is treated. If blood tests show impairment the patient should be referred to a renal specialist"

Other steps patients can take to help reduce their risk to high blood pressure are:

- Reduce any external sources of stress
- Eat a well balanced diet and try to keep within recommended weight guidelines. (Do not undertake faddy, or crash diets. If you need to lose weight, seek professional advice)
- Cut down on salt and processed foods, try to eat the recommended five portions of fruit and vegetables a day.
- Drink plenty of fluids, particularly water.

Regular exercise has an effect in lowering blood pressure. If you are new to exercise, consult your doctor before starting.

1st June–National Porphyria awareness day

Please help us to increase NATIONAL awareness of Porphyria. We are joining with the Canadian Porphyria Foundation in establishing Ist JUNE as NATIONAL PORPHYRIA AWARENESS DAY.

What can you do to help?

- Can you contact your local paper and ask them to run an article? (We can provide suitable information)
- Can you hold a fund raising event?
- Can you ask your company to have a 'dress down' day?
- Can you ask your school to help you raise funds?

Can you organise a quiz, disco, coffee morning, race night, concert, jumble sale, bring & buy, garage sale, handcrafted items to sell, for example, cards, jam, cakes, jewellery, do a sponsored walk, swim or run, wash cars, games evening etc.

The more events that can be coordinated over the week of 29th May – 4th June, the more we can do to raise public and medical awareness.

Anything that you think could help us, no matter how small, please contact us either by phone or via our web site so that we can help you to get 'the ball rolling'!

There will be an Awareness Day at Salford Hospital, hosted by Dr. Felicity Stewart, and porphyria patients living within the area will be welcome to attend.

If you are a member of a group or society that you feel would be interested in hearing a presentation on Porphyria, then please get in touch and we can try to arrange a fun and information afternoon/evening with a presentation and fundraising opportunity.

ARTICLES FOR WOMENS MAGAZINES

Anthea Gerrie, a freelance journalist looking to interview patients with Porphyria, with a view to doing articles for Women's Magazines, has approached us.

If you are interested in telling your story and helping us to raise the profile of Porphyria, please contact Karen at our helpline either by e-mail, helpline@porphyria.org.uk, or telephone, 01474 369231, and she can discuss it with you and put you in contact with Anthea.

Treasurer's Report

On behalf of the BPA I would like to thank all those members who have promptly paid their annual subscriptions, and also to the many of you who have made additional donations as well.

Many of you have completed the Gift Aid sections on the forms and this will enable us to claim back an additional 28p for each one pound of your subscriptions and/or donations. Thank you all. If anyone hasn't completed the Gift Aid section, but is a taxpayer, we can still claim back the tax you have paid if you complete the gift aid section on the membership form on the newsletter and send this to us. Just fill in your name and address, sign the Gift Aid section and mark the form that your subscription/donation has already been paid and we will do the rest.

This is a very simple way for Charities, like us, claiming back tax paid without any additional costs to the person donating the funds.

While on the subject of donations/subscriptions, I would also like to extend our thanks to all of you who make regular contributions by standing order and to those of you who have recently sent in new instructions.

Anne Newton
Treasurer

HELPLINE CONTACT TIMES

Would members please note that our helpline is not manned at specific times, due to work and family commitments.

As a guideline please try to phone during the following hours, when someone is most likely to be in attendance. Outside of these hours the answer machine will be in operation.

Monday	**19.30 hrs – 21.00 hrs**
Tuesday	**12.00 hrs – 14.00 hrs**
Wednesday	**Answer machine only**
Thursday	**14.00 hrs – 15.30 hrs**
Friday	**10.00 hrs – 14.00 hrs**

Weekends and Bank holiday – Answer machine:- Please leave, name, phone number, day and time of message and someone will call you back as soon as possible.

The BPA Newsletter is published by the BPA twice yearly.

Chairman: John Chamberlayne
Treasurer: Anne Newton
Secretary: Leigh Drake
Patron: Prof. Timothy Cox, Prof. George Elder

14 Mollison Rise, Gravesend, Kent DA12 4QJ
Tel: 01474 369 231 email: BPA@bodywise.go-plus.net

LEEDS HALF MARATHON

Paul & Leila Kelsey have kindly offered to run in the Leeds Half Marathon in May on behalf of the British Porphyria Association.

They have been making very good progress with their training programme and we would like to offer them our thanks and best wishes for the race.

They are looking for sponsorship so that they can raise as much money as possible and would be delighted if members of the association could send in pledges to our TREASURERS.

If you would like to support them, please fill in the slip below and return to us marking your envelope:

BRITISH PORPHYRIA ASSOCIATION
LEEDS HALF MARATHON
11 Blakehill Terrace
Undercliffe
Bradford
West Yorkshire
BD2 1SR

LEEDS HALF MARATHON PLEDGE

Name ....

Address ....

....

Amount enclosed ....

*Cheques should be made payable to The British Porphyria Association

Membership/ Donation Form

BRITISH
PORPHYRIA
ASSOCIATION

Registered Charity No.1089609

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

DO YOU PAY UK TAX?
If you do, you can add 28% to the value of your gift to the British Porphyria Association at no extra cost to yourself, Simply sign and date the Gift Aid declaration and for every £1 you give, we can ask the Inland revenue to give us an extra 28p.

WAYS TO PAY

Title .... Name ....

Address ....

.... Postcode ....

Email ....

Telephone ....

Date ....

I would like to pay my annual membership fee of £10

☐ I would like to make a donation of:
☐ £10 ☐ £15 ☐ £20 ☐ £25 ☐ £50 ☐ other £
☐ I would like to pay by Standing Order (please fill in the form overleaf)
☐ I enclose a cheque made payable to the British Porphyria Association

for £ ....

STANDING ORDER

BRITISH PORPHYRIA ASSOCIATION

Please send this form to: The Treasurers, 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) ....
Account no. .... Sort code ....
Starting on* (date) ....
* This date must be more than one month after today's date

Signed ....
Todays date ....

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

GIFT AID DECLARATION

I am a UK Tax payer and would like the British Porphyria Association (Registered Charity No.1089609) to treat all donations I have made since 6th April 2000, and any future donations, as Gift Aid donations until I notify you otherwise. (we can reclaim the tax on your donations at no cost to yourself)

Signature ....

Date ....